Using participatory, observational and 'Rapid Appraisal' methods: researching health and illness

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Researching locality with Community Researchers: putting long-term illness in context
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Introduction

The past 50 years have seen a burgeoning volume of sociological studies examining the implications of living with long-term ill-health for individuals and their families (Anderson and Bury 1988; Bury 1991). The rising prevalence of chronic illness makes this work ever more important as health and welfare policy seeks solutions to the growing numbers of people requiring support and care (DH 2004, 2006; DWP, 2006). The predominant methodological approach to researching the experience and implications of long-term ill-health has been face-to-face in-depth interviews, with a noted bias towards middle-class White informants who tend to be readily accessible and offer articulate, reflexive interviews (Charmaz, 2000; Williams, 2000). Influenced by social interactionist and phenomenological traditions, sociologists have sought to elicit introspective description from chronically ill people and their carers in order to construct an interpretive analysis of illness trajectories and their management (see for example seminal papers by Bury [1982] Charmaz [1983] and Williams [1984]).

This body of work has produced invaluable insights into the subjective, psychological processes of adjustment to chronic ill health (Bury 1991; Lawton 2003). However, we suggest that the dominant reliance on narrative interviews has meant limited attention to the social structural and cultural conditions that articulate with individual responses to chronic illness. The study we describe in the present chapter was concerned to counter this tendency. Thus, while we recognised the importance of listening to the personal testimonies of individuals living with long-term illness, we also aimed to understand wider contexts and processes that are commonly taken-for-granted and less open to investigation through interviews.

Seeking these insights was particularly important for the current study. The overall aim was to understand the links between long-term ill-health and dimensions of poverty. The study looked particularly at access to employment, sickness benefits and social participation and sought to identify ways in which the marginalising effects of chronic illness might be mitigated by policy and practice interventions (Salway, Platt et al. 2007). Our interest in minority ethnic disadvantage also suggested the need for tools that could grapple with underlying structural and cultural contexts. Given the disproportionately high levels of chronic illness among certain minority ethnic groups, the study included an ethnically diverse sample: Pakistani, Bangladeshi, Ghanaian and White English groups were chosen to allow contrasting, comparative analysis. We wanted to find ways of illuminating racialised processes of inclusion and exclusion that shape the experiences of minoritised individuals but which can be subtle and elusive, escaping attention in more traditional approaches to data generation (Gunaratnam, 2001; Pollack, 2003). A further objective was to understand more about the significance of place as associated with material, social and cultural value. We knew that residential locality was likely to be highly significant for people who are poor and marginalised, particularly those whose movement is potentially limited by chronic ill-health (Bentham, Eimermann et al. 1995; Haynes and Gale 1999; Jordan, Ong et al. 2000; Young, Grundy et al. 2005). This desire to learn about place again demanded additional tools. A final reason for using data generation methods that did not rely exclusively on

extended verbal descriptions was the recognition that chronically ill people vary greatly in articulacy and in the extent to which personal reflection has prepared them to offer their story.

We therefore sought to complement in-depth interviews with a package of other data generation methods that relied less on the verbal responses of individuals living with chronic illness.

Methodology and methods
Our methodological approach had three distinguishing features. First, we took a locality-focused approach, identifying four geographically delineable 'communities' or 'localities' and exploring their characteristics. Second, we worked in collaboration with a team of Community Researchers drawing on their local networks and 'insider' perspectives. Third, we employed a range of data generation methods combining participatory techniques, observation and naturalistic interaction with individuals and groups. These three elements were combined in a period of 'rapid appraisal' lasting around seven days and involving four to six researchers in each location. The total time period for the rapid appraisal across all four localities was around eight weeks. A further design decision that proved invaluable was basing ourselves in the heart of the fieldwork areas. This was possible through our collaborative partnership with Social Action for Health (www.safh.org.uk) who gave office space to the project as well as providing additional insights into local issues.

