

Organisation	London School of Hygiene & Tropical Medicine
Department	Centre for Population Studies
Proposer	Dr. Sarah Salway
Title	Limiting illness and poverty: breaking the vicious cycle

## **SUMMARY**

### **Background**

UK social policy increasingly identifies the importance of tackling poverty and exclusion in the pursuit of reduced health inequalities (DoH 1999; DoH 2003). However, while a large body of evidence confirms that disadvantaged socioeconomic circumstances are detrimental to health (Benzeval, Judge et al. 1995; Acheson 1998; Graham 2000), far less is known about the ways in which ill-health undermines socioeconomic status and security.

Recent analyses of poverty dynamics using the BHPS indicate that 8% of cases where an individual moves into poverty are triggered by a rise in the number of household members with limiting illness and 16% by a rise in the number with poor mental health (Jenkins & Rigg, 2001). Child poverty is particularly affected by adult limiting illness (Adelman, Middleton, & Ashworth, 2003), and recovery from ill-health is found to be an important route out of poverty (Jenkins & Rigg, 2001). However, little is known about the pathways that link ill-health to poverty or how they may be broken. The coping strategies used by individuals and households suffering from limiting illness and the ways in which they might be supported are also poorly understood.

Evidence suggests that the impact of limiting illness on individuals and their families can be diverse and far-reaching. While the issue of care-giving is being addressed in ongoing research, less attention has been given to other issues including employment, access to non-labour income, and knock-on effects for other household members such as children's education.

Also, while there is some evidence that the consequences of limiting illness vary between sub-groups, with higher risks of negative outcomes among minority ethnic groups (Arrow 1996; Bound, Waidmann et al. 2003), again little is understood about why this should be so. Furthermore, since the burden of limiting illness is extremely high among

certain minority ethnic groups, particularly Pakistanis and Bangladeshis (Nazroo 1997), accompanied by correspondingly high rates of economic inactivity, an understanding of the processes linking ill-health to poverty and social exclusion is central to the task of identifying viable routes to socioeconomic security for these groups.

## **Aims**

The project's aims cover three related areas each of which will consider ethnicity and sex as key axes of analysis:

1. To describe the relationships between limiting ill-health and indicators of poverty and social exclusion of individuals and households, including trajectories over time.
2. To document the range of social, economic, and cultural resources that individuals and households employ in coping with / responding to ill-health, including the barriers and opportunities for action.
3. To identify routes via which individuals and households suffering from limiting illness can (i) be lifted out of poverty, and (ii) be buffered against a fall into poverty. In particular, to highlight ways in which existing household coping strategies can be better supported.

## **Policy and practice relevance**

This work will provide valuable new insights into the pathways linking limiting illness to poverty. Such findings are of direct policy-relevance to the Department for Work and Pensions' focus on closing the employment gap between minorities and the majority, since high rates of sickness-related economic inactivity contribute importantly to worklessness. The Department for Health's current focus on tackling health inequalities and reducing the burden on the NHS via improved self-management of chronic illness will also be informed by the results. Other key users of this research will be: London Boroughs, Department for Education and Skills, Primary Care Trusts, community-based organisations, and employers' associations.

## **Research design, methods and analysis**

Collection of qualitative data will be combined with analysis of existing quantitative data from the Family Resources Survey (FRS) and the People, Families and Community Survey (PFCS). The geographical

focus of the qualitative work will be East London, supported by contextual quantitative findings for the whole of Britain.

**Qualitative work** will include four ethnic groups: white English; Sylheti Bangladeshis; Punjabi Pakistanis; and Ghanaians. Firstly, 'Rapid Assessment' will be carried out, followed by a series of in-depth interviews with individuals suffering from limiting illness and other household members. Finally, 'community feedback and consultation' will be undertaken. Detailed information and personal narratives will be gathered to gain an in-depth understanding of the implications of limiting illness for individual and household-level poverty and exclusion. History-taking methods will explore trajectories over time.

