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## EDITORIAL FOREWORD

### Jude Robinson

This year, and for the first time since launching Medical Sociology online (MSo) in 2006, we will be producing three issues of MSO: partly because of the need to publish articles in a timely manner, and partly to include the feedback from the last (2007) BSA Medical Sociology Group Annual Conference.

In this edition, we have two papers that explore some of the issues involved in the conduct of research, specifically the negotiated, situated and at times intensely personal aspects of research ethics that are often overlooked by those who devise application forms for researchers to gain approval from NHS and/or university ethical committees. Completing such application forms requires researchers to consider the potential of their proposed research to cause participants any emotional distress. Yet, as Jackie Watts' paper highlights, this approach effectively ignores the researcher's own emotional involvement with the participants in the study, and the emotional distress that they, rather than the participants, may be experiencing. Also the paper by Minnie Sample and Richard Tutton considers how studies that do 'detach' the researchers from the researched, and comply more readily with the bureaucratic and quasi-legal codes of ethical conduct (my words), can leave the 'researched' feeling less than happy with their experiences.

In her paper entitled: 'Emotion, empathy and exit: reflections on doing ethnographic qualitative research on sensitive topics' Jackie Watts explores how, through her research in a cancer drop-in facility in a community hospice trust, she extended the reflexive position embedded within ethnographic methodology to question her emotional relationship with the people she was studying. By considering how this 'emotional work' affected the data she collected for her study, she offers an insight into how researchers can explicitly relate their social and emotional links to participants by using 'mutuality as a form of ethical research practice', while reflecting on the need for balance and 'emotional protection' for researchers. This 'mutual' approach challenges other paradigms that seek to eliminate or downplay the researcher's personal feelings as potential contaminants to the research process, by explicitly incorporating them as an essential component of data collection, thereby extending the feminist approach to research that refers to interview data as co-constructed accounts, rather than simply as 'data'.

The paper by Sample & Tutton, is also an intensely personal account of a researcher's embodied experience of their taking part (as a participant) in a funded research project. This first-hand account is unsettling, as it questions many of the taken for granted ways that participants are treated during the course of apparently routine and unproblematic data collection. One example presented by the authors highlights how the use of a term such as 'overweight', which acts as a useful descriptor of the physical condition of a 'body', may become transformed into an emotionally charged label when heard by the 'person' within that body. Yet, as the authors demonstrate in their account of a (non) discussion about hypertension, this particular research project does not seek to understand how the 'results' of the research are rationalised, interpreted, acted upon and explained by participants. In the instance of hypertension, the author describing their experience tells us of the frustration and embarrassment they experienced when their attempt to try to engage on a more social and emotional level to discuss the test result was effectively rebuffed, and she became silenced.

The 2007 conference was held at the Adelphi Hotel in Liverpool in 2007, in anticipation of the 40<sup>th</sup> BSA Medical Sociology Group Annual Conference, to be held at the University of Sussex, Brighton, UK, on Thursday, 4th to Saturday, 6th September 2008. <http://www.britsoc.co.uk/events/msconf.htm>. As the move to a hotel venue in 2007, in particular the choice of the listed building of the Adelphi in Liverpool, was a major departure for MedSoc, for the first time the BSA Medical Sociology Group Committee invited feedback from the participants. The article 'What's so good about MedSoc conferences?' represents a

summary of the comments received, and it is clear that the MedSoc conference continues to offer a unique opportunity for medical sociologists working in different organisations, in different countries, and at many stages of their research careers, to come together in a friendly, intellectually stimulating environment, to talk about developments in their field.

The feedback also highlighted the need for all venues to offer a high standard of accommodation for disabled attendees, as even after two site visits by the MedSoc committee, numerous telephone calls, and having received repeated assurances from the Adelphi Hotel, on the days of the conference in September the hotel's provision for disabled attendees was deemed inadequate. However, for this year's conference in Brighton, the MedSoc committee has continued to take measures to ensure that that the University of Sussex will meet the standards we all require, and are confident that no-one's enjoyment of the conference will be impaired by poor access, poor signage, or poor acoustics.

We hope you enjoy reading this edition, and if you have any comments, or would like to contribute to the publication, please email the editorial team on [MSo@liverpool.ac.uk](mailto:MSo@liverpool.ac.uk). If you would like to submit an article for peer-review to Medical Sociology online, please use the link: <http://www.medicalsociologyonline.org/submissions.html>

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## PEER-REVIEWED ARTICLE

# Emotion, empathy and exit: reflections on doing ethnographic qualitative research on sensitive topics

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### ABSTRACT

Within ethnography, observation and participation are interwoven as sociological research practice that involves watching, listening and asking questions about people's daily lives and experiences, and the meaning they attach to these. For ethnographic researchers a close and regular engagement with participants raises both practical and ethical challenges related to intrusion, relationship boundaries and issues of 'attachment' on leaving the field. Research that has the added dimension of profound sensitivity may also present the researcher with the challenge of managing the impacts on them of emotional stress caused by watching people's discomfort and suffering. This article discusses the author's methodological reflections on an ongoing ethnographic study of a cancer drop-in centre, focusing on the ways in which emotion and empathy shape researcher-respondent rapport. An underpinning theme of the discussion is the potential for emotion deluge and fatigue on the part of the researcher and the consequent need to establish self-care strategies.

### KEYWORDS

Cancer, emotion, empathy, ethnography, participant observation

### Introduction

This article is a methodological reflection on some of the ethical and practical dilemmas of qualitative health research on sensitive topics with potentially vulnerable participants. The context for the discussion is an ongoing long-term ethnographic participant observation study of a cancer drop-in facility run by a community hospice trust in the South of England. Dickson-Swift et al (2006: 853) argue that qualitative health researchers immerse themselves in the settings they are studying and it is this aspect of 'immersion' that is central to the critical reflections on process and method that continue to engage the author in the ongoing conduct of this research. Much comment in this area has tended to view sensitivity within research primarily as an ethical issue (Alty and Rodham, 1998), particularly its effects on research subjects that Rager (2005) contends are generally well protected by research protocols. The effects on researchers, however, have been less well documented, with some commentators (Sword, 1999; Dickson-Swift et al, 2007, for example) calling for a closer scrutiny of the emotional elements that contribute both to the conduct and output of research in sensitive domains.

The possibility that emotion, as well as reason, can be privileged within the research process to positively contribute to high-quality outputs is the position taken by Gilbert (2001a). She argues that 'it is an awareness and intelligent use of our emotions that benefits the research process' (Gilbert, 2001a: 11) contrasting traditional approaches of managing,

avoiding or making invisible emotion in pursuit of 'good' research, with the claim that it is dishonest for a researcher *not* to draw on their own emotional experience in the telling of the research story. However, for inexperienced or lone researchers working on sensitive topics, this opportunity for positive integration of their emotional responses as part of the epistemological process may not be feasible, particularly if they are experiencing emotion fatigue and are working with little support or supervision (Gilbert, 2001b; Johnson and Clarke, 2003; Rowling, 1999). Because the traditions of science, that adopt the dispassionate language of researcher neutrality and objectivity, have dominated the early development of sociological research, researchers have been enjoined not to feel but to think (Campbell, 2002: 16). This is the mantra of purist positivist research that remains difficult to reject in favour of personal and individual perspectives that are theoretically unpopular and subject to suspicion and sceptical scrutiny by large parts of the academic research community, particularly those working in the medical, physical and engineering sciences.

Ethnography is one qualitative research approach that deliberately sets out to place the person of the researcher, including their emotional and affective experiences of research (Campbell, 2002: 123) and the personal experiences of research subjects, as central to the research endeavour. It seeks to report what is observed and transacted in the field, recounting what was said and done and why events occurred. It is a highly interpretive method and does not claim to represent truth, in any positivist sense, but rather offers accounts of social phenomena that are filtered through the subjective and personal experience of the ethnographer. And it is this approach that is felt to be the most appropriate for the goals of this study.

The discussion begins with a brief review of some of the recent literature on methodological aspects of researching sensitive topics, both within and outside the health-related field. This will be followed by information about the study, drawing out both the variegated features of an insider researcher presence (Labaree, 2002) and the ongoing nature of the research to highlight the 'preliminary' character of the reflections recounted herein. The next three parts of the article will consider the constitutive effects of emotion and empathy work on the reflective practice (Finlay, 2002) of building rapport, gaining trust and on the blurring of boundaries compounded by the presence of the researcher in multiple guises – as volunteer, researcher and participant. The need for emotional capacity building on the part of the researcher, as a particular form of emotional labour that provides underpinning theoretical insight (Hochschild, 1983), emerges as a key theme. The issue of departure, both from the perspective of the researcher completing phases of the research and 'leaving' research subjects and, in this context, the withdrawal of research subjects through deteriorating health and, in some cases, their death as the final leave taking (see Kellehear, 1990) raises particular emotional concerns. The ethical implications of researching sensitive subject areas are considered (Rosenblatt, 1995) in relation to both researcher well-being and to leaving the field with 'unfinished business' remaining (Burr, 1996: 172), which has the dual perspective of impacts for both researcher and research subjects.

### **Qualitative research with vulnerable subjects**

The notion of vulnerable subjects within qualitative ethnographic research traditions has been widely documented (Liamputtong, 2007). Kontos and Naglie's (2006) application of the performance paradigm to the care of Alzheimer's sufferers, Campbell's (2002) critique of the emotional impact of researching rape, Enosh and Buchbinder's (2005) focus on narrative styles within domestic violence research and Jacobsen's (2005) exploration of the potential for a very broad inclusion in the category 'vulnerable' within social research, are recent examples. Less saliently vulnerable subjects are those identified by the researcher to be at low risk of negative effects from research participation but, because of the unpredictable nature of much qualitative research, these too can be adversely affected by the conduct of research (Watts, 2006).

Much of our understanding in this area is drawn from the feminist canon, which has

highlighted the complex theoretical and practical dilemmas of qualitative research that seeks to retain participants' voices within the epistemological process. Researcher sensitivity to issues on a number of different levels is a feature of feminist enquiry that makes public the private and intimate experiences of women in their roles as workers, partners and carers (Edwards and Ribbens, 1998), and engagement with this literature has been an underpinning influence on the author's standpoint in respect of this study. Furthermore, acknowledgement of the researcher as an active agent in the production of knowledge has been central to feminist writing, rejecting as it does the supremacist claims of positivist knowledge that for many years was dominant in sociological enquiry. Sword (1999) develops this theme to argue that much qualitative research is personal work, with the researcher having a vested interest in the research topic that will inevitably influence the data produced. The sense that 'detached concern' (Fox, 2006: 944) is either realistic or necessary for the effective conduct of sensitive research has been widely debated (Fox, 2006; Rager, 2005; Dickson-Swift et al, 2007) and it is the contention of this piece that emotion work may constitute what Katz and Mishler (2003: 35) describe as 'one of the many ways to do qualitative research' in the field of medicine and health care.

Although there is potential for significant emotional distress for all parties engaged in the various domains of sensitive research, this does not necessarily lead to damage and, as Corbin and Morse (2003) argue, it is the skill and ethical awareness of the researcher that may be pivotal in yielding benefits to both the researcher and participants from the process. The's (2002) experience of using ethnographic research methods to monitor the illness trajectory of lung cancer patients in the Netherlands reveals that treading the narrow path between researcher detachment on the one hand and personal involvement on the other can allow for flexible research practice that maintains both participant and researcher congruence in the face of compelling emotional demands.

### **The aims, setting, method and subjects of the study**

The aim of the study is to explore how both cancer sufferers and cancer survivors (included in this category are those who have been bereaved through cancer) make use of a community cancer drop-in facility operated by a local hospice trust located in the South of England. It focuses on the reasons people give for coming to the centre and how they make sense of the support they receive particularly in relation to ongoing treatment. This is my first experience of conducting research on sensitive topics with my earlier work focused on the very different world of the built environment sector (Watts, 2006; 2007a). It is intended that research findings will contribute to a review of the drop-in service as it develops and attracts wider take-up of its provision.

I have been drawn to this topic of enquiry because of my professional role as a death studies educator but also because of my life experience that includes early and unexpected multiple losses. I am not in any sense an impartial observer and bring to the research my own issues connected to my inherited history. Specifically, when working with participants I look to my inner self and my fears, searching for comparability of experience. Questions of shared feelings nag at me because I am troubled about my own relationship to what I want to learn. This concern is difficult to articulate but is rooted in what can best be termed as an unspoken hierarchy of 'authentic' fear with my anxiety about being a potential cancer patient in stark contrast to the reality of the daily lived fear of participants. This negative emotion, that I feel unable to voice within the research setting, has prompted much reflection on the issues of loss and suffering, particularly the nature and experience of suffering that Cassell (2004) argues occurs when a person is confronted by their impending death. This leaves me to speculate about how I would react to cancer in my family. How well would I live with a life-limiting illness? These questions and others preoccupy me, and my research journal indicates that any sense of belonging that I have with the participant group is based on my own fears about pain, loss and death. This is shared and I am vulnerable too. A further question is relevant; does my fear obstruct or influence the data gathering and analysis? The latter is only at a very

early stage but the data collection is ongoing and there have been moments when I have not wanted to hear any more from those at the drop-in. This clearly suggests that I am exploring these issues and interpreting the data through the prism of my own biography with my emotions and fears constantly shaping the data.

The drop-in centre offers twice-weekly afternoon sessions with variable numbers attending although a group of roughly ten 'regulars' on both days seem to constitute a core group. There is a very wide age range represented amongst users of the facility with the youngest currently being thirty-two and the oldest, eight-eight. Proportionately there are more women than men who use the service and nearly all the volunteers are women. The centre has a manager and fundraiser, with informational and practical support provided by a team of dedicated volunteers, a now well-documented and familiar feature of the cancer landscape (Lawton, 2000; Armstrong-Coster, 2004). The volunteer efforts of a range of health and therapy practitioners contribute to a portfolio of different treatments available to users of the drop-in, with reflexology, Indian head massage and aromatherapy being the most popular.

