Health Inequalities and qualitative research

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The presentations

Part 1.

i. Comments on:

- Issues that should be addressed in all research
- What is qualitative research?
- The state of public health/health equity science
- The types of questions qualitative research can address
- Lay knowledge as a focus for qualitative research
- The 'status' of qualitative research in public health

ii. Examples of what qualitative research can contribute to the evidence base for public health/health equity action

Part 2:

i. Approaches/methods in qualitative research

ii. Assuring quality in qualitative research

iii. A cautionary tale – the risk of neglecting lay knowledge

But first.....

- What single word or phrase would you use to describe qualitative research?

e.g.

In-depth

biased

Six key issues to address at start of any research process

- *Ontological perspective*: what is the nature of the 'social phenomenon' I wish to investigate?
- *Epistemological perspective*: What might represent knowledge or evidence about this phenomenon?
- *Theoretical perspective*: What is the intellectual puzzle I wish to 'explain; what research questions flow from this?
- *What* are my *data sources* going to be?
- What *methods* am I going to use *to generate data*?
- How am I going to *analyse* these *data*?

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The state of the public health evidence base

- Research for health equity dominated by
  - Positivist epistemology – search for immutable 'facts'
  - Therefore focused on measurement & quantification.
- Inequalities presented in terms of:
  - relative and/or absolute magnitude of differences across social groups in for example mortality, morbidity, life expectancy;
- Explanations offered in terms of e.g.
  - level of income; scale of inequalities in distribution of income & wealth;
  - extent of exposure/degree of vulnerability across a life [course] in terms of duration, number or 'significance' of events, etc.
  - Differences in prevalence of unhealthy lifestyles/individual behaviours
- This is all important – but it isn't enough. Something is missing

What is her point of view?

Ironically health field is dominated by individuals but

These individuals are typically seen as:

- bundles of accumulated risk, vulnerabilities & resiliences
- Sets of freely chosen behaviours and life styles and
- Empty vessels to be filled with professional knowledge

In contrast, qualitative research assumes people are:

- Human actions (agency) is shaped by people's experience in a particular context
- We are therefore all **knowledgeable** subjects: our actions are logical in the context of our lives
- Social scientists call this **'lay knowledge'**

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What is lay knowledge?

- Social life is constructed in stories
- These stories give our everyday experiences meaning
- These meanings point to social determinants of human agency
- Sociologist call these stories ‘narratives’ or ‘lay knowledge’
- It is a form of expert knowledge – wisdom acquired through experience
- This wisdom - as data – is accessed using qualitative research designs.

It is a different type of 'expert' knowledge

- Quantitative scientific knowledge: pursues objective facts; seeks to answer questions of causality

  e.g. How can health inequalities be explained?

- Lay knowledge is subjective – seeks to explain experience or action in terms of their 'meaning'

  e.g. Why is this happening to me now?

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Qualitative research **isn't…**

- The opposite of quantitative research
- A way of measuring quality of life
- Always small scale
- A methods tool-kit
- Anything that includes the consumers' voice
- The easy option for the non-numerate!

- **It is a different way of 'knowing' about the 'social' world**

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The War of the Paradigms & artificial distinctions

Positivist; scientific; quantitative

- Testing hypotheses
- generalise
- Verification
- Reductionist, Inferential; deductive,
- Counting, controlled measurement, experiments, surveys, statistics
- Value free
- Researcher outsider distanced
- Rigour, proof, statistical significance

Naturalist, interpretative, qualitative

- Generate hypotheses,
- describe
- Discovery
- Expansionist, exploratory, inductive,
- Observing, in-depth interviewing, action research, case studies
- Value bound
- Researcher insider, interacts
- Relevance, plausibility, responsive to subjects

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All science has elements of both Inductive and Deductive thinking

- Qual. research is philosophically an inductive science building theory

- Principles of inductive approach
  - *Observe* particular cases
  - *Infer* logical principles which underlie these instances
  - *generalise* building up chain of axiomatic statements that collect these logical connections in formulations of increasing generality

