

# Qualitative Research in TB Dx

## How can it improve product design & implementation?

Nora Engel  
Assistant Prof Global Health  
Maastricht University

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McGill Summer Institute in Infectious  
Diseases and Global Health  
[n.engel@maastrichtuniversity.nl](mailto:n.engel@maastrichtuniversity.nl)



# 1. Primer in qualitative research

# Qualitative research =?

Not one clear definition. Usually definitions have these elements:

- “Qualitative researchers study **things and social relations** in their **natural settings** attempting
- to make sense of, or interpret phenomena in terms of the **meanings** people bring to them [and how they **act** upon them].
- The word ‘qualitative’ suggests an emphasis on ***processes and meanings***
- that are not rigorously examined or measured in terms of quantity, amount, intensity, or frequency (“numbers”).
- Most analysis is done with **words**.” (Leys, 2003b, p.323)

Type of research questions	Strategy	Paradigm	Method	Other data sources
<b>Meaning questions</b> – eliciting the essence of experiences	Phenomenology	Philosophy (phenomenology)	Audiotaped “conversations”; written anecdotes of personal experiences	Phenomenological literature; philosophical reflections; poetry; art
<b>Descriptive questions</b> – of values, beliefs, practices of cultural group	Ethnography	Anthropology (culture)	Unstructured interviews; participant observations; field notes	Documents; records; photography; maps; genealogies; social network diagram
<b>Process questions</b> – experience over time or change, may have stages and phases	Grounded theory	Sociology (symbolic interactionism)	Interviews (tape-recorded)	Participant observation; memoing; diary
<b>Questions</b> regarding verbal interaction and dialogue	Discourse analysis	Semiotics	Dialogue (audio/video recording)	Observation; field notes

(Denzin & Lincoln, 1994)

# Data collection techniques

- Interviews (semi-structured, structured),
  - Focus group discussions,
  - Participant observation,
  - Text/discourse analysis,
  - Conversation/video analysis
- Assess data collection: describe context & structure of the situation, record observations of participants, assess quality of the data, evaluate usefulness of questions, acknowledge areas of difficulty
- → going back & forth between data and questions and theory

# Data collection questions asked in qual. methods

- Aim: to elicit participants' perspective, experience, meaning, practices, processes and reason for action
- **Open-ended**
  - Tell me what it was like when you first had symptoms
  - Tell me about getting a diagnosis
- **How questions:** examples rather than opinions
  - Angotti et al., 2010 how do HIV testing counselors translate global guidelines?  
don't ask: do you understand the guidelines, but what are your experiences with counseling/testing → examples, practices, stories, iconic events, keep close to real life
- **Follow-up questions: probe** (when? where? why?)
- Different questions for different participants, no set order, questions are likely to change throughout the research

# Focus group discussion

- **Introduction** of participants, general purpose of meeting & ground rules of discussion
- **Predisposition phase:** to establish what particular problems participants experience or define with regard to main topic
  - Introduce topic of discussion
  - Short silence in which participants write down ideas
  - Individuals present ideas
  - Summary of ideas
- **Group discussion** on the questions you prepared between leader and participants as well as among participants
- Summarize results
- Short survey among participants (do they have comments, anything to add)



# Qual research on barriers to POCT (2012-2014)

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## Aim:

Identify the biggest barriers to successful implementation of point-of-care test (POCT) programs in different settings (South Africa & India)

- Home, Community, Clinic, Peripheral Laboratory & Hospital
- Focus on major infectious diseases (HIV, TB, Malaria, Syphilis, Hep.)

*Where in public/private, urban/rural settings is POCT happening?  
if not, why is it not done?*

## Team India (IPH):

Mamata Patil

Vijayashree Yellappa

Gayatri Ghanesh, Devadasan

## Team South Africa:

Malika Davids (Keertan Dheda's team, UCT)

Nadine Blankvoort (UM)

PIs: Madhukar Pai (McGill) & Nitika Pant Pai (McGill)

Funding: BMGF

# Diversity of target product profiles, users, and settings (Pai et al., 2012)

TPP1: HOME



## Self-testing (home-based)

User: Lay person  
Device: RDT (pregnancy-type) or dipstick  
Purpose: Self assessment and referral