**Quantitative work** will provide statistical information on limiting illness and its association with multiple dimensions of poverty and social exclusion among a comparable set of minority groups. Analysis of the FRS will provide detailed information on income, benefits, economic activity, employment, caring and household demographics, while the PFCS allows an exploration of social networks, support and participation. Analyses will include comparisons between those who suffer a limiting illness and those who do not, as well as investigation of the circumstances of other household members. Associations revealed in cross-sectional analyses will be explored in greater depth in the qualitative work.

### **The proposers**

**Sarah Salway**, Lecturer, London School of Hygiene & Tropical Medicine.

A medical demographer with 14 years experience researching poverty and the social dimensions of health in both the UK and South Asia, she brings to the project qualitative and quantitative research skills, as well as research management expertise. The project builds particularly on her recent work on Bangladeshi livelihoods in London.

**Lucinda Platt**, Lecturer, University of Essex.

A sociologist with extensive experience of analysing UK quantitative data sources. Her substantive focus is child poverty and ethnic minority disadvantage and her work includes critical social policy analysis.

**Elizabeth Bayliss**, Executive Director, Social Action for Health (1999-). Trained in sociology and community development, she has 30 years experience developing and managing community development projects with a focus on health, poverty and exclusion issues. She will provide strategic guidance to the project and play a particular role in linking researchers to the policy arena.

SAfH is a community development charity with a grass roots focus and well established relationships with minority ethnic communities in East London. SAfH has a strong record of successful collaborative research with universities and effective dissemination to policy makers and primary stakeholders.

### **Expected outputs**

In addition to a *Findings* and an accessible report, results will be presented to policy, programme, academic and primary stakeholder audiences via a series of dissemination events and tailored publications.

## PROPOSAL

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### Background

UK social policy increasingly identifies the importance of tackling poverty and exclusion in the pursuit of reduced health inequalities (DoH 1999; DoH 2003). However, while a large body of evidence confirms that disadvantaged social and economic circumstances are detrimental to health (Benzeval, Judge et al. 1995; Acheson 1998; Graham 2000), far less is known about the ways in which ill-health undermines socioeconomic status and security.

Recent analyses of poverty dynamics using the BHPS indicate that 8% of cases where an individual moves into poverty are triggered by a rise in the number of household members with limiting illness and 16% by a rise in the number with poor mental health (Jenkins & Rigg, 2001). Child poverty is particularly affected by adult limiting illness (Adelman, Middleton, & Ashworth, 2003), and recovery from ill-health is also identified as an important route out of poverty (Jenkins & Rigg, 2001). Other recent analyses of dynamics have highlighted the complexity and diversity of relationships between income, employment and ill-health (Burchardt 2000a; Burchardt 2000b). However, little is known about the pathways that link ill-health to poverty or how they may be broken. The coping strategies used by individuals and households suffering from limiting illness and the ways in which these might be supported in order to buffer against a decline in living conditions, or offer an escape from poverty, are also poorly understood.

Evidence from the UK and other settings suggests that the impact of limiting illness on individuals and their families may be diverse and far-reaching. While care-giving and the extra costs associated with long-term illness and disability are being examined (Baldwin 1985; Matthews and Truscott 1990; Berthoud, Lakey et al. 1993; Ahmad 2000; Martin and White, 1987; Grundy and Young 2004; Zaidi and Burchardt 2004)

less attention has been given to other issues including employment, access to non-labour income, and knock-on effects for other household members such as children's education.

While there is evidence from Germany and the US that the consequences of limiting illness are not uniform across population sub-groups, with higher risks of negative outcomes among minority ethnic groups (Arrow, 1996; Bound, Waidmann et al., 2003), little is understood about why this should be so, and these issues have not been examined in the UK. Furthermore, since the burden of limiting illness and consequent economic inactivity is extremely high among certain minority ethnic groups, particularly Pakistanis and Bangladeshis (Platt 2002)), an understanding of the processes linking ill-health to poverty and social exclusion is central to the task of identifying viable routes to socioeconomic security for these groups.