Initial contact with the centre was by serendipity, through engagement with the work of the local voluntary sector in an unrelated area. The opportunity to visit the centre and become an informal volunteer helping with social aspects of the drop-in sessions was a pre-cursor to the researcher role and this has now been ongoing for six months with a further twelve months projected. It is this volunteer function that has shaped the participant observer role and has been the key influence in determining method and framing an insider approach to data collection (Watts, 2006). The methods being used are a mix of participant observation and informal (Hammersley and Atkinson, 1995: 139) and guided (Mishler, 1986) conversations with users of the twice-weekly drop-in sessions. Because these interactions are not interviews in the accepted sense, audio-recording of these is neither possible nor appropriate, particularly given the public space in which they occur and the associated ethical concern of confidentiality. Also, some of the data is drawn not from conversations between participants and myself, but from listening to talk between group members and from watching their body language. I can recall the clear discomfort shown by one man as one of the younger female group members, with advanced breast cancer, described the detail of her continuing bouts of sickness during ongoing chemotherapy treatment. He was physically squirming in agitation in his chair and his unease was almost palpable. I later learned that his chemotherapy treatment was soon to begin. These observational elements of the research are illuminating and this confirms Jones and Somekh's (2005) claim that observation is an important, but often under-rated, method of data collection. The making of detailed notes in the form of a research journal (Rager, 2005) constitutes the documentary data and a narrative approach to data analysis, following a broadly grounded theory paradigm (Glaser and Strauss, 1967), will inform the analysis.

Following approval from the management committee for this study I set about planning the ethical framework for the conduct of the research, with particular initial attention directed towards the issues of confidentiality and anonymity for participants. Concerns, however, about ethical rigour in the design and conduct of this research have, as the research has got underway, centred on the issue of informed consent and have been experienced as far from straight forward. Asking individual participants to sign consent forms, as one way of acknowledging the researcher aspect of the author's presence, has not felt very meaningful. Instead, a brief outline statement of research interests has been made available at the sessions and, as part of interaction with new users of the service, taking care to refer to research as well as volunteer features of my role, has contributed to ethical conduct. That said, I am still not fully confident about the ethical aspects of the research, not least because the volunteer self appears often to overshadow the research self, with the latter appearing to be of minimal relevance to participants who, unlike Peel et al's (2006) participant sample, demonstrate very scant interest in the enquiry. I am, therefore, currently exploring ways of raising the researcher profile to strengthen the ethical dimension of the study, with the intention of reporting on these, along with the research findings, once the study is complete.

The language that outlines the context of the research and methods used is deliberately framed in the present tense. This is because the methodological critique presented is a reflection on work in progress rather than a comprehensive synthesis of research completed. The discussion that now follows is an attempt to engage the reader primarily with continuing methodological concerns rather than with emergent themes from the data: that would be premature and may well form the subject of future writing.

## Emotion

Pitts and Miller-Day (2007) suggest that the development of rapport with their participants is a priority for empirical researchers in the field and Gaglio et al (2006) argue that this is an essential component of successful qualitative research in the health care sector. A further consideration, however, is that rapport is mutually constructed between those who can empathise with each other and is developed through a willingness of each to look into the world of the other. The subject of cancer can be emotive, evoking as it does a sense of one's mortality (Morris, 2001; The, 2002). An ethnographer getting to know participants and building rapport in the context of what, for some, is their dying is not an emotion-free endeavour. What, for this research, has been the most emotionally challenging aspect has been participants' telling and re-telling of their cancer stories, often in very raw terms as 'wounded story tellers' (Frank, 1995), with dependence on, and an almost desperate loyalty to the professional role of medic, rather than to any individual doctor or physician, clearly evident (Kellehear, 1990). This tenacious and powerful faith in medical treatment seems to be unshakable even in the face of advancing disease.

In the case of participants either with active disease or in remission (only two thus far have described themselves as recovered from cancer), the story begins with a narrative describing their symptoms that led to diagnosis and subsequent experiences of treatment regimes, hospital visits, continuing medication and the uncertain and non-linear path to remission. Armstrong-Coster (2004) found a similar pattern in her ethnography, with participants displaying a particularly heightened recall about the first presentation of symptoms and all the emotions these raised. The emotion that has dominated participants' narratives in this study is fear, and their dread of what is to come has been almost tangible and, for some, brings an attendant need for reassurance that, as one participant put it, 'it's all going to be all right'. The seeking of reassurance is emotionally distressing because whatever response I give, it will not be the one they covet which is the promise of cure and the certainty of longer life. Whilst they continue to hope I am sometimes laid low in spirit and my enthusiasm for this research work is temporarily diminished. This leaves me questioning whether, despite now regular attendance at these sessions, I can even begin to enter their world of cancer that feels like a very distant land.

Although a majority of users of the cancer drop-in are supported by friends, family and neighbours, the most striking feature of accounts to date has been the isolating effect of cancer. The sense I have of their 'aleness' in dealing with the physical and social reality of the disease has been very powerful and is illustrated by the following comment from one participant 'You can't keep talking about it to people, can you? You just have to get on with it the best way you can'. This awareness of the ways in which cancer separates has been difficult to deal with and respond to. At times I have found myself 'walking on eggshells', as both a listening and a feeling agent, in the narrative encounter and specifically in the co-constructing of positive possibilities even in the face of some participants' rapidly deteriorating physical and emotional bodies. Central to this has been the realisation that it could so easily be me, or my loved ones telling the cancer story, and it is this inescapable sense of cancer as a lottery, in which my emotional reactions are rooted. This has given rise to feelings of guilt and disappointment at what I have come to regard as my own emotional self-centredness. On one occasion I can recall the compulsion to retreat from the research engagement altogether, feeling overwhelmed by feelings of threat to the ontological security of myself and 'mine'.

Elsewhere I have written about the personal within death and dying education (Watts 2007b) but I now also have an appreciation of the emotional impacts on the person of the researcher working with those who are dying or living with life threatening illness. In this emotionally charged terrain I find it difficult to see how researcher detachment (Fox 2006) can be maintained, particularly within ethnographic research conducted over a long time span and through which attachments are formed and friendships made. Thus far the impact of emotion on me as the researcher has caused me to consider that emotional engagement, far from undermining or devaluing research practice, may authenticate it in ways similar to the positive effects of emotion work in some aspects of palliative care nursing practice (Li and Arber, 2006). Emotions act as a 'doorway' to the inner terrain of people. This 'doorway' can be open or closed and in respect of this research it has been mostly open, enabling me to feel with participants some of their anxiety. On one occasion, for example, I found myself worrying with a participant about a forthcoming scan they were due to have and this seemed to result in a co-constructed emotional space where we both could begin to talk about some of the most difficult 'what ifs'. Within highly sensitive research of this kind, without a shared emotional space that offers the possibility of trust, a shared narrative space may be difficult to establish.

Authentication derives from an understanding of the data that is informed by the emotional exchanges between the researcher and the researched, which includes elements of self-disclosure on the part of the researcher in the creation of a shared narrative space (Liamputtong, 2007: 72). Emotional difficulties experienced by participants in telling their stories with, for example, tearful episodes and problems with fragmented discussion of events, have alerted me to significant aspects of accounts that I may have overlooked without this emotional engagement.

## Empathy

Empathy is closely connected to emotion work in developing and sustaining rapport within qualitative research relationships. The instrumental application of a rapport model to interview methods, in particular, has provoked debate about the ethical issues of sincerity, friendship, reciprocity and the commodification of emotion or human feeling within sociological research (Duncombe and Jessop, 2002). Such concerns extend to methods beyond interviewing and have relevance for ethnographic observational research where trust is built between researcher and participants over time and becomes the basis on which disclosures are shared in an atmosphere of safety. This safety, however, may hold dangers for participants, particularly those who are vulnerable and not fully cognizant of the research in which they are a player. Safety can also lure the researcher into investigator behaviours that are intrusive, breaching participants' right not to be made aware of their innermost thoughts and feelings (Duncombe and Jessop, 2002). During the past six months I have observed the stamina of participants' optimism that is at the root of recovery narratives, which serve as a refusal to die. With one participant, an eighty-year-old woman, this intransigent optimism has been sustained despite her obvious increasing frailty. Her ability to attend the drop-in underpinned her engagement with what I see as 'relative hope' epitomised by the phrase 'I come because I can'. I perceive relative hope as a group metaphor for continuing survival and one that is shared by all participants. The temptation on my part to interrogate the rationality of the phenomenon of relative hope is prompted by both safety and familiarity within the research relationship but is tempered by an understanding that relative hope is all that remains of the future for some attendees at the drop-in. Whilst not yet having a full grasp of the meanings that may attach to this concept, it nevertheless is proving useful for building understanding of what Coreil et al (2004: 905) term 'member-group fit'.

Empathy behaviour has both verbal and non-verbal components and I have found each to be significant in different ways; for example, the power of touch to ease emotional distress is a technique I have used to settle participants in their story telling, which they often find stressful and painful. For me this creates a further connection to participants and their

embodied discourses of illness. The careful use of language that reflects the needs and preferences of this research population (Thulesius et al, 2003) together with maintaining eye contact with them are the combined techniques I use to 'do' empathy, which I understand to be the giving of one's whole attention as committed presence, being alongside, with the ability to feel with the other (Liehr, 1989). Listening with concern and compassion but without judgement and absorbing the feelings of others are further features of my empathic approach that are centred on the participant rather than on me as researcher (Campbell, 2002:138). As the study has progressed my research journal reveals that I seem to be doing much less of the talking and less direct questioning of participants. Initially I think I would have found this troubling, feeling that I was not sufficiently focused on the goal of data collection; now, however, I am conscious that participants often seek me out to tell me how they are getting on with their lives, which often seem to involve crisis and profound anxiety. When uncertainty and exhaustion combine under the weight of fear about the future, the reliable presence of someone genuine, warm and empathic can provide a useful counterbalance (Egan, 1990). This leads me to reflect on the ways in which empathy and emotion can be seen as instrumental tools of both data collection and analysis in researching sensitive topics. Also, I now recognise that feelings (both mine and participants') can be reconceptualised as a form of data to be analysed as part of the research process. This includes the possible impacts on participants of disclosure of my own personal life experiences (Liamputtong, 2007), producing an interwoven assemblage of individual subjectivities.

One impact of empathy and the associated trust placed in me by participants has been a heightened awareness of my epistemic responsibility that points to the need for boundaries (Dickson-Swift et al, 2006) that Gilbert (2001a: 12) argues involves 'maintaining a clear internal sense of difference from the other'. My experience has been that this also involves creating a sense of emotional balance, taking care to be close, but not too close, to participants, ensuring that I can retain the filtering and distilling functions that are core to the agency of the qualitative researcher when conveying the stories of participants. Added to this, it is useful to be aware that boundaries in ongoing research relationships are not static but may shift over time as a function of the changing personal circumstances both of the researcher and participants. The propensity for friendship arising from regular contact between researcher and subjects in qualitative social research is a boundary issue and one that has been discussed in the literature (Duncombe and Jessop, 2002) in relation to both temporary (Gilbert, 2001a) and simulated friendship and the power balance present in research with sensitive subjects that usually operates in favour of the researcher. Empathy is not synonymous with friendship and avoiding false or insincere friendship contributes to ethical research conduct.

My final reflections on this topic consider the view that it is shared experience that promotes empathy and rapport (Duncombe and Jessop, 2002). Those whom I encounter at the drop-in appear to have their cancer experience as the current key signifier of their identity. That is why they are there, to act out their cancer role in a dedicated legitimate space. If shared experience is the determinant of empathy then someone who has not been affected by cancer will struggle to empathise with those who have. I have been puzzled by this proposition and this has prompted me recently to settle on an alternative, more satisfactory, understanding of empathy encapsulated in the phrase 'empathy is what someone *is*, not what someone *does*'. Its intrinsic attribute is relational. It is an intuitive connectedness to others that, without words, communicates interest in and care about others. This meaning of empathy rather contradicts my 'doing' of empathy described above but is one that, as the study progresses, I am increasingly more comfortable with and may well explain why I find myself doing less of the talking and questioning as discussed above. Within this paradigm empathy is not a learned behaviour but is the intuitive relational self, rooted in an affirmative disposition of being that is difficult to deconstruct, yet which most of us are able to recognise when we meet it.

## Exit

Discussion in the literature about ethnographers completing their fieldwork and having to halt interaction with their research subjects has centred on the possible impacts for participants from what could be seen as a form of harm or exploitation, with a focus on implications for responsible ethical practice (Taylor, 1991). Focusing on impacts on researchers, Stebbins (1991) poses the question of whether researchers ever actually 'leave the field' in relation to the often lasting emotional consequences of working with sensitive topics. For this discussion, however, it is the impacts on the researcher of the curbing of relationships that provides the focus, particularly possible implications for the depth of engagement with participants as the study develops. The need to keep in view that the well-being of the researcher is just as much an ethical concern as that of participants is apposite, as is the need for reflexive approaches that contribute to what Doucet and Mauthner (2002: 141) characterise as 'situational ethics'.

Although this study has not yet even reached the half way stage the issue of exit has already presented itself in a number of ways. Soon after my volunteer work had begun I was away on holiday for three weeks and, on returning, was told that two of 'the regulars' had died and a third had weakened and was finding it difficult to attend the drop-in sessions. This unexpected news was saddening and, despite the psychological preparation I had made in anticipation of these losses over the period of the study, the sense both of the anguish for the bereaved families, and of seeing cancer as an emotional roller coaster, was very profound giving rise to 'compassion stress' (Rager, 2005: 423). As a lone researcher, there is limited opportunity to talk through my feelings at a peer debriefing (Sampson and Thomas, 2003; Rager, 2005) and this has made me aware of the importance, within sensitive qualitative research of this kind, of self-care strategies and establishing a support network where feelings of distress can be unloaded. The possible usefulness of accessing professional support by researchers experiencing emotional distress is addressed by Corden et al (2005) whilst Hubbard et al (2001) identify the benefits of research teams in this regard, highlighting the ways in which these can provide a safe shared space for taking seriously the negative emotional effects of research. In the case of this study, the manager of the drop-in sees emotional support for volunteers, as well as for users of the service, as part of her responsibility but this, too, has proved difficult because of the guilt I have felt for drawing on both her time and energy in this way.

The disruption to social patterns of interaction within the small society of the drop-in caused by the death of fellow sufferers that have been members of the group sessions operates on a number of levels. On one level I have observed denial whereby those that are now missing are not referred to and, on another, the reluctant but reconciled acknowledgement of a similar potential fate for them voiced by one participant as 'they (the medics) can only do what they can do'. In the face of these losses efforts to remain cheerful and positive on the part of all of those involved at the drop-in sessions is a demanding form of emotional labour (Hochschild, 1983) but is congruent with the dominant survival interest of group individuals and their families.

## Concluding remarks

The research on which this article draws continues to present methodological challenges in a number of ways, not least of which is the need to reconcile the intention of researcher integrity (Watts, 2008 – forthcoming), that stems from an ethics of care approach (Gilligan, 1993), with ethical contradictions and imperfect solutions to practical problems despite careful efforts to make the right choices. Qualitative research can be a messy business, particularly ethnographic work that is very much a front-line activity and one subject to many variables, most of which are likely to be beyond the control of the researcher. Emotions, both of the researcher and participants, as one variable of this type of research, may also be difficult to manage, and awareness of the potential for feelings to 'disrupt' even the most

carefully made plans, should form part of the ethnographic researcher's ethical and practical toolkit.

