The experiences affecting Sub-Saharan African patients' engagement in antiretroviral clinical trials: an exploratory participatory action research study.

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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 sub-Saharan African patients into anti-HIV trials?;
- 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 (MacIsaac 1995)

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
  - HIV clinicians
Research advisory group (RAG)

Diverse communities of African professionals, patients/users, academic researchers and HIV clinicians with differing:

- roles/responsibilities
- tools & resources
- challenges
- interventions
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<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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| Academic researchers (co-opting Research Assistant & African professionals from within the African communities) | •facilitate funding bids  
•establish RAG  
•co-ordinate data collection & analysis  
•developing interview guide | •research expertise  
•opinion leadership  
•knowing community based issues e.g. recruitment sites, CBO’s  
•interview guide  
•African co-researchers | •knowledge of community issues  
•representation  
•knowledge of methodology  
•sense of alienation  
•project schedule  
•in-depth interviews  
•validity & reliability | •recruit (co-) Research Assistant from African communities with local knowledge  
•recruit to RAG  
•seminars  
•lobby NASS, DoH re: RAS issues |
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| African users & patients               | • inform research process  
• active participation e.g. data, analysis, user involvement  
• provision of data, analysis of data  
• develop user involvement forum | • local knowledge  
• community networks  
• experience of problem/part of solution | • levels of knowledge  
• attitudes/belief systems  
• confidentiality  
• motivation levels | • invitation to RAG  
• referral to Services |
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| HIV clinicians (physicians, nurse specialists, research nurses) | • provision of data  
• analysis of data  
• participate in developing user involvement forum | • patients’ trust  
• clinic setting  
• opportunities | • attitudes  
• power relations  
• overcoming perceived threats to professionals’/boundaries | • transparency of information  
• invitation to RAG  
• increase visits to the clinic more informal contacts |
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