#### Conceptual framework: livelihoods and coping strategies

Our conceptual framework draws on livelihoods approaches to understanding poverty and related conceptualisations of social exclusion, particularly the work of Wood (Wood and Salway 2000) and Room (Room 2000). This approach places the household at the centre of the analysis and sees individuals as active agents in the management of complex sets of inter-related forms of 'capital'. Moving beyond a purely material definition of poverty, this approach seeks to understand people's strengths, how they are deployed, and the interplay between the economic and the socio-cultural dimensions of coping strategies. Such an understanding, it is believed, will lead to the identification of policies and intervention strategies which build upon, rather than undermine, people's strengths at the same time as recognising the structural barriers to livelihood enhancement (Wood 1999).

While taking the household as its focus, a livelihoods analysis must also look *within* the household to understand how resources are distributed along age and gender lines. Different household members, by virtue of their own portfolio of capitals, vary in their degree of vulnerability.

A number of related descriptions can be identified in the literature (De Waal 1989; Swift 1989; Moser 1998). Here we draw on Room's schema in which he conceptualises households as being endowed, to a greater

or lesser extent, with 'resources', 'relationships' and 'welfare entitlements' (Room 2000). 'Resources' include not only the material (current income, assets, stores, savings, gifts) but also 'human capital' – skills, education and importantly, health status. 'Relationships' include intra- and inter-household networks, links within the local neighbourhood, religious and ethnic communities, and a person's relationship to the system of production. Relationships yield access to various resource flows and vary in their degree of reciprocity and coercion. 'Welfare entitlements' refer to the various types of support provided by public and private organisations which are based on formal entitlements underpinned by state legislation.

Research to-date highlights various ways in which ill-health, as one element of a household's resources, interacts with other dimensions of livelihoods. However, the evidence base also indicates many areas where our understanding is poor.

#### *Resources:*

Clearly ill-health may directly affect an individual's ability to perform paid work and thereby earn an income. People with long-term limiting illness have poor job security (Bartley and Owen 1996; Bartley and Plewis 2002) and are more likely to end up unemployed, economically inactive and in financial difficulties than those who are not ill (Burstrom, Whitehead et al. 2000). However, these links have been shown to be stronger for those in working-class occupations (McDonough and Amick 2001; Lindholm, Burstrom et al. 2002), and minority ethnic groups (Arrow 1996; Bound, Waidmann et al. 2003). The impact of illness on employment is therefore apparently modified by the quality of an individual's human resources (skills, qualifications and experience) and perhaps also social and cultural networks. More needs to be known about the processes linking ill-health to inactivity and unemployment, the barriers and opportunities for continued paid work, including how these are patterned by ethnicity. A greater understanding of the knock-on effects of ill-health for the labour deployment of other household members (paid work, caring and household maintenance) and the implications of these adjustments for socioeconomic security, is also needed.

As well as labour-based income, other types of material resources may be undermined by, or buffer against, the negative impacts of ill-health. Salway and colleagues' work in Bangladesh revealed a variety of coping strategies adopted in response to ill-health, most commonly: taking small loans, reducing household expenditure, using savings, sub-letting rooms and selling assets (Kabir, Rahman, Salway & Pryer 2000). Little is known of the types of strategies that individuals and households adopt in the UK and how they might be supported.

#### *Relationships:*

Aside from an individual's relationship with the labour market, ill-health may have implications for other relationships within and beyond the household.

Illness may impact upon intra-household relations. The burden of caring, loss of income, rising expenditure and need for adjustments may produce internal conflict (Anderson and Bury 1988; Phillipson, Ahmed et al. 2003), which in turn may have consequences for living arrangements and the intra-household distribution of resources. Salway's recent work on Bangladeshis in London suggests that limiting illness may hamper parents' ability to support their children's education and lead to weak relationships with teachers, resulting in reduced investments in the human capital of the next generation (unpublished research report). Ill-health may also cause reduced social participation beyond the family, though these processes have not been explored in the UK.