- But separation between inductive and deductive reasoning is difficult to sustain – all science has some of each. In qualitative research:
  - Induction is embedded in approaches to data collection and analysis e.g. constant comparisons and deviant case analysis
  - But dominant approach to sampling (theoretical sampling) is deduction – test whether generalised case 'holds' in other situations

- Theory (not statistical probability) supports generalisation but you don't need a new theory from every study – theories are tested and refined with accumulating knowledge

Approach to phenomena studied in qualitative research

- Not objective 'reality' but product of interpretations shaped by people's perceptions, beliefs & experiences
- Viewed from point of view of people being studied.
- Research is a contextually bounded 'meaning-making' process between researcher and researched
- Researcher needs to be aware of this interaction and make their standpoints clear so strengths, weaknesses and relevance of studies can be appraised
- *Reflexivity* & *transparency:* describe these processes

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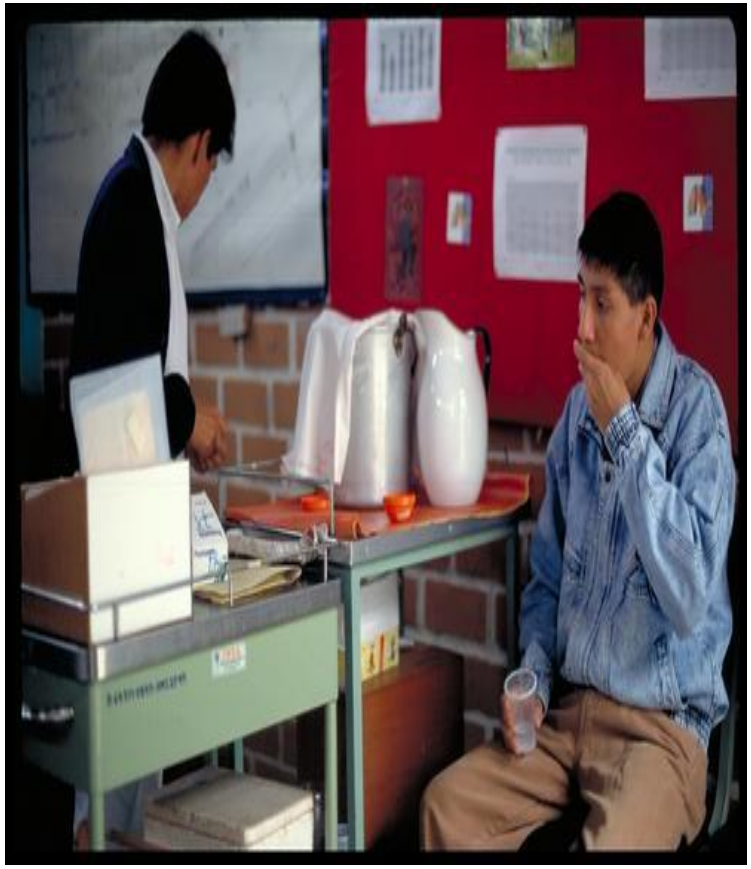
Some examples of can research on lay knowledge can inform action to address the social determinants of health

1. **Are interventions focusing on the 'right' problems?**

e.g.

- **Help seeking for diagnosis and treatment of TB**
- **Re-framing public health problems e.g. children's accidents**

The case of Directly Observed Therapy (DOTS) for the treatment of Tuberculosis



- **DOTS:** branded package of interventions including observing people take medication
- **Cochrane Review:** reported absence of evidence for or against DOTS compared with people treating themselves
- **Systematic review of qualitative research** on factors shaping people's help seeking behaviours

What does qualitative research contribute?

Challenges the assumption:

- That barriers to help seeking and compliance with treatment are cultural and/or that people act irresponsibly

Highlights other barriers:

- material e.g. Low income, transport
- Side effects of the drugs
- Stigma:
  - Within communities
  - within services/from professionals

Reveals resourcefulness:

- people go to great lengths to seek help despite barriers

Suggests ways of improving interventions: e.g.

