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Trust and health research in developing countries: summary of the issues

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Introduction:

This brief literature review looks at some of the key features of trust in social relations discussed in broader social science literature, as they relate to the practical challenges of negotiating trust in health research in developing countries. It starts with a discussion of the main issues and concerns with health research in developing countries and how trust may feature in those. This is followed by discussion of some conceptual and theoretical framings of trust, the iterative process of trust building, and dimensions of trust, such as personal attributes and characteristics that engender trustworthiness. The paper concludes by reflecting on the role of community/public engagement, and suggests some research questions around trust and health research in developing countries.

Trust and health research: what are the issues

"The foundation of trust in any relationship, and the associated moral obligations, is based on an assessment of whether the interests of the trustor are considered and respected in the decisions made at an individual or organisational level" (Gilson 2006 p365).

Health research particularly in developing countries faces multiple complex challenges which may influence how it is perceived, received and understood. Widely documented challenges include:

- disproportionally low investment in health research in developing countries compared to their health disease burden globally, popularly known as the 10/90 gap (Benatar and Fleischer 2007);
- debates about appropriate standards of care during and at the end of research, which became particularly prominent with the advent of HIV research in developing countries. The main debates and controversies with standard of care are around whether to provide universal standard of care[1] or local standard of care, whether placebos should be used when an effective treatment exists though not locally available, and what should be offered to participants who develop the condition being studied or unrelated conditions during and after the research (Wendler, Emanuel et al. 2004; Benatar and Fleischer 2007);
- the extent to which the social value of research gets to the communities that bear risks of the research, and whose responsibility should it be to ensure that benefits are equitably distributed (Bhutta 2002; Lairumbi, Molyneux et al. 2008).
- Concerns with out-sourcing of clinical trials into developing countries with weak regulatory systems, and of whether profit making interest may erode ethical goodwill (see for example the recent developments on registration of clinical trials in India (Tharyan 2009).
- The ethical, legal and social-cultural challenges and dilemmas of genome-wide association studies especially on risks to individuals and communities from current and future GWA studies, how to safeguard participants' privacy and confidentiality, issues around ownership and custodianship of samples and data (O'Doherty, Burgess et al. 2011).

Many of these concerns and controversies are widely debated in both academic and public mass media. For more dramatic cases see controversies around public perceptions of and reactions to polio vaccines in Nigeria and India, concerns around HIV and anti-retrovirals (Page-Shafer, Saphonn et al. 2005), and current issues around HIV research with key populations especially men who have sex with men (MSM) in Kenya (Taegtmeyer, Davies et al. 2013).

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[1] Defined as the best treatment or care available anywhere in the world but which may not be available locally.

At the micro-level, challenges with informed consent process are widely documented. Comprehension of research information and unfamiliar research terminologies, such as placebo and randomization, are areas that have received particular attention (Weijer 1999; Krosin, Klitzman et al. 2006; Upshur, Lavery et al. 2007). The extent to which individual autonomy and voluntariness could be achieved particularly in communitarian societies facing constraining situations such as unmet health care needs is an area of ethical concern (Lindegger and Richter 2000; Nelson, Beauchamp et al. 2011). Therapeutic 'misconception' (TM), a perception that what is proposed in research is primarily aimed at an individual's health care and has a reasonable level of success, has been described to influence participants' consent to research all over the world, but particularly in developing countries (Appelbaum, Roth et al. 1982; Molyneux, Wassenaar et al. 2005). Even in the absence of therapeutic misconceptions, choices to join research can be based on accessing basic health care in a context of severely constrained health systems (Molyneux, Peshu et al. 2004; Benatar and Fleischer 2007). Thus participants may join research not because they understand it but because of the nature of relationships they have with those they closely interact with, the research teams.

There are certainly multiple complex factors contributing to these controversies, including nature of North-South collaborations, issues of justice and equity, historical injustices and the public interest and perceptions of science and research. Trust can be envisaged as an underlying feature both at the micro-level and macro-level, because research conduct is ultimately a human activity with all the trappings of human interactions and social relations. Thus for research in developing countries, trust is a salient feature in relationships between and within study teams, research participants, the community and research institutions. Trust can influence the information people choose to believe, perceptions of specific studies and research institutions, and decisions around participation in research. Lavery (2007) discusses trust in biomedical research as an aid in decision-making based on a shared framework of understanding and comprehension of research between research participants and researchers. Trust "…..must be earned by investigators and felt by individuals and communities that consider participating in research" (Lavery 2007 p275)

Unpacking trust (what is trust?)