Using the time and energy of people who are dying or bereaved for research purposes raises ethical concerns that are centred on the potential 'unnecessary exploitation' of research subjects. However, other research has shown that the research medium of crafted conversation can be significant for potentially vulnerable participant populations in a number of ways, including bringing about positive cathartic effects (Watts, 2006: 400). The primary utilitarian value of participants to the research enterprise is mediated in this case by the volunteer effort being devoted to the work of the centre in its support of patients. In this sense, I can claim mutuality as a form of ethical research practice (Watts, 2006: 400) replicating the approach of other researchers working in this area (for example, see Lawton, 2000).

Participant observation, as ethnographic research method, connects well the dual roles of volunteer and researcher and allows for a flexible, responsive approach to a range of situations within the research setting (Sharkey and Larsen 2005: 186). However, because I do not have and never have had cancer or been bereaved to cancer, I am not a full 'insider' at the drop-in sessions, with this status reserved for those who suffer. The extent, therefore, to which, as an ethnographer, I can be integrated into the 'host' community (Ezeh, 2003) of suffering, is a source of on-going reflection. Frank's (2001) question to the wider health research community of whether we can research the lived reality of suffering, which resists articulation, is also one for this research.

This article contributes to the call by Kinard (1996: 69) for 'more published accounts of investigators' experiences in dealing with the effects on researchers of conducting studies on sensitive and emotionally laden topics'. It particularly draws attention to the difficulty of maintaining emotional balance in sensitive qualitative research that I understand to mean not being too close or too distant, with researcher reflexivity an important methodological tool within this 'balancing' process. The issue of providing 'emotional protection' for both new and experienced researchers working on sensitive topics is an area that would benefit from further exploration.

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## REFLECTIVE PAPER

# Biobank as biographical disruption: conversations on some first person reflections

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### ABSTRACT

This paper comprises a first-hand account of being a participant in UK Biobank, a longitudinal prospective cohort study funded by the Wellcome Trust, Medical Research Council and the Department of Health. The account both captures the unique individual experience of enrolling in this project, which involves providing biological samples and personal data, and illuminates wider debates of social scientists, ethicists and policymakers about biobanks. The personal account is accompanied by a commentary that seeks to make these connexions between this 'singular experience' and themes in the research literature.

### Introduction

In July 2007, one of the authors of this paper (MS) participated in UK Biobank.<sup>2</sup> This is a longitudinal prospective cohort study funded by the Wellcome Trust, Medical Research Council and the Department of Health; it aims to enrol 500,000 people in the 40-69 age range who are asked to attend assessment centres and provide samples of blood and urine, undergo various physical measurements, and complete an on-screen questionnaire about their health and lifestyle. The promise of UK Biobank is that by combining information from molecular analysis of biological samples, health records, and lifestyle questions, scientists will be able to elucidate the risk factors involved in the development of common, complex diseases which could lead to the development of new diagnostic tools or therapies.

This paper evolved out of conversations between the authors about MS's experiences as a participant and how these related to the existing social science literature on biobanks. As an early participant in this study, we thought these reflections might be of interest to scholars in the sociology of health and illness. The paper is divided into two parts, starting with MS's first person account of participating, followed by some reflections on this singular experience.

### Before

A letter arrives inviting me to participate in UK Biobank.<sup>3</sup> I email my colleagues to field views about whether I should participate. Richard offers to meet me to help me think through the pros and cons. After talking with him, I realise I am actually quite ambivalent about the project. I'm already sceptical about the genetics aspect, the model of susceptibility genes seems to be fading even in the genetics community, and anyway, are people really interested in and prepared to respond to predictive health risk information in the absence of symptoms? Well, I think, maybe there are a few of us who are embracing our 'biological-selves', but the rest of us are just getting on with living our lives. Maybe the project will identify some new biomarkers, early warning signs of disease progression and severity, and help to understand disease pathways. Okay, but how will the environment be conceptualised? And how will the

information be used? Are pharmaceutical companies likely to access this public resource? If this leads to the development of new drugs and diagnostics, will there be any profit sharing?

My 'confirmation of appointment' letter arrives, with a 'pre-assessment questionnaire' that asks for details of medications, major operations, family medical history and details about my birth. The family history section asks about any major diseases and conditions my parents or siblings might have. The next section asks how much I weighed when I was born, whether I was breastfed, and what was my address. I wonder how many people will be able to answer these questions. And how long do you have to be breastfed for it to count? I completely forget about this questionnaire until the night before my appointment, when I am fishing out the joining material and the map. It's too late to ring, so I text my mum to ask how long my dad has had high blood pressure (BP), and the details about my birth.

## Arrival

My appointment is at 9 a.m. I find the address quite easily - it's a new office building in a substantially redeveloped part of the city. I enter into a lobby area; there are no particular indications that this is the home of the regional Biobank assessment centre. I ask the man at reception and he points to a solid wooden door across the lobby, which is closed. Opening this door reveals a long corridor with several identical solid wooden doors on either side, none has a name shield. At the end of the corridor is an open door and perhaps a small sign saying Biobank. Beyond this, I see a reception desk and a large open plan room. The room is divided up into different 'stations', it reminds me of a blood donor centre.

Someone is already sitting at the reception desk; I hover just outside the door, feeling a bit uncertain. Eventually this person moves off and I sit down opposite the receptionist. She's very friendly. She takes all my details and then gives me a memory stick. This is mine for the duration of my participation - I must carry it with me for my data to be recorded directly onto it.

## Questioning Self, Behaviour and History

There are a number of research nurses or assistants around (I never find out their status). One escorts me to the first 'station' - a bank of desks, each partitioned off with dividing panels. On the desk is a computer. My escort plugs my memory stick into the computer and sets me up and leaves me on my own. The first task is a touch screen questionnaire. I take out an A4 pad and paper and start to jot down the questions as I answer them. The first ones are easy enough as they seem to be about socio-economic indicators of one sort or another: what sort of home do I live in, what's the tenure of the house, how long have I lived there, household composition, car ownership, type of heating, income and so on.

The next section on employment is trickier: how many hours do I work on a typical week? I wonder what a typical week might be and struggle to answer the question. I have been mostly working from home for the best part of the last 3 years, first writing up my PhD, and now as a post-doc. My working patterns go in fits and starts, it depends on deadlines, conferences and so on. How many times do I travel to work and how many miles do I travel? I go to my department about one day per week and I guess that it's about 80 miles away. When I enter the figure 80, a popup window appears: 'Are you sure you have entered the right number, this seems very high'. I begin to reflect on my rather unconventional life, the absence of external structure to my work, and the down-sides to living so far from my department.

The next set of questions relate to physical activity. On a typical day do I walk for at least 10 minutes? Do 10 minutes at least of moderate exercise? How many times do I walk up or down a flight of stairs? Over the last month how many days have I walked for pleasure? How often and how long do I undertake various levels of physical exercise from mild to strenuous? I struggle to reflect back over the last few weeks to work out some answers. Apart from the

regular once a week gym session with my partner, what else have I done? What did we do at the weekends, did we manage to get to the allotment or go for a walk? I find the 'average day' questions difficult, and I am starting to feel cranky.

I also feel bad about my lack of physical activity. Here is a long catalogue of things I could be doing and I am failing. I have been known not to leave the house for 2 or 3 days on end. My office is upstairs - I try to work out how many times I traverse the stairs on an average day (with breakfast, lunch and several cups of tea, putting out the laundry and hearing the post arrive, I estimate this to be 10-15 times a day). My lack of physical activity brings me back to reflecting on my working patterns - there was a time when I was a relatively normal person, who went out to work in the morning and came home in the evening.

I answer several sections on social contacts, TV, computer and mobile phone use, driving habits, and sleeping patterns relatively without problems. Next comes eating habits. I am interested that a portion of cooked vegetables is defined as one heaped tablespoon. This is accompanied by a picture of a dinner plate with one segment containing discs of carrots to represent this amount. I'm mostly vegetarian so my vegetables generally don't come segmented on my plate, but mixed in with everything else. The night before I had cooked a pasta sauce with a mountain of chopped vegetables; I try to work out how many tablespoons this might be. There are no pictures to help me. I have a stab at the questions on the average number of portions of cooked vegetables, salad, fruit and dried fruit I eat a day, but can't help thinking it would have been easier if I had kept a food diary or something. A question on breakfast cereal stumps me. Do I eat a biscuit cereal or an oat cereal? Well actually, I've started eating Oatibix and I don't know which is the important bit here, the oat part or the biscuit part. I feel a bit stupid, but I enquire and get an understanding, friendly and authoritative response.

Several sections on, I am completely floored by the following question:

What would happen to your skin if it was repeatedly exposed to bright sunlight without any protection?

The list of responses starts with 'Never tan, only burn' through to something like 'tan deeply'. I wonder whether this means continuously exposed or exposed in short bursts. I also wonder how I am expected to know the answer to this, as I've never tried it. It is really frustrating that I do not know what the question is driving at. I ask for clarification, does this mean in short bursts or continuously, but the assistant just reads the question out again as if it self-explanatory. I say I don't know because I've never tried it. She says it means... and then reads out the question again, and suggests if I don't know the answer I should put 'don't know'. I am exasperated.

The section on sexual history is preceded with a special warning that some people might find it too personal and a get-out clause allowing the participant to skip the section entirely. On the day, I have no problems with the idea of completing this section. On reflection, however, I start to worry that this will be used for research into the biological basis of sexual orientation.

Overall, I have found this questionnaire very long and frustrating. I have done my best under the circumstances, but I am unsure how accurately I have answered and feel like I have inevitably 'made up' quite a lot of my answers. I am also quite wound up. I can't help thinking that the research might lead to a case of 'garbage in, garbage out'. When I have finished, an assistant unplugs my memory stick and puts it in my hand. I am then directed to the waiting area for the next station.

## **Bodily Measures**

I sit in front of three curtained off cubicles. I think they don't provide much privacy. I chat a little with the man sitting next to me. He tells me he has had trouble answering the questions about smoking habits - his smoking history was not easy to fit into the possible range of

answers. I think to myself that probably everyone has their own areas of difficulties or ways of 'not fitting'. This is the only occasion where I talk with another participant.

I go into the cubicle and immediately forget how audible everything is. The nurse asks for my memory stick and plugs it in. She asks me what my occupation is. I think I say I'm a researcher at a University, or maybe I say I'm a sociologist. 'Ah', she says, 'were you the lady making notes?' Apparently this had been the source of some fun for the staff. The nurse goes through my family history and asks for further details of an operation I had. I only remember later that everyone waiting outside will probably have heard this. Then it's time for blood pressure. I'm a bit anxious about this. I know I have had a problem with 'white coat' hypertension on a couple of occasions, but I also suspect that I might be developing the 'Sample' problem with high blood pressure. She puts the cuff on my arm and inflates it; then it slowly goes down. I hear the beeping of the machine and feel a pulse in my arm at the point at which the flow returns. We chat jovially through this procedure (I am trying to jolly myself along). My blood pressure is very high and I am shocked. The nurse says that I laughed at the point of the reading and she will try again. I try to be very calm, I close my eyes; I will my blood pressure to be lower. The second reading is equally high. I start to tell some story about having had a high reading at the doctors last year, but attributing this to white coat hypertension and that it was normal in the past, but perhaps I should ask the practice nurse to take it again (I recognise that I am trying to account for my behaviour, show that I am the sort of person who takes responsibility for my health). I realise that the nurse is not interested; I think she's more concerned about the big queue of people waiting for her attention. I feel embarrassed, and a bit shaken. The nurse gives me a British Heart Foundation pamphlet on blood pressure. I say I'll go back to my GPs. She says 'I wish you would'. She gives me my memory stick and I walk to the next waiting area.

### Third station

This cubicle is a bit larger than the previous one and I notice some pieces of equipment – a weighing scale, a height measure, and something else on the floor. The nurse introduces herself. We start with something to do with lung capacity. I blow into a small tube connected to some kind of metre. Next is a measure of hand-grip strength. I hope I get acceptable results, although I have no idea what good results might be. The nurse asks me to take off my shoes and wipe my heel with a disinfectant wipe. I place my foot in a machine that measures bone density. It's a bit like the electronic foot-measuring machine in shoe shops. The first measure fails. I have apparently moved during the reading, although I thought I was holding still. The second attempt is successful. I don't remember the order of the following measures. But there was height, and weight, and waist and hip. I stand on the weighing machine. The nurse instructs me to grip the two handles on either side and pull down. I think she says this measures BMI. She tells me that I class as 'overweight'. I am not surprised by this, but, later, my partner is incredulous on my behalf, which I find endearing.

### Taking the Blood

I have to wait for a while before I enter the final cubicle. I sit down opposite a man wearing latex gloves. On the desk there is a cage stand with about 4 or 5 empty glass vials, each with a different colour rubber lid. As the nurse or phlebotomist puts a tourniquet on my arm, I make my usual pre-emptive joke - my veins are there, I've just hidden them under a layer of insulation. He is charming. He says something soothing, and has no problem finding my veins. It takes a while to fill all the different vials. At the end he gives me two printed sheets of A4 and a sample bottle. He explains exactly which bit and how much of my pee they want, directs me to the loo, and asks me to put my sample in the fridge, which he points out – it's near to the reception desk. He says that after that, I'm done, and I can help myself to a cup of coffee if want. There is a coffee machine behind the receptionist.

Returning from the loos, I put my sample in the fridge and look around. I see the coffee

machine, but I don't see anyone drinking coffee, or anywhere obvious to sit. I have been here for ages anyway, and I'm quite agitated about the whole experience, so I slip straight off. I look at the 2 sheets of paper in my hand. One is a print out of my signed consent form. The other is a short report on my physical measures (see figure 1).

Figure 1

Measurement Results Form Page 1 of 1

## biobank<sup>uk</sup>

**Results from baseline assessment visit**

---

Name: ██████████  
 Date: 24-07-2007

Factor	Finding	Interpretation
Smoking:	██████████	Good
Blood pressure:	██████████	High
Weight:	██████████	
Height:	██████████	
Body mass index: (weight divided by height squared)	██████████	Overweight
Waist circumference:	██████████	High
Percent body fat	██████████	High
Heel bone ultrasound	██████████	Good
Lung function FEV1 value FVC value FEV1/FVC ratio	██████████ ██████████ ██████████	Good Good

The interpretation of findings is based on information from previous studies linking these factors with health risk. Participants with undesirable findings may be at higher risk of some diseases, and may wish to consider appropriate lifestyle changes (e.g. stopping smoking; reducing dietary intake of salt, meat and other sources of animal and other "saturated" fats; increasing physical activity). Some advice leaflets are available from reception. Those with high blood pressure levels or reduced lung function may also wish to have them checked again by their own doctor.

file://C:\BB\CONSENT\at\_info.xml 24/07/2007

### Afterwards

I wait at the bus stop feeling rather stirred up. I am more aggravated than worried about my

blood pressure. I'm disappointed that I really do seem to be following on from my dad and grandma on this, and that I'm going to have to do something about it now. It's unpleasant being reminded that I am 'overweight', but the assessment came as no surprise.