A serious knowledge gap exists regarding the links between limiting illness and social relationships. Investigation is needed into how relationships are drawn upon or weakened, due to incapacitation and the implications for household poverty and exclusion

#### *Welfare entitlements:*

In the UK context, the tax and benefit system should play a major role in cushioning the effects of ill-health. However, in practice its operation may not be optimal. People suffering from intermittent illness (and their dependants) appear to fare worse than those who have more chronic conditions (Adelman, Middleton et al. 2003). While this may relate to both eligibility and take-up of benefits, little is known about the factors facilitating or hindering access, and how the system itself can better



recognise the financial consequences of ill-health (Baldwin 1985; Martin and White 1987; Matthews and Truscott 1990; Berthoud, Lakey et al. 1993; Kemp, Bradshaw et al. 2004; Zaidi and Burchardt 2004).

## **Aims**

1. To describe in detail the socioeconomic profiles of individuals and households suffering from limiting illness.
2. To determine whether associations between limiting illness and indicators of poverty and social exclusion vary between ethnic groups.
3. To examine histories of individuals and households and transitions across states in relation to :
  - experience of limiting illness
  - poverty
  - employment and activity
4. To identify and describe the range of social, economic, and cultural resources that individuals and households employ in their coping strategies.
5. To identify routes via which individuals and households suffering from limiting illness can (i) be lifted out of poverty, and (ii) be buffered against a fall into poverty. In particular, to highlight ways in which existing household coping strategies can be better supported and additional avenues for action created.

## **Policy and practice relevance**

This work will provide valuable new insights into the pathways linking limiting illness to poverty. Findings will be of direct relevance to policy discourse and programme action aimed at reducing poverty and health inequalities.

Department for Work and Pensions:

Closing the employment gap between minorities and the majority is a major policy issue for the DWP upon which little progress has been made over the last 20 years. With the shift from a focus on

unemployment to a concern with economic inactivity, the DWP have made numerous steps towards engaging more effectively with the issue of work-limiting ill-health, including pilot employment rehabilitation interventions (DWP 2002; DWP 2003). The proposed research will provide new evidence on the difficulties people with chronic illnesses face in remaining in, and re-entering, employment and will thereby inform the development of more effective intervention.

The work will also throw light on the household-level gains of long-term sick members being in work, including the way in which such gains may vary according to overall employment prospects and labour market disadvantage. Whether the benefits of work for the long-term sick are equal across ethnic groups is an unanswered question of great policy relevance.

Social security benefits have been shown to be affected by household size and form, and insofar as that differs with ethnic group, by ethnicity (Platt 2003a). A greater understanding of the different role and value of benefits in different contexts is of important policy-relevance.

Department of Health, Primary Care Trusts, Health Action Zones:

At both the national and local level in East London, tackling health inequalities and reducing the demand for NHS services are key policy agendas. The role of carers and self-management of chronic illness are receiving particular attention. This research will provide a rich understanding of the interplay between inequalities in health and socioeconomic status among different ethnic groups and thereby suggest routes of intervention that will more effectively tackle cycles of deprivation. The findings will also feed into policy work around increasing the cultural competence of DoH initiatives.

Social Action for Health and other Community Based Organisations:

Findings will directly inform the development of SAfH's own programme work on self-management of chronic illness and economic empowerment. It will also be of importance to organisations seeking to reduce poverty among different ethnic groups in London and nationwide.

## **Research design**

Collection of new qualitative data will be combined with secondary analysis of existing quantitative data from the Family Resources Survey (FRS) and the People, Families and Community Survey (PFCS). The qualitative work will provide a detailed understanding of household coping strategies and livelihoods, including the interplay of economic and sociocultural factors. Furthermore, history-taking techniques will provide insight into the transitions into (and out of) limiting illness, poverty and material deprivation (something that cannot be explored quantitatively at the present time due to a lack of appropriate data sources.)<sup>1</sup> In addition, we recognise the importance of relating qualitative findings to broader patterns and of comparing households with and without members suffering from a limiting long-term illness. This is clearly best achieved through statistical analysis of representative sample surveys. Moreover, the research process will be iterative. Quantitative analyses will be informed by the initial stages of the qualitative research and will in turn indicate avenues for further in-depth exploration.

