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# **‘We shed tears, but there is no one there to wipe them up for us’: narratives of (mis)trust in a materially deprived community**

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**ABSTRACT** This article reports on a qualitative study in a materially deprived locality in northern England, which originally aimed to explore local residents’ views of proposed changes to local health care provision. However, participants also quickly moved the research agenda onto widespread discussions of (mis)trust. Unlike much sociological literature that defines trust as operating on two levels (inter-personal and system-based), their narratives of trust were constructed on several inter-connected levels. We explore mistrust in local general practitioners (GPs) as a factor of mistrust of a number of local and national organizations and social systems, rather than solely related to the medical system. Widespread mistrust of ‘authority’ was narrated through a shared history of disinvestment and loss of services in the locality and ‘broken promises’ by a range of institutions, which precipitated feelings of social exclusion and disembeddedness.

**KEYWORDS** *dependence; inter-personal trust; materially deprived communities; social inclusion/exclusion; systems-based trust*

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## **Background**

It is a common assertion that the move from what is termed ‘modern’ to ‘late/high modern’ society has been accompanied by decreasing levels of trust in individuals and institutions (Giddens, 1990, 1991, 1994; Beck, 1992). This declining trust has been witnessed in health care along with other institutions (Birungi, 1998; Davies, 1999; Mechanic and Meyer, 2000; Welsh and Pringle, 2001; Gilson, 2003; Russell, 2005), and may be linked to broader epistemological challenges about the authenticity of knowledge (Giddens, 1991), the confidence in the power of science (Wynne, 1992) and the

capacity of experts to deliver to us control over our bodies (Beck, 1992). Indeed, Crawford suggests that ‘When the life-world is colonized by medical insecurity, medicalized subjects come to suspect the messenger and the knowledge they bear’ (2004: 524). On a more immediate temporal and geographical scale, recent scandals in the UK over illegal removal of organs, the Harold Shipman case, the Bristol doctors, MMR (Brownlie and Howson, 2005) and BSE (Irwin and Michael, 2003) have fuelled public scepticism and lack of trust in science, medical authorities and individual medical practitioners. The purpose of this article is to explore notions of trust in a materially deprived locality, as they relate to trust in general practitioners (GPs), the health care system in a context of social exclusion and the wider institutions of the state in an era of disorganized capitalism (Scambler, 2002).

The study we report on here did not set out to explore the notion of trust. The study’s original objective was exploratory, rather than specifically focused, with the aim of investigating user perspectives of the health care needs of Pakistani and ‘white’<sup>1</sup> people in a materially deprived locality in northern England. The study was commissioned by the local primary care trust (PCT), which was undergoing organizational changes and considering reconfiguring the provision of primary care services. In particular, the PCT was considering reducing the number of GPs in the local area – namely closing down a GP surgery. Therefore, within an approach akin to a public consultation, the PCT was interested in the views of local residents regarding current health care provision and suggestions for how these services could be reconfigured in ways most appropriate to expressed needs.

During the study, it became acutely apparent that the over-riding narrative was one of mistrust expressed in a variety of complex ways and with inconsistent targets. Therefore, this mistrust could not be neatly levelled at a particular person, organization, institution or system. Personal experiences of the local residents over many years had led to a mistrust of most organizations and those working within them. Therefore, this article seeks to perform two main tasks. The first is to highlight and explore the narratives of mistrust within the community, and the reason for the mistrust (in particular, links with social exclusion were revealed as important). Second, mistrust was constructed and operationalized at a number of levels, and therefore we wish to add to the theoretical development of the sociology of trust by suggesting that rather than trust being on two levels (i.e. inter-personal and system-based), it is more like the layers of an onion – it is and can be on multiple levels, and related to multiple social systems (Luhmann, 1989).

## **Literature on the concept of trust**

It is not intended to provide an in-depth review of the concept of trust here, since this has been done admirably elsewhere (Gambetta, 1988; Luhmann, 1989; Giddens, 1990, 1991, 1994; Simmel, 1990; Misztal, 1996; Mollering,

2001; Gilson, 2003; Goudge and Gilson, 2005). Most theorists suggest that trust is operationalized at two inter-related levels: inter-personal trust and system-based trust (also called generalized trust, institutional trust or trust in abstract systems). In terms of trust in health care professionals, inter-personal trust has been defined by Russell as being 'built, sustained or damaged through face-to-face encounters with health providers and is more likely to increase with long-term doctor-patient relationships' (2005: 1397). Trust in systems is based around the belief that the health system and medical profession will operate in the best interests of the patient. Luhmann (1989) also talks of trust in multiple (social) systems, which may include the medical system, but also includes other systems such as economic, political and legal systems. The resonance of Luhmann's ideas will be outlined in this article.