- more support less inspection
- Training for health professionals

Reframing public health problems – child accidents

About 5,000 children under 16 die or are seriously injured on the UK's roads each year –very steep social gradients

Action focus on teaching parents/children how to stay safe

Most data quantitative and collected after accidents:

- What was the injury?
- What were the consequences?
- What was the treatment?

These data won't generate information needed to prevent accidents e.g.

- What are the antecedents of accidents,
- What aspects of environments increase/decrease risks
- What behaviours—of planners, architects, drivers and others, as well as of children and parents— increase/decrease risks?

"Not everything that counts can be counted. Really interesting question about child accidents is that given all the dangers, how do so many people manage to keep their children safe in unsafe environments? Only qualitative data can help us unravel this". (Helen Roberts, 1997)

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Child accidents - Insights from qualitative research

•Safety may be just one of ‘a seamless web of insecurities’ including damp housing, poor nutrition, chronic ill health, unemployment

•Mothers trade off one health promoting behaviour in favour of another e.g. leaving children unsupervised rather than carrying them down stairs to put washing out to dry or not allowing them in the kitchen when they are cooking.

•Lack of ‘fit’ between prevention messages and realities of keeping children safe

•Mismatch between ‘official’ and lay perspectives:

Professional: ‘I think that the parents perceive that their road is actually very bad. But that’s a perception of course. …There is a general perception that cars are travelling faster than they actually are…If you look at the roads, and the amount they are used, and the complexity of them, they’re not really that dangerous’

Parent:: ‘There are too many cars…when you have parking on both sides, you can’t get by…it is dangerous for the weans [children], because they go in between the motors to see if another motor is coming’.

•Safety promotion can cause anxieties: *‘to keep the kids safe, you’ve got them trapped in the house, you’re trapped in the house, you’re under more pressure, and that causes accidents”*

2. Understanding ‘risky’ behaviours

- Risky behaviours are not primarily explained by lack of knowledge – typically logical in context of people’s lives

- Need to be understood in context of ‘everyday’ life e.g.

  - Smoking as a coping mechanism amongst poor white mothers
  - Breast feeding: men, gender relationships and body image

3. Understanding lay perspectives on health inequalities

A study of people's experience of living in one of the most disadvantaged places in England

What is the significance of place in people's lives?
What causal 'theories' do lay people use?
What, or whom do they blame for ill health?
What are the implications for policy and/or action to address the social determinants of health**?**

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1. Popay, J, Thomas, C. Williams, G. Bennett, S. Gatrell A. & Bostock, L. (2003) A proper place to live: health inequalities, agency and the normative dimensions of space, Social Science & Medicine, 57:1, Pp 55-69
2. Popay, J Bennett, S. Thomas, C. Williams, G. Gatrell, A. Bostock, L. (2003) Beyond 'Beer, Fags Egg and Chips? Exploring Lay understandings of social inequalities in health. Sociology of Health and Illness. 25:1; pp1 – 23

Study Design

- Four neighbourhoods in two cities in NW England: one disadvantaged in health and material terms the other advantaged in each city

- Three 'levels' of data collection/analysis:
  - Routine ward level data on 'opportunity structures' and health experiences .
  - Survey using semi-structured questionnaire with sample of 2000 drawn from two smaller contrasting areas in each of the four neighbourhoods
  - Longitudinal qualitative research involving in-depth interviews on two occasions with purposive sample of 40 people from the surveys

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Comment on two sets of findings:

1. Shared characteristics of ‘good’ place to live and impact of ‘dissonance’
2. Nature and relevance of lay theories about causes of health inequalities

Three key characteristics of a good place to live i.e. normative aspects of place

1. The characteristics and behaviour of people
2. The characteristic of the physical place
3. A sense of belonging in place

Elaborate a little but no time for many quotes!