On the way home, I drop in to my General Practice, but the next appointment with the practice nurse is not for a few weeks. Three days later I pop in to see an acupuncturist-friend of mine, who has offered to monitor my blood pressure over the next few weeks. She doesn't think much of single readings and is concerned that doctors might be a bit quick to prescribe medications. I have the same concern. I lie down on the consultation table and try to stay calm. My blood pressure is still high, but much lower than at Biobank. When I get home, I go on the British Hypertension Society website and find out that my current reading classes as mild hypertension. I look at the treatment guidelines – they're quite complicated. Treatment depends on cumulative cardio-vascular disease risk not absolute BP. I am relieved when I notice that there doesn't seem to be any level of cholesterol at which medication would be recommended for me, but I'm still keen to try to get my BP down.

I flick through the British Heart Foundation leaflet and think about what things in my life I might change. I have a long chat with my partner. We look up hypertension in our home medical book. My acupuncturist friend also gives me a sheet on hypertension which gives advice from the Chinese medicine perspective. These three texts have a number of common recommendations, and some conflicting advice. We decide that I should try to get more exercise and cut down on salt. I am trying to make sure I get 3 sessions of proper exercise a week. I've been running a few times. I'm making more effort to get out the house everyday, even if it's just for a few minutes. Cutting down on salt is more tricky than I anticipated. Unconsciously, I am avoiding cooking some things which have been standard fare in our household. Things that involve stock or soy sauce, halloumi or feta cheese, for example. I'm also conscious when I'm eating out how salty things are. I had a second reading with my acupuncturist friend, which was about the same as the first with her. I'll see if she can fit me in again in a couple of weeks. It has been 5 weeks since I participated in the Biobank. I can't say whether participation will have a long-term impact on my behaviour.

I have a long chat with Richard about my experiences. He reflects that the blood-giving had been perhaps the most unremarkable and least irksome part of my participation. He asks me whether I had reflected on the blood giving part and something about identity. I think I was fleetingly aware as I gave blood that this would also be used for DNA analysis as well as a bunch of other colour-coded things. I tell him I don't think that my identity resides in my genome. Oh, he says, where do I think identity comes from? I can't quite tell if he's joking. I think to myself that that would be the start of a very long conversation, and move onto something else.

## Reflections on Minnie's Singular Experience

I am Minnie's colleague and friend and have had a long standing interest in the development of biobanks, their scientific, medical and economic promise, and, in particular, on questions to do with how publics are enrolled as participants in these initiatives. I encouraged her to write up her reflections when she told me that she had decided to take up the Biobank's offer of becoming one of its participants. I have of course read many of the qualitative studies that have documented and analysed the participation of publics in various types of biobanks in the UK and Sweden (Haines and Whong-Barr, 2004; Goodenough et al, 2003; Hoeyer, 2003) as well as in other kinds of studies involving the provision of tissue samples to aid medical research (Busby, 2004; Dixon-Woods, 2008; Tutton, 2002). But, given that UK Biobank had only very recently begun its recruitment of volunteers, I had yet to know someone who had agreed to be a participant. Therefore, I was very excited about Minnie's involvement and I find her experience, although idiosyncratic, to illuminate a number of more general points addressed in the sociological and bioethical literature on biobanks.

I think it is fair to say that, typically, the focus of much of the literature on biobanks has been on the social, ethical, legal or economic significance of the collection of human tissue or

the analysis of DNA. This has meant that less attention has been given to the issues entailed in accessing medical records and asking individuals potentially complex and detailed questions about their behaviour, attitudes and family history. The Danish anthropologist Klaus Hoeyer (2002; 2003), in his excellent work in Sweden on the Vasterbotten Medical Biobank, does question how and why blood and DNA have become infused with such ethical significance in contrast to the collection of personal and medical information (see Hoeyer, 2002). Evidence from his own interviews with volunteers in the Vasterbotten Biobank indicated that some saw the information they gave in the questionnaires as being as 'essential' to themselves as the blood samples they gave to the researchers. Minnie's experience is of interest in relation to Hoeyer's discussion because her account of giving blood and urine samples seemed to be a relatively unproblematic part of the enrolment process compared to completing the questionnaire (and physical measures as I discuss below), which seemed to impinge more directly upon her sense of self. Perhaps, therefore, we need to pay greater attention to this aspect of people's enrolment in biobanks.

This is not to say that there has not been discussion about the scientific and practical issues to do with the collection and analysis of medical and personal information by biobanks. For instance, GeneWatch (2006) and some other critics of UK Biobank such as the sociologist Hilary Rose (cited in Jha, 2006a) have tended to highlight what they see as the shortcomings of the project in generating good quality lifestyle and environmental data. The concern is that environmental factors will be poorly measured because people will find it impossible to provide reliable information about their lifetime exposure to chemicals or other aspects of their lifestyle over time. The worry, then, is that with these unreliable datasets scientists will tend towards genetically deterministic accounts of disease causation not least because the genetics might be seen as a more reliable source of information.

Minnie's reported difficulties in completing some of the questions would seem to bear out some of these concerns about measurement and reliability. There is no easy answer to the problems of collecting data of this kind from individuals – there are limitations to the touch-screen method where there might be uncertainty, as Minnie expressed, about what some of the questions are asking, but other approaches such as nurse-led interviews have their own problems especially on sensitive topics. Minnie's experience, however, does indicate the potential benefit of giving volunteers advance notice of the questions that they will be expected to answer and, since Minnie's enrolment, the questionnaire can now be found on the UK Biobank website. Other commentators have also suggested that UK Biobank should not rely on self-reported data alone. Writing in *The Lancet*, Lyle Palmer notes the 'growing evidence that the correlation between objective measures and questionnaire data for key indices (e.g. physical activity) can be poor and lead to misleading conclusions if only the self-reported data are available' (Palmer, 2007: 1981). Therefore, he advocates that UK Biobank should undertake more detailed phenotyping of participants so as to provide reliable biomarkers for various lifestyle and environmental factors.

The lifestyle information component also surfaced as a concern in the design of UK Biobank because it was feared that certain questions, about sexual behaviour for example, could be particularly problematic for certain social groups. There was a concern that Muslims or other volunteers with strong religious beliefs would be offended by such questions and might choose to withdraw if they were asked such questions. In other contexts, such as statistical surveys, there is evidence to suggest that questions about sexual history and sexual identity are seen as sensitive matters with the potential to undermine the quality of the data collected; leading for instance, to non-completed questions (Wilmott, 2007). As Minnie reports, this has led to the special handling of these questions in the UK Biobank questionnaire, with an option to bypass this section completely. While it would seem therefore that for UK Biobank, the problem of collecting this kind of data is framed in terms of it causing offence to certain groups; it is equally pertinent to consider that questions of this kind could raise concerns for others who might want reassurance on its relevance for health-related research. This is strange perhaps given the long and contested history of research into the biological basis of sexuality (Conrad, 2001).

Another issue of note in Minnie's account of her participation in UK Biobank is that of individual feedback. It has long been recognised that researchers, while enrolling otherwise healthy volunteers, might discover something that is clinically relevant about these individuals and this has been an ethical dilemma which professionals have had to negotiate. Amongst lawyers and ethicists, there has been some debate about whether individuals have legal or moral rights to information held about them by projects such as UK Biobank (Johnston and Kaye, 2004). While some other initiatives such as the Estonian Genome Project promised that its participants would receive detailed information about their genetics so they could benefit from personalised medicine in the future, the organisers of UK Biobank have been at pains to stress that individuals would not receive detailed feedback. They were concerned that people would come to see their involvement in UK Biobank as a way of getting a 'health check'. As the CEO Rory Collins recently remarked when interviewed in *The Guardian*, participants are 'making a gift, getting no information back' (quoted in Jha, 2006b). However, as Minnie's account reveals, the current practice is to provide some information to participants on certain physical measurements taken at the time of enrolment (see figure 1).

Although UK Biobank does not want to be seen as a clinical intervention but as a long-term research project, participation in this project is likely to have clinical and psychological implications for some individuals and their families as has been documented with respect to other epidemiological studies. This was evident in Minnie's account that demonstrated how physical measures such as blood pressure and BMI, which are important indicators of long term health, are also imbued with a range of moral, social and personal significations. She candidly discusses what the results of her measures mean to her in terms of her current lifestyle and family history, which show how these measures, much like the questionnaire part of the participation, impinged on her sense of self. In her account, she indicates that perhaps she will monitor indicators of her health more regularly and make changes to her diet and other aspects of her life. Therefore, Minnie is not fatalistic despite her family history and the experience of being involved in UK Biobank has prompted her to reconsider her current lifestyle and to try to take appropriate action. This reaction is certainly in keeping with now seminal work by Charlie Davison and colleagues (Davison et al 1989; 1992) on lay understandings of heart trouble. This suggests that an hereditary aspect to heart disease has long been recognised in lay accounts of the condition, but that areas not within personal control, particularly the field of luck/fate, are subsidiary to lifestyle, and the scope to change individual behaviour is seen as counteracting the effects of heredity. It is notable that this work long predates and foreshadows contemporary discussions of lay responses to genetic risks.

Certainly, as a 'side effect' of participation in UK Biobank, raising people's awareness of their health risk factors and prompting them to consider making certain changes to how they live their lives in light of this information should be viewed as largely positive. Nevertheless, the research literature suggests that these kinds of changes can be difficult to effect in practice due to a host of intrapersonal, interpersonal and structural factors (Jones et al, 1996; Maio, no date). The impact of participating in UK Biobank on the health and behaviour of participants, and how they cope with the information they do receive from their assessment centre visits, would be an important focus of future research.

In summary, while Minnie's experience is of course particular to her as an individual, it does, nonetheless, provide some interesting insights into the kinds of scientific, ethical, operational, and social issues that many have discussed in relation to biobanks. More broadly, it also serves to illustrate the value of ethnographic material: in juxtaposing experiential accounts with expectations articulated in ethical guidelines, policymaking and existing academic discussions, certain themes are reinforced and new questions of interest emerge. Therefore, as UK Biobank continues its recruitment – over 100,000 individuals enrolled already at this time of writing – research on the personal experiences of being participants would be a valuable source of sociological knowledge.

## Notes

1. Minnie Sample is the pseudonym of a Research Fellow at Robin Hood University, UK. She has elected to assume this pseudonym because the paper reveals some personally sensitive information, which she did not want to omit because it is integral to her account. However, at the same time, she has uncertainties about the kinds of uses that might be made of that personal information.
2. See [www.ukbiobank.ac.uk](http://www.ukbiobank.ac.uk) for more information.
3. An early reader of this paper asked about the information provided by Biobank before participation and the expectations this raised beforehand about the process and outcome of participation for individuals. Such a comment seems to attribute the Participation Information sheet with more impact than it appears to have had in my case. I remember that there was information and that I read it, but I cannot recall the details and I don't remember having any particular expectations about the process of participation.

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## What's so good about MedSoc Conferences?

Jude Robinson

The annual MedSoc conference has been a fixture in medical sociologists' diaries for nearly four decades, and for a number of years conferences took place in mid-September at the University of York. For many people, when funding was perhaps less of an issue, these are seen as the 'golden years' of MedSoc: the total experience perhaps best encapsulated by the disco/ ceilidh, where a hundred or more academics, ranging from professors to students danced the Saturday night away.

Since the early 2000's delegate numbers have slowly declined, as have university budgets generally, and Sociology departments specifically. Alongside a huge hike in conference costs at York, there was consistent feedback indicating that many attendees were bored by attending the same venue and felt a need to try new locations. Thus, the conference has moved on literally and figuratively from York, to Edinburgh Herriott-Watt in 2006, to the Liverpool Adelphi in 2007 and next to the University of Sussex, Brighton, UK, on the Thursday, 4th – Saturday, 6th September 2008, <http://www.britsoc.co.uk/events/msconf.htm>.

The Liverpool venue was chosen to be a hotel, rather than campus accommodation, by popular request from the membership, but the committee were quite heavily restricted by the budgetary limitations as to the standard of hotels, and indications are that hotels are not a viable option if the conference size remains stable (ie between 200- 250 delegates).

To make sure the conference's organising committee keeps in touch with its membership, for the first time last year, Liz Jackson, on behalf of the MedSoc committee, sent a questionnaire to all the people who attended the conference to ask for people's views about issues such as the price of the conference and the location to use for future planning. To make sure the questionnaire was easy to fill in and to maximise the response rate, most of the questions required tick box responses. However a final open question was included to really help the process of identifying the answers to the question, 'What makes a really good MedSoc Conference?'

We would like to know what people particularly enjoy about attending MedSoc conferences, what makes a great conference and what could be improved. If you have any further comments you would like to make, please do so here. A selection of comments will be published anonymously in Medical Sociology online (MSO).

The findings thus include qualitative comments with the statistical data.

### Response rate & BSA membership

Of the 252 people contacted, 101 people responded, with 44.3% stating that they were current members of the BSA with 55.7% non-members. Despite the relatively low cost of membership (concessionary membership starts at £28), and a clear statement that BSA Membership is open to anyone and everyone who has an interest in sociology not just UK based academics, the reasons for not joining the BSA included: the cost of joining, particularly for those in the higher membership categories; none residency in Britain; membership of other organisations; working outside academia; and a few people stated their intention of either renewing a lapsed membership, or joining as a new member.

### Networking and contact with other medical sociologists

Over 68% of respondents stated that the chance to catch up with colleagues, meet new people working inside and outside Universities was the reason why they came to MedSoc year after

year. In addition, 35% strongly agreed, and 64% agreed that the conference offered good networking opportunities. Respondents also made the following comments:

The collegiate atmosphere, the idea of belonging to a group with the same interests and enthusiasm for sociological health research that is not always found in the institutions we work in.

The reason [I] go to MedSoc is [to] meet old friends and discover new ones, to learn something new by going to sessions which do not relate to my work and to see what issues people are playing with in areas I work in.