Identifying 'communities'
The notion of 'community' can tend to suggest homogeneity and clearly delineated social and geographical boundaries, while in practice 'community' means different things to different people and individuals are active in creating networks of support (Alexander, Edwards et al. 2004). Nevertheless, having a particular ethnic identity and residing within a particular geographical area can have significant implications for the options available to individuals (particularly if disadvantaged by poverty and poor health). Processes of inclusion and exclusion, which can have both ethnic and geographic dimensions, can shape entitlements in important ways. This may be particularly true for some UK minority ethnic 'communities' since there has been significant 'building of community' in many urban areas across the country in recent years (Alam and Husband, 2006). Therefore, while exercising caution in using the term 'community', we nevertheless chose to identify four geographic localities, each within London, that were home to significant concentrations of people who self-identify as: Pakistani, Bangladeshi, Ghanaian or White English. Exploring the meaning and implications of these ethno-geographic 'communities' was then part-and-parcel of our research endeavour. In practice, this approach proved relatively unproblematic for the Bangladeshi and Pakistani 'communities' since, by and large, local residents strongly identified with these ethnic categories, there were many ethnically-based community organisations that served as points of contact, and people also strongly identified with the local area that had been chosen. In contrast, though the notion of a Ghanaian 'community' was meaningful to many respondents, it was much less visible and more geographically dispersed. Varied waves of migration and a diverse linguistic and socioeconomic profile meant significant intra-group divisions so that, despite large numbers of voluntary organisations and associations, these often did not cater to an overarching 'Ghanaian' community. Finally, identifying a White English ethno-geographic community was also challenging. Though a meaningful geographical area was identified with little difficulty, individuals often did not readily self-identify on the basis of ethnicity and no community organisations were overtly for White English people. Indeed, the idea that our research should seek to identify such a social grouping was greeted with hostility from some community-level workers. Nevertheless, as fieldwork progressed, the salience of the White English ethnic identity did become apparent both in terms of people's self-identification in opposition to perceived 'others' and its relevance for access to local resources.

Working with Community Researchers

Recent years have witnessed a rise in health and social research that aims, and claims, to engage 'the researched' as active partners. Terms such as 'user involvement', 'participatory approaches', 'community consultation' and 'inclusive research' are frequently used. Arguments in favour of such approaches usually centre around (i) a belief that research itself should be an empowering tool, particularly for people who are marginalised within society, and/or (ii) a desire for more authentic and useful accounts. In practice, a wide variety of research approaches have been labelled as 'user involvement' or 'participatory'. Here we adopted a model of working in partnership with a team of Community Researchers. A Community Researcher (CR) is usually an individual who is a member, and has a detailed understanding of, a particular 'community' and uses this knowledge to facilitate the gathering and interpretation of information[1]. Though some researchers have made strong claims relating to the transformatory power of such research approaches (see for instance, Fletcher 2003), our focus was on the contribution to knowledge that the CRs could facilitate. Limited resources mean that aspirations for an empowering effect at local level were unrealistic, but we believed that CRs could build successful relationships within the communities.

A total of 12 CRs, at least two representing each 'community', were recruited through a variety of local networks. These were individuals who self-identified with one of the ethnic 'groups' of focus and who had strong links within the localities. A mix of ages, gender and experience was achieved. The CRs generally had no prior research experience, though most had worked for their 'community', for instance as health trainers or volunteers. A key criterion for recruitment was that they should be confident interacting with the public, be able to develop trust and explain the research in a positive way. As illustrated in Box 1, the CRs were provided with training and support at regular intervals throughout the project. CRs were remunerated at a fixed daily rate for their contribution. Owing to different skill levels, experience, availability and interest, the nature and degree of involvement varied between individual CRs. Nevertheless, all were involved in publicising the research, identifying suitable locations and informants, guiding the university researchers in and around the local communities, and some direct collection and interpretation of data. Training was designed to be fun and interactive but also to ensure ethical and professional standards were maintained during the research.

