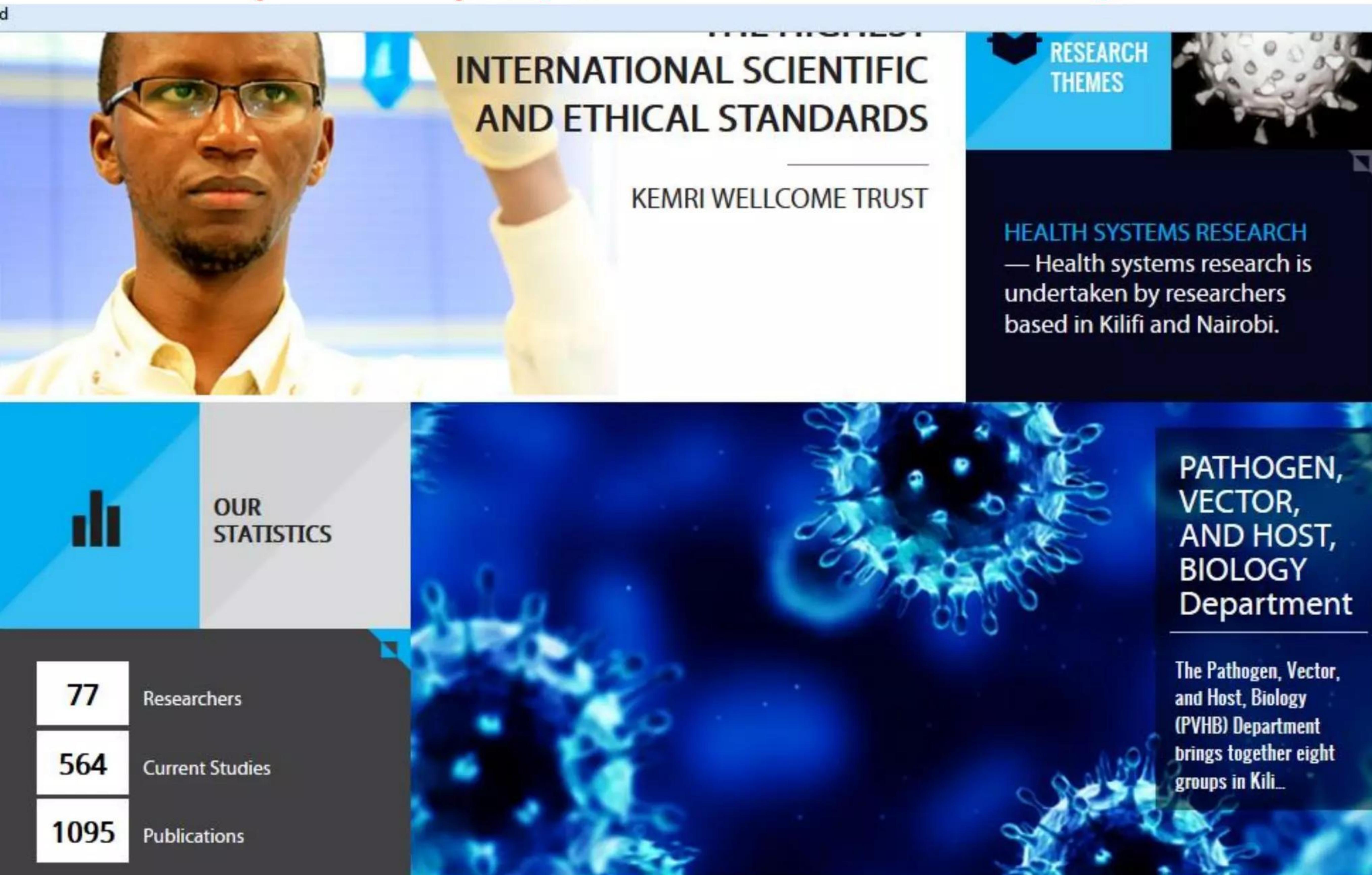


Household decision-making dynamics for research, and implications for informed consent

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KEMRI –Wellcome Trust Research Programme (KWTRP) <http://www.kemri-wellcome.org/>



The image is a screenshot of the KEMRI-Wellcome Trust Research Programme (KWTRP) website. The header features the text 'KEMRI –Wellcome Trust Research Programme (KWTRP) <http://www.kemri-wellcome.org/>' in red. Below the header is a large banner with a portrait of a man in a white shirt and glasses, and the text 'INTERNATIONAL SCIENTIFIC AND ETHICAL STANDARDS' and 'KEMRI WELLCOME TRUST'. To the right is a 'RESEARCH THEMES' section with a COVID-19 virus image and a 'HEALTH SYSTEMS RESEARCH' section. The main content area features a blue background with a glowing blue virus model and sections for 'OUR STATISTICS', 'PATHOGEN, VECTOR, AND HOST, BIOLOGY Department', and a sidebar with researcher and publication statistics.