Over 98% of respondents felt that attending MedSoc was 'useful to their work', and over 47% cited '*The programme must link to my area of work*' as one of the most important aspects of a BSA conference. Some medical sociologists working within Medical faculties or institutions described how the MedSoc conferences gave them a welcome opportunity to discuss their work and ideas in an alternative environment:

I find medical sociology to be an isolating job as many of my colleagues are clinical practitioners, so having a medical sociology conference is a great opportunity to touch base with other people in a similar area.

I have attended Med Soc for 10 years or so. I think it's good to get together with other medical sociologists, as we're often pretty isolated in medical institutions where the social gets lost amidst the test tubes.

In contrast with other work-related activities and conferences, MedSoc conferences were described as 'fun', and 'enjoyable, and also as providing an environment conducive for working and talking:

... relaxed environment within which to share your work and appreciate the work of others.

Atmosphere, participants, and value of meeting other medical sociologists.

It's the most relaxed conference I attend. I feel at home at MedSoc.

The relaxed and friendly environment was also appreciated by people new to the conference, who may not yet be part of the more established social and research orientated networks. In particular, the annual newcomers' reception was singled out for praise:

I enjoyed the conference - very welcoming group and enthusiastic and interesting audience as well as presentations.

Very friendly atmosphere, genuine meeting of minds!

It was a friendly environment in which to make new friends and talk to sympathetic medical sociologists!

The whole atmosphere was friendly and I had no qualms about introducing myself to other delegates and chatting to them (something I no longer do at 'medical' conferences due to a bad experience!)

It is my first time attending the MedSoc conference and I was attending on my own, so was particularly impressed with the newcomers reception--I met lots of interesting people and it was a chance to network informally.

A number of respondents commented that despite attracting a number of 'big names' in medical sociology, newer researchers, in particular PhD students, were made to feel very

welcome. The general tone of the conference enabled them to present and discuss their work in a very supportive environment.

I find the supportive atmosphere of the conference particularly valuable, meaning that new presenters, students and early career researchers gain useful input and encouragement as opposed to unhelpful criticism. Having attended many conferences, this is not always the case and a unique feature of Medsoc!

The conferences are always very supportive for newer researchers.

Although overall the comments were very positive, some people put forward suggestions as to how the networking opportunities could be improved by more 'breaks' in the programme, rather than people deciding to 'sit out' for a session, and even more formal networking opportunities, including interest groups, meetings etc.

I would also like to have an ideas feedback session where we could actually sit down with groups of people under themes and tell them the kinds of things that I am thinking of and get spontaneous feedback on it. I know that conferences are supposed to offer this 'service' in general but it is not always easy to get really focused on specific ideas within sessions.

Networking was also really important but this could have been improved by designated tea breaks. It was difficult to discuss presentations when there were no designated breaks.

### **Full disabled access**

One aspect that concerned many of the participants was the poor access for wheelchair users provided by the Adelphi Hotel, and also for people with sensory impairment, and generally the venue was described as having poor 'acoustics'. Although 11% of people thought the session rooms were 'excellent', 33% 'good' and 39% 'satisfactory', 17% of people thought they were 'poor' or 'unsatisfactory'. Also, while over 94% of people described the presentation equipment as either 'satisfactory', 'good', or 'excellent', 6% found it 'poor'. While the number of people directly experiencing problems was relatively low, issues about accessibility were raised by many people in the open question, indicating that this was clearly an important issue:

I enjoyed the conference and the range of papers presented, however I was disappointed that some of the sessions were in rooms which were inaccessible for people with mobility impairments and the hotel was generally very difficult to get around - broken lifts, narrow passage ways and a very long way around to get to bedrooms for which a member of staff had to escort so could not move freely around the building.

The venue was wonderful for me but v difficult for participants in wheelchairs.

My main message for feedback here was the disabled access to the building... We were forced to use the service lift at all times and we had to enter and exist the building and the restaurant through the kitchens and rubbish area. None of the lifts went to every floor which meant that some rooms (the ones at the back above the foyer) were only accessible by going up to the first floor along the length of the entire building and down again. The Executive Room was entirely inaccessible for my friend, which meant she missed a stream in which she had a particular interest. There were tables and chairs in the way of the route into the two large side rooms and the rooms behind those could only be accessed by going through the middle of the large rooms and out the back door. The lifts were also extremely temperamental and there were two occasions in which we were forced to carry my friend up stairs in order for her to participate fully in the conference. Sorry to go in so much detail but it was very frustrating for all involved. The sheer time and effort to get anywhere meant that we both missed papers and were so tired by the end of the day that we missed useful networking opportunities in the bar.

The acoustics in the rooms in which papers were presented were poor for me - I am deaf. I would have appreciated getting the programme in advance rather than on arrival. All in all, a fantastic conference!!

The disability access was very problematic at time[s]. However, the Adelphi is a very old building so in some ways it is to be expected. What did surprise me was the decision to hold the conference in such a venue, given that there is an emphasis on the social model of disablement within sociology. Even so I had an excellent time and both the BSA and Adelphi staff were very helpful.

Despite the best efforts of the MedSoc committee to ensure that the Adelphi Hotel met their requests (and their legal obligation) to provide good access to all the rooms, the ongoing building work, linked to the constraints of working within a listed building, meant that the committee were only informed that the access ramps had been condemned as unfit for use less than 24hrs before the conference started. Therefore, despite prior discussions, and clearly stated requirements, the Adelphi Hotel did not at this time meet the needs of disabled delegates.

Generally the signage and navigation of the building was rated as 'satisfactory' or more highly by over 80% of respondents, although 19% found it 'poor' or 'unsatisfactory'.

### **The quality of the research papers presented at the conference**

Reassuringly, many respondents (88%) commented that the most enjoyable aspect of the conference for them was the consistently high quality of the papers presented, with over 78% of respondents citing this as one of the most important aspects of a BSA conference. Enjoyment came from the variety of topics presented (53%), the methods of presentation and generally the high academic standard of the work. Others (32%) commented on their enjoyment of the symposia and roundtables, and panels of interest, although this was clearly of secondary interest to the papers themselves, with 38% of respondents citing '*high profile plenary speakers*' as a further important reason for attending BSA conferences.

Really enjoyed the papers (probably more than the plenaries and the symposiums).

The wide range of papers was excellent.

I really enjoyed the conference--brilliant speakers and interesting talks.

I thought the standard of paper presentations was generally excellent and provided lots of intellectual stimulation.

This was the first MedSoc conference that I attended. I enjoyed it very much and gained some very useful information that I have used in my work.

... this conference had the highest quality papers I have ever experienced and I have been attending since 1995.

People working outside universities, or outside sociology, valued the chance to hear about current research of colleagues, a chance not only to share ideas, but to keep up to date:

Being currently without an academic institution it was an invaluable opportunity to meet people and to hear about different areas of academic research that are connected to the work I do

As a non-sociologist, it was interesting to find out how sociologists are currently thinking.

Others commented on how important it was for them to get feedback on their work, which

could be at a critical stage, relating to earlier comments on the friendly and supportive nature of the comments and questions from the audiences.

It is my field of study and is a must in terms of finding out what people are doing, how they are doing it and what the general preoccupations for this group of scholars are from year to year. I also need to know what people think about my work and how I can improve it. Thanks.

I can rely on there being excellent quality papers and getting good feedback for work I present

Apart from one exception the questions from delegates were non-threatening and comments were constructive.

Although the majority of respondents praised the high quality of the papers, there were a minority of people who were disappointed (12%).

Also the quality of some of the presentations was quite poor - including by some high profile people, which was very disappointing.

There seem to be too many strands competing and the quality of papers was very uneven. Some people seemed poorly prepared and had not timed their papers well, so their findings were rushed. Some were very lightweight.

A few people were concerned that there could be too many papers, and too many streams, and not enough of an audience to go round, perhaps relating to earlier comments about timed breaks, rather than people sitting out on particular sessions.

I wonder if there are too many streams now. Some talks had only 3-4 people, which must have been disappointing for those presenting, particularly since they came from overseas.

I think I'd prefer fewer strands and more selectivity.

If number of parallel strands could be reduced, this might be an opportunity for more people to attend sessions. Having two people in the audience I think is not helpful but is demoralising.

One person suggested that it might be helpful to have a strand devoted to presentations by PhD students, so that people who have not necessarily completed their studies, but are looking for feedback, could present their work to an audience.

Another key issue for some respondents was the need to have a good chair for each of the sessions, to keep the speakers to time, to pick up on some of the issues they raise, and generally involve the audience with the speaker in a constructively critical discussion.

Provide chair people who not just introduce the speakers and time keep but who can add seriously to the discussion afterwards. In the past this was always the case, and I learnt a huge amount from the critical comments by the chairperson, which filtered through to the audience.

Many chair people did not seem to be experts in the field, and hence did not initiate interesting discussions, or make critical comments about the presentation. For example in many presentations, important aspects relevant to the topic were not mentioned/left out, and therefore the presentations were one sided. However this was not picked up by the chairperson. In one instance no chairperson was available, which I think was really poor. Moreover many chair people did not stay for the whole strand, but changed constantly, which was not helpful for the overall running of the strands.

Good chairing was thought to lead to a satisfactory session for both the audience and speaker, and so there is clearly a need to maintain high standards in all these areas. One person commented on the apparent lack of engagement by some senior colleagues, whereas another

person wished there were more senior figures in medical sociology present at the conference.

A disappointment for me this year was the number of more 'experienced' sociologists who were attending but not presenting (other than the plenaries).

It would be good if more of the senior figures in medical sociology attended. I think this would strengthen our enterprise.

One area that a number of people commented on was the need to 'present' ideas and findings within a paper, rather than just to read their paper out. Complaints centred around the fact that not only was this extremely boring for their audience, but also that it could be a practice adopted by people whose spoken English was poor, and who possibly should either not be presenting to an English speaking audience, or who should have practised their presentation until it was of a suitably high standard.

Before the conference please make clear that people might want to practice their talk beforehand, avoid reading off their content word by word and have some command of English, otherwise the presentation is not useful for presenter and audience.

A number of presenters spoke English not adequately for a presentation, therefore it was impossible for me to understand what they try to say and I therefore could not engage in a discussion with them.

... many of the presenters read off the whole content of their presentation, and had no contact with the audience, hence the presentations were really boring....

## Venue, accommodation and meals

The Adelphi Hotel in Liverpool evoked a range of responses from conference attendees. Some people found much to like in both the location and the hotel itself, with over 82% rating the service provided by the venue staff as either 'Excellent' (12%), 'Good' (40%) or as 'Satisfactory' (30%), and 68% rating the venue itself as either 'Excellent' (10%), 'Good' (19%) or as 'Satisfactory' (39%). Over 94% thought that the city of Liverpool was easy to travel to, and over 85% of respondents found it easy to get around the city. In response to the question asking respondents to respond to a list of important aspects of BSA conferences, over 40% cited '*a venue accessible to public transport*' as important, while only 9% thought that it was important to have a venue '*in a city with family/ friends/ tourist attractions*'. However over 68% found that the venue did offer access to tourist attractions, with 77% agreeing that there were '*good bars, restaurants and nightlife nearby*'.

I enjoyed the conference this year. I liked being in a hotel and near the city centre.

It is important that the venue provides good areas for relaxing among colleagues, with publishers' stands, coffee/tea, lounges and a very close pub.

The venue was accessible by public transport, which was excellent (and people should be encouraged to come by train wherever possible).

... I had an excellent time and both the BSA and Adelphi staff were very helpful.

I found the conference venue much better than the usual campus accommodation.

I found the venue excellent.

Over 75% of respondents thought that the other facilities at the venue were either 'Excellent'

(8%), 'Good' (40%) or as 'Satisfactory' (27%). However some people appeared to enjoy it for its eccentricity and style rather than for its high standard of accommodation and service, and gave more qualified approval:

I enjoyed the conference greatly and thought the Adelphi hotel was a great coup. The hotel was enjoyably ramshackle... I liked the way that various things were broken in my room and didn't mind the hopeless lack of service at breakfast time, because of the general grandeur.

The venue was excellent except for the building work noises that impacted on every room. Overall, well done!

... the hotel was quite adequate -- worn-out former elegance has more charm than a place with all mod cons but no personality

Other people were clearly less happy:

The Adelphi was a disappointing venue. I had no cold water in my room and it took two further changes of room to resolve this.

I wasn't so keen on the venue though--hard to get around, staff not particularly helpful, the food was pretty poor, no microphones for the speakers, quite expensive... I think an established conference venue (university/proper conference venue e.g., Harrogate, Glasgow) might be more appropriate.

The accommodation was not very good (I had a room that smelt of stale smoke and there was a piece of cardboard on my door where a pane of glass should have been). This is the most expensive conference I attend, in terms of registration, which is a problem for younger scholars.

The food and drink provided were rated as 'Excellent' (10%), 'Good' (31%) or as 'Satisfactory' (36%) by 77% of the respondents. The issue of food invited a lot of comments, and the timing, delivery and overall quality of the food was commented on by a number of respondents:

Lunch was difficult. That type of arrangement with not dining tables and chairs is very difficult for people with certain types of disability.

Lunch ran out on the Friday; there was also insufficient water provided during some of the paper sessions.

Two people commented that it would have been good to have been provided with a meal on the first night, as eating as a group is not only good for networks and meeting up, but also good for people who can get the whole of a conference paid for, but cannot make a separate claim:

One thing that would improve it would be an opportunity to socialise on the first evening - as no evening meal was provided, if I hadn't met up with old friends, I would have been on my own. This could be off putting for people who didn't know other delegates.

I strongly believe that a meal should have been included on Thursday night. This is usually a good opportunity for networking but also means people are not left without companions for dinner and also makes it easier for lower income delegates to get a meal included in what is paid for by their funding source.

Concerns about the venue and accommodation were bound up for some people with the overall affordability of the conference, and also the value for money it represented, although over 70% of people either 'Agreed' (54%) or 'Strongly Agreed' (16%) that the conference

represented good value for money:

The BSA Med Soc conference was great and I appreciate receiving financial support to attend this event.

Others suggested that a 'day rate' should be available for people only able to attend for one day,

Cost is a major factor for our Centre, especially as no day rate was available.

While 44% of respondents thought that the cost of attending a conference was an important factor for BSA conferences generally, only 36% rated their accommodation in Liverpool as '*affordable and close to the conference venue*'. This could have been due to problems with the way in which the question was phrased, as although staying in the Adelphi meant they were close to the venue, a number of people thought it was over-priced:

Hotel rooms were below average and given the total price of the conference I feel that the venue was too expensive for what it could offer

To host the conference in such an expensive hotel I found inappropriate, a university campus would be fine.

Given the high cost of attending I thought the venue wasn't that great - the presentation rooms were noisy because of building work, parts of the conference were inaccessible for participants in wheelchairs, the breakfast area was crowded and cramped and food items ran out without being replaced for ages.