Box 1: Recruiting, training and supporting Community Researchers (CRs)

1. Preparation of job description and person specification
▼
2. Advertisements in local media and word-of-mouth recruitment drive
(A total of 16 responses)
▼
3. Informal 1/2 day briefing with potential Community Researchers
(Two-way discussion regarding role and expectations)
▼
4. Offers given and accepted/rejected by applications
(12 CRs recruited)
▼
5. Two day training programme
(Generic skills, project focus and specific data generation activities)
▼
6. Phase One: Rapid Appraisal planning
(CRs and university researchers brainstorm and develop fieldwork strategy)
▼
7. Phase One: Rapid Appraisal fieldwork (7 days each location)
(Daily feedback and debriefing with university researchers)
▼
8. Half-day debriefing and analysis workshop
(Participatory exercise on theme identification, gaps, alternative perspectives)
▼
9. One day training programme
(Interview techniques, 4 CRs continued to this phase)
▼
10. Phase Two: in-depth interviews
(Regular debriefing and support from university researchers)
▼
11. Analysis, interpretation and write-up
(Lead by university researchers in consultation with CRs)
▼
12. Explicit reflection on CR experiences
(Individual exercise, group reflection, interviews with independent party)

Though working with CRs added complexity to the management of the research project and raised a number of ethical and methodological issues discussed more below, they brought unique perspectives and skills. In particular, the CRs contributed to the research process by: articulating the experience of the research participants in their own language; alerting the university researchers to issues that might have been overlooked; introducing the researchers to the physical and social geography of the communities; providing a link between the researchers and community members to increase trust and confidence; advising the researchers of appropriate ways of carrying out the research; offering alternative interpretations and counter-examples to the data emerging, and guiding the ways in which the research findings represented the communities.

A package of data generation tools
As illustrated in Box 1, the research project involved two main phases of data generation. Our focus here is on Phase One, the intensive seven-day period of Rapid Appraisal fieldwork that was conducted in each of our four localities. Following completion of the two-day training programme, each CR worked individually, and with support from a university researcher, to brainstorm ideas regarding suitable locations and useful informants for inclusion in the fieldwork. The team of 3-4 CRs for each locality then worked with the researchers to develop a fieldwork strategy for the seven days, usually beginning with a Transect Walk and proceeding on to a package of data generation activities designed to elicit insights from a wide variety of perspectives (see Box 2). The broad aim of this phase was to gain an overview of the patterns of social, material and cultural resources available to members of the four 'communities' as well as an understanding of how chronic ill-health is perceived and its prominence in people's everyday lives. Box 3 provides an example of a planning sheet illustrating the package of tools utilised in one locality. CRs and university researchers were each provided with a custom-made, hard-cover Fieldnote Diary which included guides for all the data generation activities and templates for the recording of information and observations. Shortly after the completion of each of the fieldwork periods, a half-day debriefing and analysis workshop was held.

Box 2: Data generation methods

Following a number of preparatory visits and meetings with numerous people living and working in the selected localities, a seven-day period of assessment was conducted by a team of 4-6 researchers. Six distinct data collection tools were employed by the team in each of the four geo-ethnic 'communities'.

Transect walk (x2 per locality): Pre-planned, purposive walks through the selected areas with the aim of identifying key features of the local community and observing local people going about their everyday business. CRs identified suitable routes and in some cases, other local residents accompanied the research team pointing out places of significance. Researchers actively engaged the CRs and local people in discussion about the local area. Detailed notes were taken. These walks yielded information on both current and past physical and social geography of the areas.

Observation and informal discussions (x4-6 each locality): The research team spent time chatting with people informally in places where they normally go. We visited numerous locations including: mosques, churches, shops, job centres, travel agents, cafes and restaurants, hairdressers, community centres, work places, leisure centres and parks. A list of topics and questions was used to guide the discussions. These observational exercises provided insights into people's daily lives, networks of interaction and support as well as relevant local terminology.