The geographical focus of the qualitative part of the project will be the east London Boroughs of Hackney, Tower Hamlets and Newham. Within this area we will include Punjabi Pakistanis, Sylheti Bangladeshis, Ghanaians, and White British, in order to have culturally, relatively homogenous groups. The quantitative analysis will not allow such specificity, but will cover comparable groups of Pakistanis, Bangladeshis, Black Africans, and White UK respondents.

This choice of ethnic groups is based on both practical and theoretical grounds. Firstly, the research team has prior experience working with these groups and extensive community links which will facilitate the collection of high quality data. Secondly, these groups display diverse socioeconomic, cultural and health profiles. Cross-comparisons should thereby provide insights into the interplay of social, cultural, historical, geographical and economic factors in the patterning of the impact of ill-health.

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<sup>1</sup> We hope that future work may include an analysis of data from the Newham Household Panel Survey though these data have not yet been released for general use.

The burdens of poverty and limiting ill-health are extremely high among Pakistanis and Bangladeshis in Britain (Nazroo 1997). These groups are disproportionately afflicted by heart disease and type 2 diabetes, particularly at younger ages (Greenhalgh, 1997; Erens, 1999). Whilst sharing many dimensions of deprivation, the more extreme position of the Bangladeshis is often concealed through the practice of grouping the two together (Platt, 2002). This research will provide a disaggregated analysis.

Black-Africans are a significant minority in London and are second only to the Bangladeshis and Pakistanis in terms of income poverty (Platt, 2002). They also experience very high levels of unemployment particularly when their high educational attainment is taken into consideration. Evidence suggests a lower burden of illness among Black-Africans than for the general population (Pevalin 2003). However, Black-Africans have rarely been the focus of investigation and little is known about the types of livelihoods they have established in the UK or the specific barriers they face to achieving economic security. We also know nothing about the ways in which ill-health is responded to or the implications of ill-health for individual and household socioeconomic circumstances among this group.

The lived experience of limiting illness in Britain's white majority has not been the subject of research since the 1980s (Cornwell 1984; Anderson and Bury 1988). It is important to compare the socio-economic consequences of illness in minority ethnic groups with the majority to avoid problematizing certain ethnic groups. Whilst having a more advantaged socioeconomic profile than other ethnic groups, the white population in East London is also heavily affected by chronic illness, particularly compared to other Londoners (Platt 2003a). Our approach will enable us to distinguish between processes that reflect the deprivation of the East End in general, and those that reflect minority ethnic experience in particular.

### Qualitative

Three phases of qualitative data collection are planned. Firstly, a phase of 'Rapid Assessment' will be carried out by Community Researchers involving informal conversations, mapping/ranking exercises and observation (Scrimshaw and Gleason 1992). The aim of this phase will

be to gain a broad overview of the patterns of social, economic and cultural resources available to members of the four ethnic groups as well as an understanding of how limiting illness is perceived and the prominence it has in people's everyday lives. This phase will also inform interview guideline development for phase two and identification of respondents.

In phase two, in-depth interviews will be conducted with (i) individuals suffering from limiting illness (~10 per ethnic group), and (ii) at least one other member of the household where the sufferer lives (~10 per ethnic group). For this work our definition of 'limiting illness' will be flexible and respondent-driven, allowing us to explore subjective interpretations of ill-health and its consequences. Our focus will be on working-age adults, with adequate representation of both sexes and a range of occupational backgrounds. In addition, the selection of respondents will be sequential, employing 'theoretical sampling' to ensure data gathering is driven by the emerging theory (Spradley 1979; Strauss and Corbin 1998).

