



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

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SHARPENS YOUR THINKING

# Outline of the talk

- Overview of the bigger research project
- Overview of the qualitative methodology
- Why and what types of locality-based methods
- What went well
- Complexities and challenges





# Overview of the bigger research project

- Joseph Rowntree Foundation-funded project.  
“Limiting illness & poverty: breaking the vicious cycle”
- Collaboration: Social Action for Health, University of Sheffield, University of Essex.
- Large component of new, qualitative data collection.
- [www.long-term-illness.group.shef.ac.uk](http://www.long-term-illness.group.shef.ac.uk)

# Research objectives



- Describe the relationships between long-term health problems in working age adults and indicators of well-being, poverty and social exclusion.
- Document the range of social, economic, and cultural resources that individuals and households draw on in coping with / responding to ill-health.
- Identify routes via which individuals and households suffering from long-term health problems can be better supported.

# Theoretical starting points



Informed by three sets of theoretical literature:

- Sociology of chronic illness – subjective interpretation of events, wide diversity
- Livelihoods Frameworks or Resource Profiles approaches to conceptualising poverty processes
- Ethnicity as social capital (identities, inclusion and exclusion)

# Theoretical starting points



## Ontology:

- Individuals as active agents, but nevertheless constrained by broader structures.
- Self-identities a central concern – belonging, possibilities.
- Ethnicity as a 'deep structure' that patterns allocation of resources and opportunities.
- Intersection / inter-relationships between individuals and wider structures. Bhavani and Phoenix's notion of identity as the '*site where structure and agency collide*'

# Theoretical starting points



Epistemology: 'Critical ethnography'? (Wainwright 1997)

Synthesis of the traditional ethnographic focus on subjective meanings and beliefs of respondents with a broader structural analysis.

A central place given respondents' descriptions and experiences of long-term illness, but such accounts require *situating*.

Interview narratives, if complemented with other forms of data generation, can provide evidence of structures and processes operating beyond the interview setting.

# Why and what types of locality-based methods



- Underlying assumption was that locality is relevant – that the place of residence shapes resources available to the individual.
- But also, locality-based methods can give insight into resources and relationships *beyond the immediate locality* that provide the context for the experience of, and response to, long-term illness.
- Working closely with a team of Community Researchers.
- Four 'communities' – ethnically and geographically defined (though not clear-cut)

# Who is a Community Researcher?

- A community member.
- Detailed understanding of a particular 'local community'.
- Uses knowledge & networks to facilitate data gathering and interpretation.
- 12 CRs, men/women, varied ages, Pakistani, Bangladeshi, White English & Ghanaian.



# Methods



Adapted from Participatory or Rapid Appraisal methods.  
Intensive period of 5-8 days with each 'community'.

- Transect Walk
- Local resource inventory
- Informal discussions and observations out in the locality
- Group discussions at community venues using matrix, ranking and problem tree exercises
- Key Informant & Ethnographic Interviews