While both of these levels (personal and system-based) of trust involve 'leaps of faith' (Simmel, 1990: 179) or are in some way 'quasi religious' (Giddens, 1990: 26-7), the trust that people have in systems is more abstract. Indeed, Giddens (1990) usefully distinguishes between 'facework commitment' (inter-personal trust) and 'faceless commitment' (system-based trust).

The two levels of trust are inter-related in that the GP, for example, is the public face of the health care system, and therefore in some way will influence levels of trust in the system. Nevertheless, the theory suggests that an individual may have trust in their GP due to personal experience, although have mistrust in the medical system or NHS (e.g. due to media reporting). They may feel that their GP is doing everything for them, within the restraints of a system that is unhelpful or inequitable. Conversely, an individual may have complete mistrust of their GP, while still retaining trust in the system.

### **Importance of (mis)trust in late modern society**

Giddens (1991) argues that public mistrust in systems is a core dimension of the character of life in late modernity.<sup>2</sup> Giddens (1994) argues that we look towards expert systems (e.g. medical system) to anticipate, predict and control the future and are therefore ever more reliant upon such systems. However, the medical system cannot adequately predict the future, which has led to public mistrust (Wynne, 1996; Crawford, 2004). Indeed, Crawford (2004) provides evidence for the emergence of a 'culture of anxiety', which has also been termed an 'era of insecurity' (Bauman, 1999), 'ontological insecurity' (Giddens, 1990) and 'existential anxiety' (Giddens, 1991), in which 'stasis' becomes the norm, and individuals and groups constantly reflect upon their place in society and the role of traditional institutions.

Some may suggest that the medical system has actually never been able to predict the future, and the difference in contemporary society has been

the shift from 'productivism' to 'consumerism' (Bauman, 1996; Scambler and Britten, 2001). This shift in emphasis, which is accompanied by a mushrooming provision of different forms of health care (belonging to biomedical and other 'alternative' paradigms) has meant that members of society are encouraged to 'shop around' for health, which has resulted in so-called 'reflexive actors' (Giddens, 1991), who may indulge in pragmatic 'healer hopping' (Ernst, 2002). In this way, trust in the medical system can no longer be simply taken for granted or expected, 'it has continually to be "won"' (Giddens, 1994: 90) and 'is therefore being constantly renegotiated with lay audiences' (Bissell et al., 2001: 9). Indeed, such a process of negotiation and lack of guaranteed trust for lay audiences may represent a loss of status by the medical establishment and a deconstruction of the formally perceived dichotomy between 'lay' and 'expert' as, in the process, this distinction becomes increasingly meaningless and subjective.

Mechanic and Meyer state that 'trust is fundamental to effective interpersonal relationships and community living' (2000: 657), and therefore a decline in trust may lead to continuous vigilance and anxiety within society. One reason for the decreasing levels of trust in the medical system is bound up in contested and divergent epistemological claims about the validity of knowledge. The popular media (including the Internet) is awash with multiple and conflicting claims to medical 'truths' (Williams and Calnan, 1996), which has led to a burgeoning academic literature around the development of 'lay knowledge' (Phillimore and Moffat, 1994; Williams and Popay, 1994, 2001; Popay et al., 1998) and 'lay expertise' (Lupton, 1997; Hardey, 1999; Ward et al., 2000). Claims to 'expertise' around health, illness and medicines are no longer the sole provenance of medical practitioners, and Williams and Calnan argue that there is evidence of a 'critical distance' opening up between the lay populace and modern medicine: 'all knowledge is tentative, corrigible and therefore open to subsequent revision or abandonment . . . Systems of expertise come to represent multiple sources of authority that are frequently contested and divergent in their implications' (1996: 262). This contestation and divergence effectively challenges not only the epistemological superiority historically claimed by biomedical science but also the coherent authenticity of its underlying paradigm, as users actively select components of health care from multiple sources. As such, the medical system becomes not only contested but also locally determined by the same users (Ernst, 2002). Furthermore, Scambler and Britten (2001) state that medical doctors have experienced a change in their status from 'legislators' to 'interpreters' (Bauman, 1987), who are no longer able to be 'unchallenged to prognosticate on matters of health' (Scambler and Britten, 2001: 62).