An area of growing interest and attention in recent years are the relational aspects that inevitably permeate research encounters; of which trust and health research in developing countries is morbidly under investigated. Trust is described as a relational notion between people (interpersonal trust), between people and organizations (institutional trust) and people and events (Gilson 2003; Goudge and Gilson 2005). A broad definition of trust as the "optimistic acceptance of a vulnerable situation in which the trustor believes the trustee will care for the trustor's interests'(Hall, Dugan et al. 2001 p615) draws attentions to four main features of trust; that it (trust) is a relational notion, a voluntary response towards expectations of how the trusted will behave towards the trustor in a future event/activity, and thus it involves degrees of vulnerability and risk (Gilson 2006). These descriptions refer to interpersonal trust (between people) which can be voluntary (as described above) or involuntary. Interpersonal *voluntary* trust can be strategic and calculative, rooted in judgements of prevailing circumstances, risks and expectations that the trusted will behave in the best interest for the trustor (Goudge and Gilson 2005). Interpersonal *involuntary* trust is revealed in unequal relationships (such as between a patient and care provider) where the trustor has limited choices and inevitably depends on the trustee to serve their best interests. Another school of thought views trust as intuitive, a moralistic or altruistic behaviour based on moral values of how people should behave towards each other and on the goodwill of others. This type of trust has emotional rather than calculative roots, derived from the belief that most people share moral values (Goudge and Gilson 2005).

Impersonal trust could include trust between strangers and trust in social systems (Gilson 2003; Goudge and Gilson 2005). Trust can be extended to strangers if the trustor has adequate information with which to judge the trustee either from the people that the trustor knows who can vouch for the stranger or from shared norms between the stranger and the trustee (e.g. people from same neighbourhood, frontline research staff). Trust in strangers can also be based on institutions they belong to which have mechanisms for monitoring and disciplinary procedures that promote consistent behaviour embodied in expert systems (e.g. technical and professional knowledge, ethical codes, licensing those who receive training) (Gilson 2006) such as trust in medical systems, or in research regulatory systems.

Thus, institutions involved in communication and decision-making practices could be central in shaping generalised public trust as they generate information of how people are treated by others, create expectations of values that drive behaviours, influence judgements about motivations and intentions, and provide opportunities for constructing perceptions about meanings (Miller 2004; Gilson 2006). Organisations also encompass chains of relationships and thus provide opportunities and frameworks for development of various sets of mutually trusting relationships, within staff, between staff and employers, and with other social networks and institutions (Miller 2004).

Stages in building trust

An iterative process of trust building over time is generally described in the literature. Goudge and Gilson (2005), describe three main phases of trust-building in patient-provider relationships. These include initial naïve trust based on high expectations (from both sides), which is quickly shattered when those expectations are not met or through conflicting perspectives. Unmet expectations lead to a phase of mistrust in which disenchantment, extreme anxiety and frustrations lead to a reconstruction of alternative forms and levels of trust. The third phase includes resolution phase of the reconstructed trust, contingent on revised expectation and roles of both the trustor and the trustee (Goudge and Gilson 2005). Through this process, forms, levels and depths of trust are renegotiated (Mechanic and Meyer 2000).

Dimensions of trust: Attributes and characteristics of trustworthiness

Trust is contextual, constructed depending on the particular issue, individuals involved and the relational context (Mechanic and Meyer 2000; Miller 2004). Personal characteristic and attributes that promote perceptions of trustworthiness are central in understanding how trust is build, shaped and maintained over time. Five commonly described attributes include *fidelity/dependability* - also called agency/fiduciary - which is the obligated responsibility of the trusted to act as an agent and for the best interests of the trustor. Competence (technical, cognitive and communication), honesty and confidentiality (protecting private information) are other attributes. It is also argued that the attributes described above are interconnected and that trust has an irreducible quality, such that ‘trust’ is used as a catchall label to imply an overall quality that cannot easily be reduced to its constituent parts (Mechanic and Meyer 2000; Goudge and Gilson 2005; Gilson 2006).

Strengths and challenges with trust

Potential benefits of trusting relations at the micro-level include establishing mutually stable relationships, cooperation and reduction in transaction costs in situations of uncertainties (Gilson 2006). Additional benefits at macro-level include overall efficiency associated with reduced transaction costs, redistributive action (ensuring everyone in the group benefits) and solidarity, and tolerance. Trust in institutions could contribute to well-ordered society and legitimize actions and authorities of leaders (Miller 2004; Gilson 2006), but can also be problematic as described below.

Trust relations could also lead to undesirable consequences and outcomes. At micro-level, it could lead to corrupt behaviours (gaining at expense of others), exploitation due to unequal power relations; particularised trust (in a confined group/common interests) could lead to sub-cultures such as criminal gangs to develop. Unequal distribution of trust in a society could lead to unequal distribution of benefits (Gilson 2006). The legitimisation of authorities and leaders noted above may also be problematic if it prevents their actions from being appropriately scrutinised.