Community resource inventory: Utilising information gained through the transect walk, observations and informal discussions with community members and the Community Researchers, an inventory of local resources available to community members was prepared. A structured template was prepared for Community Researchers to complete and this enabled the listing of items under the following broad headings: work & training; information & advice; support & care; cultural/religious; leisure/socialising; healthcare; and other facilities/resources.

Small group exercises at community venues (x2+ each locality): Facilitated exercises with small groups of men and women using two tools: an employment matrix which explored local job opportunities and preferences; and a problem tree which explored the knock-on implications of long-term health conditions for families and the wider community. These group exercises were arranged in mosques, churches, schools, community centres, workplaces and residents' homes and involved free-flowing discussion and debate. These exercises gave insights into the salience and implications of long-term illness at individual, family and community level.

Key informant discussions (x4-10 each locality): Semi-structured conversations were held with individuals who we identified as having particular knowledge about the community, and in particular some understanding of how long-standing health problems may affect families. We talked to a wide variety of individuals including community workers, job agency staff, employers, shop keepers, pharmacists, long-term residents, a police officer, religious teachers and school teachers.

Ethnographic interviews (x2 each locality): Detailed, open-ended interviews were conducted with a small number of people in each of the four locations who were identified as having a long-term health condition. The focus of these interviews was on understanding the personal experiences of respondents. These interviews were tape-recorded and transcribed. These interviews shaped the form and content of later individual interviews.

Box 3: Illustrative example of Rapid Appraisal planning sheet

Day	Day & Date	am/pm	Data gathering tool	Location details / informant details	Team members & roles	Comments
1	Mon 23rd	11:30 – 1:00	Problem tree	Women's group	KH, MM, PC	*arrange refreshments*
		3:00 –5:00	Transect walk	Local area start: Neighbourhood Centre	All	
2	Tue 24th	10.00- 12.00	Informal observation	Dressmaking ESOL class	KH, SA, PC	
		3:30-5:30	Problem Tree	Community Centre 50+ group	MS, KH, PC	*arrange refreshments*
3	Wed 25th	10:00-12:00	Key Informant (Development Worker)	Mr X, Address/phone	KH (SY –note-taking)	
		1:30-4:30	Key Informant (Carer) Key Informant (Local business person)	Mrs Y, Address/phone Mr Z, Address/phone	KH (SY–note-taking)	
		7.00-9.00 pm	Informal observation	Park	KH	
4	Thur 26th	10:00-12:00	Informal observation	Drop in (Women)	PC, KH, MM	
		1:30-3:30	Employment Matrix Key Informant (Imam)	Mosque	MS, PC, KH	
5	Fri 27th	10.00-1:00	Informal Observation	Henna class community centre Chemists/Market	KH, SA, PC	
		1:30-3:30	Employment Matrix	High street new mosque (women)	KH, SA, PC	
		7.00-9.00 pm	Informal observation	Parents group at school	KH, MS, SY	
6	Sat 28th	10:00-12:00	Ethnographic interviews	Mr Q, Address/phone Mrs J, Address/phone	SA, SY	
7	Mon 29th	11:00 –1:00	Transect walk	Local area start: Mosque	All	
		2:00-5:00	Community Inventory	Local office	All	

Note: The names of individuals and places have been anonymised to maintain confidentiality.

Gaining insight and understanding
We now consider some of the ways in which our methodological approach offered additional insight that might not have been gained from an exclusive reliance on in-depth interviews. We first identify a number of general advantages that accrued and then describe in more detail three areas that were significant for our particular research focus.

