# LIVING WITH LONG-TERM ILLNESS: THE EXPERIENCES OF SUFFERERS AND THEIR FAMILIES IN EAST LONDON

***Preliminary qualitative research findings: 1*** | ***October 2005***

## Why is this research important?

East London communities are heavily affected by long-term (chronic) illnesses and disabilities. These health problems have serious implications for individuals, households and society as a whole. Government and community organisations are working to support people with long-term health problems, in particular by helping individuals to find jobs and to manage their health. However, we need to know more about the personal experiences and needs of sufferers and their families to ensure that such initiatives really work to improve individual lives. This research project aims to provide such detailed information.

## What does the project aim to achieve?

The project's aims cover three related areas:

1. To describe the relationships between long-term health problems in working age adults and indicators of well-being, poverty and social exclusion of individuals and households, including change over time.

2. To document the range of social, economic, and cultural resources that individuals and households draw on in coping with / responding to ill-health.

3. To identify routes via which individuals and households suffering from long-term health problems can be better supported in order to protect and improve living conditions and well-being.

Findings from the project will be shared with government and non-government agencies with the aim of improving the services and benefits being provided to sufferers of long-term health conditions. Findings will also be shared with community participants through workshops using community languages.

## What is being done in this project?

A team of university researchers are working alongside local people who have been recruited and trained to work as Community Researchers. In order to capture the diversity of people's experiences, the team have been working in four different locations across East London and have been talking to men and women, younger and older people, and people from different ethnic and cultural backgrounds. The research has focused in particular on people identifying themselves as Ghanaian, Pakistani, Bangladeshi or White English.

The project design includes three phases of data gathering. Phase 1 was completed in June and July 2005 and involved a 'Rapid Assessment' using interviews, informal conversations, mapping/ranking exercises and observation (see below). The aim of this phase was to gain a broad overview of the patterns of social, economic and cultural resources available to community members as well as to understand how long-term illness is perceived and the prominence it has in people's everyday lives.

**University of Sheffield, University of Essex & Social Action for Health, with funding from Joseph Rowntree Foundation**

Phase 2 began in August 2005 and, building on the knowledge gained in Phase 1, consists of a series of detailed interviews with (i) individuals of working age who are suffering from a long-term health condition, and (ii) other family members or carers. Interviews, while being open-ended and flexible, include life-history methods to explore changes in people's circumstances over time.

Phase 3, in January 2006, will involve a period of 'community feedback and consultation' in which emerging findings will be shared through a series of informal meetings. This phase will allow community members to consider the validity and usefulness of study findings, and to comment on the ways in which they represent their community.

### What has been done so far?

Between May and July 2005, an intensive period of 'Rapid Assessment' was completed over a period of seven working days in each of our four locations or 'communities', centring on (1) West Green Road and surrounding streets, plus Broad Water Farm in Haringey (Ghanaians); (2) Green Street, East Ham, Katherine Road and surrounds in Newham (Pakistanis); (3) Whitechapel Road, Brick lane, Stepney Green and surrounds in Tower Hamlets (Bangladeshis), and (4) Hoxton Street, New North Road and surrounds in Hackney (White English).

The seven-day period of assessment followed a number of preparatory visits and contact with numerous people living and working in the areas. Six distinct data collection tools were employed by the team in each of the locations.

*Transect walk*: The research team undertook 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. Community Researchers identified suitable routes and in some cases, other local residents accompanied the research team pointing out places of significance. This tool, together with the other tools described below, was used to complete an inventory of local resources available to community members.

*Observation and informal discussions*: 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. We found many people willing to spend time with us talking about their lives. A list of topics and questions was used to guide the discussions.

*Key informant interviews*: Semi-structured interviews were carried out using a guideline 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 conducted between four and ten of these interviews in each location. 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*: Detailed, open-ended interviews were conducted with a small number of people in each of the four locations who were identified as suffering from a long-term health condition. The focus of these interviews was on understanding the personal experiences of respondents.

*Small group discussions*: The research team facilitated discussions with small groups of men and women using two different 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 problems for families. These group discussions (at least two in each location) were arranged in mosques, churches, schools, community centres, workplaces and residents' homes.

Following the period of data collection, a two day debriefing workshop was held for each location/community in which the research team, including the Community Researchers, worked together to synthesise the findings.