However it is important to note that the majority of the concerns about the overall cost of the conference related to the quality of the venue, rather than to the quality of the conference itself.

## Summary

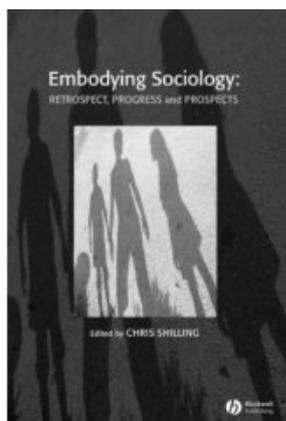
Despite some drawbacks to the venue, particularly in terms of the access issues, over 82% of respondents considered that the conference was a 'must attend' event for them, and clearly the MedSoc conference represents a highlight in the working calendar of many people working in and around the field of medical sociology. It is also reassuring that people working in the area of medical sociology, many from academic institutions, rate the social interaction with others, and the academic excellence of papers as the most important reasons for continuing to attend MedSoc year after year. The collegiate atmosphere, provided by senior academics conversing easily with people at an early stage in their career, seems to be a factor unique to MedSoc, providing a welcome contrast with the more clearly defined hierarchies that may perpetuate at other 'medical' conferences.

It is these 'less tangible' aspects of conferences that need to be recognised as the strengths of the MedSoc conferences, and aspects that need to be supported and fostered through the coming years. The comments received by the committee clearly demonstrate the requirement for senior academics to continue to attend MedSoc, as their willingness to give papers and attend the papers of others, to ask questions, chair sessions, give encouragement and praise, and to share their own insights into research, are genuinely valued by other attendees. The fact that this happens at MedSoc is due partly to the motivation and disposition of senior academics to share their knowledge, partly due to the environment created by the planning committee in terms of the venue, sessions, streams, breaks, refreshments etc., and also partly created by the 'tone' of the conference, set by the 'welcome' to the conference, the conference pack, marketing material, and the choice of plenary speakers, and events such as the

newcomers' reception, the conference dinner, and the disco.

Feedback such as this represents an important way of keeping in touch with the membership and making sure that the conference continues to develop in ways that not only meet the needs of the current membership, but encourages people to come year after year and perhaps, after reading this, to consider attending a MedSoc conference for the first time.

## BOOK REVIEWS



Chris Shilling (Ed)

### **Embodying Sociology: Retrospect, Progress and Prospects**

Blackwell Publishing/The Sociological Review 2007  
£17.99 (pbk)

(ISBN: 978-1-4051-6794-9) 169 pp

**Reviewed by Carrie Purcell, University of Edinburgh, UK**

As part of the Sociological Review Monographs series, this edited collection brings together work which contributes to the embodying of sociology, an area that has previously been somewhat under-developed. It includes a range of theoretical and empirical approaches, and draws together classical and contemporary sociology, as well as anthropology and feminist scholarship over its ten chapters.

Given that embodying sociology has been the main concern of his work, it is unsurprising that the collection is edited by Chris Shilling, who also provides a comprehensive introduction to the area. Shilling's chapter traces the role of embodiment in sociology from the discipline's inception, and the writings of Comte, Durkheim and Simmel, through the 'rise of the body' in sociology from the early 1980s to the present day. Shilling emphasises that the notion of embodiment should not be confined to the area of the body, but rather that it applies to all sociology and mounts a challenge to its dualistic nature. The chapter touches on the notion of 'body pedagogics', which the author conceptualises as 'the central pedagogic means through which a culture seeks to transmit its main corporeal techniques, skills and dispositions, the embodied experiences associated with acquiring, or failing to acquire these attributes, and the actual embodied changes resulting from this process' (p.13). Shilling – and indeed the collection overall – looks to the future of embodied sociology in the hope that this approach will both bring together and allow for the analysis of the aspects of power, social control and lived experience which feature in social reproduction or change.

The volume goes on to present a number of chiefly theoretical contributions from sociologists well known in the field of the body. Among these is Bryan Turner who writes on 'prolongevity' technologies and the social implications of 'living forever', a chapter which, given its focus, surprised me slightly in its distance from the materiality of ageing bodies. Kathy Davis' chapter, on the other hand, appealed with its aim of drawing attention back to feminist theory and the need to link the latter with embodied practice. Taking Haraway's 'The Virtual Speculum in the New World Order' (1999) as her starting point, Davis identifies the need for a more grounded critique of feminist health practices which allows for the material realities and vulnerabilities of female bodies, which are in turn influenced by social and historical location. With reference to her own research on the embodied experience of women, Davis proposes a phenomenological approach to the body as a way to consolidate feminist theory with embodied practice, and to overcome this absence of tangible bodies in contemporary feminist theory.

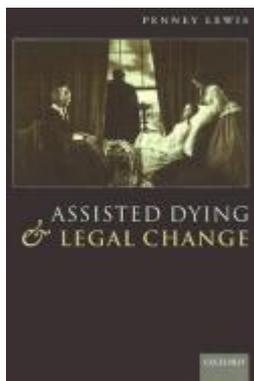
An interesting contribution from an anthropological and cross-cultural perspective comes from Judith Okely, who takes steps towards unpicking the much neglected role of the researcher's own body in fieldwork. However, it was Nick Crossley's chapter, which

continues on the theme of the transmission of cultural attributes, which I found most valuable. Crossley builds on Mauss' theory of 'body techniques', offering a more practicable methodological approach than is present in the original work. He argues that rather than having been disembodied and dualistic in the mould of philosophy, the very lines along which sociology was established allowed it to 'circumvent' such dualistic thinking. Crossley does not deny the absence of the body in sociology, but rather wishes to highlight this absence as being a (perhaps necessary) backgrounding to allow us to focus on the world our bodies are in, alongside its meanings and structures. Given this, Mauss' approach is proposed as a way to bring knowledge and meaning together with embodiment. Ultimately Crossley advocates utilising Wacquant's 'observant participation' – and specifically in relation to the teaching/learning process – in what I found to be the most convincing methodological argument in the volume.

The latter half of the book includes several engaging, empirically-focused chapters, the first two of which were, for me, the highlights of this text. Brian Lande's chapter focuses on the breathing techniques of army cadets. Lande takes up Shilling's concept of 'body pedagogics', and gives an informative account of how institutional priorities become embodied practices. The subsequent chapter sees Anna Aalten re-visit her research on professional ballet dancers, a professional culture shot through with issues related to bodily dys-appearance and control. Aalten considers aspects of the transmission of embodied ways of being which are both negative – frequent injuries and eating disorders – and positive, such as the associated feelings of transcendence.

The penultimate contribution, from Erin O'Connor, uses both written and photographic narrative to effectively convey the pedagogical experience of learning glass blowing, a skill involving extreme fine-tuning of body techniques, not least of which is a very steady hand. The volume closes with a phenomenological take on sleep from Simon Williams, which addresses the inherent vulnerability of people/bodies in the state to which we must all at times resort, as well as the rituals and body techniques which book-end this particular form of embodiment.

As a post graduate researcher currently grappling with the issues associated with embodiment in my own research, I found this volume extremely motivating. The broad scope for embodying sociology is well represented through the range of contributions, and the vast possibilities for future work in this area are highlighted. The book will be of specific interest to any researchers or graduate students working on the area of the body and body work, but is also accessible enough to be of broad relevance in our approach to the discipline of sociology on the whole.



Penney Lewis

### **Assisted Dying and Legal Change**

Oxford University Press. 2007 £50.00 (hbk)

(ISBN: 0199212872) 280pp

#### **Reviewed by Clive Seale, Brunel University, UK**

In this book Penney Lewis, Reader in Law at King's College London, describes the differing principles that lie behind legalisation, and attempted legalisation, of assisted dying (euthanasia and assisted suicide) in different countries. She demonstrates quite convincingly that human rights-based arguments stand little chance of becoming the basis for legislation. Such arguments include the view that every person should have the right to determine the circumstances of their own death because of individual rights to liberty, dignity, autonomy, privacy or even property rights over their bodies.

The problem with such arguments is that they clash head-on with other arguments based on rights: the right to equal protection under the law, for example, which some people feel may be violated for certain marginalised individuals such as elderly or disabled people, whose right to life may be compromised by the imposition of a duty to consider assisted dying. Rights discourse, Lewis argues convincingly, is characterised by absolutist claims and lack of willingness to compromise on both sides, so cannot be the basis for legal solutions.

Mistakenly, some believe that the legalisation of euthanasia in the Netherlands is based on the principle that terminally ill and other suffering individuals have the right to medical assistance to end their lives. In fact, Dutch legalisation is based on the principle of necessity as it governs the actions of doctors, such that where a course of action becomes necessary, a doctor ought not to be blamed for taking it. Thus the doctor who separates conjoined twins, knowing that by doing so one life will be saved and the other ended, justifies this act by an appeal to necessity. By virtue of their profession, doctors are obliged to relieve suffering and if euthanasia is judged, after due exploration of other options, to be the only available solution to suffering, doctors are then considered in Dutch law to provide it out of necessity.

Lewis diverts briefly to consider compassion as the basis for legalisation considering, at this point, proposals recently put forward in France that would justify assisted dying if all concerned believe it to be the compassionate thing to do. Amusingly, she concludes that compassion 'as a driver for legal change has no legal status either in common law or civilian legal systems', quoting one authority who describes compassion as 'a curious kind of legal anti-matter'.

Having thus accounted for the place of compassion in legal proceedings, Lewis goes on to propose her main thesis, which is that the legal experience of one country may not easily be relevant for another. This argument is explored most thoroughly in her consideration of why the Dutch legal solution has not been applied in jurisdictions such as the UK. It is at this point that Lewis comes closest to drawing on sociological observations. In the UK, opponents of legalisation have successfully argued that factors like the availability of palliative care and the likelihood of a slide down the slippery slope towards non-consensual euthanasia mean that legalisation is both unnecessary and potentially harmful. Unlike the Netherlands, the medical profession has not lobbied for legalisation and various attempts to introduce legislation that would permit assisted dying have failed.

In the Netherlands, Lewis points out, there is a strong cultural preference for depoliticising

controversial moral issues (seen for example, in issues such as abortion, prostitution and the control of drugs). Trust in the medical profession is high and that profession has shown itself willing to support assisted dying. Thus, when forming legal judgements Dutch and British judges have been influenced by these things. However, British judges know, when considering cases that come before them involving, for example, the prosecution of a doctor reported for having deliberately ended the life of a patient, that the democratic consensus expressed through the will of parliament is to avoid a decision that would effectively bring in a permissive law. Leniency in such cases is exercised by other means and the law stays the same. In the Netherlands, by contrast, the defence of necessity achieved the same solution without going against the spirit of Dutch public and medical opinion. At the same time, the Dutch experience is due, at least in part, to 'happenstance' in that cases came before Dutch courts at a particular time that were amenable to the argument from necessity, with case law developing from that point to reach the present state of affairs.

Lewis is concerned particularly with legal change achieved through court decisions and is less concerned to explore changes brought about by the passing of new laws in legislative assemblies or through ballot measures, such as those which have legalised assisted dying in Oregon, Belgium and, briefly, in the Northern Territory of Australia. As the Australian experience of legal reversal shows, and as is shown by repeated attempts by the US federal government to overturn the Oregon state legislature's decision, legal change brought about by such methods may be less secure than that which is forged through a series of cases in the courts.

The final chapter of the book considers empirical evidence for the 'slippery slope' argument – the view that legalisation must lead to unwelcome or harmful extensions of a permitted practice - providing a comprehensive review of survey and other research-based evidence about the practice of assisted dying around the world. Lewis concludes that empirical evidence for the slippery slope is at present lacking, and that conclusive evidence would be hard to obtain. In this chapter she shows an exemplary appreciation of the methodological issues involved in doing social research in this area. This is a well argued and scholarly book that provides the reader with a clear overview of international variations in the law covering assisted dying, and a compelling argument for understanding national contexts before generalising from one nation's experience to that of another. I can recommend this book strongly to sociologists who want to understand the role played by the law in this issue.



John A. Vincent, Chris R. Phillipson and Murna Downs  
(Eds)

### **The Futures of Old Age**

Sage (Published in association with the British Society of Gerontology) 2006 £20.99 (pbk)

(ISBN 1-4129-0108-1) 255pp

**Reviewed by Carla M. Rodríguez García, Healthy Cities Programme, Aviles, Spain.**

There is no doubt that the field of gerontology continues to be challenged by the ageing of society. The British Society of Gerontology (BSG) has clearly assumed this challenge with the publication of this book, which aims to provide a major assessment of the different

changes involved in the future of old age, alongside the key questions concerning old age. The book is organised into seven parts, each one of them consisting of an introduction and three contributions.

Part I, 'The Future of the Life Course', with contributions from Blaikie, Bengtson/Putney and Dannefer/Miklowski, assesses changes in the life course, and the relationships between generations and cohorts regarding the ageing experience. It pays attention to the continuing hegemony of youthful attitudes among the baby-boom generation, and convincingly challenges the weakness of the intergenerational contract, arguing that a viable social contract between generations will remain a characteristic of society in the future of age-group interactions. It also places emphasis on the importance of the life course as an area of study, urging consideration of this kind of analysis when examining current social changes such as new risks or globalisation.

Part II, 'The Future of Social Differentiation', with chapters by Walker/Foster, Arber and Nazroo, examines the impact of social class, gender and ethnicity when experiencing old age. Its main contribution is to underline how these issues will continue to reflect the inequalities among the elderly and will be the main influence on their experience of old age.

Part III, 'The Future of Retirement and Pensions', with contributions by Price/Ginn, Evandou/Falkingham and Minns, analyses a number of key issues in relation to the future of pensions and income in old age. Price and Ginn draw attention to the difficulties and problems related with pension provision, paying particular attention to their role in alleviating social inequality for some groups such as women, and they call for the strengthening of the state pension scheme to promote equality. Evandou et al. show how, despite the fact that baby-boomers are better off than previous generations, variations of significance prevail between them. The last chapter reports the failure in the reforms of pension systems towards private-funded schemes.

Part IV, 'The Future for 'Self' in Old Age', with chapters by Biggs, Gubrium/Holstein and Coleman/Mills/Speck, explores growing old from a subjective perspective. Biggs's contribution investigates how relationships between older and younger age groups might change through time, and the kind of implications they can have for the self and identity in old age. Gubrium and Holstein present an alternative model and consider the self as a product of ongoing biographical work, leaving the future of ageing self-dependent upon the dynamic of available interpretative possibilities. Lastly, Coleman et al. introduce an interesting discussion about religiosity and the increasing disenchantment with organised religion among the older population.