The combination of working with CRs and employing a range of data generation tools that facilitated engagement with a diverse range of social actors had the advantage of encouraging broad and holistic thinking, of recognising the interconnections between dimensions of people's lives and of the ways in which community-level factors influence the options open for individuals. Being out-and-about within the neighbourhoods with the CRs meant that physical landmarks and places prompted discussion, in turn revealing relevant structures and processes. For instance, when meeting at an underground station within the Pakistani locality the researchers were offered fliers from a man specialising in traditional African spirit healing, which the CRs contextualised locally by offering their opinions about the usefulness and authenticity of spirit healing for chronically ill people; recounting stories of people they knew who had used these services; giving further information about other places where spiritual services are advertised; and hinting at the types of cultural cross-overs that Pakistani Muslims might experience when they receive 'African' spirit healing. Similarly, the presence of large numbers of hairdressing salons and nail bars in the Ghanaian locality prompted discussion about UK Ghanaian women's behaviour patterns and how these might reflect broader changes in gender relations and marital instability in the Ghanaian community.

Another important advantage of the approach was its potential to alert the research team to the distance between norms and practice, and also between private and public enactments. Observing people in the public realm doing things (or not doing things) prompted discussion and further clarification. For instance, among the Ghanaian community we observed that individuals whom we knew to be suffering from long-term ill-health maintained a veil of secrecy in public and this prompted us to investigate in greater depth what turned out to be a complex of factors relating to stigma and vulnerability that discouraged people from identifying themselves as 'chronically ill'. Finally, the naturalistic observation and interaction with community members provided researchers with the opportunity to hear local language and gather context-related information. When terms were used or references made the researchers could readily seek clarification from CRs and incorporate this understanding into subsequent interactions and data generation making them more sensitive and more productive. For instance, researchers witnessed a 'tally man' in action on a housing estate and were able to find out more about the operation of these unregulated lenders through discussion with the White English CRs and subsequently to incorporate sensitive questioning around debt and access to loans into in-depth interviews.

We now illustrate the usefulness of our approach further by highlighting three areas of understanding that were of particular relevance to our research topic.

The significance of 'invisible resources' to marginalised individuals
As well as providing an opportunity for researchers to observe physical landmarks and infrastructure within the communities of focus, our locality-based approach was successful in revealing less immediately visible resources. Furthermore, discussion about transformation over time and the loss of resources was prompted, as the CRs recounted stories from their own lives and those of their close family about the salience and meanings of local places. For instance, in the White English area the presence of many boarded-up pubs prompted discussion about social networks, identity and sense of belonging. Informants identified

many places where pubs had been in the past. Further investigation revealed that socialising in local pubs within walking distance of home was an important manifestation of identity for many local White English people and that their demise had had a significant impact on their sense of wellbeing, particularly among men. The loss of this local resource was associated with the changing demographic make-up of the local area, which people perceived as increasingly populated by 'outsiders' distinguished by their affluence or minority ethnicity. In another example, one of our Transect Walks with our Bangladeshi CRs revealed the employment agencies that specialised in placing Bangladeshi men within the Asian restaurant sector. While this local resource was relatively visible (as were the many shops and community centres serving the needs of the Bangladeshi community) the observation of these agencies and related conversations with CRs and visitors gradually revealed the existence of similar resources catering specifically to the needs of those in vulnerable positions due to debt, complex legal situations or without permission to work in the UK. Though such resources are well known to community members, they are not openly discussed and the existence of these 'invisible' resources only became known to us due to the informal chatting with users and degree of trust engendered by the CRs.   Similarly, the Transect Walk and informal observations within the Ghanaian locality revealed that several shops doubled up as regular meeting places for associations and groups often with regional affiliations and social support functions.