1. People make ‘good’ places

- Social relationships between neighbours
- Social relationships in the wider community
- Respect for public and private property

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2. Physical factors are important

People's definitions of good health highlighted two aspects of the environment:

- The physical risks or benefits of place e.g.
  - Safety, convenience and cleanliness
- The normative influence of places
  - Provides a frame promoting acceptable or antisocial behaviour and positive/negative values for young people
  - Promotes and maintains social relationships between people

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3. A sense of belonging and personal identity

A good place to live was generally described as one in which you feel an affinity to people around you

'I still like the area. I know everyone around here. Well, you feel comfortable. . .I know it's not much. It's not like your Timperley and your Lymms and all that, but when you grow up you know I've spent 30 years around here. It's hard isn't it? ...looking at it it's not much to look at but...well it's like yourself, you know, where ever you were brought up, you see it declining and it's a problem isn't it? You feel sorry for the area don't you?' (S491)

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But some people didn't 'belong'

'People here seem like they've settled, come to the end of their journey whereas I see myself progressing from this place. So I think I'm different' *Greg, aged 23*

'I don't want him out there. I don't want him mixing with them people. We're different'. (R1536) *Nicola (R1536) a lone mother talking about her young child:*

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Linking experience of place and behaviour?

- People shared normative understandings about a good place to live across very different socio-economic neighbourhoods
- But in poor places there was considerable 'dissonance' between people's lived reality and these normative understandings of a 'good place'
- People's used different resources to manage this dissonance:
  - Material Resources
  - Social Resources - family & friends
  - Ontological resources: a sense of belonging to difficult places
- But these resources were unequally distributed – two potential pathways linking experience of 'normative dissonance' and health inequities
  - Indirect: Increasing social divisions and privatisation in neighbourhoods
  - Direct: lack of coping resources/mechanisms linked to unhealthy behaviours

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Normative dissonance in places and health damaging behaviours

'The doctor put me on Prozac a few months back for living here. Because it's depressing. You get up, you look around and all you see is junkies….I know one day I will come off, I will get off here. I mean I started drinking a hell of a lot more since I've been on here. I drink every night. I have a drink every night just to get to sleep. I smoke more as well. There's a lot of things' (Nicola – lone mother)

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The second set of findings: Lay theories about health inequalities

At the beginning of the interviews:
Responses to data on health inequalities in the 2 areas

- *Divergent responses to the initial question about health inequalities*

- *People living in poorer areas disputed the evidence whilst those in wealthier areas did not*

- *I don't believe it…*

- *That puzzles me….*

- *I can't believe em..*

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Two factors underlying disbelief

1. For some people the evidence contradicted the ‘facts’ as they understood them and in any event they distrusted statistics

I would think, actually that they, the rich, weren’t as healthy as the poor cos of all the spirits they drink and stuff they eat. I mean if you eat the basics like we do I think you’re much healthier…I mean they just make the figures look bad.. I don’t trust statistics as all

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2. More commonly people rejected evidence on inequality because they rejected the stigma and inevitability of pre-mature death that this implied:

I don't believe it…They look at Salford as being a dump. They think nobody lives there..they are seen as outcasts. Yes there's pollution but other than that it's attitudes.. They are making out that it's all like scum and they're all dying… it doesn't make sense

But as the conversations moved on people spoke about their experience of social and health inequalities

These accounts highlighted multiple risk factors

I'm a strong person. I can deal with a lot of things but this particular area and living in this area has made me ill.. At the end of the day you've got to feel happy in the place your living in cos that is your source, it's where you're based.

They are poorer up this way and they probably don't eat as well. I mean they have less money whereas if you are more posher, as I call them, you have the money to spend on different foods. To have more vegetables.. It's because of the money

But in general these lay theories emphasised 3 pathways:

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Emphasised indirect mechanisms

- Many accounts suggested 'stress' mediated the relationship between poor material circumstances and ill health

- Social comparisons – with people better off then yourself – were also described as a source of stress

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It's only obvious that we would not feel health wise as someone would who has all the comforts and luxuries around them. You know they go on holidays three times a year..whereas we can't afford to go on one holiday so that's the difference. Their outlook on life is more relaxed and at ease and comfortable. Whereas we are struggling day to day with pressures and to keep up with things.