TPP2: COMMUNITY



## Testing in the community by health workers

(e.g. village workers, paramedics)  
User: Minimally trained health worker  
Device: RDT  
Purpose: Triage and referral

TPP3: CLINIC / HEALTH POST  
(Out-patient)



## Testing in the clinic by healthcare providers

(e.g. doctors, nurses)  
User: Clinic staff  
Device: RDT, handheld instruments  
Purpose: Diagnosis and treatment

TPP4: PERIPHERAL LAB



## Testing in the peripheral laboratory

User: Lab tech  
Device: RDT, molecular tests, ELISA, microscopy, etc  
Purpose: Diagnosis treatment monitoring

TPP5: HOSPITAL  
(In-patient)



## Testing of in-patients in hospitals

(e.g. ER, OR, ICU)  
User: Hospital staff  
Device: RDT, molecular, smears, etc.  
Purpose: Diagnosis treatment monitoring

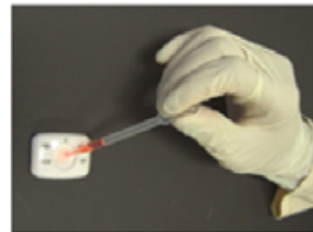
*Simplest*



HIV self-testing



Malaria, HIV, dengue



HIV, malaria, syphilis, dengue, Strep A



TB, HIV, malaria, HBV, C.diff, CD4, HCV, MRSA, flu, UTI, viral loads, etc.



TB, HIV, malaria, HBV, HCV, flu, MRSA CD4, Strep A, C.diff, etc.

*Relatively sophisticated*

# Study Design - ethnographic

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**Semi-structured interviews** with healthcare providers (doctors, nurses, specialists, trad. healers, informal providers), patients, community health workers, test manufacturers, laboratory technicians, managers, policy-makers

**FGDs** with groups of patients, CHWs, nurses, laboratory technicians on major challenges in diagnosing in their specific setting

- **South Africa: 100+ interviews, 7 FGDs** in Cape Town, Durban & Eastern Cape
- **India: 74 interviews, 13 FGDs** in Bangalore & a rural district in Karnataka

**Topics explored:** diagnostic processes & challenges therein, understanding of diagnosis, visions of an ideal test

# Data analysis

- No 'right way', yet: systematic approach
  - Careful reading of material, make notes, code, reflect (keep framework, questions in mind)
  - Look for patterns, regularities, recurrent themes
  - Label categories, use overarching concepts
  - Look for relations between concepts, comparisons, contrasts
  - Relate back to theoretical framework, adapt theory
- Theory based (deductive) – building theory (inductive)
- Analysis (incl. hypothesis development) and data collection go hand in hand

# Coding

B. Dierckx de Casterlé et al. / International Journal of Nursing Studies xxx (2011) xxx-xxx

The screenshot shows the ATLAS.ti software interface. The main window displays a text document titled 'P23: Report 11.ttf' with the following content:

21.10.2003

Vo Tanh

5 fishermen (Mr. Diep)

Some 500 fishing boats with many big trawling (24000 \$). It takes them government loans. The million VND (???)

They use mainly dragn is a law that prohibits break the law and go fishing trips to fishing fishing trip last for abo

Fish catch is down from 100% 10 years ago to 30%.

In November people go fishing for lobster fry and can make up to 50 million VND a night.

Some people own small boats and go fishing with gill nets.

"Every job in town is related to fishing."

Their vision is that the government builds a harbour to protect their boats against the rainy season storms and the big waves. Besides that it would ease to load and unload the boats, which takes long time and costs substantial amounts of money. Then they would even invest in bigger boats.