Complexities and contingencies in ethnic identities
Observing interactions between individuals in the community setting, the space that they shared or did not share, hearing local taxonomies, observing exchanges, and importantly having the opportunity to seek clarification in discussion with the CRs, allowed us to uncover complexities and contingencies in the boundaries and content of ethnic and gender identities that would not have been possible in one-to-one interviews. In carrying out the Transect Walk within the Pakistani locality, for example, we observed the CRs to negotiate skilfully between a number of different languages, dialects, accents and registers of interaction, emphasising different parts of their complex identities in relation to different spatial contexts and social relationships. In the market, the CRs chatted in broad cockney accents with White English and Black Caribbean traders, asking about their children, their state of heath, or how they had been getting on since their last meeting in the hospital. In the residential streets, the CRs conversed with relatives about extended family and village micro-politics in the Mirpuri dialect. Outside the mosque, they exchanged Urdu greetings with Pakistanis from urban migratory origins and with Bangladeshis. This kaleidoscope of social interactions illustrated our CRs' ability to draw simultaneously on diverse identities.

Similarly, observing the interactions between our Ghanaian CRs and various community members revealed complexities in their ethnic identities. Our two CRs spoke different languages and identified themselves as belonging to different lineages within Ghana. They also occupied different positions in terms of socioeconomic status. These markers of difference alerted us to the multiple processes of inclusion and exclusion that operated within the Ghanaian 'community' that were further illustrated through the CRs' interactions at community level. For instance, while one CR was able to draw on professional and alma mater networks that spread across London, he was less able to call on his Ghanaian identity to seek cooperation from working class individuals living on council estates. However, a different incident illustrated how a broader Ghanaian identity can be meaningful at times and be drawn upon to demarcate difference from other West African communities. Here we observed a heated argument between one of the Ghanaian CRs and the director of a local organisation who herself had migrated to the UK from Nigeria. The exchange revolved around the two women identifying and denigrating various cultural practices that they felt were not shared by, and indeed confirmed fundamental differences between, 'Ghanaians' and 'Nigerians'.

Our locality-based approach also revealed racialised associations with places. For instance, despite the sheer ethnic diversity of Newham, the Pakistani CRs and local people referred to the area spontaneously as 'our area' as compared with nearby Barking and Dagenham, which was the 'English people's area'. Similarly, in the White English locality the significance of place was very salient in people's ideas about identity and belonging. Such intuitive perceptions of un/comfortable spaces were found to influence people's willingness to move into new areas, which might present other opportunities, or to seek employment further afield.

These insights into the complex processes of ethnic identification greatly informed our subsequent fieldwork strategies, both in terms of guiding our questioning and prompting flexible use of our own identities.

Local economies and histories of industrial change
Observing and mapping out the local shops, businesses, factories and the infrastructures of administration, transport, health, school and leisure facilities provided by the local authority allowed us to understand how individual experiences and responses to chronic ill health are shaped by and embedded in local economies and histories of industrial change. For example, in the White English area the CRs pointed out dilapidated workshops and small factories that were used for the manufacturing of garments, furniture and electronic elements, and told stories about their previous owners and how they had closed down. They showed us the up-market restaurants, nightclubs and expensive new housing that was being converted out of old warehouses. Their negative and sometimes vitriolic reactions to the developments in the locality sensitised us to some the ways in which the old working-class White English population had been marginalised and excluded from the new economic opportunities that were opening up for those people they called 'yuppies' or 'outsiders'. The historical insights provided by our familiarisation with the locality and the CRs' personal memories proved to be important contextual information alongside the later in-depth interviews, in which we found that for many of the informants local deindustrialisation, economic decline and the slow transition to the service economy coincided with the onset of chronic ill health and left a cohort who had little alternative to long-term unemployment. However, comparisons between the four 'communities' indicated further important differences in the extent to which the lives of people with chronic ill health were constrained by the economic opportunities prevailing in their local areas. The localities differed with respect to the density of transport infrastructure allowing for rapid and easy commuting to areas with more job opportunities; a weighty consideration for people whose mobility is constrained by ill health. The 'communities' also differed with respect to the distances that people were prepared to travel for work. In particular, the Ghanaians seemed to be the most mobile and often travelled long distances across London to find work, articulating with their more geographically and socio-economically diverse 'community'.