# Transect Walk

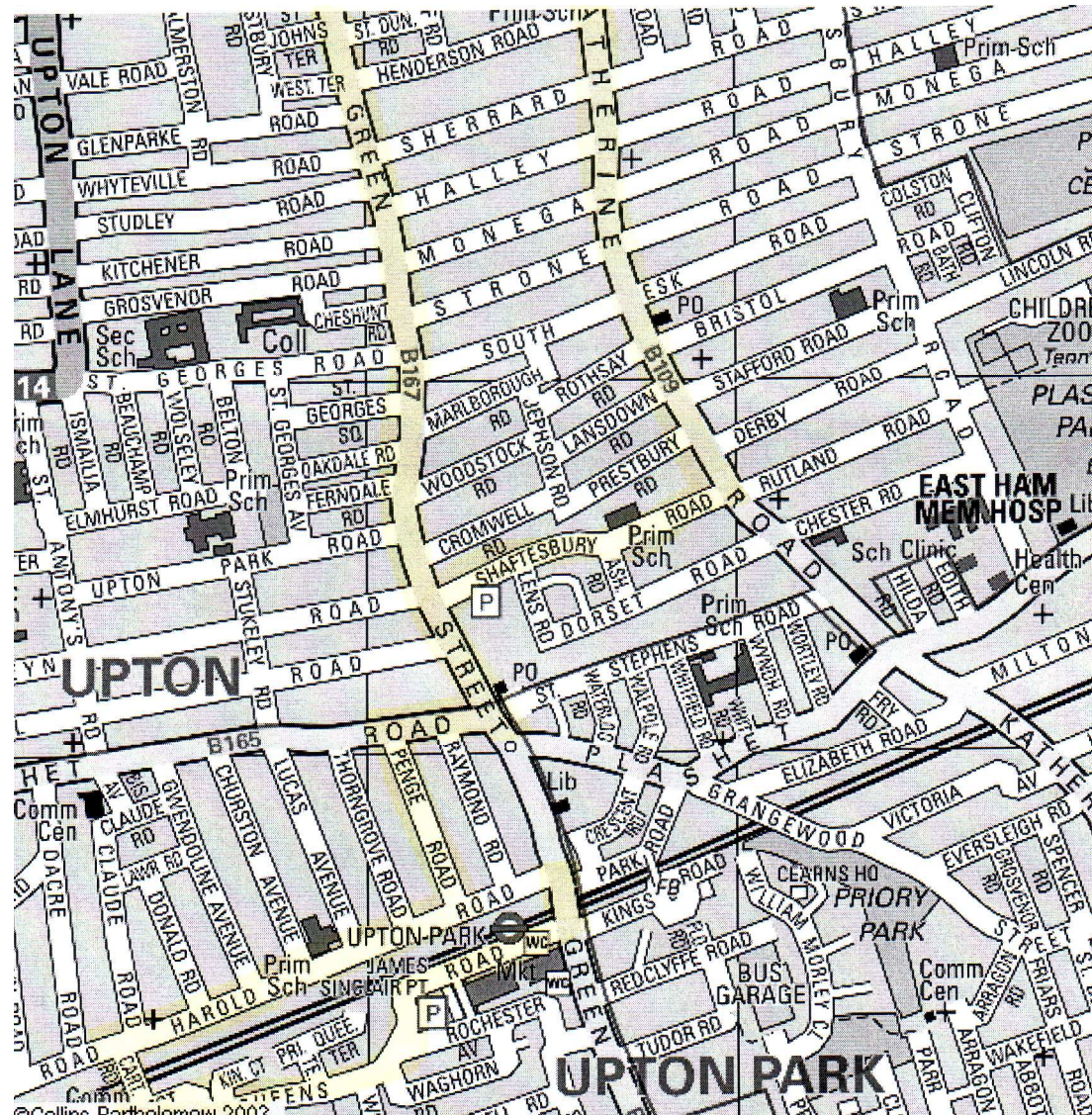


A means of reconnoitre.

A pre-planned, purposive walk through a geographical area with the aim of identifying key features of the local community and observing local people going about their everyday business.

2 such walks for each 'community'

# Example of Transect Walk



# Section of Transect Walk record sheet

## Transect Walk Record Sheet

Date: <b>09/05/2005</b>	Start Point: <b>Brady centre</b>	End Point: <b>Whitechapel tube station</b>
Researchers: <b>PC/EH/AI</b>	Start Time: <b>2.15pm</b>	End Time: <b>4.30pm</b>
Summary of route: <b>Hanbury St -&gt; Spelman St -&gt; Princelet Road -&gt; Fasion St -&gt; Brick Lane -&gt; Monthorpe Rd -&gt; Hoptown Rd -&gt; Montague St -&gt; Old Montague St -&gt; Gretorex St -&gt; Whitechapel Road -&gt; end</b>		

