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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
- **ACTION PLANNING**: Considering alternative courses of action
- **SPECIFYING LEARNING**: Identifying general findings
- **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>
</tr>
</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></td>
<td>marketing: help develop flyers, posters</td>
<td>confidentialiity</td>
<td>attitudes/belief systems</td>
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<td></td>
<td>develop user forum</td>
<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></td>
<td>■ establish Research Advisory Group (RAG)</td>
<td>■ opinion leadership</td>
<td>■ representation</td>
<td>■ recruit to RAG</td>
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<td></td>
<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>
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<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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<td>clinicians (physicians, nurse specialists, research nurses, health advisors)</td>
<td>provision of data</td>
<td>patients’ trust</td>
<td>attitudes</td>
<td>transparency of information</td>
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<td></td>
<td>analysis of data</td>
<td>clinic setting</td>
<td>power relations</td>
<td>invitation to RAG</td>
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<td></td>
<td>participate in developing user involvement forum</td>
<td>opportunities</td>
<td>immigration status of patients</td>
<td>increase visits to the clinic</td>
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<td>overcoming perceived threats to professionals’/boundaries</td>
<td>more informal contacts</td>
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</table>
Acknowledgements

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- St George’s Healthcare NHS Trust Research and Development Committee, London
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