I've been invited on a fishing trip for 4 days after TED New

The Code Manager window is open, showing a list of codes:

- Community organization to protect coastal resources
- Conflicts between fishermen and authorities
- Corruption
- Crab fishing
- Culture and values
- Decline of coastal fishery resources
- Decline of traditional fishing methods/gear net

The list of codes on the right side of the interface includes:

- Off shore fishing/Dragn net
- Loans and banking
- Income
- Fishing regulations/fishing area
- Illegal fishing/Dragn net
- Off shore fishing/Dragn net
- Decline of coastal fishery resources
- Local INRM approaches/Off shore fishing development

was, van het moment dat ge het onderwerpen probleem

was, van het moment dat ge het onderwerpen probleem  
vraag naar euthanasie weg. Maar meestal is  
arts mij roept "Nu, het moet geen arts zijn, het  
ie zijn. Het mag ook een verpleging zijn. (Eum  
gevalleke verplegen. Dat was ook heel recent.  
huisdokter mij gebeld omdat de familie daar  
ad en hij zei "Ik ben daar niet in beslagen. Wilt  
if gaan uitleggen?" En dat heb ik dan gedaan  
arts. Dat is in de thuisituatie. Maar eum ik zeg  
genlijk nogal zeer strikt wat er volgens de wet  
En ik vind het heel belangrijk dat men de  
er hoort. Dat ge kunt (nadruk) uitleggen dat er  
e dingen zijn. Dat er iets is tegen de pijn, dat er  
onrustigheid. En dat men heel bewust kan  
n als men bepaalde medicamenten gebruikt. En  
and verliest enzo want daar hebben heel veel  
van. En als mensen dan toch uiteindelijk bij  
ven naar euthanasie en die is ook terecht gezien  
stand, dan vind ik dat men dat moet volgen of  
lijk moet zijn. Ik heb heel veel respect voor de  
zegt "Nee, ik doe dat niet". Ik heb geen respect  
e zeggen "Ik ga u helpen" en die het  
et doen. Dat vind ik heel erg. Daar heb ik echt  
speet voor en zo lopen er ook nogal wel wat  
vind ook niet dat ge iedereen op dezelfde  
t krijgen. Binnen een verpleegteam die  
d worden met zo'n geval, bestaan nogal wat  
e moet het kunnen uitleggen en ge moet respect  
iedereen zijn mening maar ge gant nooit een  
pe op een lijn krijgen daarvoor. En daar moet  
in praten. En er moet tijd voor genomen  
gezien mijn functie en gezien mijn statuut in het  
n ik dat. Ik kan mij dat permitteren om daarbij  
twee uren, drie uren als het moet zijn. Maar dat  
vind ik. Ook voor die mensen omdat één of  
sen daarna verder moet. En als ge daar uw tijd  
en ge hebt heel veel dingen niet aangeraakt  
ken, dan gaat het voor die mensen achteraf zeer  
Dat is mijn persoonlijke visie daarover. Dus, ge  
e tijd nodig voor dat aan te raken. En bepaalde  
n meer als een keer besproken geweest zijn.

→ geïnformeerd v.  
nettel. proced.  
palliat. filter  
→ alternatieven

arts - kritische  
advise.  
duidelijkheid!  
is belangrijk.

praten  
tijd nemen.  
concl. in Hv be  
als in fam. ab  
in pt.

Daar:  
verwerking

# Excerpt CHW FGD, project POC testing in South Africa

- *INT: “Ok, let’s go to a next one. So we have here, patient not willing to work with the health team.”*
- *CHW 2: “Sometimes we get that... they come into the clinic, they come to get help, but when they there, because of that long period they needed to wait, when they eventually get to a health worker, then that patient doesn’t want to work with you. You can ask questions, that patient is just sitting there not answering you. The patient is getting impatient, the patient is getting rude, all those kind of things. These are things that we are dealing with in these clinics because some of the staff is even overworked. And now you get this patient and you are already overworked; now you even as the health member, you don’t want to work with that patient because you tired already. You’ve already seen 20 people whereas we are supposed to see 10 to 12 per day. Now you are already at 20, 22, and 30. Now this one comes and you not even introducing yourself to that patient, just like, ‘yes, and why you are coming?’ and that patient is not going to work with you, not at all.”*