Interviews, while being open-ended and flexible, will include history-taking methods to explore individual and household trajectories over time, and will include the following issues:

- Experience of illness (onset, manifestations, severity, duration).
- Employment, economic activity, earnings.
- Barriers and opportunities for accessing benefits and other non-labour income.
- Caring.
- Responses and modifications (roles and responsibilities, expenditures, lifestyle, living arrangements, social engagement).
- Sources of support, kinship and wider social networks and community groups (information, contacts, emotional support, practical support, investments ).
- Experiences with statutory services.
- Concerns, stress and coping.

Interviews will be in the language of respondent's choice and the research team will include fluent Punjabi and Sylheti speakers. Subject to respondent approval, interviews will be tape-recorded and

transcribed. Analysis and integration of data into theory will be ongoing during data collection. Translated interview transcripts will be subjected to line-by-line coding and a combination of domain, taxonomic, componential and theme analysis (Spradley 1979; Strauss and Corbin 1998). The software package NUDIST will be employed to enable researchers to work together effectively on the coding and integration of data.

Thirdly, a phase of 'community feedback and consultation' will be undertaken during which emerging findings will be shared with community members via a series of informal meetings. This will allow primary stakeholders to consider the validity and usefulness of study findings, and to comment on the ways in which they represent their community. Detailed field notes will be taken and salient points integrated with earlier findings.

Our previous experience shows that accessing respondents may be difficult and time-consuming. Furthermore, different strategies will be needed for the four ethnic groups (McLean and Campbell 2003). A systematic strategy for locating respondents will be developed using multiple points of entry to the communities to ensure a wide range of respondent experience. We are confident that the extensive community contacts that SAfH brings to the team will ensure that targets are met.

### Quantitative

The quantitative research will provide generalisable information on limiting illness<sup>2</sup> and its association with multiple dimensions of poverty and social exclusion among a comparable set of minority groups. Analyses will include comparisons by ethnic group between those who suffer a limiting illness and those who do not, as well as investigation of the circumstances of other household members.

The Family Resources Survey is a large nationally representative cross-sectional survey covering around 25,000 households and 40,000 adult respondents each year. In any given year, around 400 Pakistanis, 200 Bangladeshis and 200 Black Africans are included. Seven waves of the FRS will be pooled to allow detailed examination, using both descriptive and multivariate regression techniques, of the intersections of poverty,

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<sup>2</sup> Both the FRS and the PFCS include standard questions on long-term illness which limits daily activities or work.

material deprivation, ill-health and benefit receipt by ethnic group (controlling for relevant demographic and other factors).<sup>3,4</sup> Moreover, pooling will enable us to exploit the regional information to explore the extent to which relationships between variables found for Inner London (the qualitative study area) differ systematically from those found in Britain as a whole.

The analysis will link information from individual, and benefit unit files, into the household level to explore the characteristics within households. Standard income poverty measures such as various proportions of mean and median household equivalised income will be created for each year prior to pooling of the different years of the data. Year dummies will be incorporated into multivariate analyses to take account of any year-specific factors. Income poverty measures will be supplemented by information on possession of consumer durables. Limiting illness will make use of the variable defining whether such an illness is experienced by the respondent; and variables on care given or received will enable some understanding of the burden of care implied by the illness and whether it is carried out within the household. Variations in state support in households with a member with limiting illness will be explored by examining receipt of carers benefits as well as sickness and disability benefits and other state benefits. The analysis of welfare benefits is obviously connected to levels of economic activity (and in particular, employment) within the household. Detailed examination of associations of between limiting illness and levels of employment and economic activity within the household will also be performed. The analyses will examine differences by ethnicity in the association between chronic illness and worklessness, and also whether differences are gendered.

Analyses of the People, Families and Communities Survey will complement those of the FRS by providing more detail on social resources and relationships. The PFCS was carried out in 2001 and sought to obtain information on levels of civic activity, social networks and contacts, as well as attitudes to the neighbourhood and experiences

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<sup>3</sup> Previous work by Salway and by Berthoud (1998) has used such pooled datasets.