## What have we found out so far?

### *Community: networks and resources*

The great majority of individuals that we spoke to felt that it made sense to speak of an ethnic community in their local area; for instance a 'Bangladeshi community in the Brick Lane area'. Many would use the word 'community' in everyday speech and most expressed a sense of belonging to such a community. However, the degree to which ideas of community were bound up with location varied. For many of our White English respondents, their sense of community was closely tied to place, and for some at certain times their community did span ethnic and religious lines. In contrast, our Ghanaian respondents often appeared to see their community as covering several locations within London that have residential concentrations of Ghanaians and key resources such as community centres and churches.

Furthermore, the widespread perception of the existence of ethnic communities does not mean that these communities were homogenous, or that their boundaries were clearly demarcated and universally recognised. Different individuals held divergent notions of what and who constituted their community. Furthermore, individuals appealed to different identities and membership of different communities at different times and in different places. Many Ghanaians appear to have particularly complex sets of allegiances. A plethora of community organisations and associations exist established on a variety of commonalities including home town in Ghana, school, church, clan, language group and so on. Therefore, while most agreed that being 'Ghanaian' does mean something in the UK context, bringing with it certain claims and obligations, respondents also highlighted more micro-level 'communities' to which they belong. Divisions were also recognised along social class and educational lines. In common with the Ghanaians, the existence of internal divisions, conflict and exclusion was clearly evident among the other three communities.

Despite these complexities, the role of community appears central to the task of understanding how individuals and families respond to and cope with long-term health conditions. Membership of a particular community has relevance for two related reasons. Firstly, via the community-level resources that are available to draw on; and secondly because of the options and constraints placed upon individuals via community norms and expectations.

In terms of community-level resources, some important differences were identified between the four locations that have relevance to our topic of focus. Firstly, the level of knowledge about and experience of the state benefit system appeared to differ between the groups, with 'collective wisdom' being least well-developed among the Ghanaians. Secondly, the local labour market conditions varied between the locations as did the employment networks utilised by community members. In the Hoxton area, discussions were dominated by references to the 'black' economy and the informal nature of much employment, particularly of men.

However, in addition, there was widespread awareness of change in the population profile, services and employment opportunities, particularly in connection with the New Deal for Communities. Many local White residents felt a sense of detachment from these processes of 'development' and expressed regret at some of the changes occurring in the area, particularly the decline in the 'pub culture' and reduced 'sense of community'.

In all three of the minority groups, the importance of intra-ethnic networks for securing information and employment opportunities was apparent. However, as has been documented elsewhere, the Pakistani and Bangladeshi groups were particularly heavily concentrated in a narrow range of locally-based jobs.

Space prohibits a detailed discussion of the various organisations and services available in the four communities. However, it is important to highlight that the extent to which individuals can access services that are specifically tailored to the needs of a particular ethnic group varied between the locations. Interestingly, the idea of services being designed for those with a White English ethnic identity was shocking to some respondents, particularly Key Informants from the voluntary sector, and no such initiatives were found. However, several White respondents expressed the feeling that their needs were not being met and that services they received were not culturally-competent.

### Community: norms, values and expectations

During the fieldwork, the research team intentionally refrained from offering any precise definition of 'long-term illness'. We were instead interested to find out how local people understand and talk about long-term health conditions, and how salient these issues are in people's lives. Across the board, we found that people were aware of long-term illness being a widespread concern for their community and many respondents had personal experiences to relate. This was particularly true for the Bangladeshis in Tower Hamlets and Pakistanis in Newham. A community-level 'way of talking about' the high prevalence of chronic illnesses, particularly diabetes and heart disease, and their perceived causes (lack of exercise, the 'Asian diet', lack of knowledge and stress) was evident. Among the White English community, initial comments relating to long-term illness often focused on the elderly reflecting the fact that the area of focus does have a disproportionate number of older people. However, further discussion usually led to recognition of the issue among younger, working age adults, with mental illness and injury through work-based accidents being identified as prominent problems. Interestingly, among the Ghanaians, there appeared to be a current awakening to the fact that chronic illness is a problem afflicting large numbers of people in their community. Discussions with Key Informants revealed their growing awareness of the significance of these issues for their community, in particular the high prevalence of hypertension and the large numbers of premature deaths. The relative infancy of this public awareness appears to relate to the culture of silence that exists around these issues among the Ghanaian community (as discussed further below). Importantly, in all four communities, mental illness was highlighted as a large and growing problem.

