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The Quality of Social Existence in a Globalising World

Exploring the challenges and responsibilities of mutual engagement within participatory action research.

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Themes

- Participatory qualitative methodologies that centralize the voices of those most easily marginalized by mainstream policies
- Shaping the study methodology
- Key responsibilities of the co-researchers within this process of mutual engagement
- Challenges and responsibilities of identifying the perspectives of co-researchers in a methodology striving to mutually engage diverse communities of academic researchers, NHS clinicians and service users
- Issues emerging of relevance for policies on social exclusion, cultural competence and user involvement
**Terminology**

- *Action Research* = a research methodology based on learning-by-doing
- *ARV* = Anti-Retroviral medication (drugs thought to slow HIV replication and the onset of AIDS)
- *RCT* = Randomised Controlled Trial
- *NASS* = UK National Asylum Support Service part of the Home Office Immigration and Nationality Department
- *National Dispersal Scheme* or *Dispersal* = enforced & involuntary relocation of asylum seekers within UK
- *Vouchers* or *Voucher Scheme* = a stigmatizing state benefit system for asylum seekers that uses vouchers instead of cash
Aims

Share, implement and disseminate good practice through identification of:

- clinicians/service users' perspectives;
- local knowledge that inhibits/enables subject engagement;
- factors that sustain adherence;
- factors that enhance local research capacity.
Research questions

- what factors enable/constrain greater recruitment of HIV-positive London-based sub-Saharan African patients into anti-HIV clinical trials (ARVs)?
- what factors facilitate/impede subject adherence whilst enrolled?
- what service developments could accommodate above findings?
- what inputs enhance social research capacity of research nurses?
Anticipated outcomes

- enhance enrolment strategies;
- increase African user consultation;
- developing clinical strategies in context of 'lay' health beliefs.
Action Research Process
(after Susman 1984)


DIAGNOSING
Identifying or defining a problem

SPECIFYING LEARNING
Identifying general findings

ACTION PLANNING
Considering alternative courses of action

EVALUATING
Studying the consequences of an action

TAking ACTION
Selecting a course of action
Action Research Process
(after Kemmis 1985)

cited in Hopkins D (1985) *A teacher's guide to classroom research.*
Philadelphia: Open University Press
Participatory action research (after Stringer 1999)

- Participatory action research aims to be:
  - democratic
    - enables participation
  - equitable
    - acknowledges equality of worth
  - liberating
    - provides freedom from oppressive conditions
  - life enhancing
    - enables expression of individuals' full potential
Research advisory group (RAG)

- Assists in achieving study aims/objectives

- Forum to agree:
  - Methodology
  - User involvement
  - Data analysis
  - Differing perspectives
  - Social factors
  - Ethical issues
  - Funding

- Invites participation of related communities

- Engagement of related communities:
  - African professionals, users and patients
  - Academic researchers
  - Clinicians
Research advisory group (RAG)

- Diverse communities of London-based African professionals, patients/users, academic researchers and clinicians with differing:
  - roles/responsibilities
  - tools & resources
  - challenges
  - interventions
<table>
<thead>
<tr>
<th>Related communities of ‘co-researchers’</th>
<th>Role/Responsibility</th>
<th>Tools &amp; Resources</th>
<th>Challenges</th>
<th>Interventions</th>
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</thead>
<tbody>
<tr>
<td>African users &amp; patients</td>
<td>inform research process</td>
<td>local knowledge</td>
<td>knowledge levels</td>
<td>invitation to RAG</td>
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<tr>
<td></td>
<td>active participation e.g. data, analysis, user involvement</td>
<td>community networks</td>
<td>NASS dispersal</td>
<td>referral to Services</td>
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<td></td>
<td>provide data, analysis of data</td>
<td>experience of problem/part of solution</td>
<td>multiple economic challenges e.g. vouchers</td>
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<td>marketing: help develop flyers, posters</td>
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<td>attitudes/belief systems</td>
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<td>develop user forum</td>
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<td>motivation levels</td>
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<td>Academic researchers (co-opting Research Assistant &amp; African professionals from within the African communities)</td>
<td>facilitate funding bids</td>
<td>research expertise</td>
<td>knowledge of community issues</td>
<td>recruit (co-) Research Assistant from African communities with local knowledge</td>
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<td>establish Research Advisory Group (RAG)</td>
<td>opinion leadership</td>
<td>representation</td>
<td>recruit to RAG</td>
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<td>co-ordinate data collection &amp; analysis</td>
<td>knowing community based issues e.g. recruitment sites, CBO’s</td>
<td>knowledge of methodology</td>
<td>seminars</td>
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<td>developing interview guide</td>
<td>interview guide</td>
<td>sense of alienation</td>
<td>lobby NASS, DoH re: RAG issues</td>
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<td>African co-researchers</td>
<td>project schedule</td>
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<td>in-depth interviews</td>
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<td>validity &amp; reliability</td>
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| clinicians (physicians, nurse specialists, research nurses, health advisors) | - provision of data
- analysis of data
- participate in developing user involvement forum | - patients’ trust
- clinic setting
- opportunities | - attitudes
- power relations
- immigration status of patients
- overcoming perceived threats to professionals’/boundaries | - transparency of information
- invitation to RAG
- increase visits to the clinic
- more informal contacts |
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