Part V, 'The Future for Health and Well-Being in Old Age', with papers by Victor, Downs/Bruce and Bond/Corner, examines with accuracy a range of health issues arising from demographic changes. Here we can find a well-developed and convincing contribution by Victor where three scenarios of future health development among the elderly are discussed. In addition, contrasting with the expected physical health improvements among the elderly is Downs and Bruce's analysis of the social inclusion of people with dementia and their families. This topic is strongly related with the last chapter of this section which discusses the need for a clearer conceptualisation of well being and quality of life.

Part VI, 'The Future of Family and Living Arrangements for Older People', with contributions by Harper, Davidson and Peace, examines the family life and living arrangements of older people. There is no doubt about the influence of demographic and social change on family structures and relationships. Their consequences and implications are also of vital importance for the elderly, not least for their housing arrangements.

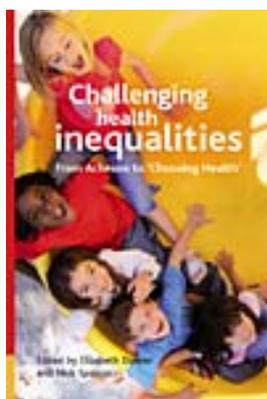
Finally, the last section of this book, 'Globalization and the Future of Old Age' includes contributions by Vincent, Phillipson and Warnes and explores the impact of globalisation on the lives of older people. This part discusses the following issues: the need for science to value old age; the challenge of introducing old age as participant of the new global environment; and the implications that migration patterns can have on older people.

Taking into account not only the multidisciplinary forum in the field of ageing that the BSG encourages but also the rising diversity of issues that lie ahead for the 'futures of old

age', this book is an excellent point of entry to a wide range of topics and provides an extensive overview of some of the current debates in this field. However, it is primarily focused on the British context, and the scarcity of comparative data and references from other European countries is one of its weaknesses. In addition, I consider that more emphasis on political and institutional aspects, or the existing social arrangements generating policy feedback which can affect the scope of present of future reforms, could have given strength to the arguments developed when discussing the future of stock market pensions.

Last but not least, the discussion about dementia could have signalled further implications than those that are included. I would personally point to the necessity for the development of integrated attention to dependency situations in old age, that is, the development of renewed concepts of integrated health and social care for older persons. These issues have already been included in the agenda of some European countries, such as Spain, with the passing, at the end of 2006, of the Law of Promotion of the Personal Autonomy and Attention to the People in Situations of Dependency.

All in all, this is a highly recommended book to anyone interested in old age issues and I encourage other national associations to accomplish work similar to that promoted by the BSG.



Elizabeth Dowler and Nick Spencer (eds)

**Challenging Health Inequalities. From Acheson to 'Choosing Health'**

Policy Press, 2007. £24.99 (pbk)

(ISBN 9781861348999) 272 pp

**Reviewed by François Briatte, University of Grenoble, France**

*Challenging Health Inequalities* contrasts the current scientific evidence on health inequalities with the efforts that New Labour governments have put into tackling them. It does so by referring to two key policy documents that reflect different political contexts as well as divergent policy orientations. The *Independent Inquiry into Inequalities in Health*, chaired by Sir Donald Acheson in 1998, was conducted immediately after New Labour came into power with its manifesto promise to tackle ill health. The subsequent *Saving Lives White Paper* (1999) then seemed to reconcile public health research and health policy over the social determinants of health and the need for public action, in opposition to the dismissal of the Black Report under Conservative governments. The *Choosing Health White Paper* (2004), on the other hand, reflects a shift amongst New Labour health policy elites towards the primacy of individual choice in health care.

The core issue underlying discussions of health inequalities is the articulation of structural and individual imputation. While scientific and political views of the same issue rarely coincide, this is clearly the case here. Both views do not strike the same balance between structure and agency, between public services (such as education, housing and health services) and private individuals; as a consequence, they come to different conclusions and emphasise different solutions. The scientific view embodied in the book, collectively supported by its authors through extensive references to research in public health and social epidemiology, acknowledges the role of collective processes in generating inequalities and ultimately in shaping individual health status. On the other hand, the political view extracted

from the wording of policy documentation shows that governmental orientations towards health inequalities have fluctuated: whereas *Saving Lives* targeted social factors ‘beyond the control of individuals’ as the most effective catalyst for change in health policy, *Choosing Health* focuses on encouraging individualised health-enhancing behaviours and emphasises the benefits of informed choice.

The authors of *Challenging Health Inequalities* clearly collectively regret the latter individualistic turn taken by the *Choosing Health* White Paper. To the authors of Chapter 4, who capture the overall impression created by the book (and which is restated in its conclusion), the retreat of public health policy into the subgroup of social determinants of health formed by lifestyle factors ‘certainly represents a shift, albeit a regressive one, in the government’s approach of tackling health inequalities’ (p.58). This feeling of disenchantment persists throughout the book, as the hope embodied in the Acheson report is obliterated by the reductionist view of health promotion that seems to have recently become the paradigmatic backbone of governmental policy towards health inequalities. The common concern, expressed here in the words of the authors of Chapter 3, is that ‘the bold statements and unprecedented promises of New Labour’s first years in power...have been wholly overtaken by the individualistic rhetoric of behavioural prevention’ (p.48), which seems to forget that choice, like all other determinants affecting agency such as rationality and organisation, is naturally bounded. As shown in the subsequent chapters on early life, ethnicity and housing conditions (Chapters 5-7), a wide array of social determinants of health fall outside the boundaries of personal choice. Even lifestyle factors such as nutrition or nicotine intake (Chapters 8-9) are heavily conditioned by structural characteristics that are clearly beyond individual control and personal preferences, such as food pricing and stress (p.132 and p.162 respectively).

One chapter of *Challenging Health Inequalities* claims that *Choosing Health* brings England back to Margaret Thatcher’s view that ‘there is no such thing as society,’ which is slightly mistaken (Chapter 3, p.43). The complete quote from Margaret Thatcher is: ‘There is no such thing as society, just individuals *and their families*’ (*Women’s Own*, 3 October 1987; my emphasis). If choice is to remain in the sole hands of the individual under the policy trend initiated by the *Choosing Health* White Paper, then the current ideological context of health policy should actually be considered as even more reductionist than past ones. However, the very recent publication of *Health Inequalities: Progress and Next Steps* (Department of Health, 9 June 2008) shows some ambivalence about the exact path to follow: while the document states that ‘(h)health inequalities are a reflection of wider inequalities, which in turn are linked to inequalities in opportunities and aspirations’ (p.5), it persists in its focus on lifestyle attributes, stating that ‘(m)any inequalities in health are a preventable consequence of the lives people lead, the behaviours and lifestyles that cause ill health, many of which show a stark relationship with social-economic factors’ (p.7). It hence remains unclear whether health inequalities are to be tackled through a typical act of government of self – an internalised sense of discipline (helped by ‘health trainers’) resulting in ‘healthy choices’ – or through public authorities addressing the wider social circumstances in which individual choices are made.

The book shows, finally, that the science-policy relationship is very dynamic in the English context, as illustrated by Chapter 2, which is authored by a civil servant of the Health Inequalities Unit. Other countries, such as France, have very different records on that matter, for a number of reasons that are out of the scope of this review. The reader might then regret that *Challenging Health Inequalities* concentrates entirely on the single case study of England. Comparative research indicates that national differences exist in the perception and treatment of health inequalities, partly because the internal politics of public health take various forms in different states. The comparatively exceptional level of academic interest in the United Kingdom for health inequalities is, in itself, an indicator that cross-country variations exist at the science-policy level, and further research is hopefully needed in this domain for a full understanding of health inequalities to develop.

## Submitting a book review

MSo welcomes the submission of book reviews within the discipline of medical sociology. A list of books available for review will be published in each edition (see below), and books may be obtained from the editorial team. However, the editorial team will also be happy to consider reviews of books not listed, provided they are of relevance to the medical sociology community. There is no prescribed format for reviews, although reviewers should provide the full reference of the book, including the price, number of pages and the ISBN. Book reviews should be no longer than 1000 words. Completed reviews should be submitted as a Microsoft Word document via email to [mso@liverpool.ac.uk](mailto:mso@liverpool.ac.uk). Book reviews will not be subject to peer review, and the decision to publish will be made by the editorial team. The editorial team also reserve the right to edit articles prior to publication.

The editorial team would also strongly encourage readers of MSo to specify particular areas of medical sociology that they would like to see book reviews in, or key medical sociology texts they would be interested to read a review on.

## Books available for review

Tim Blackman (2006) *Placing Health: Neighbourhood renewal, health improvement and complexity*. Bristol: The Policy Press

Martin Davies (Ed) (2008) *The Blackwell Companion to Social Work* (3<sup>rd</sup> Edition). Oxford: Blackwell Publishing

Robert Dingwall (2008) *Essays on Professions*. Aldershot: Ashgate Publishing Limited

Bruce M.Z. Cohen (2008) *Mental Health User Narratives: New Perspectives on Illness and Recovery*. Basingstoke: Palgrave Macmillan

Klaus Bergdolt (2008) *Wellbeing: A Cultural History of Healthy Living*. Cambridge: Polity Press

Anne Llewellyn, Lorraine Agu, and David Mercer (2008) *Sociology for Social Workers*. Cambridge: Polity Press

If you wish to review one of books listed above please contact the editorial team, [mso@liverpool.ac.uk](mailto:mso@liverpool.ac.uk)

## CURRENT RESEARCH

### Development of a patient based outcome assessment instrument for depressed older adults in secondary care services



**PhD researcher: Maggie Lo**

*Department of Psychiatry, University of Liverpool, UK*

[maggielo@liv.ac.uk](mailto:maggielo@liv.ac.uk)

Maggie Lo began her PhD in January 2006 on a full-time basis and expects to complete in December 2008. Funded by the University of Liverpool, the thesis is titled: Development of a patient based outcome assessment instrument for depressed older adults in secondary care services.

#### **Supervisors**

Professor Kenneth Wilson, University of Liverpool;

Professor Liz Perkins, University of Liverpool;

Dr Pat Mottram, University of Liverpool

#### **Aims and Objectives**

The research aims to develop a depression specific patient based outcome instrument for older adults that are statistically valid and be sensitive to changes over time.

#### **Methods**

The study adopted a Grounded Theory approach. A total of 30 patients aged 65 years and over (twenty three females and seven males) participated in the study. All were either undergoing treatments for Major Depressive Disorder or had recently recovered. In-depth interviews were used to encourage participants to share their experience of depression and, where appropriate, recovery. All interviews were tape recorded, transcribed and analysed using Nvivo

#### **Description of argument / Results to date**

The interviews revealed that for each individual, depression was hugely complex and variable. At its most severe, depression imposed a muteness on people which removed their ability to explain or even describe how they were feeling. For these people depression was characterised by a loss of abilities arising in most instances from a lack of desire. As reported

in the literature there was also an association between their mental state and their physical state.

### **Stage of research process**

Data collection has been successfully completed, currently conducting data analysis and hoping to complete this by July 2008.

### **Contact details**

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## Addressing the needs of children of drug using parents



### PhD researcher: Kerry Woolfall

*Centre for Public Health, Liverpool John Moores University, UK*

[K.Woolfall@ljmu.ac.uk](mailto:K.Woolfall@ljmu.ac.uk)

Kerry is a Senior Researcher in the Centre for Public Health at Liverpool John Moores University. She began her PhD in 2006 on a part time basis and has now, after two years, moved to studying full time, with a view to completing in March 2010. In addition to her PhD she will continue her work within the centre on drug prevention research with children and young people. The next research project she will be involved in will investigate the needs of young homeless people in the city of Liverpool.

### Supervisors

Dr H. Sumnall (Liverpool John Moores University)

Dr L. Porcellato (Liverpool John Moores University)

Professor Cliff Cunningham (Liverpool John Moores University)

### Aims and Objectives

This study aims to evaluate two community-based services (Families First, Middlesbrough & PSS IMPACT, Liverpool) which are providing support for children and families affected by substance use, whilst also providing an exploration of issues which impact upon the lives of children, parents and kinship carers. The study aims to add to the UK evidence base and inform the development of future interventions for children affected by parental substance use.

### Methods

This is a multi method study incorporating both quantitative and qualitative research methods including: semi-structured interviews; interactive focus groups; research diaries and questionnaires.

### Description of argument / Results to date

As part of the 2 evaluations 33 semi-structured interviews and questionnaires have been conducted, involving parents from 9 families who took part in 3 interviews over a 12 month period. To date, 149 children and young people have completed structured questionnaires. Seven interviews have also been conducted involving kinship carers from Liverpool and Middlesbrough. These interviews aimed to explore the experiences of grandparents, aunts and

uncles who provide care for children as a result of parental substance use.

### **Stage of research process**

All qualitative and quantitative data for the evaluation of Families First's Intensive Family Preservation Package in Middlesbrough has been collected and analysed with the write up stage in progress. All other data collection and transcription stages are ongoing.

### **Related publications**

Woolfall K., Sumnall H. and Porcellato, L. (2008). Evaluating Community Based Interventions for Children of Substance Using Parents: A Review of Outcome Measures. Paper submitted.

### **Related Conference Presentations**

Woolfall, K. and Sumnall ,H. (2007). *Evaluating Community Based Interventions for Children of Substance Using Parents: A Review of Outcome Measures*. Evidence Based Practice Conference, 18<sup>th</sup> May 2007 & Institute for Health Research Annual Conference, 9<sup>th</sup> May 2008, Liverpool John Moores University.

Woolfall, K., Sumnall, H., Porcellato, L., Jones, D. and Owen, L. (2008). Preventing young people's access to cigarettes. 14<sup>th</sup> Qualitative Health Research Conference 2008, Banff Canada 3<sup>rd</sup>-6<sup>th</sup> October 2008.

Woolfall, K., Sumnall, H., Porcellato, L., Jones, D. and Owen, L (2008). Young people's response to smoking prevention campaigns. 14<sup>th</sup> Qualitative Health Research Conference 2008, Banff Canada 3<sup>rd</sup>-6<sup>th</sup> October 2008.

### **Contact details**

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**University of Greenwich  
School of Health and Social Care  
Avery Hill Campus, London SE9 2UG**

## **PhD Studentships in Health and Social Care**

Applications are invited for two three-year, fulltime postgraduate research studentships in the School of Health and Social Care leading to a PhD. Candidates will have a background in social science and/or the health and social care professions (nursing, midwifery, public health, health management or social work). One of the studentships will focus on aesthetic medicine, which encompasses treatment or procedures that affect the external appearance of the patient. The emergence of this new specialty is an opportunity to study how important issues of risk and regulation are negotiated by interested parties in addition to the professions. The topic of the second studentship is open. Applications are invited in any area of health and social care, including health services research, public health, patients and carers experiences, and human resource management in health and social care. Joint supervision can be arranged with other Schools for students who seek to work across disciplines. For further enquiries and early discussion of your research proposal please contact the Director of Research, Professor Elizabeth West ([e.west@gre.ac.uk](mailto:e.west@gre.ac.uk)).