Despite this awareness, across all four communities, a prominent theme that emerged was the reluctance to openly discuss ill-health and the concealment of incapacity. Among the White English, this norm appeared to be particularly strong among men and seemed to relate closely to preserving a masculine identity. Reluctance to discuss their health was explained in terms of the boundaries of friendships and that ill-health is not an acceptable topic of conversation. As one long-term sufferer said: *"if I asked someone about their illness, they'll punch me on the nose, people play poker, not ask about health."*

Among the Bangladeshi, and particularly the Pakistani respondents, concealing illness and its effects seemed to be more closely related to concerns regarding how the situation would be perceived by the wider community, that is to issues of status, respect and acceptance. For these groups, 'coping' with an illness was often expressed in terms of nobody else knowing that anything was wrong.

The norm of concealing illness appears to be particularly extreme among the Ghanaians. Several respondents told us that even when someone dies people do not find out what they have died of. In common with the two Asian communities, many of our Ghanaian respondents were very conscious of being observed and judged by their wider community; a kind of moral policing of behaviour. As one respondent said: *"the news even gets back to Ghana, everyone knows that your family is not functioning well!'* However, the almost complete silence around illness among Ghanaians requires further explanation. There is some indication that a contributory factor may be religious ideas about 'attribution'; the notion that talking about an illness or problem will mean that the speaker will then acquire that problem. Furthermore, superstition and beliefs regarding witchcraft appear to act as obstacles to disclosure for some. In addition, the very strong priority given to income generation through work (discussed further below) may also feed into the reluctance to acknowledge illness, even to oneself and close family members.

In all four communities, secrecy around ill-health was heightened for mental illness and there was evidence that stigma related to mental illness presented barriers to individuals seeking and receiving support. One respondent said, *'my friends let me down when I became mental health, they could not understand, through the years I was strong,'* and another told us, *"I have not* *told my family back home about this. I don't tell anyone about her [wife with severe depression]. You know Ghanaians."*

Despite this common theme, it is important to note that in some cases respondents had been able to be open about their illness within and beyond the family. This disclosure seems to depend, at least in part, upon the individual achieving a personal and public identity that is valued (as discussed above). In addition, in some cases it was evident that individuals had changed their patterns of social interaction and been able to gain membership of new networks or 'communities', in some cases founded upon the illness state itself. When this occurs it seems that opportunities to talk about the experience of illness are beneficial . It will be useful to understand more about the ways in which this is achieved.

Community (and family) norms and values also affect the range of options people see as being open to them, constraining choice and guiding behaviour in a number of areas including caring, employment, the taking up of state benefits and so on. Some of these are discussed below, others will be taken up in more detail in Phase Two.

The discussion that follows highlights a number of ways in which our four 'communities' showed divergence. However, we caution against over-generalisation. While being a member of a particular ethnic community does imply certain 'ways of being and doing', as well as access to certain 'resources', wider structural forces also affect the experience of long-term illness. Furthermore, individuals can and do find ways of redefining their ethnic identity so that responses to ill-health are diverse within groups. It is also clear that many of the issues facing families with long-term illness sufferers cut across ethnic lines.

### *Living with long-term illness – the significance of individual identity*

Our discussions with individuals who had personal experience of long-term health problems, either as a sufferer or family member, suggest the central importance of the sufferer's personal identity to the process of adapting to, and living with, chronic illness. Respondents varied greatly in the ways in which they responded to having a long-term health condition and the extent to which they experienced 'identity dilemmas' because of their illness state. As one Key Informant put it *'some people go on kicking and screaming all the way, whereas others are able to accept the situation'*. Many factors appear to feed into the identity that a sufferer takes on and the extent to which 'being ill' becomes a central component of self-identity.

Of course, the actual nature of the condition plays an important part. Not all 'sufferers' have symptoms, and some would not describe themselves as 'ill' at all. The extent to which sufferers experience pain and disruption to their daily lives also varied greatly, as did the degree to which their illness was outwardly visible to others. All these factors affect the degree to which the health problem becomes a central part of an individual's identity. However, it also appears that objectively similar physical experiences mean very different things to different people and pose different sets of challenges. Our phase 1 fieldwork suggests a number of factors that are important. Firstly, the sufferer's pre-illness identity is significant -- what was important to the individual's sense of self and what has been 'lost'? Also, the extent to which personal identity is founded upon one's relationships with others as opposed to being predominantly tied to one's own existence seems to be important. For instance, some individuals seem to live their lives through their children so that the achievements of their offspring contributed to their construction of a valued self-identity. How easily the individual can adopt a modified identity that is 'legitimate' and valued in their own eyes and those of people around them, is also important. Age and perhaps more importantly, stage of life, appear to affect this process, but so too do cultural norms and expectations. Varying notions of independence versus dependence were prominent in people's conversations, and will be explored in more detail in phase 2. Religious faith emerged as important in helping some people to accept their circumstances, particularly among the three minority communities.