<sup>4</sup> Pooling the last two years of data (2001/2 and 2002/3) provides samples of 200 Pakistani, 106 Bangladeshi and 93 Black African respondents who are experiencing a limiting illness. Therefore we estimate that a seven-year pooled data set will include approximately: 700 Pakistanis, 350 Bangladeshis and 350 Black African individuals with long-term limiting illness.

of racial harassment. It has a sample size of 10,000 with a minority ethnic booster sample of 5,000. The sample includes 193 Pakistani, 101 Bangladeshi and 96 Black African respondents suffering from limiting illness, and 245 Pakistani, 141 Bangladeshi and 62 Black African respondents live in a household with another member who suffers from such ill-health. Analyses will compare the form and extent of networks for those with and without limiting illness and variation by ethnic group. Comparisons with those not experiencing limiting illness, will enable us to examine how incapacity (own or within the household) strengthens or weakens community relations and participation. This analysis will involve descriptive statistics (including cross-tabulations and summary statistics of variables of interest) and more complex multivariate analysis where the sample sizes allow.

### **Ethical Issues**

The project will adhere to the SRA ethical guidelines and will also undergo ethical clearance by the LSHTM Ethics Committee. Particular attention will be paid to ensure confidentiality, voluntary participation, and effective referral given that several language and cultural groups will participate.

### **Timetable**

Please see below.

### **Staffing**

#### Centre for Population Studies, LSHTM

Sarah Salway is a Non-HEFCE Lecturer. A medical demographer with 14 years experience in poverty and health research in the UK and South Asia, she has qualitative and quantitative research skills, as well as project management expertise. The proposal builds on her recent work on livelihoods and poverty among Bangladeshis in London and earlier work in Bangladesh. She will take the role of coordinator and be primarily responsible for conceptual and methodological development and the integration of different components. Her language skills will enable direct participation in qualitative data collection and dissemination among the Bangladeshi community, as well as the White English and Ghanaian. She will supervise the RF and KH on a day-to-day basis. She has prior experience of analysing data from the FRS and will support LB and KH in their quantitative work. She will commit 40% time to the project for the first 12 months and 30% thereafter.



Research Fellow (*to be appointed*): Ideally a Sylheti speaker with masters training in sociology/anthropology and experience of qualitative data collection and team supervision. S/he will contribute to the design of the qualitative work, carry out the bulk of the in-depth interviews, and participate in the analysis, documentation and dissemination of results. S/he will supervise the work of the Interviewers and Community Researchers. S/he will work full-time on the project for 12 months from March 2005 to February 2006 and be seconded to SAfH.

Kaveri Harriss is a PhD student in the Centre for Population Studies. She will commit herself to the proposed work *free of cost* to this proposal. Kaveri has Punjabi language skills and experience of working with Pakistanis in London. She will play a major role in the qualitative work among the Pakistani group. She will also assist LP with quantitative analyses.

CPS is home to an internationally recognised group of social scientists with extensive experience of analyses of the social dimensions of health. Ongoing work on Carers (Grundy and Young) and the socioeconomic impact of HIV/AIDS (Hosegood and Timaeus) are particularly complementary to the research proposed here.

#### Essex University

Lucinda Platt is a Lecturer in Sociology and Social Policy with advanced statistical skills and extensive experience of analysis using UK data sources. She also has substantial experience of critical social policy analysis in the areas of child poverty and ethnic minority disadvantage. She will perform the statistical analyses of the FRS and PFCS and work in collaboration with SS to integrate the results with those from the qualitative wing of the study. LP has strong working relationships with colleagues in both the Department of Sociology and Institute for Social and Economic Research which will assist her contribution to the project. She will commit 40% time for three months in year one of the project and 40% time for two months in year two.

#### Social Action for Health

Elizabeth Bayliss is trained in sociology and community development, and has 30 years experience developing and managing projects with a

focus on health, poverty and exclusion. She also has policy-related research experience and managed the Community Psychiatry Research Unit in City and Hackney NHS 1985-1997. She will provide strategic guidance to the project and play a particular role in linking researchers to the policy arena. She has been the Executive Director of SAfH for five years.

