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

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KINGSTON
UNIVERSITY



St George's Hospital
Medical School
UNIVERSITY OF LONDON

Aims

Share, implement and disseminate good practice through identification of:

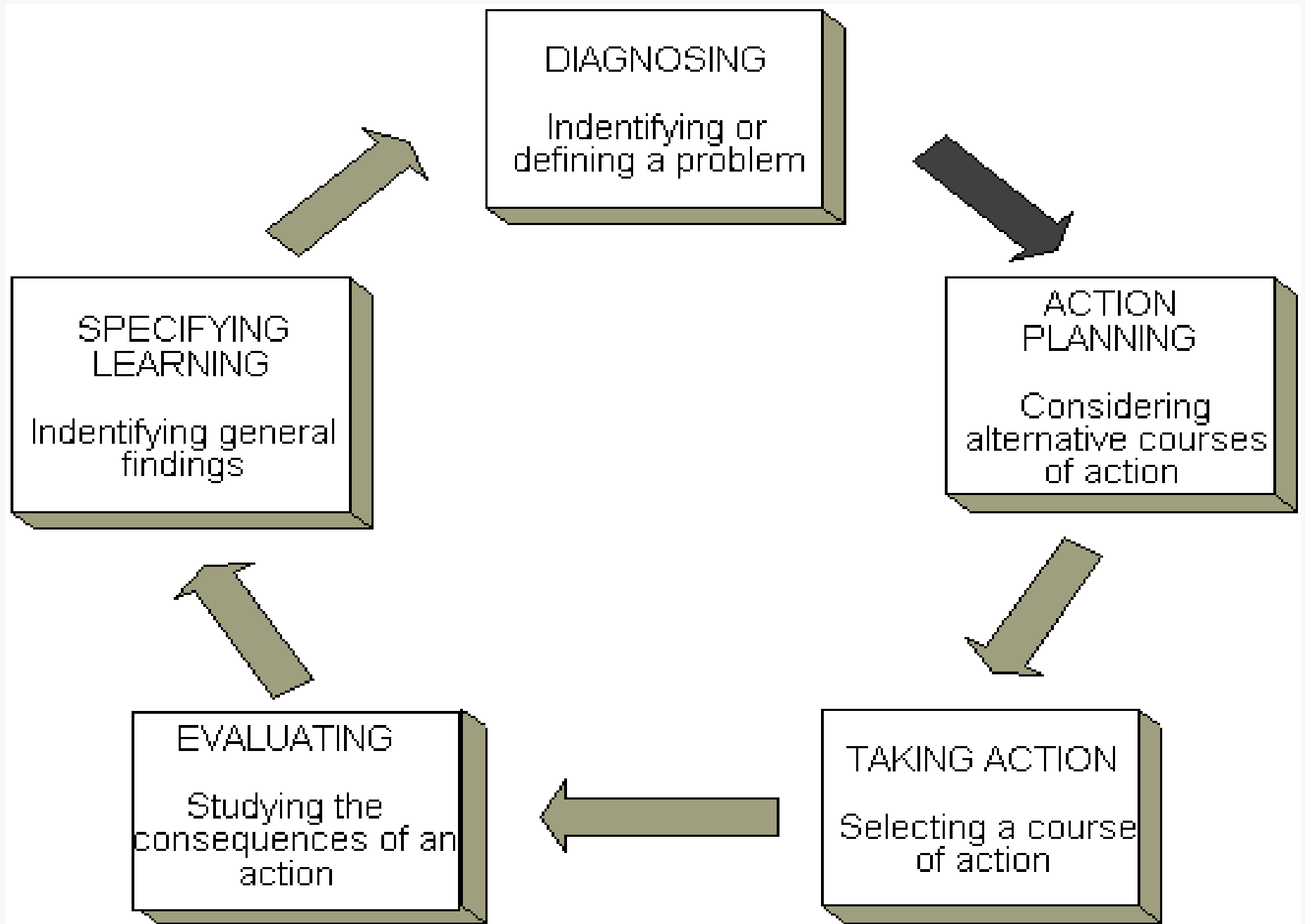
- clinicians/service users' perspectives;
- local knowledge that inhibits/enables subject engagement;
- factors that sustain adherence;
- factors that enhance local research capacity.

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?