The multiple truth claims and contested nature of medical expertise has led many theorists to suggest that we are all in a state of liminality ('no man's land') (Armstrong, 1993: 409); in 'non-health' (Gifford, 2002: 217); 'betwixt and between health' (Crawford, 2004: 521). Although there are

arguably increased spaces for empowerment of lay people, the latter is left on uncertain ground from which to act on their improved possibilities for agency. The consequences of such liminality are that lay people begin to question the validity of medical knowledge and hence the 'trustfulness' of both medical practitioners and the system on which their knowledge is based. Indeed, Crawford elegantly suggests that:

People are left wondering about the efficacy of medical advice: as the map of danger is filled in, safe passage appears all the more difficult; but as the map of safe passage becomes illegible, people do not know what to believe or how to act in order to be safe. (2004: 511)

All of this literature highlights the centrality of 'trust' in contemporary society, specifically as it relates to health care (Scambler, 2001; Scambler and Britten, 2001). There have been a number of empirical studies which have explored the issue of trust in health care professionals (Birungi, 1998; Mechanic and Meyer, 2000) or the health care system more generally (Straten et al., 2002; Gilson et al., 2005; Russell, 2005). However, this article will add to, and extend this literature by showing the inter-connectedness of mistrust in GPs, mistrust in the health care system and also general levels of mistrust in wider institutions and systems. Previous research tends to focus its radar on health care professionals and the health care system, while ignoring the importance of wider instruments of the state and the capitalist system. The study presented in this article will argue that 'trust' in GPs, primary care trusts (PCTs) or the health care system cannot be disentangled from 'trust' in systems related to employment, the environment, education or the institution of the government (in a similar vein to Luhmann) and the relative positioning of individuals in relation to these institutions.

## **Research method and analysis**

The study was undertaken in 2003 in a materially deprived locality in northern England. The locality has suffered from dis-investment in services over many years and had chronic unemployment. It is an ethnically mixed area, with approximately 20 per cent of the population being of Pakistani origin.

Given the PCT's requirement for both a depth of understanding and statistical generalizability to reflect perceptions of needs and suggestions for future services, we undertook a mixed method approach. First, we conducted five focus groups with members of the local community. Second, we undertook a community survey with a 10 per cent random sample of the community. This article focuses specifically on the findings from the focus groups.

## **Choice of research method**

The use of focus groups allowed for explorations and discussions of relevant events in people's lives, in addition to creating a flexible atmosphere conducive to an open and uninhibited flow of conversation between participants (Silverman, 2002) whose potential diversity is recognized (Kitzinger, 1994). Focus groups may be seen as a way of 'prospecting' for the respondent's feelings and points of view (Holstein and Gubrium, 2003; Seale, 2004). However, they also allow for knowledge creation through interaction, since the respondents are not seen as passive vessels from which 'facts' can be extracted but as participants who 'actively and communicatively' construct meanings in the group context of a social encounter (Holstein and Gubrium, 1997: 114). By listening to the views and concerns of the participants in this way, the research process is shaped as far as possible by the respondents' (not the researchers') views.

## **Recruiting participants and developing topic guides for focus groups**

The recruitment of participants for the focus groups and the development of the topic guides were undertaken with the local community forum (a voluntary organization which aims to represent the views and needs of local people). The community forum constitutes members of the local community who meet on a monthly basis and represent the 'voice' of the local community within the local council and the PCT.

The topic guide for the focus groups was initially developed by the researchers (PW and AC) in conjunction with the PCT. However, the community forum spent a number of meetings refining and redeveloping the topic guides so that the issues covered were those deemed important to the local community. The original topic guide was focused on a medical model of health, whereas the community forum worked with a more holistic, social model of health, and therefore widened the variety of topics to include their physical environment (e.g. parks, streets), pollution (visible and non-visible), education, employment and other services. Both researchers tried to cover the topics during the focus groups, while also allowing latitude for participants to discuss issues important to them. This approach allowed for the centrality of 'trust' to emerge within the focus groups.