The project builds on SAfH's prior programme and research experience in the areas of economic empowerment and self-management of chronic illness. SAfH has close working relationships with a wide range of communities, including the Bangladeshi, Turkish/Kurdish, Caribbean, and West African communities. The credibility that SAfH has in the eyes of local people will greatly facilitate the research process.

SAfH has a strong record of successful collaborative research with universities and effective dissemination to policy makers and primary stakeholders. SAfH is regularly commissioned to undertake local research.

'Community Researchers' will carry out 'Rapid Assessment Exercises' and 'Community Feedback Exercises' in phases 1 and 3 of the qualitative work. SAfH has trained a panel of Community Researchers covering many of the main languages spoken locally. These individuals are locally-resident and selected for their personal attributes and local knowledge.

Interviewers (*to be appointed*): To cover all languages and ensure a mix of male and female interview staff, a number of Interviewers will be recruited to work on a 'per interview' payment basis. SAfH and Sarah Salway have successfully worked in this way before and a network of contacts exists which will ensure skilled personnel are engaged.

## **Dissemination**

In addition to a *Findings* and an accessible report, results will be presented to policy, programme, academic and primary stakeholder audiences at a series of dissemination workshops and via tailored publications.

Policy makers: Results will be of direct relevance to policy discourse around social and health inequalities, as well as the intersection between economic (in)activity and ill-health. We will use our connections within the DWP (in particular, Berthoud and Shukur, currently in the Family and Disability Analysis Division) to disseminate summaries of findings both in writing and via seminars. CPS has strong links with policy makers at DoH, and SAfH has established relationships with PCTs and LAs in East London which will also be drawn on.

Programmes and practitioners: Results will have direct relevance to SAfH's own work on self-management of chronic illness and poverty and will also be disseminated to a wide network of CBOs within and outside London. SAfH's links with organisations in Bradford and Birmingham will be used.

Academics: Results will contribute to ongoing debates surrounding the conceptualisation and measurement of poverty, links between poverty and ill-health, and usefulness of ethnicity as a variable of analysis. Seminars will be held at LSHTM and University of Essex. In addition, SS is coordinating an ESRC-funded seminar series on ethnic inequalities in health which offers a wider forum for dissemination with seminars planned in Warwick, Sheffield, Leeds, Edinburgh and London. Academic papers will be submitted to relevant journals.

Primary stakeholders: Emphasis will be placed on dissemination to primary stakeholders. Summary findings will be prepared in each of the study languages and translation services will be provided at community-based dissemination events. SAfH recently completed a series of six highly successful bi, or tri-lingual seminars which attracted no less than 150 participants each, demonstrating their ability to engage local people.

### **Other support**

LSHTM provides office space, a networked computing system, specialist computing help and excellent library facilities. SAfH will provide office space for the RF and KH as well as meeting/training rooms and support in developing community links. KH holds an ESRC scholarship which will allow her to contribute her time to the project free of cost to this budget.



Timetable	2005												2006					
	J	F	M	A	M	J	J	A	S	O	N	D	J	F	M	A	M	J
<b>General:</b>																		
Literature review (SS/RF)																		
Integration of findings (SS/LP/EB)																		
Dissemination events (All)																		
<b>Qualitative:</b>																		
Build community links (SS/KH)																		
Recruitment (SS/EB)																		
Tools development (SS/RF/KH)																		
Training (SS/RF/KH)																		
Rapid assessment (SS/RF/KH/CR)																		
Interviews (SS/RF/KH/I)																		
Feedback (SS/RF/KH/CR)																		
Analysis and writing (SS/RF/KH)																		
<b>Quantitative:</b>																		
Preparation of datasets (LP/KH)																		
Preliminary analyses (LP/KH)																		
Advanced analyses (LP/KH)																		
Writing up (LP/SS/KH/EB)																		

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