INTERNATIONAL SCIENTIFIC AND ETHICAL STANDARDS

KEMRI WELLCOME TRUST

RESEARCH THEMES

HEALTH SYSTEMS RESEARCH

— Health systems research is undertaken by researchers based in Kilifi and Nairobi.

OUR STATISTICS

77 Researchers

564 Current Studies

1095 Publications

PATHOGEN, VECTOR, AND HOST, BIOLOGY Department

The Pathogen, Vector, and Host, Biology (PVHB) Department brings together eight groups in Kili...



**The context in
which this work
was based**

Relevant key concern

- *Excessive reliance has been placed on international declaration to define what is ethical, but declaration, like constitutions, need to be interpreted*

[Benatar and Singer 2000](#)

- Challenges everywhere; especially where strong inequities in resources, power and information



INFORMED CONSENT

One theme from my broader study

- *How do interactions between fieldworkers and research participants in community based studies influence study participation?*
 - Amount and nature of interactions
 - Challenges fieldworkers (FWs) faced
 - If and how resolved, and FW roles in resolving them

Mixed method approach:

- Qualitative – in 2 case studies
- Quantitative survey - 362 households (HH)
- review of HR documents

Context: typical household decision making dynamics



- Extended and nuclear families (Molyneux 2002; Parkin 1990)
- Largely patrilineal society,
 - Severe consequences for wives for disobeying husbands and HHH
- Also exceptions: with increase in education, income, and out-migration

Who made decisions about research participation?

- Normative gender roles:
 - Still pronounced role of male household members (head) involvement,
 - Consideration of how research participation might affect normative gender roles
- Other factors included:
 - Responsibility for bearing risks : - Risks of the study, of being involved in KEMRI-WT activities
 - Type, level and distribution of study benefits,
- Leading to considerable time in **consultations and negotiations** for research-related decisions
 - However, differences across HH on who was consulted and whose decision counted the most

Differing (discordant) research decisions:

- Women and minors decisions often not considered, they found other ways to influence/subvert decisions

“It’s the woman [to make decision], she is the one who carried the child and also struggled to give birth, the man just gave the seeds and then went to drink mnazi [local brew] (laughter) ...” (Pax2, female, CSB/FGD13).

- Buy-in from other household members
- Subtle subversion

- Men appeared to recognise the power of women (and others) to choose how and when to participate in research, but appeared unable to do anything about it

“If the father wants the child to join [the study] but the mother doesn’t want that, the child won’t go...and there is nothing you can do about it... you can chase her away, but then will you cook for the children?” (Pax1 male CSB/FGD15).

Not saying yes or no to research participation...

...and have “credible” reasons for dodging

Why?

- safeguard important relations and avoid conflicts within households, with FWs, with researchers, and with KEMRI-WT;
 - Being polite,
 - masking genuine refusal (e.g. not openly disobey HH head
 - masking research participation ('silent participation')
 - Time to gain buy-in from the rest of the families
 - Handling 'unfounded' fears of other household members

Participation on own terms; continued access to study benefits; avoid unpopular procedures (subtle power).

The dilemmas for Fieldworkers

- Whose decision to consider (household head, majority, senior members?) – the study SOPs? Culturally accepted norms?
 - how to avoid conflicts while respecting decisions
- Prioritise the participants or researchers' needs and preferences?
- What really are researchers' real preferences:
 - Yes/no/three visits
 - Avoid damage to within HH relations and with researchers (and to studies) and KEMRI-WT
 - Maintain numbers and study targets

Reflecting on guidelines and contexts

- One set of complexity in interpreting ethical guidelines - influence of important relations on research choices about – and on individual autonomy
- sensitivity to contextual differences –how can these be taken account of? How much flexibility? Potential for unanticipated perverse outcomes?
- Other approaches to inform gap between theory and practice?

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