The community forum also helped us to gain access to members of the community, many of whom would be seen as 'hard to reach' (e.g. older Pakistani men and women) and advised on the constituent members of each group. While agreeing with our intention to undertake separate focus groups with 'white' and Pakistani participants, they also suggested that we needed to subdivide the focus groups by gender, and by age for the Pakistani women. The suggestion was that these groups would have

different experiences of services (particularly in relation to consulting services for children); that Pakistani women needed the space to discuss issues pertinent to them; that first generation Pakistani women would differ in views from younger women; and that the latter may feel restricted (particularly in relation to sexual health) in the company of older women from the same local community. Therefore, our 5 focus groups were as follows: white men ( $n = 9$ ); white women ( $n = 10$ ); Pakistani men ( $n = 9$ ); younger (under 30 years) Pakistani women ( $n = 10$ ); and older (over 30 years) Pakistani women ( $n = 8$ ).

Participants for the focus groups were recruited through a local newspaper announcement (in English, Urdu and Punjabi) and by snowball sampling through members of the community forum. All focus groups were conducted at a local community centre, lasted between one and one and a half hours and a corresponding male or female facilitator was used for the women's and men's groups. Although sometimes problematic (with multiple conversations occasionally occurring simultaneously), the use of an interpreter for the three groups with Asian participants was important to allow those who did not speak English to participate. Local NHS research ethics committee approval was granted for the study.

## Data analysis

All focus groups were tape-recorded and transcribed verbatim. All transcripts were analysed separately by both PW and AC, but the codes and categories were refined together using an interpretative analysis approach (Seale, 2004), based upon *open coding* and *categorization* (Strauss and Corbin, 1990, 2004) through close examination of the data. Thus we were able to compare categories within and between transcripts and look for similarities and differences (i.e. between and within different focus groups or even within the narratives of individuals themselves).

The main themes were fed back to the participants and to the community forum to ensure that they accurately reflected the complexities of their views and interpretations of experiences. This was a successful process, albeit the key themes identified by different analysts, and indeed by participants, may not always concur because of differing assumptions brought to the interpretation (Stacey, 1991; Opie, 1992; Ramazanoglu and Holland, 2002). However, it was recognized that gaps and contradictions in the data and identified themes can be viewed as enriching and illuminating, rather than necessarily problematic, as they highlight the complexities of social research and the world it investigates.

## Main findings

The findings from the study are presented in two main sections. First, we present narratives which relate to inter-personal trust, and specifically focus

on the lack of trust afforded to local GPs. Second, we present narratives which relate to system-based trust, which focuses not only on health care organizations, but also on wider institutions of local and national governance.

One of the criticisms levelled at the reporting of findings from focus groups has been that the interaction and discussion is often neglected; indeed, Kitzinger stated that ‘reading some reports it is hard to believe there was ever more than one person in the room at the same time’ (1994: 104). Therefore, we endeavour to retain some of the discussion in the use of our direct quotations, which means that these are often fairly lengthy, although we have kept this to a minimum for the benefit of the readers.

### **Inter-personal trust – lack of trust in their GP**

Participants in all of the focus groups had witnessed what they saw as a disinvestment in primary health care services in their locality. This had led to perceived poor quality infrastructure (in terms of number of GP surgeries and their state of repair) and a resultant unwillingness for GPs to stay in the locality. Therefore, many of the surgeries were staffed by locum GPs, with whom it was difficult to develop a long-term relationship. Participants complained strongly that all doctors were locums and that they usually did not see the same doctor on more than one occasion. Participants stated that the development of a long-term relationship was a prerequisite of developing trust in the GP, and therefore participants felt a lack of trust in their locum GPs. In the following excerpt (younger, Pakistani women), one participant responds to another’s complaint about locums by relating the problem directly to a lack of trust in the doctor’s ability to know about their individual medical history, as well the discomfort experienced in the patient–doctor encounter:

*Participant A:* People at my clinic have no idea who the doctors are. Today there is somebody else, tomorrow is somebody, there is no continuity.

*Participant B:* No, ‘cos if it’s a locum doctor, you’re not going to know him are you? If it’s just your normal doctor who see regularly then yes, you should be more comfortable yeah, because they know you, saying about what problems you’ve had before, but if it’s a locum doctor, he can just read the notes, they’re not going to, you’re not going expect him to talk to you much.

