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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

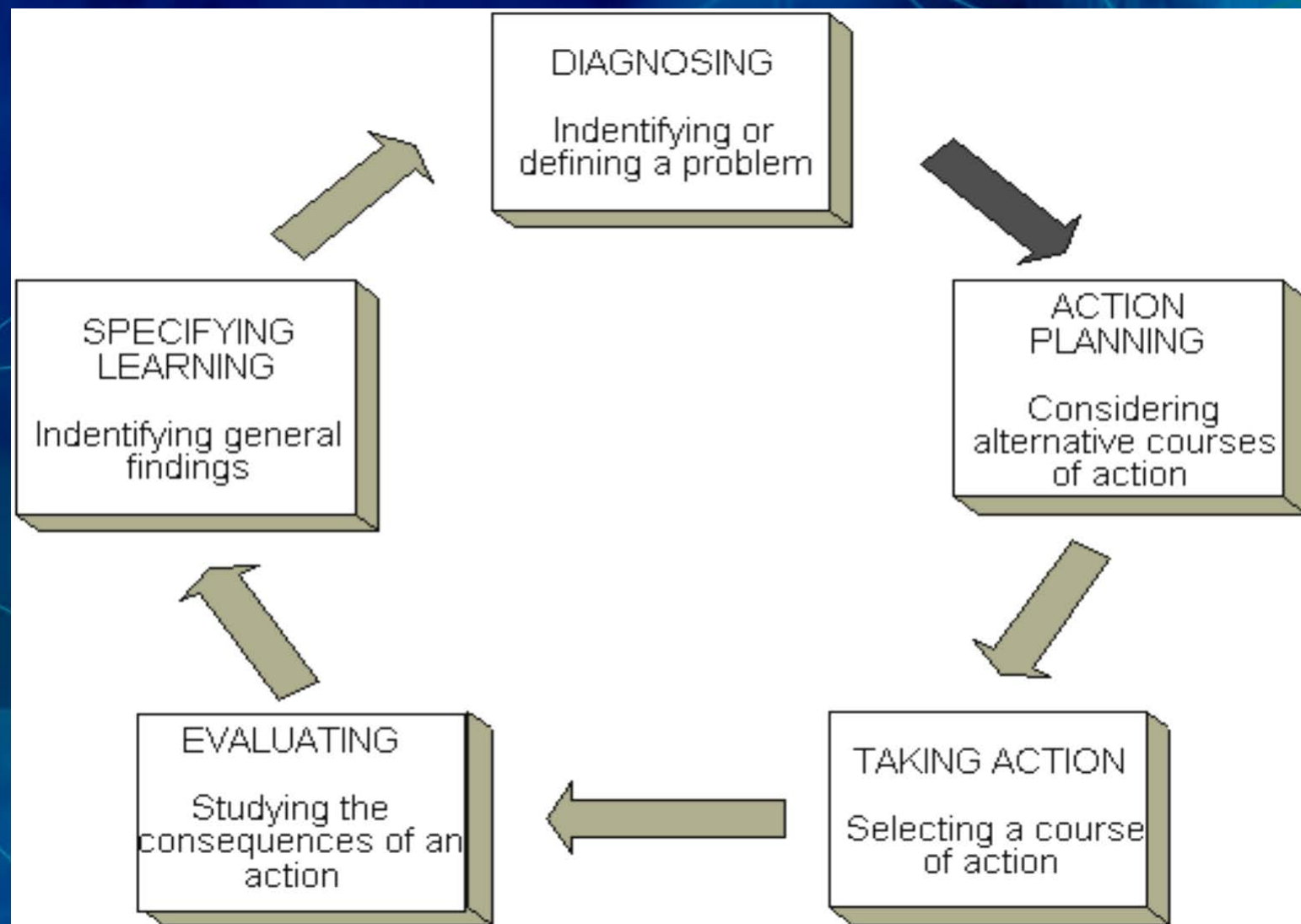
- what factors enable/constrain greater recruitment of HIV-positive London-based sub-Saharan African patients into anti-HIV clinical trials (ARVs)?;
- what factors facilitate/impede subject adherence whilst enrolled?;
- what service developments could accommodate above findings?;
- what inputs enhance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

Anticipated outcomes

- enhance enrolment strategies;
- increase African user consultation;
- developing clinical strategies in context of 'lay' health beliefs.