Clearly, long-term illness sufferers do not adapt their self-identities in isolation from others. Other family members and members of the wider community play a part in shaping personal responses to illness. However, it appears that those who are involved in the diagnosis and categorisation of an individual as ‘ill’ or ‘incapacitated’ (such as GPs) may be particularly significant, and this deserves more exploration. The reformulation of self-identity following the onset of a chronic health condition is an ongoing process, not least because the condition and its symptoms will often change over time.

### *Importance (and complexity) of intra-household relationships*

Findings from Phase One tend to reinforce a number of themes common in other recent literature on chronic illness and disability. Firstly, it was clear that for many living with a long-term health condition, their support and care rests centrally with their family. However, it was also evident that such support cannot be taken for granted and is frequently a source of tension across all the groups. In common with earlier work, our findings dispel the stereotype of cohesive South Asian families with unproblematic support structures.

Among the White English community, we came across several long-term illness sufferers who were living alone with very little in the way of family contact or support. While this situation was less common among the three minority ethnic communities, the themes of isolation and loneliness were nevertheless prominent. Among Ghanaians, many respondents talked of the contrast between being in Ghana where one is constantly surrounded by family members and living in the UK where relatives are distant and one feels alone.

It is important to note that respondents often drew attention to structural factors beyond their control that importantly affected the form and quality of family relationships. For instance, in the White English community the change in local authority’s rules regarding the allocation of council properties was given as an important reason for why older people were left without children nearby. Benefit rules were cited as a reason why partners may choose to live separately and even why some couples may choose divorce.

The negative impact of long-term illness on marital and familial relationships was a theme common to all four communities and one that seemed to be highlighted particularly by women. Importantly, numerous respondents drew attention to the significance of the nature and quality of intra-family relationships *before* the onset of an illness as an important factor in how well the illness is managed. Strained relationships prior to illness onset appear unlikely to improve once a family member falls sick. Strained and sometimes abusive marital relationships were a theme that was particularly prominent among our female Bangladeshi respondents. However, perhaps not surprisingly, in all four groups we found variation in the degree of cohesion within families.

A theme that was common across all four locations was the mismatch between family members’ perceptions of the needs of the sufferer and the sufferer’s own wants. While some sufferers feel overwhelmed by attention, others are dissatisfied with the level of care they receive. Carers and other family members also spoke of the unreasonable expectations of sufferers, exhaustion and feelings of guilt, highlighting the strain that long-term illness can place on family relationships. It is clear that the individual suffering from the health condition is not always in a position of weakness. On the contrary, the ‘ill identity’ may be a powerful ‘resource’ that individuals draw upon in claiming entitlements of various kinds, including other people’s attention, within the family context and beyond.

Notwithstanding the stress that long-term health problems can have on families, in all four communities, individuals who were providing care and support to illness sufferers expressed both feelings of obligation and duty as well as of affection and love for those they were supporting. Women were found to be taking a disproportionate burden of caring duties across all four communities, though with some differences in form (see section below on children). Nevertheless, male carers were also found in all four communities. There was evidence of differences between men and women in the form that caring takes and the extent to which alternative roles (particularly paid work) are retained alongside caring duties.

### *Effects on and support from children*

Concerns about the negative impact of adult long-term illness on the well-being and life chances of dependent children was prominent for many. As one Key Informant said '*It is a constant worry on lots of levels. Like someone I know with MS, she worries that the children will get the disease, that they are not getting the attention they need, they want the children to have a normal childhood. I think people worry more about the children than about the person who they are caring for.'*

Having a parent suffering from a long-term illness was linked to a wide range of negative implications for children including: taking on adult responsibilities; assuming direct caring duties and the associated stress and tiredness; worry and emotional problems; being forced to assume wage-earning duties; and curtailing schooling and training opportunities.

Among several Bangladeshi respondents, high levels of chronic illness among parents was perceived to be linked to a set of inter-related issues including overcrowded living conditions, weak inter-generational communication, breakdown of parental authority, drug dependency, and anti-social behaviour of young men in particular.