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Emphasised ‘strength of character’

I think if you have poor housing or are unemployed and don’t have a lot of money you are going to have a different outlook but I mean a lot of people think it’s more the outside but at the end of the day it’s what goes on in your own home, what sort of morals and standards and ethics you’ve got… at the end of the day it’s what sort of person you are.

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Emphasised structural inequalities

I mean everybody has a bit of worry. But it's our own worry brought on by ourselves.. .but outside worries that you haven't got any influence on changing that has a bigger effect on you I think. You can't sit down and think 'well I've got this problem and how can I solve it'. Cos you can't solve it if it's outside your house… It's an outside influence that you can't control, you can't change it, you haven't the power to change it and it takes over your life….

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The important issue for public health: understand the purpose of these theories

1. *'Reconstruct' moral worth : 'To acknowledge inequality would be to admit an inferior moral status for oneself and one's peers: hence perhaps the emphasis on 'not giving in' to illness. This can be seen to be a claim to moral equality even in the face of clear economic inequality* Mildred Blaxter, 1997, 754

2. *Re-assert individual control through emphasis on indirect rather than direct mechanisms particularly stress as a key factor mediating between material circumstances and ill health. Stress could be in people's control in way that structural/material inequalities can not.*

3. *Reconcile individual need for control with recognition of wider determinants: no lack of knowledge here about structural constraints on people lives but lack of power to change these*

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Implications for policy & practice?

- Recognise moral nature of public health discourse about health inequalities
- Avoid increasing the stigma of inequality
- Give people more control over action to address social determinants of health inequalities

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Lot of evidence for the relevance and value of qualitative research evidence

But it is still relatively neglected in public health

why is this?

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Why is lay knowledge neglected?

- Some dismiss qualitative evidence as:
  - Primitive, left over from an unscientific less rationale age
  - untrustworthy anecdotes
  - Just beliefs that lead to risky and/or irrational behaviours

- It often raises challenging political issues – an illustration

Why is this wisdom neglected?

- Some dismiss qualitative evidence as:
  - Primitive, left over from an unscientific less rationale age
  - untrustworthy anecdotes
  - Just beliefs that lead to risky and/or irrational behaviours

- It can raise issues that are 'political' – a joke to illustrate

- Social science approaches that *access* it - qualitative and/or participative research – has lower status in health field

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Discussion

- Choose a topic that you might want to investigate, for example, breast feeding behaviour or racism

- What is the intellectual puzzle you are interested in?
- Do you think qualitative research can help?
- What research questions might flow from this
- What would be the sources of data?

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part 2
Approaches and methods in qualitative research

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- What approaches and designs are there?
- What methods can be used to collect data?
- What methods can be used to analyse data?
- How is trustworthiness to be assessed?

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Principles of Qualitative Research

- Aims to develop concepts and theories that help us to understand social phenomena studied in naturally occuring situations not experimental settings.

- Addresses questions about action/behaviour (‘*agency*’) and the relationship with *social structures* by exploring meanings attached to experiences and how these are shaped by social contexts.

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Qualitative Study Designs

- *Ethnography:* holistic, indepth, understanding of a social context / 'way of life through immersion

- *Case-study*: systematic study of an individual, group, or event in particular context

- *Action-research:* cycles of action and research aimed at developing action/practice

- *Grounded theory*: interative data collection, analysis and theory development until 'saturation' occurs

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Data Collection Methods

- In general the approach is based on
    - Theoretical sampling of 'cases'
    - Constant comparison between cases to develop 'theory'
    - Look for and analyse deviant cases to 'test' theory

- Operationalise this approach through different methods e.g.
  - *Observation*: participant/non-participative using field diaries,video and audio recording
  - *Individual interviews:* unstructured (eg oral history) or use topic guide
  - *Focus groups:* Topic guide focuses discussion.
  - *Diaries/auto-biographies*: more or less structured; longitudinal data collection; can be paper, computer based, or online blogs.
- Data often in the form of transcripts

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White male age 47 – mental health experience study

I've been separated about 3 years which came as a shock, we'd been married like, I know I don't look old enough, 10 years. I thought everything was hunky dory and then obviously it wasn't, the wife moved out and, err, it's the same, I think men don't deal with illnesses well, and I suppose stress is a bit of an illness, and you don't go see the doctor, but in the end I did go because I'd lost a lost of weight and, erm, I wasn't sleeping, and they offered to give me sleeping pills well I didn't want that, so I don't know why I went really (laughs), but, err, I just, I dealt with it in my own way really, which involved some alcohol and , and things like that, err, but that isn't the answer because you wake up and the problems are still there aren't they, but that's about it.