For many participants, trust was directly linked to familiarity with personal circumstances as well as with medical histories. These points were most vociferously stated in the three female focus groups, no doubt because of their more frequent uptake of GP services for consultations regarding their children’s health. In particular, many of the white and some of the younger Pakistani women made comparisons to experiences earlier in their lives when they had ‘a family doctor’ in whom they had trust. The

following excerpt from the white, female focus group highlights the changing nature of the GP over one participant's lifetime:

When I was younger, when our family, I mean I'm the eldest of five and we weren't the only family he looked after, soon as he came through the door, he knew you . . . He knew everything about us and it was the same with every other child in the road. And now, I mean, he probably doesn't even know where half the people live, or like what road they live on. (female, white FG)

The lack of an 'old-fashioned family' doctor is significant not only because it contributes to lack of trust in the GP, but it has connotations for trust in the GP's advice, diagnosis and prescriptions. In short, participants, particularly in the female focus groups, spoke of their ambivalence at accepting the advice of the locum GPs and their lack of 'compliance' with their recommendations. This can be seen in the following dialogue that took place in the focus group with white females:

*Participant A:* Never seen him before, never seen him before at all. Explained to him a little bit about what happened and he went, no word of a lie, 'what antibiotics do you want me to give you?' [raised voice] What antibiotics I wanted him to give me? . . .

*Participant B:* Well if I feel that I can trust the doctor to diagnose and treat whatever I have got or my daughters then I will be more inclined to do what he asks and take the medicine. If I don't trust what the doctor says then I will be more inclined not to take the medicine because I don't think it will make me better.

*Participant C:* They prescribed antibiotics and I said to 'em you can give them me but I'm not taking them. She gave me the prescription and I didn't even go the chemist to go and fetch them.

It is clear, therefore, that the combination of irregular doctors and the pressured nature of the consultation (because of time constraints) results in the alienation of patients from the consultation experience. This alienation heightened the issue of trust (or mistrust) for participants in the focus groups, who suggested the need to develop a positive inter-personal relationship before trust can be gained.

Pakistani men also expressed less trust in the expertise of their GP services. In a similar strategy to that of white women's comparisons with the past, unfavourable comparison was made to the health service and general health status in Pakistan. While such comparisons may reflect idealized nostalgia for both white women and Pakistani men, the existence of such negative comparisons indicates a general dissatisfaction with services which is likely only to be dissipated by improvements in regular GP services and, subsequently, increased levels of trust in the adequacy of current provision.

However, there was a significant gender difference in the specific emphasis given to aspects of, and interpretation of trust within, the GP relationship. For men, the existence of a regular GP was also important.

However, the relationship of trust was judged to be based more upon knowledge of medical history and perception of expertise rather than upon a personal relationship. Indeed, some white men dismissed the latter, stating it to be irrelevant to the quality of the GP service and one man remarked of a specific doctor that: 'It's just he's a bit on the brusque side that's all, he's fantastic' (white, male FG). Despite this lack of emphasis on personal characteristics, however, knowledge of medical history was seen as crucial to developing trust in the advice given. One male respondent had a particular experience whereby he had consulted a number of different locum GPs, which had subsequently led to confusion about his medication history at the hospital. He needed to complete a medication history sheet for the hospital, and a locum GP had not included all of the medicines he currently takes. He suggested that if he had a specific GP who knew him and his medical history, this problem would not have occurred.

Whether on the basis of medical or personal knowledge, then, the overriding narrative of participants in this study was one of a lack of trust in local GPs, primarily because they were generally locums with whom participants could not build up a shared history. This fits in very much with both Simmel and Giddens, who state that inter-personal trust can only be built up over time. In addition, it was also stated that a lack of trust in their GP had led some participants to be less confident about their diagnosis, less confident about taking their prescribed medicines and, in some cases, to not even get their prescriptions dispensed.

### **Institutional or systems-based trust**

In all of the focus groups, participants talked lucidly about what it was like to live in their locality and their experiences of under-investment and disinvestment in the area. Talk often centred on the depletion of local services (schools, job centres, community centres, advice centres and health care services) and 'broken promises' by agencies that offered to increase local jobs and decrease local pollution. While at first this did not seem entirely relevant to the discussion, it soon became clear that participants interpreted 'health' as a holistic issue and, therefore, directly associated it with other issues in their social environment. It was also evident that local people felt disillusioned, socially excluded and disembedded from what they saw as 'mainstream society' and that they were relating their experiences and perceptions of health services to this more generalized feeling. Therefore, any suggestion by the PCT of 'reconfiguring' health care services was seen with suspicion and distrust and was often regarded as a metaphor for 'cutting services'. As a direct result of the depletion of local services over the years, participants had developed widespread negative attitudes and a general lack of trust towards policy makers, government departments and statutory sector organizations. The following dialogue in the focus group with white men clearly reveals that lack of trust in health services has not

developed in isolation but is rather configured within a context of a general lack of trust in social services and in the politicians who are directly charged with their provision:

*Participant A:* We've had a school in [name of locality] close down . . . Err, we've had the [name of locality] Advice Service, which again is a valuable thing to a lot of people in [name of locality], that closed down.