While examples of adult children providing significant support to sufferers were found in all four communities, there was evidence to suggest that norms of obligation and entitlement do vary between the four ethnic groups. Among the White English, respondents commonly expressed the idea that adult children 'are busy and have their own lives', so that support cannot necessarily be expected. Several respondents talked of not wanting to be a burden or to ask for too much and thereby jeopardise future relations. While similar sentiments were expressed by Bangladeshis in relation to their married daughters (whose primary responsibilities are seen to rest with their husband and in–laws) sons, and particularly daughters-in-law, are generally seen as a legitimate source of support. However, as mentioned above, such familial obligations and expectations are frequently contested. Disputes over the channelling of time and financial resources to their respective parents were reported as a common source of discord between Bangladeshi husbands and wives.

Notwithstanding the various potential problems for children, it should be noted that long-term ill-health was perceived by some to bring positive knock-on effects. A number of incapacitated men who had stopped work were pleased to be able to spend more time with their children. Some women spoke of more time together and more help with household work since their husbands had dropped out of the labour market. Others mentioned how their children had matured and risen to the challenge of being more responsible and caring.

### *Financial hardship*

In all four locations, the link between long-term illness and financial hardship was a prominent one, particularly among male respondents. Respondents spoke not only of having to go without and needing to budget carefully, but of the mental stress that living on a low income brings. As one Key Informant noted: *"People feel overwhelmed by debt, they don't open their letters, bills."* However, here again we found diversity in people's responses to having to live on low income with some appearing to find it much easier than others to come to terms with their limited resources.

Families were found to adopt various strategies not only to reduce expenditure but also to make keeping track of bills and expenses easier and less stressful. Nevertheless, it was apparent that over the long-term, living on low income had significant implications for quality of life as 'things wear out, break down' and homes fall into disrepair. Costs of transport seem to be a particular issue for many who are long-term ill. Giving up a car to reduce expenditure had left some feeling house-bound. Buses were often inconvenient and difficult to manage, while taxis are prohibitively expensive.

### *Waged work and barriers to employment*

Clearly, whether or not a sufferer and his/her family members give up work in response to ill-health is a central factor determining the financial condition of the household.

Phase One fieldwork suggests a complex set of factors that affect whether or not someone with a long-term illness is economically inactive. Community and family-level norms regarding the position of formal employment in people's lives appear to be a significant factor in how illness impacts upon a person's labour force activity. Among Ghanaians, there appears to be a very strong focus on the importance of earning an income through work for both men and women. Individuals were found to be working long hours, often in multiple jobs and to express a definite preference for working over claiming state benefits. The image of someone coming home tired after a hard day's work was a positive one for many Ghanaian respondents. This strong 'work ethic' reduces the likelihood that individuals who are ill will withdraw from work. In contrast, chronic ill-health appears to be a more legitimate reason for not working, particularly for those regarded as 'older', among the Bangladeshi and Pakistani communities.

Also important is the 'place' individuals and 'groups' occupy within the labour market and the options open to them. Some respondents felt they had a limited range of possible options open to them and that their ill-health made all of these inappropriate. For instance, a Bangladeshi man who had only worked in restaurants and as a tailor in the past could not see any other avenue open to him and did not feel well enough to carry out such physically demanding jobs. The degree of latitude that individuals have is no doubt partly dependent upon qualifications and experience. However, how employers and colleagues respond to chronic ill-health is also important. There are indications that these factors may be racialised and gendered, but this requires further exploration.

At an individual level, decisions about whether or not to withdraw from work are also affected by the extent to which an existing job is enjoyed, perceptions of barriers to work, and whether alternative roles within the household can be adopted, among other things.

In addition to the financial implications, whether or not a long-term illness sufferer becomes economically inactive, and/or 'on incapacity', can have consequences for an individual's valued self-identity. In several cases, being actively engaged in work was identified as a factor that helps people to cope with illness. However, for many sufferers voluntary work appears to be the only option available, since paid work opportunities lack the flexibility they require (for instance to attend hospital appointments). A lack of employment opportunities was a source of frustration for several people we spoke to with long-term health conditions.

Being long-term ill and unable to find work, but not qualifying for incapacity benefit, appears to be a particularly difficult position to be in. This situation implies not just financial hardship but also threatens a valued self-identity and emotional well-being as feelings of guilt and worthlessness may be encouraged.

The impact of long-term health problems on the employment status of other family members was also of great concern to many. One Key Informant stated that *"many carers feel cheated"* since they see no alternative to caring for their loved ones and receive such poor levels of compensation from the state in the form of Carer's Allowance.