Q: what did you discuss with you doctor?

...it's very difficult to see my doctor unless you, you have to book your illness about 3 weeks in advance, but as it happen I did see him fairly quickly and he was good, because he listens, and like I say it's difficult for men going and saying they are stressed. You just don't. Erm , men are butch aren't they and deal with it and like I say he did offer sleeping tablets, and, erm, he gave me some erm, beta blockers, are they?

ID 1: Instead of, just to slow things down rather than valium and things like that, because I didn't want to start taking things like that. Like I say I think it was basically just going to, you see I had pains in my chest, which I originally went with to the GP and he said that could be stress related. You know, I thought I was having a heart attack. Ermmm, so he was quite good actually.

Pakistani origin female age 34

I never talk to my friends,…. I've got loads of really good friends but I just tell them the basic things really. My husband, he's the only one I can really, really tell everything to because I know he is listening..... with his heart and he's feeling what I am feeling. I think talking to someone really helps you as well, which I never really used to do before. But then you know, you have some bad experiences where you tell someone and then suddenly everyone knows and then you stop telling them thing, you stop talking because you lose the trust. Then after that, like, I went for a few counselling sessions and that was the second person I spoke to in detail and that kind of talking was well…it was mainly different because of talking to a professional."

Q. So has talking helped to resolve your problems or is it….?

When I was on my own and my husband would be at work, I did think – no, there's no hope. I'll never be able to get pregnant, this has happened now, it's for a reason, God took it away to punish me . But when my husband came home, he'd just say you should be glad. There are people in the world who haven't even got one child and you have two lovely children. Why not look at what God has given you and spend some time with them. I did go to the doctor. I was hoping they'd give me some stress-tablets or something, but she said not when you are trying for a baby. And so I did go to the counsellor well it did help, but then I thought, you know, the things I am telling her, she's a total stranger to me! I can do this at home, rather than coming here to see a stranger each week and she can be seeing someone who really needs it, who is totally alone and *really* depressed.

Analysing qualitative data

- Dependent upon *conceptual* not numerical analysis
- Involves identifying themes, concepts, categories to develop ideas ('theories') about relationships in data
- Brings data and theory together to generate new understandings and explanations.
- Two key elements:
  - the purpose of analysis: what is being sought
  - the practice of analysis: how it is done

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The purpose of qualitative data analysis

- Different approaches can be used with same data so study aims and questions should determine approach as well as data type

- Qualitative analytical approaches include:
  - *Narrative analysis*: how a story is constructed using language, imagery, metaphor and/or rhetorical purpose
  - *Content analysis*: how themes/ issues arise across text; focus on context, frequency , patterning by e.g. Gender, etc
  - *Conversation analy*sis: structure of communication and conversation management revealing how 'meaning' is constructed in interaction:

    turn taking,, pauses, intonation, etc.
  - *Discourse analysis*: how knowledge is produced through specialised language/theories, performances, interaction and rhetorical devices in e.g. Interviews, letters, policy documents

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The Practice of Qualitative Data Analysis