# Analysis: Developing themes, narratives & descriptions (Rubin & Rubin, 2005)

- **sorting & summarizing:** write a summary of the data units for each code, list main points (no judgment) → what seems to be missing? why? what is present? why?
- **sorting & ranking:** within one code summary, some aspects of a problem/phenomenon might be considered minor other major → why? who is affected how? which ones are addressed?
- **sorting & comparing:** sort again, now by source and see whether different actors highlight concepts, themes, events in different ways → look for differences & commonalities, why?
- **weighing & combining:** combine different views/definitions of the same concepts, or combine explanations of processes from different actors, weigh contrasting versions of same process (back up with additional sources, look for contradictions, credibility)
- **integrate, check, modify:** check summary themes against other coded data, double check if you side with one group, make sure you are able to document every step if you identified causal relations

# Quantitative and qualitative methods

## Quantitative methods

useful for generating numerical findings  
for statistical manipulations

- Statistical generalizations
- Predictions
- estimations of causal explanations
- Hypothesis-testing

## Qualitative methodology

useful for understanding processes,  
context & considering experiences or  
perspectives

- Analytical generalizations
- Setting research questions & hypotheses
- Interpreting or explaining numbers & causal events
- Theory-building

## Treatment as diagnosis and diagnosis as treatment: empirical management of presumptive tuberculosis in India

A. McDowell, M. Pai

McGill International TB Centre & Department of Epidemiology  
University, Montreal, Quebec, Canada

**BACKGROUND:** Mismanagement of TB is a concern in the Indian private sector, and empirical management might be a key contributor.

**OBJECTIVE:** To understand factors associated with empirical diagnosis and treatment of presumed TB in India's private sector and examine their effects on TB outcomes.

**DESIGN:** In this ethnographic study, 110 private practitioners of varying qualification who interact with TB patients (90 in Mumbai and 20 in Patna) were interviewed, and a subset was observed while providing clinical care. Interviews and observations were used to identify indicators of empirical diagnosis and treatment.

**RESULTS:** All non-specialist practitioners began a patient on antibiotic treatment, especially quinolones, for persistent symptoms.

Ethnography: observations and 110 interviews with private practitioners:

Drivers of empirical treatment:

- Using medications as diagnostic tools
- Providing quick relief of symptoms
- Keeping cost low
- Uncertainty about presentation of TB
- Effects of broad spectrum antibiotics on TB symptoms
- Uncertainty about accuracy of TB tests



# Why are inaccurate tube widely used in the Indian sector? A root-cause ana

Szymon Jarosławski <sup>a</sup>, Madhukar Pai <sup>b,\*</sup>

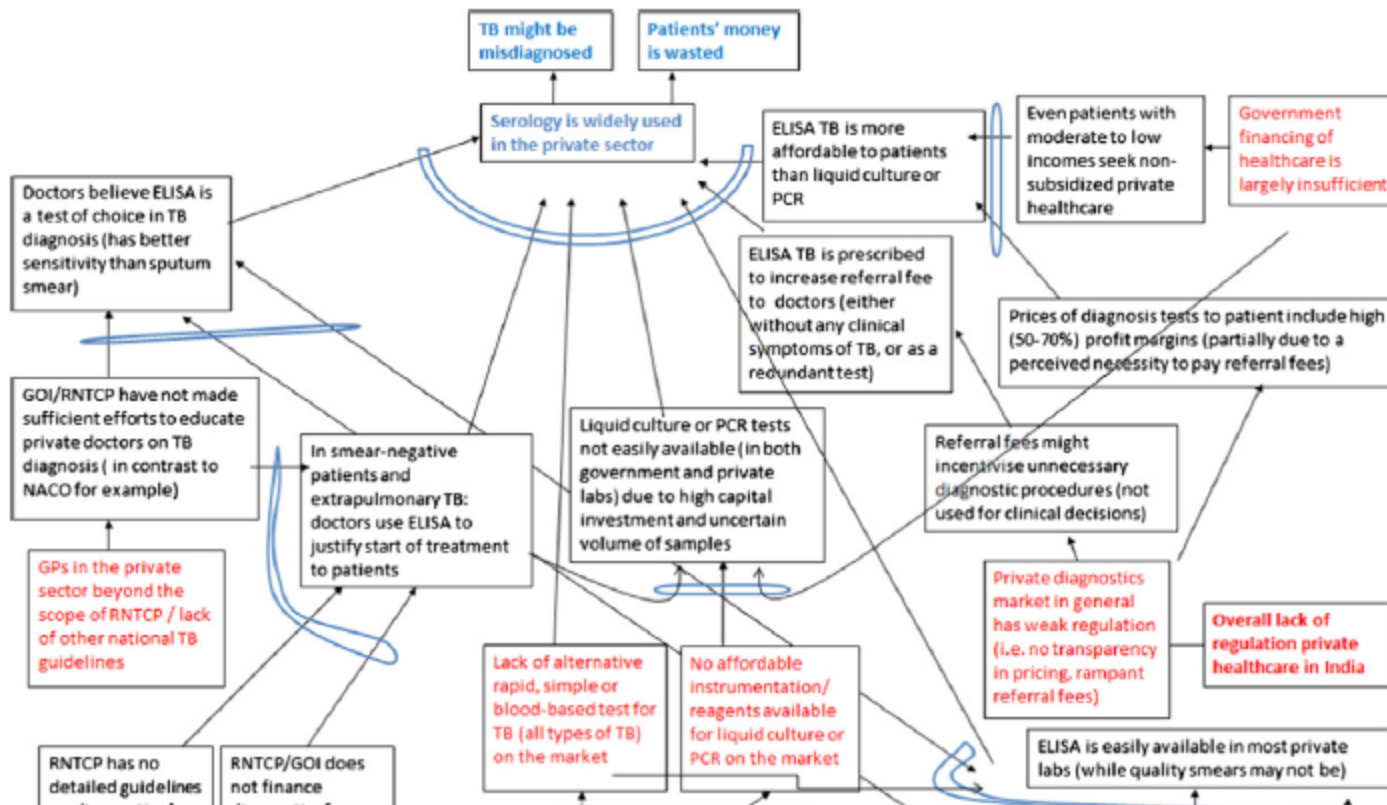
<sup>a</sup> *Institute of Bioinformatics and Applied Biotechnology, Bangalore, India*