The bursary will be £14,500 per annum in 2008/09; tuition fees will be met in addition to this sum. Successful candidates will be expected to undertake taught course in qualitative and quantitative research methods and key research skills if required. Students may be asked to undertake some teaching support activities of up to three hours a week and are expected to contribute to the life of the School and to play an important role in developing the research culture.

A Masters degree or a First or Upper Second Honours Degree is required.

A full application includes:

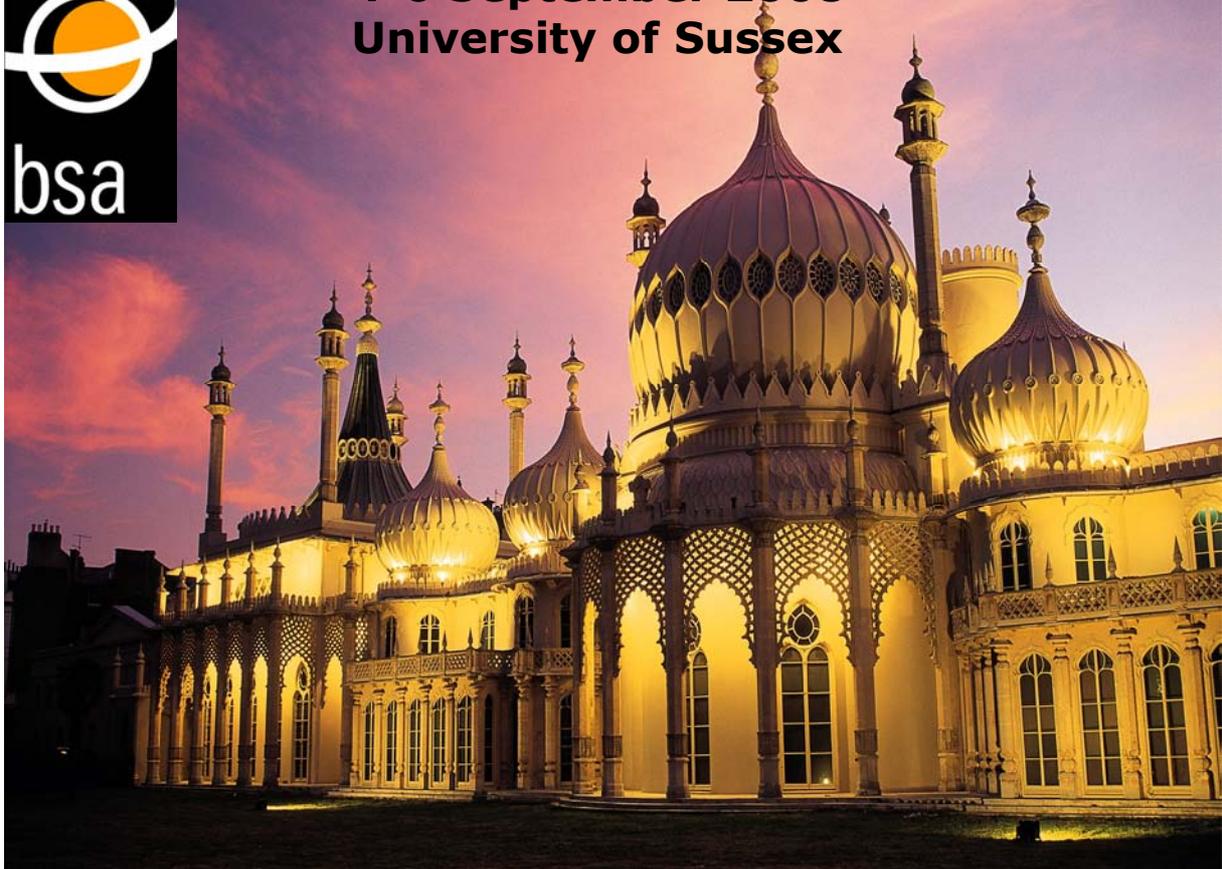
- **An application letter**
- **CV (including details of education, qualifications, research and other relevant experience)**
- **Research proposal of up to 2,000 words**
- **The names of two academic referees; to speed up the process referees should be asked to send their references immediately, by post to the address below, or by email to [p.r.rogers@gre.ac.uk](mailto:p.r.rogers@gre.ac.uk)**

Please send your application to the address below or email to [p.r.rogers@gre.ac.uk](mailto:p.r.rogers@gre.ac.uk) by July 31<sup>st</sup> 2008. Interviews will be held in August and studentships will commence on or before October 2008.

**Professor Elizabeth West  
Director of Research  
School of Health and Social Care  
Mary Seacole Building  
University of Greenwich  
Avery Hill Road  
Eltham, London SE9 2UG**



## **BSA Medical Sociology Conference 4-6 September 2008 University of Sussex**



The 2008 conference will celebrate 40 years of medical sociology with plenary sessions reflecting on both the origins (including some of the original founders) and the future of the group.

The conference takes place at The University of Sussex, nestled in the South Downs. The University is the only university in England which is entirely situated in a designated 'Area of Outstanding Natural Beauty', with easy access to Brighton, London and Gatwick Airport.

The University campus, set in 200 acres of beautiful parkland, is like a large self-contained village with lecture theatres, seminar rooms, accommodation, restaurants, bars, shops, sports facilities, libraries and laboratories all within easy walking distance.

In 2007, the MedSoc Annual Conference attracted over 250 delegates from around the world. The event was a great success and enjoyed by all - this year we celebrate its 40<sup>th</sup> Anniversary. The annual conference provides delegates with the opportunity to discuss the discipline's 'hot topics' within a real community of medical sociologists. Past delegates have referred to the event as a 'must' for anyone within the medical sociology arena and those within closely related fields

Gill Bendelow and Kim Clarke on behalf of the conference organizing team

## Conference Programme

Registration starts from 11.30am on Thursday 4 September, with the first paper sessions at 1pm. The conference ends with the closing plenary at 1.45pm on Saturday 6 September.

You can see the outline programme at <http://www.britsoc.co.uk/events/medsocprog.htm>

## The Plenary Sessions

In celebration of the forty years of the medical sociology group, the opening plenary on Thursday 4 September will be a special occasion with memoirs from the founding members Raymond Illsley and John McKinlay, and reflective contributions from Mildred Blaxter and Mike Bury.

The closing plenary on Saturday 6 September is called 'Futures thinking: the next 40 years of medical sociology' and will break with the traditional format for plenary sessions.

Paralleling the opening plenary which will look back over our history, a panel of speakers will reflect on their visions for the future of the discipline. These include David Armstrong, Mary Dixon-Woods, Julia Lawton, Catherine Pope and Clive Seale.

## Sociology of Health and Illness Book Prize

The winner of the 2008 SHI Book prize will be unveiled at the conference. This year's shortlist is:

- Corinne Squire *HIV in South Africa* (Routledge)
- Carol Thomas *Sociologies of Disability and Illness* (Palgrave)
- Andrew Webster *Health, Technology, and Society* (Palgrave)

See previous winners of this prestigious prize:  
[www.britsoc.co.uk/medsoc/MedSoc\\_SHI.htm](http://www.britsoc.co.uk/medsoc/MedSoc_SHI.htm)

**For more information about the conference to Medical Sociology Group Conference website at:**  
[www.britsoc.org.uk/events/msconf.htm](http://www.britsoc.org.uk/events/msconf.htm)

## Symposia

Building on the success of last year's conference, we will again be holding a number of specialist symposia during the conference. This is an opportunity for speakers and participants to engage in greater depth with a particular topic, theme or sets of questions. This year we have 4 symposia.

### **NEUROSCIENCE AND SOCIETY: SOCIOLOGICAL AGENDAS**

Organized by: Simon Williams (University of Warwick) and Paul Martin (University of Nottingham)

The past two decades have witnessed significant developments in the neurosciences – a term that includes molecular neuroscience, psychiatric genetics, behavioural genetics, cognitive neuroscience, brain imaging and psychopharmacology. These developments carry potentially profound implications for understandings and explanations of our selves, identities, minds, moods, memories, emotions, desires, behaviours based on the brain and its neurochemistry, including novel neurotechnologies designed to study, diagnose, treat or enhance us.

The symposium will be chaired by Professor Robert Dingwall (University of Nottingham) and features the following speakers:

- Dr Paul Martin (University of Nottingham): 'The making of neuroscientific futures'
- Dr Katie Featherstone (University of Cardiff) 'Genomics and psychiatry: neuroscience, behavioural genetics and psychiatric practice'
- Professor Simon Williams (University of Warwick): 'Psychopharmaceuticals, enhancement and the neurobiological self: Thinking through Modafinil'

### **AUSTRALIAN SOCIOLOGY PANEL**

Organized by: Alan Petersen, Professor of Sociology, School of Political and Social Inquiry, Monash University, Melbourne, Australia.

Over the years there has been a considerable exchange of ideas between Australian and British health sociologists. This panel will explore recent developments in Australian health sociology, making reference, where appropriate, to comparative developments in the UK. The panel will comprise Australian scholars (all members of The Australian Sociological Association) who have worked in this field for a number of years, either in departments of sociology or in centres of health research. The panel will provide the opportunity to examine points of convergence and divergence in intellectual interests and, hopefully, assist in the effort to forge links between health sociologists working in the two countries.

Speakers include:

- Evan Willis, 'State of the art: Antipodean health sociology in review'
- Fran Collyer, 'Health sociology since 1990: Australia and the United Kingdom'
- Karen Willis 'Remaining relevant: teaching sociology in practice based courses'
- Marilys Guillemain 'The place of sociology in Australian medical curricula: challenges and opportunities'

## **MEDICALIZATION – DEMEDICALIZATION OF DEPRESSION**

Organized by: Renata Kokanovic, The University of Melbourne, Australia

Contemporary society is witnessing increasing levels of various ‘mental disorders’, including a range of ‘dysthymic’ emotional states which are receiving diagnosis as formal psychiatric disorder. As the boundaries of what constitutes depression continue to expand, various forms of ‘professional help’ and so-called ‘psy therapies’ providing advice and instruction how best to manage ourselves increasingly infiltrate everyday life. Many depression researchers argue that trends in labeling and language-use in diagnosis of depression should be viewed as an indicators of important social processes, particularly among mental health professions. It is argued that the most influential and the most accepted perspective in psychiatric circles posits depression as having a biological, psychological and genetic basis, with ‘environmental’ conditions operating as mediating factors. The problematic though is that social processes are often reduced to subsidiary elements within overall biomedical problems. Medical discourse creates a dichotomy between the individual’s experiences of misery and the wider social context that underpins it. As a result, the emphasis is then on the treatment of individual patients, rather than on tackling the underlying social context of distress.

Speakers include:

- David Armstrong ‘Depression: the label and the metaphor’
- David Pilgrim ‘Ontological and epistemological aspects of misery’
- Ann Rogers ‘Primary Care a new field for the management of mental health problems?’
- Chris Dowrick ‘Coherence and engagement: transforming narratives of depression’

## **LIFE COURSE INFLUENCES ON HEALTH AND DEVELOPMENT: APPLYING MEDICAL SOCIOLOGY TO QUANTITATIVE LONGITUDINAL DATA**

Organized by: Melanie Bartley (Professor of Medical Sociology, University College London) and David Blane (Professor of Medical Sociology, Imperial College London).

Birth Cohort and Longitudinal Studies have been described as The jewels in the crown of British social science and are unrivalled in any other country worldwide. The newly commissioned UK Household Longitudinal Study is depicted as the social science equivalent of the Cyclotron atom-smasher. All these data sets contain information on health, which increasingly will include DNA. The symposium will present analyses of some of these studies; and end with a demonstration of how to access, handle and analyse such data.

Speakers include:

- Lidia Panico will use Millennium Cohort data to report ethnic differences in infant development.
- Ann McMunn will use 1946 Birth Cohort data to analyse women’s roles and health in middle age.
- Bola Akinwale will use ONS Longitudinal Study data to examine the relationship between health and retirement from paid employment.
- Juliet Stone will use Boyd Orr Cohort data to examine life course socio-economic position and health at older ages.
- Noriko Cable will use 1970 Birth Cohort data to demonstrate how to access UK Data Archive and download & analyse a quantitative data set.

## Sociology of Mental Health Study Group: AGM

Since its inception in 2004, this Group has burgeoned, and now boasts a large and broad-based membership. The aims of the Group are to: heighten the profile of the sociology of mental health; provide a forum for dissemination and discussion of work being conducted in this area; facilitate networking, information-sharing and provide a support forum for those working within or studying the sociology of mental health; and provide a core of expertise in this study area.

This fifth annual general meeting will give the opportunity to meet members of this very active group, which has hosted and supported a variety of events and activities over the last four years. New members are extremely welcome to come and join. The meeting will also provide opportunity to review and discuss the Study Group's recent activities, and to hear about and contribute towards future plans.

The meeting will conclude with a presentation from Susie Scott, University of Sussex, based on her award-nominated book, *Shyness and Society: The Illusion of Competence* (2007, Palgrave), after which there will be opportunity for discussion of the substantive content of her work as well as what interactionist perspectives can offer studies in the sociology of mental health:

### **The medicalisation of shyness, Dr Susie Scott**

A common perception of shyness is that it is a 'problem' existing in the minds of some individuals and something to be overcome. By contrast, a sociological approach considers the condition to have emerged as a social problem, in relation to contemporary Western values of assertiveness, vocality and extroversion. In recent years, new mental disorder categories have been created that turn 'normal' shyness into Social Phobia and Social Anxiety Disorder. Drawing on symbolic interactionist theories, my research explored 'shy' people's experiences of social reactions to their culturally deviant behaviour, experiences which in some cases led them to seek help from mental health services. Pharmacological remedies, shyness clinics and self-help websites provide different ways of controlling the social problem of shyness; however, we can also detect hints of resistance.

For further information about the Sociology of Mental Health Study Group, please see our web site: <http://www.britsoc.co.uk/specialisms/MedSocMentalHealth.htm>.

**Convenors:** Lydia Lewis, University of Warwick and Helen Spandler, University of Central Lancashire

## SHI Foundation Medical Sociology Register

**Join the SHI Foundation online register of medical sociologists. Go to <http://www.shifoundation.org.uk/members/>**