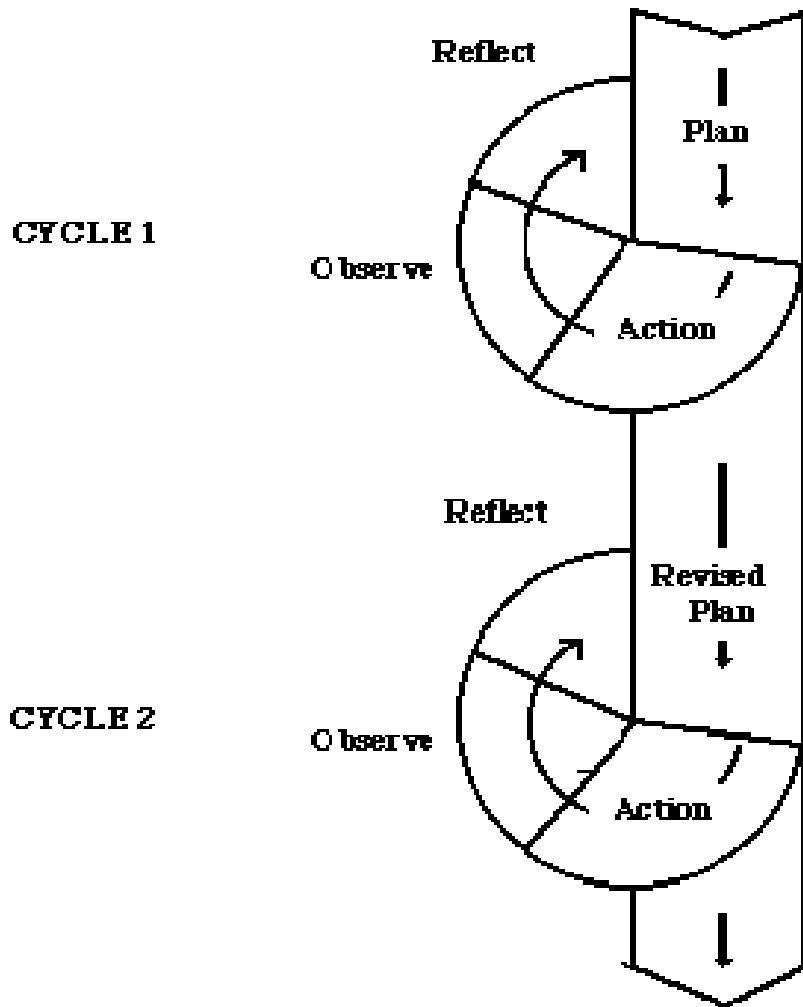
Anticipated outcomes

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



Gerald I. Susman, "Action Research: A Sociotechnical Systems Perspective," ed. G. Morgan (London: Sage Publications, 1983) 102

Action Research Process (MacIsaac 1995)



Dan MacIsaac, "An Introduction to Action Research," 1995,
<http://www.phy.nau.edu/~danmac/actionrsch.html> (22/03/1998)

Participatory action research

(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
- invites participation of related communities
- forum to agree:
 - methodology
 - user involvement
 - data analysis
 - differing perspectives
 - social factors
 - ethical issues
 - funding
- 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

Related communities of 'co-researchers'	Role/ Responsibility	Tools & Resources	Challenges	Interventions
Academic researchers (co-opting Research Assistant & African professionals from within the African communities)	<ul style="list-style-type: none"> •facilitate funding bids •establish RAG •co-ordinate data collection & analysis •developing interview guide 	<ul style="list-style-type: none"> •research expertise •opinion leadership •knowing community based issues e.g. recruitment sites, CBO's •interview guide •African co-researchers 	<ul style="list-style-type: none"> •knowledge of community issues •representation •knowledge of methodology •sense of alienation •project schedule •in-depth interviews •validity & reliability 	<ul style="list-style-type: none"> •recruit (co-) Research Assistant from African communities with local knowledge •recruit to RAG •seminars •lobby NASS, DoH re: RAS issues

Related communities of 'co-researchers'	Role/Responsibility	Tools & Resources	Challenges	Interventions
African users & patients	<ul style="list-style-type: none"> •inform research process •active participation e.g. data, analysis, user involvement •provision of data, analysis of data •develop user involvement forum 	<ul style="list-style-type: none"> •local knowledge •community networks •experience of problem/part of solution 	<ul style="list-style-type: none"> •levels of knowledge •attitudes/belief systems •confidentiality •motivation levels 	<ul style="list-style-type: none"> •invitation to RAG •referral to Services

Related communities of ‘co-researchers’	Role/ Responsibility	Tools & Resources	Challenges	Interventions
HIV clinicians (physicians, nurse specialists, research nurses)	<ul style="list-style-type: none"> •provision of data •analysis of data •participate in developing user involvement forum 	<ul style="list-style-type: none"> •patients’ trust •clinic setting •opportunities 	<ul style="list-style-type: none"> •attitudes •power relations •overcoming perceived threats to professionals’/ boundaries 	<ul style="list-style-type: none"> •transparency of information •invitation to RAG •increase visits to the clinic •more informal contacts

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