### *The importance of social participation*

Patterns of socialising and social participation were found to vary importantly between the four communities, as well as between men and women, older and younger, within these communities. Nevertheless, the importance of social participation to people's sense of well-being was a common theme. For the three minority groups, social participation was also explicitly linked to social status. Respondents in all four communities linked the financial impact of long-term health conditions with a reduced ability to maintain social contact. Respondents also noted other ways in which long-term health conditions led to reduced or changed social interactions. For instance, physical manisfestations of illness had made some sufferers wary of meeting new people for fear of negative reactions. Mobility problems restricted other sufferers, and some stated that long-term ill-health had meant a loss of interest in socialising. In a small number cases, sufferers or carers had engaged in new social networks as a result of the long-term illness.

### *Formal support: disparity and dissatisfaction*

In relation to the health service, we found huge variation in people's levels of satisfaction and personal experiences. However, among Pakistanis in particular there was a strong theme of serious inadequacy of provision.

In relation to social services support, a common theme was the mismatch between people's own identification of what is needed and what they actually receive. Respondents often viewed the provision of services to be inflexible, and it was common for people to talk of 'fighting' to get what they needed. Many respondents simply did not bother to pursue social services for things like aids and adaptations as they perceived the process to be arduous and stressful.

Variation in people's tenacity no doubt contributes to the differential receipt of services that is clearly evident between individuals and families. Whether there are also systematic differences in treatment of different groups is less clear from our Phase One work. Respondents did, however, express concern that the wide disparities between families are unjust. There was some suggestion that older sufferers and female carers may receive less support than their younger and male counterparts.

Speaking about a male carer who had managed to secure extensive care for his chronically ill wife and was still able to work full-time, one Key Informant remarked: *"This is enormously unusual. I think it is wonderful that they have got it, but why haven't we got it for others?"* The feeling was that individuals needed to be well-informed of their rights and to be very pro-active and confident in claiming them. However, our discussions with sufferers suggest that often when individuals are most in need of support they are unlikely to be able to go through the procedures necessary to get it. The systems are perceived to be complicated, and people feel overwhelmed by paperwork and the need to prove their entitlement.

Gaining entitlement to Incapacity Benefit was also often spoken of in adversarial terms. In several cases respondents had had the benefit stopped after a period of time for reasons they found inexplicable. In particular, insufficient consideration appeared to be given to the constraints imposed by frequent hospital/doctor appointments and the types of work available given the skills and qualifications of the individual.

Illiteracy was found to compound problems related to accessing formal support of various types for significant numbers of individuals in all four communities.

### *Immigration and residential status issues*

We were somewhat surprised at how salient the issue of immigration status was for all three of the minority communities. This was a particularly prominent theme in the Ghanaian community.

Long-term illness complicates matters for individuals with temporary (or restricted) rights of residence in the UK in various ways. Long-term illness may change people's priorities, affect their reasons for being in the UK and their options for leaving the country. It may prevent individuals from pursuing proper immigration channels, and may mean that other family members are forced to give up work and in some cases overstay. Also, importantly, becoming long-term ill without residential rights seriously compromises well-being as individuals are unable to gain access to the health or social care services available to those with legal status. Even charitable/voluntary organisations were found to be unable to offer assistance since these commonly rely on referrals from statutory bodies.

## What will we be exploring in Phase 2?

Above we have presented some of the preliminary findings from the first phase of fieldwork. Much of the discussion has been descriptive, and we are necessarily cautious regarding some of our conclusions. Phase Two will seek to explore these issues in more detail through in-depth interviews with individuals and families suffering from long-term illness.

The project is a collaborative venture between the University of Sheffield, Social Action for Health and the University of Essex, funded by the Joseph Rowntree Foundation under their 'Ladders out of Poverty'' programme.

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## Where can I find out more?

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In addition to the detailed fieldwork described above, a complementary statistical analysis is also being carried out as part of the project. Further details are available from Lucinda Platt, University of Essex, lplatt@essex.ac.uk

## How can I get involved?

Fieldwork will continue until December 2005. If you would like to be included as a respondent or if you know someone else who would be interested to participate, please contact us. **We are particularly keen to hear from people identifying themselves as Ghanaian since this group is currently under-represented in our research sample.** Alternatively, if you would like to attend one of our dissemination workshops in January 2006, please get in touch so that your details can be added to our mailing list.

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