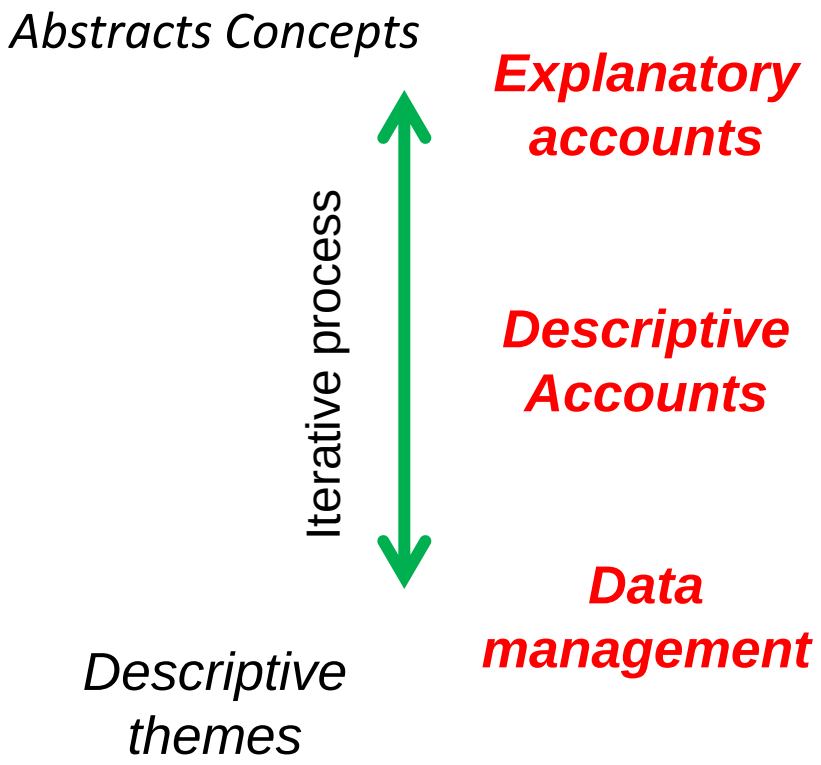
- *Familiarise* – read, read and read again
- *Map and describe* initial events and/or themes
- *Concept/theory development* through further analysis

Step 1: Thematic analysis most common method e.g 'code and retrieve'

Step 2: Relationships between themes/concepts then explored through other methods e.g. Conceptual mapping

Computer software can help manage the process BUT it can't perform analysis. Intellectual work of devising coding schemes and developing theories is researcher's responsibility

Analytical Hierarchy in Qualitative Research



Adapted from Ritchie and Lewis (2003)

Key elements in thematic analysis

- Initial codes may emerge from theory or reading of data
  - Applied across whole data set (e.g. all interview transcripts) to exploring areas of difference or non-conformity.
  - Indexing manual or computer aided

- Preliminary mapping to order/sort raw data
- Ensure rigorous and transparent e.g. dual coding.

- Allow within and across case searching to identify
  - recurring themes, categories and/or typologies
  - Explore areas of difference and non-conformity

- Move from themes back to raw data checking link between analysis & data is maintained during abstraction
- Allow revision and additions to themes, categories and/or typologies as ideas are ‘tested’.

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Initial codes:

1. Gendered approaches to illness
2. Help seeking and symptom experience
3. Approaching health professionals
4. Somebody to listen
5. Relationships – trust and familiarity
6. Causal factors - Social isolation
7. Self worth

Dealing with the sceptics?

- “How could a mere act of mind lead to a discovery of new information?” Medawar, 1991 Nobel Prize Winner Immunologist

- Ensuring ‘trustworthiness’ of research findings is central to any tradition of enquiry

- There are methods for appraising quality in qualitative research

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Appraising Quality in QR

- Many criteria used to assess ‘quality’ are same as in other research paradigms

- There are also specific ‘technical’ criteria for judgement of ‘trustworthiness in QR e.g. role of theory

- But it can also argue there is a non-technical ‘primary marker’ for quality of QR

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Common technical quality criteria in qualitative research

- Are the method appropriate to research question
- Is there an explicit link to theory?
- Are aims and objectives clearly stated?
- Is there a clear description of context
- Is there a clear description of sample method and achieved sample?
- Is there a clear description of fieldwork methods and problems encountered?
- How is data analysis validated?
- Is sufficient data (e.g. quotations) reported and do they support the interpretation

Social Meaning: a Primary Marker of Trustworthiness in QR

- Does the research, as reported, illuminate the meanings attached to experiences by those studied?
- Does it adopt a *verstehen* approach to knowledge – seeking to show how behaviours are viewed from within a culture, society or group?
- Is the focus of explanation 'adequacy at the level of meaning not at the level of cause' ? (Max Weber)

Why should the evidence base for health inequalities policy/practice be extended?