Conclusions
The examples above illustrate some of the insights gained from our Phase One data generation activities. More generally, our approach allowed an understanding of the ways in which individual responses to chronic ill-health were shaped by the socio-cultural and geo-physical context of people's residential neighbourhood. These insights shaped our recommendations to policy-makers and practitioners across the health and welfare arenas. For instance, exploring contextual factors as well as individual experiences alerted us to the limitations of ethnic-specific support networks and the need for statutory agencies to provide a range of modes through which those with chronic illness can enhance their coping skills.

The advantages of our methodological approach to researching the experiences and implications of chronic ill-health seem to have resulted from the combination of the three elements: a locality-based focus, partnership with CRs and a package of varied, participatory methods of data generation. It seems likely that any one element alone would not have been so successful. For instance, without the active contributions of the CRs it seems unlikely that such a limited about of fieldwork could have yielded so many important insights. At the same time, however, working effectively with the CRs was greatly enhanced by the use of interesting and well-structured tools. We would, therefore, recommend the combination of elements to other researchers interested in addressing issues with a strong link to place. While our approach had many strengths, it is also important to highlight a number of challenges that presented themselves.

First, working with CRs raises both ethical and methodological challenges. The CRs' much longer standing knowledge of their communities offered authenticity to our analysis. However, being members of the local community inevitably meant that the CRs offered particular interpretations, emphasising some dimensions and downplaying others. While all researchers shape the generation of data, bringing their own social and political position to the interpretation and presentation of findings, the insider status of the CRs meant that they had a particular stake in the emerging claims and accounts. We were concerned to draw on the CRs' insights while not privileging particular representations. We therefore adopted an approach to the co-production of knowledge that involved the use of carefully structured and facilitated analysis workshops. CRs and university researchers participated side-by-side and the workshop environment encouraged critical reflection and debate. Participants were prompted to both consider and challenge each others' interpretations, as well as gaps and silences, in arriving at a set of preliminary claims and issues to be explored in the second phase of fieldwork. In addition, the CRs' insider status made it difficult for some of them to undertake certain tasks, such as interviewing across gender, for fear of contravening social codes. Furthermore, it was clear that CRs could become indebted to local people as they sought opportunities to gain information and negotiated access (Salway, Chowbey et al. 2005). These ethical issues persisted long after the university researchers had left the field sites and deserve careful consideration in future work.

Second, our rapid, locality-based approach could risk the production of partial understanding, since chance and limited time may mean that only certain aspects are observed and noted. This problem was minimised by the use of multiple methods in multiple locations by a team of several researchers. In addition, the team was alert to that which was not visible and sought to combine incisive questioning along with careful observation, constantly asking 'who is not here?', 'what is not happening?' and so on, as well as seeking interpretations of that which was observed directly. Furthermore, the approach is quite heavily dependent on note-taking skills and effective debriefing without which there is the potential for much data to be lost. We found that university researchers working side-by-side with CRs to capture their insights and observations was a useful approach. The area-based approach can also suffer from being too locally-specific, highlighting local specificities to the exclusion of (i) elements of community that transcend geography and (ii) commonalities across settings and communities. It was therefore important to consider the body of data across all four localities and to provide opportunities for the CRs representing the different communities to interact and share their findings.

Finally, weaving an argument and presenting evidence that is derived from these methods can be challenging. The heavy dependence on direct quotation in much sociological work on chronic ill-health does not suit these methods and alternative ways of conveying findings, perhaps drawing more on anthropological traditions, are needed. In practice, we found that combining the Phase One data with the Phase Two in-depth interview material was

productive in generating detailed understanding that could be conveyed effectively to those beyond the research team. Bearing these challenges in mind, we would encourage other researchers to experiment with these fieldwork approaches which can be both enjoyable and insightful.

Notes:
1. 'Peer researchers', 'lay researchers' and other terms are also used to describe individuals who contribute to research studies in this way

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