*Participant B:* Yes, it's just opened again but it's not opened like it was before . . . But again, when it was being closed, we had all the politicians down, all promise, yes, we'll do something, we'll back this and we'll do this. As soon as the election had gone . . .

*Participant C:* Well, yep, but since then Labour's got in and it didn't get reopened to how it was before, but we've seen a lot of other things, other organizations come into [name of locality], have funding to do a specific job, run the course and then leave and [name of locality] been no better than when they came other than something's been looked at going to be done and hasn't been . . . Everything seems to have been like a carrot being put in front of you.

This dialogue highlights the negative experiences of social services by participants and, thus, may underline the reasoning behind their general and enduring levels of distrust, which are likely to translate to the local health services. In addition, it also highlights the importance of understanding the different domains within system-based trust, and its inter-relatedness with inter-personal trust. The lack of trust in locum GPs may be understood in terms of general lack of trust in systems and institutions, rather than solely a factor of a lack of trust in the medical system per se. While the PCT may have 'rational' reasons for reconfiguring local health care services, respondents suggested that local people have developed a widespread level of 'mistrust' which is based on their past experiences of dis-investment. While this mistrust is not specifically directed towards the PCT, there may be a need for the PCT to expend efforts on developing trust within the community.

One element of this distrust manifested itself in terms of negative or fatalistic attitudes about the provision of health services promised for the future. Respondents suggested that they have been promised improved and/or new services in the past, only to find that they do not materialize in reality. This difference between rhetoric and reality was encapsulated in the following quotation:

The meeting I went to, they were talking about having a dentist here, they were talking about having some kind of a chemist . . . they are talking about bringing other services in and it all sounds great in theory but the downside is, which as we've found out before, it usually finishes up being one less person than what we thought we were going to get. (male, white FG)

This person went on to suggest that while the PCT may promise new health services, facilities and personnel in the locality, local people are likely to

view these promises with suspicion and mistrust, given their negative experiences in the past. Participants were also ambivalent (and sometimes rather negative) about the actual impact on their health of reconfiguring health care services. This was particularly the case because of the holistic theory of health held by many participants, especially from the Pakistani community. A number of respondents suggested that attaining health was much more than simply taking their prescribed medicines or following medical advice. We have reported elsewhere (Ward and Coates, 2006) on the relationship between 'health' and 'happiness' in our study group. Therefore, in order to be healthy, respondents talked about the need for a cleaner physical environment (e.g. clean streets, parks and other public spaces), reduced traffic noise and pollution, reduced industrial pollution, more jobs and better local services (e.g. schools and advice centres in addition to health care services). In this way, respondents were referring to the primacy of a social (as opposed to purely biomedical) model of health. The observation of a lack of improvements to other services related to this model of health meant that trust in the combined efforts of all such services to deliver good health, whatever the configuration of health services specifically, was limited.

Therefore, while respondents talked about the current and future configurations of health care services in the area, there was a recognition that any future primary care services should be seen in this wider context. Indeed, given the importance of wider influences on health, it was suggested in the Pakistani male group that changing the configuration of health care services alone may have little affect on the health of residents:

So, basically, if the Primary Care Trust can't change the environment, I mean, to me personally, this is a waste of time because I will live in the environment for so long and then I will have to run away from it. If the environment is killing us slowly, then there's no point me personally being here talking to you saying I want a good doctor. A good doctor will give us medication, help us to die slowly but will not increase our lifestyle. Correct! (male, Pakistani FG)

## **Discussion**

The notion of trust 'existing' at different levels was partially substantiated in this study. Participants talked about the importance of both interpersonal trust (and mistrust) and trust in more 'abstract' systems. However, the trust that people developed (or lacked) in systems could not be conceptualized in a one-dimensional manner (it was more like the layers of an onion or in Luhmann's terms, related to multiple social systems). Participants had developed distrust of institutions and organizations at all levels of state bureaucracy (from local PCT, to Local Education Authority and the City Council, to the Environment Agency, the Labour government and the capitalist system in general). Therefore, we need to reconsider the two-layer conceptualization of trust.