Brief overview of trust in health care systems

Health care systems are social institutions which can influence and mould social values "…, they [health care systems] establish the social norms that shape human behaviour and so act as a repository and producer of wider societal values" (Gilson 2006 p362). A vast amount of literature from developed countries and increasing literature from developing countries describe the centrality of trust in patient-provider relationships, in health systems and in employer relations. Trust in health care is particularly important as it can potentially influence adherence to treatment, patients' perceptions of provider motivations, and may contribute to therapeutic effects (Miller 2004; Gilson 2006). Trust can also lead to necessary cooperation within the health care system and across multiple relationships; public trust in health authorities can legitimise their actions and power (Miller 2004). They thus can lead to generalized trust among the population towards public institutions, which can promote ethical outcomes such as redistributive actions, unity among communities and societies (Gilson 2006). As noted earlier, trust in health systems can be problematic particularly where it can lead to legitimization of otherwise unpopular policies and governments, and can contribute to corrupt behaviours (Gilson 2006).

What could be the role for public/community engagement in building appropriate levels of trust?

Earlier discussion on trust and health research highlighted the complex issues underpinning health research in developing countries; trust was described as an underlying factor. Discerning and unpacking trust and mistrust can be a daunting task. Miller discusses how gaining access to 'backstage' behaviours, perceptions, and attitudes (usually not shared publicly with others) can be an indication of having gained trust and access to deeply personal spaces especially in insular communities such as in research with refugees (Miller 2004). Abelson (2009) discuss similar behaviours of trust building through forming alliances with those with similar interests and who are considered worthy of trust and cleavages within the local community and with health research institutions (Abelson, Miller et al. 2009). Insights from recent discussions among Wellcome Trusts Major Overseas Programmes based on a paper by Gikonyo et el highlighted the negotiations and re-negotiations inherent in trust building and that instead of complete trust in researchers or research organizations, the optimal maybe a healthy mistrust in which participants and communities can voice questions, demand explanations and hold research organizations to account. It was also noted that a level of trust is inevitable in research relations otherwise unequivocal mistrust could lead to high transaction costs and unhealthy relationships since not every aspect of every research decision needs to be questioned (Gikonyo, Bejon et al. 2008). Rumours surrounding research activities have widely been described as indicative of deep rooted concerns and worries about the research, of inequities and of unequal relations (Graboyes 2010). For example, rumours associating research activities with devil worship and of research as attempts to control populations points to deeper concerns and fears towards research which may not be addressed by simply providing factual information. The issue for research is not about gaining unrevoked trust, but about establishing a balance of trust and mistrust, a 'healthy mistrust', in which participants and communities feel able to raise issues, scrutinise researchers, research governing bodies, opinion-forming spaces. Importantly, institutions, systems and structures that engender trust in health research need to proactively be accountable to participants, communities, publics and other relevant stakeholders. Approaches aimed at redressing inequities such as benefit sharing, meaningful engagement of publics and communities, accountability mechanism for research conduct (such as feedback of results, research governance), engagement with communities and with mass media remain relevant in building public trust towards research.

One approach to rebuilding trust in science and research has been through engaging the public and the lay people through various mechanisms including in consultative forums, in advisory boards (such as community advisory boards/committees – CABs), and in public juries. Community engagement in health research with both its instrumental goals (such as strengthening informed consent processes), and the intrinsic goals (such as show of respect to communities) remain important on building mutual understanding and trust (Participants 2011) (Marsh, Kamuya et al. 2008; Tindana, Rozmovits et al. 2011). There are considerable challenges with community engagement including those associated with its key elements (i.e. what is community, engagement, appropriate levels and depths, who is engaged it) (Tindana, Singh et al. 2007; Marsh, Kamuya et al. 2011).

Another approach gaining traction in developing countries is employment of community members into research activities (such as fieldworkers) to strengthen mutual understanding of research, provide employment and capacity building to community members. However, there are also considerable challenges including the potential for FWs to exploit trust bestowed on them so as to attain recruitment quotas; and the possibility of compromising privacy and confidentiality entrusted in them (Gikonyo, Bejon et al. 2008; Molyneux, Goudge et al. 2009; Marsh, Kamuya et al. 2010). These approaches described, while important in addressing some of the challenges, are not panacea, other strategies and approaches continue to be relevant.

Some questions of interest in investigating trust in health research in developing countries

Trust and health research is under-investigated in developing countries despite its centrality in research encounters and relations, and in how research is perceived and understood. The theoretical and conceptual framing discussed earlier, and the arguments for trust relations in health care and health research presented above provide food for thought. Some theoretical and practical questions include: What are the different ways in which trust is framed in research encounters and across different settings? What is the role and contribution of trust towards research (at micro-level and macro-level)? What are the appropriate levels of trust, and how can these be achieved, maintained and investigated? What is the basis of trust/mistrust in research? What factors contribute/undermine trust? How can trust be negotiated and re-build? What role, if any, does mass media play in forming public opinions and trust of research? How is institutional trust manifested and how can it be achieved and maintained? What contribution, if any, does community/public engagement make towards building appropriate levels of trust? What are some of the generalizable findings across settings and issues? Goudge and Gilson, 2005 provides a conceptual framework for developing tools and for investigating trust, which can be modified to specific contexts and for specific elements of research in trust (Goudge and Gilson 2005).

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