Name of road	Section of road	General description	Facilities / landmarks	People observations	Interactions/exchanges
Hanbury Street	Starting section from Valance rd	Estates, women in veils, lots of vehicles parked on the road	Tower Hamlets Council for racial Equality; Bethnal green neighbourhood Office; Bangladeshi training centre, Citizens Advice Centre	A man 30s standing smoking cigarette, woman in veil, young girls wearing salwar kameez	People were curious, looking at us and smiling at us
Hanbury Street	Middle section	Clean, new and old sections of housing estate, children's play area, not very clean section of estate	Bengali grocery stores; small car park	Mostly young Bengali men (20s); loading and unloading from a truck	
Princelet Road	Off Spelman Street	Rubbish bin; narrow street, several cars parked, council buildings; huge map of area; mural with poetry depicting life in Bangladesh	Specialist travel agents; Habitat huge shop	Bangladeshi men in 30s, 40s. No women on this street.	Someone stopped us and asked about directions

# Community Resource Inventory



- Compiled during the course of phase one fieldwork drawing on all other methods and existing knowledge of Community Researchers
- Broad areas covered:
  - work & training
  - information & advice
  - support & care
  - cultural/religious
  - leisure/socialising
  - healthcare
  - other facilities/resources

# Section of inventory

## COMMUNITY RESOURCE INVENTORY

Community: \_\_\_\_\_ Geographic coverage: \_\_\_\_\_ Date: \_\_\_\_\_

	Available? (tick one box)	Type (tick all that apply)	'Community'/Ethnic group focus? (tick one box)	Participants (tick all that apply)	Usage level (tick one box)	Name & location of one or two examples
<b>Work &amp; training</b>						
Specialist job recruitment agencies	None [ ] Some [ ] Many [ ]	Govt [ ] Private [ ] NGO [ ] Informal [ ]	Focused [ ] General [ ]	Men only [ ] Women only [ ] Mixed [ ]	High [ ] Medium [ ] Low [ ]	
Workplaces/employers	None [ ] Some [ ] Many [ ]	Govt [ ] Private [ ] NGO [ ] Informal [ ]	Focused [ ] General [ ]	Men only [ ] Women only [ ] Mixed [ ]	High [ ] Medium [ ] Low [ ]	
Skills training	None [ ] Some [ ] Many [ ]	Govt [ ] Private [ ] NGO [ ] Informal [ ]	Focused [ ] General [ ]	Men only [ ] Women only [ ] Mixed [ ]	High [ ] Medium [ ] Low [ ]	

# Informal discussions and observations



- Variety of local places (many identified during Transect Walk), included
  - mosques & churches
  - community centres
  - shops
  - hairdressers
  - cafes / restaurants
  - work places
  - markets
  - parks & playgrounds
- Checklist to guide observations

# Section of observation record sheet

## Observation and Informal Discussion Guide

Location. <b>East London Mosque (women's section)</b>	Date: <b>_11 / _05 / 05_</b>	Researcher name: <b>_SS (with AA)_</b>
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### Section A: General setting description:

**Carpeted room upstairs, only women, bright, no chairs, all sitting on the floor.  
Different ethnic groups, Bangladeshis and Somalis, but two groups sitting separately.  
[Bengalis have been sharing snacks and having some kind of group discussion it seems]  
One woman with a [2] year old daughter, child is fussing, mother quietens he and says that they will be leaving soon.  
Azan starts from the room next door and all fall silent. Silence does not last until the end of the Azan, people son start to fidget and mutter to each other.  
Older woman behind the others rocks rhythmically and vaguely chats 'Allah'  
around 30 Bengali women and a similar number of Somali women  
The room has windows all along one side, quite high, which look out over the men's section but at a height which means that you cannot see from normal standing height.  
a few preschool children present, both Bengali and Somali**

# Section of observation record sheet



## Section B: Records of observations

Obs. #	Description of people present	Description of activities	Language/phrases/exchanges	Other observations & comments
1	When we first enter we go towards a group of about 10 women who are sitting on the floor in a group, various ages. AA is greeted by one of the women [group leader?]. Everyone seems friendly and listens to our introductions	Women appear to have been holding a discussion of some sort and sharing snacks. AA knows them and starts to introduce me and talk about the project. Some women ask after AA's child.	"I need to go soon and pick up my child" [women wanting to leave after prayer]	AA's mobile phone rings in the middle and nobody seems at all bothered.
2				

# Informal discussions



- Flexible and opportunistic – but selection of locations intended to provide breadth in our respondents.
- Guideline used flexibly.
- Individuals or small groups.  
e.g. East London Mosque visit: one group of 6 women, one individual interview.