In addition, Giddens (1990: 27–8) suggests that our trust in individuals lies in the authenticity of the expert knowledge they apply. Therefore, trust in GPs in this study would merely be a factor of participants' trust in medical knowledge, the medical system or even medical science. This was obviously not the case. Trust (or lack of it) in GPs was bound up in a wider sense of mistrust of local and national government organizations, in part related to a sense of lack of personal attachment, in addition to political and economic systems in which they are seen to be based.

We wish now to turn to wider debates about the relationship between trust and reflexivity, given its contemporary importance in academic debates. We wish to temper the trust-reflexivity dyad with the notion of dependence. In our view, and the view of others (Lupton, 1997), dependence on medicine and medical practitioners acts as an intervening or confounding factor on the way in which reflexivity and reflexive modernization affect trust.

### ***Trust, reflexivity and dependence***

While this study highlights the reduced levels of trust in GPs, the medical system and wider institutions of government, this does not necessarily result in widespread rejection of medical knowledge or in patients no longer consulting GPs. Participants in the study still consulted their GPs, even if they did not always follow their advice. This 'dependence' on GPs (and the medical system which underpins them) may be seen as an antidote to the wholesale adoption of 'reflexive actors' who are willing and able to challenge the dominant expert authority. We draw here on the work of Lupton (1997) who eloquently critiques both Beck and Giddens in terms of their over-privileging of the notion of reflexivity. Lupton suggests that both Beck and Giddens do not fully acknowledge the 'dependence [that] patients may have upon doctors' (1997: 380) and that the reflexivity (in terms of process and outcome) may lead to 'undermining the very trust and faith that very ill people seek in the medical encounter' (1997: 380). Lupton raises a number of extremely pertinent points, which require elaboration in the context of the current article.

First, Lupton highlights the potentially asymmetric relationships between trust, dependency and reflexivity. While Giddens suggests that as individuals have become more reflexive, they have begun to question their trust in individuals and institutions. As such, Giddens argues, we have seen a reduction in the levels of trust throughout society. However, as stated earlier, this does not take into account the dependency that people have on their GPs and the medical system at large. In terms of dependence on GPs, the notion of being a 'good', 'compliant' patient seems important. Ehrenreich and Ehrenreich (1978) discuss the importance of being a 'good' patient, who does not question the knowledge or authority of the doctor, and if they attempt to do so, Ehrenreich and Ehrenreich found that they may receive comments such as 'Where did you go to medical school?' or 'You'll have to find another

doctor'. While their work is more than 25 years old and we have seen an upsurge in consumerist publications and policy documents, it is unlikely that the following statement is wide of the current mark: 'it is a manifestly benevolent relationship [between patient and doctor]: disobeying a teacher or boss might be seen as gutsy, but disobeying a doctor can only be construed as irrational' (Ehrenreich and Ehrenreich, 1978: 60).

While participants may well talk about lack of trust during focus groups, this did not necessarily bear relationship to their actions when they become ill (or one of the friends or family become ill). For example, participants still consulted with their GPs and did not actually talk about particular instances where they actively 'challenged' their GP. Participants often recounted occasions when they questioned the views of the GP (although they rarely did this during the clinical encounter), did not take their medicines as prescribed or even did not get their prescriptions dispensed, but these may be seen as forms of passive challenge. One may expect that a lack of trust in the advice of GPs would lead to active challenges to their authority, and that participants would recount these during focus groups. However, we need to bear in mind the disenfranchised, disempowered nature of the participants in this study. Indeed, it has been suggested (Lupton, 2003) that social class may influence patients' motivations to challenge their doctors and resist medical dominance: 'those who are socio-economically disadvantaged have less access to education, resources and such publications as consumer guides compared with people of greater socio-economic advantage' (2003: 125). In this way, Lupton argues that disempowered individuals, such as those in this study, may be less likely to challenge their GPs, even though they may have little trust in them.