When two ‘rivers’ meet

- There will be some turbulence

but

- Change & adaptation creates a new and more substantial river

Public health is missing the point

- Lay people are skilled interpreters and translators of their experience

- Neglect of lay knowledge in health inequalities field
  - Restricts the evidence shaping action to knowledge that is disconnected from the context in which people live
  - This undermines the potential for creative interplay between different forms of knowledge
  - So interventions may be inappropriate and/or ineffective
- One last example.....

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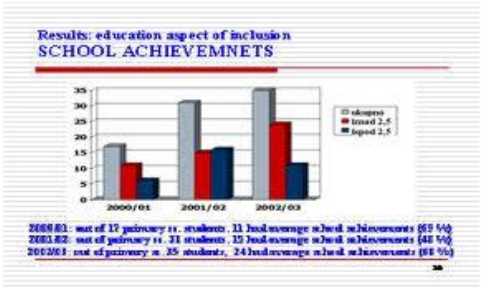
Roma children and school: the operation of exclusionary processes

1



Bus Stop

Whilst Roma parents are taught about the value of education

2

3

4

Roma children get lessons in personal hygiene

5

The Moral of the Story?

- Social, cultural, economic and political exclusionary processes interact

- Actions to address one dimension may unintentionally exacerbate exclusionary processes along another dimension

- If the voices of Roma parents had been heard problems could have been avoided and more appropriate and effective solutions found

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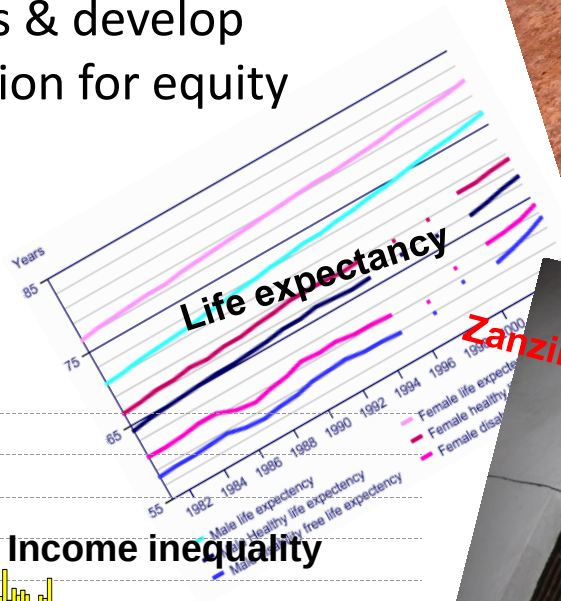
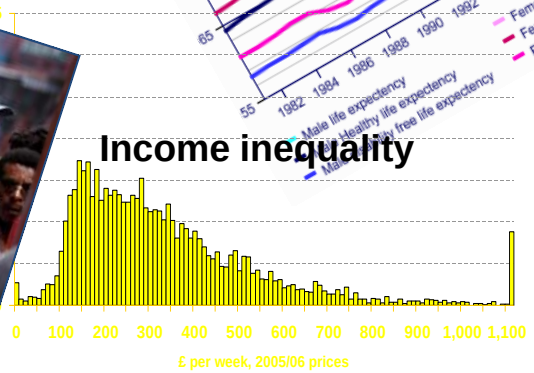
The challenge for a public health science

- There is increasing interest in the relationship between science and civil society
- *Public health science* needs to find ways to access and use accounts and interpretations of lay people alongside other knowledge
- This requires more inclusive knowledge spaces bringing together diverse evidences & develop collective intelligence to inform action for equity



Experiential knowledge



Have you changed your mind?

- Choose a topic that you might want to investigate, for example, breast feeding behaviour or racism

- What is the intellectual puzzle you are interested in?
- Do you think qualitative research can help?
- What research questions might flow from this
- What would be the sources of data?

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