# Analysis workshops



A half-day debriefing with each group of Community Researchers:

- A participatory exercise of theme identification and grouping into larger topic areas.
- Reflection on overall picture, gaps, alternative perspectives etc.
- Use to inform Phase Two focus and in-depth interview tool development
- Also, used to contextualise Phase Two data.

# Positives (What went well)



## Process-related:

- Shifts power/control in favour of the Community Researchers
- Makes research team visible to local people – helps process of building trust and familiarity
- Engages community members
- Increases the researchers' confidence and competence in a new 'cultural scene'
- Identification of contacts for later fieldwork
- Fun!

# Positives



Product-related – data generated:

- Encourages broad/holistic thinking
- Physical landmarks/observations prompt discussion that reveal structures and processes of interest e.g. pubs closing down
- Can alert researchers to distance between norms and practice; and also private vs. public manifestations – see people out there doing things (or not doing things)
- Provides researchers with language and context-related information – later, more detailed interviews more productive

# Positives: examples of insights gained



Extent to which people's lives (especially long-term sick) are constrained by opportunities within their 'local areas':  
e.g. how far people are able or willing to travel for work

- Local deindustrialization/economic decline trigger into long-term unemployment
- But, variation in the extent to which economic opportunities were embedded within local labour markets
- Differences in adaptability between Ghanaians and the other 'communities', linked to their more geographically and socio-economically diverse 'community'

# Positives: examples of insights gained



Racialized feelings towards localities:

- 'Our area' vs 'English people area' – shapes people's willingness to move into new areas, which present other opportunities
- Dense sociality with 'our people' that characterise local areas – networks of support, pervasiveness of 'moral community' for some groups.
- Feelings of particular ethnic communities being sidelined or favoured by local authority e.g. White English feeling neglected.

# Positives: examples of insights gained



Local 'discourses' (or lack of):

- 'Asian diseases', 'Asian diets' – and implications for individual responses
- Varied levels of 'community awareness' regarding chronic illness
- Lack of local discourse around 'Self management' despite the strong emphasis in policy and programme intervention was surprising.

# Positives: examples of insights gained



Local manifestations of national-level policy:

- Extent to which health services in Tower Hamlets seemed to operate with a sub-text of reducing dependence on Incapacity Benefit and DLA
- Divisive nature of certain policy interventions e.g. New Deals and Sure Starts – postcode lottery

# Complexities and challenges



## Process-related:

- Heavily dependent on note-taking skills & effective debriefing. Potential for much data to be lost.
- 'Cold calling' not easy for everyone – needs certain characteristics and dependent on Community Researcher networks.
- Working with Community Researchers is not unproblematic – indebtedness, dilemmas, support.



# Complexities and challenges

Product-related – data generated:

- Complex meanings of 'community': locality only one dimension, a locality-based approach might preclude recognition of the ways in which community may transcend place - need to be flexible and open to diverse forms and meanings of 'community'
- Need to be alert to that which is not visible – Who is not here? What is not happening? Incisive questioning must accompany observation.



# Complexities and challenges

Product-related – data generated:

- A danger of stereotyping? Need to be looking for the exceptions – otherwise may overlook those cases that deviate and therefore give insight into how positive change may be brought about.
- A danger of being too localised in descriptions and explanations? Need to look for commonalities across settings and communities too. Particular danger when working across ethnic groups.

# Complexities and challenges



Product-related – data generated:

- Community Researchers – respondents or researchers?  
How to encourage reflexivity?
- Weaving an argument – How to present evidence that is derived from these methods? – heavy dependence on direct quotation in much work does not suit these methods. How to convince the reader of the depth and breadth that this evidence adds to your argument?