In addition, the notion of reflexivity may well be socially patterned, whereby certain members of society may have access to wider forms of information or possess certain forms of capital (in Bourdieu's terms) to enable the space for reflexivity. The move to late modern society has been accompanied by an information explosion, with some commentators suggesting that we now live in an 'information society' (Webster, 2002). The Internet allows people to traverse boundaries between different knowledges, professions and practices, and provides a medium for the new 'medical pluralism' (Cant and Sharma, 2002). Studies have shown how the use of the Internet has increased patients' knowledge about health, illness and medicine (Hardey, 1999) and may impact on the doctor-patient relationship (Broom, 2005). However, even if access to information on health is democratically increased throughout society, the effects of its access are unlikely to be socially neutral. Reams of sociological writings have shown how health beliefs/knowledges/experiences are socially patterned, and new sources of health information are unlikely to ameliorate these long-standing effects. Indeed, Shilling (2002) draws on the work of others (Bourdieu, 1984) to state that 'different patterns of socialization

result in class-based orientations towards symbolic knowledge which affect the degree to which the social world is seen as open to individual intervention' (Shilling, 2002: 634). In addition, it has also been suggested that 'knowledge does not empower to the same extent everyone who possesses it, while the organisational power of the medical professional also means that many individuals experience themselves as being on the receiving end of "knowledge transfer" from health professionals' (Fuller, 2000: 28). Therefore, the whole notion of the 'body project', 'lay re-skilling' or the 'project of the self' needs to be seen in this class-based analysis, whereby it may only be those with the financial resources, time and cultural capital who are most likely to 'act' on their mistrust by challenging medical authority.

## **Conclusion**

Findings from our study in a materially deprived locality highlight the centrality of a discourse of mistrust, which was presented at a number of inextricably linked levels and related to multiple social systems. While participants talked about their lack of trust in local GPs, this could not be disentangled from their mistrust of the local and national health care system or wider social systems. This fits neatly with Giddens' ideas of the links between the local and the global: 'the local community is not a saturated environment of familiar, taken-for-granted meanings, but in some part a locally-situated expression of distanced relations' (1990: 109). This was very much the case for the community in this study.

Our study included a mix of 'white' and Pakistani participants, although we did not find any major differences in terms of (mis)trust of authority. While we thought this may have been the case, with hindsight, it is not entirely unexpected, given their shared histories of living in the same locality over many years. The disinvestment, loss of services and 'broken promises' have affected everyone in the locality, rather than having differential impacts. However, this may not be the case in other localities, where policies and actions may have differential effects. We did find some differences in terms of gender, although any conclusions would be difficult from this study. Therefore, we would suggest the need for further research into the relative influences of ethnicity and gender on (mis)trust.

At the level of inter-personal trust, participants talked about the necessity of developing a relationship with a GP in order for trust to be 'built'. This 'relationship' would necessarily mean that the GP had a good understanding of the health, family and social history of their patients. Participants often juxtaposed their current GPs with 'old-style family GPs', although this may be a nostalgic representation rather than 'reality'. Nevertheless, in this locality, many of the GPs were locums with whom a relationship, and hence trust, could not be built. This lack of trust in their GPs had led many participants to question the validity of GP decision making, in terms of diagnoses, management plans and prescriptions. In addition, a number of

participants recounted occasions where problems were encountered as a result of the locum GP not knowing their medical histories.

On its own, the lack of trust in locum GPs *may* have a fairly simple remedy: the PCT could seek to employ salaried GPs with whom local residents could begin to develop relationships. However, participants talked about lack of trust and distrust in organizations, systems and institutions which have remits and roles much wider than individual GPs, local PCTs or even the health care system as a whole. Participants had experienced a shared history of disinvestment in the locality, loss of services and of 'broken promises' by a range of organizations and institutions, which led to a general scepticism and distrust. This was not aimed at any specific individual or organization, but seemed more like a pervading dimension of life in the locality. Feelings of social exclusion and disembeddedness went hand-in-hand with feelings of mistrust. To compound this, participants felt that their voices are not heard and have not been taken seriously in the past: 'we shed tears, but there's no one to wipe them up for us' (male, Pakistani FG).

On one level, our findings may be interpreted as being rather pessimistic for the future. It seems that in order for local residents to gain trust in GPs, the medical system and in authority in general, joined-up action is required involving a number of local and national agencies. This may be a long-term, and rather utopian view. However, in the shorter term, one way of fostering more trust within the local community would be for the PCT to act as advocate for the local community, which may also develop feelings of social inclusion.

### Notes

1. The terms 'Pakistani' and 'white' are used throughout this article – it is recognized that Pakistani refers to a place of origin, whereas 'white' refers to a racial group. Both authors are fully aware of the difficulties of using these mixed terminologies and also of using a term that refers to race rather than ethnic group, although they are used in this article to reduce complexity in the text.
2. The authors recognize that the term 'modernity' (in relation to descriptions of societies in the industrialized world) is by no means an undisputed term. However, we employ it here because of its wide usage in the theoretical literatures to which we refer.

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