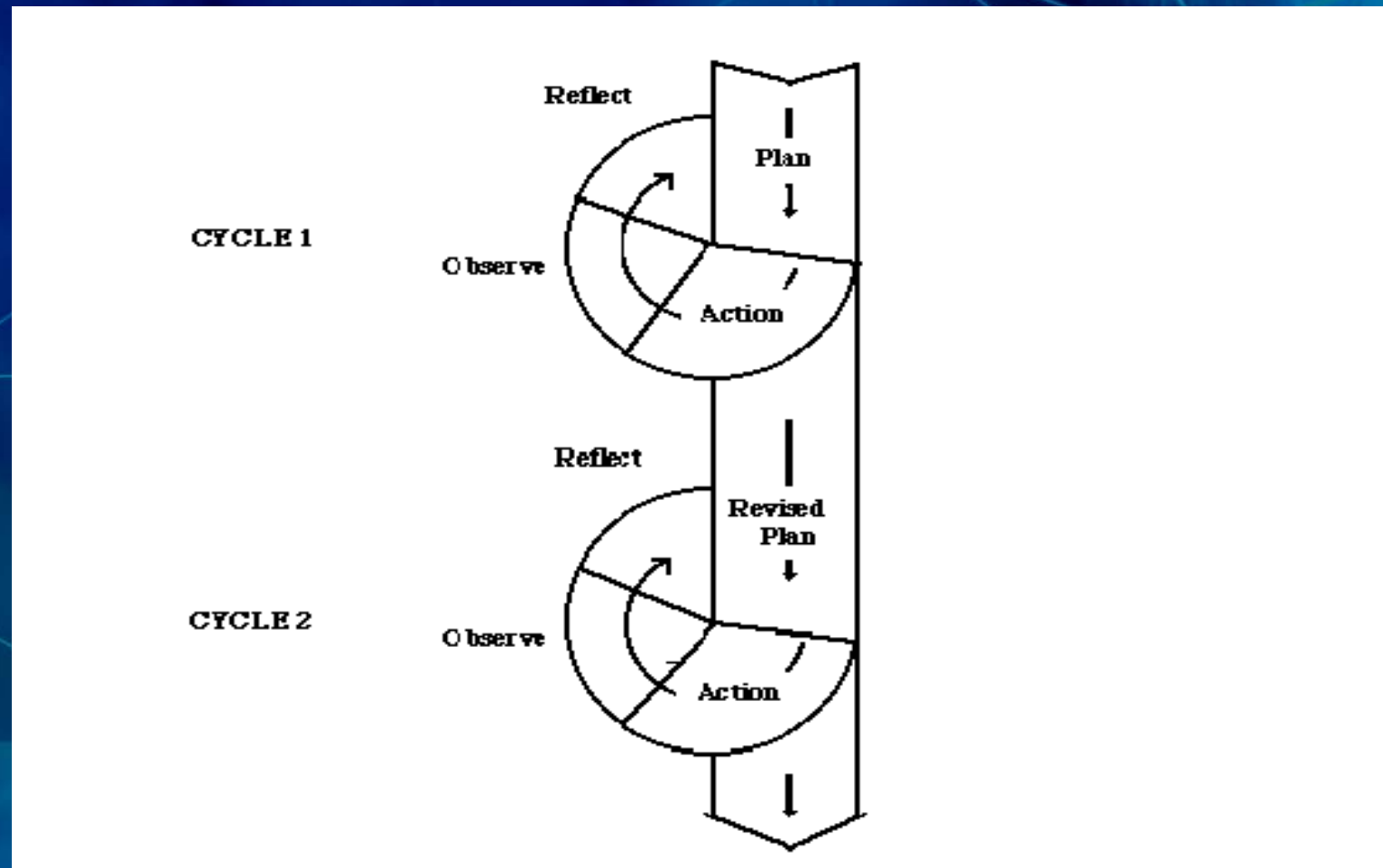
Action Research Process

(after Susman 1984)



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

Related communities of 'co-researchers'

Role/Responsibility

Tools & Resources

Challenges

Interventions

African users & patients

- inform research process
- active participation e.g. data, analysis, user involvement

- provide data, analysis of data
- marketing: help develop flyers, posters

- develop user forum

- local knowledge

- community networks

- experience of problem/part of solution

- knowledge levels

- NASS dispersal

- multiple economic challenges e.g. vouchers

- attitudes/belief systems

- confidentiality

- motivation levels

- invitation to RAG

- referral to Services

Related communities of 'co-researchers'

Role/Responsibility

Tools & Resources

Challenges

Interventions

Academic researchers (co-opting Research Assistant & African professionals from within the African communities)

- facilitate funding bids

- establish Research Advisory Group (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: RAG issues

Related communities of 'co-researchers'

Role/ Responsibility

Tools & Resources

Challenges

Interventions

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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- African HIV Policy Network, London
- Department of Health Sciences, University of York
- Faculty of Health and Social Care Sciences, Kingston University/St George's, University of London

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