<sup>b</sup> *McGill University, Montreal, Canada*

**Example**



Face-to-face/ telephone interviews with 41 stakeholders: private doctors, hospital laboratory staff, private stand-alone laboratories, test distributors, test manufacturers, hospital doctors, NGOs  
→ Questions focused on: reasons for use of ELISA, interests of stakeholders, cost, experiences



→ Qual research helps you to understand & navigate through complex environments



(Jaroslowski & Pai, 2011)

# Potential of qual research to support TB Dx underused (Engel & Pai, 2013)

- Diagnosis as **categorization**\*:
  - Nichter, M. 1994. Illness semant the Philippines
  - Bennstam, A.L., et al 2004. Per
- **Social process** of diagnosis:
  - Watkins, R. E. & Plant, A. J. 200
  - Rintiswati, et al. 2009. Jour
  - Sagbakken, M., et al. 200
  - Ababa, Ethiopia
  - Murray, E. J., et al. 2013. High l
  - impetus for tuberculosis diagnos
- **Consequences** of diagnosis
  - Ngamvithayapong-Yanai, J., et al. 2005. "If We Have to Die, We Just Die": Challenges and Opportunities for TB and HIV/AIDS Prevention and Care in Northern Thailand
  - Isaakidis, P., et al.. 2013. 'I cry every day': experiences of patients co-infected with HIV and multidrug-resistant tuberculosis. *Trop Med Int Health*, 18(9), 1128-1133.

Sagbakken et al, 2008: how symptoms of TB are perceived and managed → explain diagnostic delay, **Interviews & focus groups** at different treatment stages to examine (a) symptom identification and interpretation; (b) interaction with health personnel; (c) social support factors; and (d) financial and structural barriers  
→ Health personnel confirms health beliefs (sin, punishment) to interact with patients →→ reinforce stigma & blaming

\* Diagnosis as categorisation, a social process & as a label with consequences (Jutel & Nettleton, 2011)

## 2. Qual research to help inform product design

# Qualitative research is useful to..

Help inform Dx **product design**:

- ..support **user involvement**
- ..support **needs assessment** (defining the problem, diagnostic eco-systems, markets and policy environment)
- ..support **clinical trials** (experience of trialists)
- ..support **interpretation** of quantitative/RCT results

Help inform Dx **implementation**:

- ..understand **social context** of biomedical interventions → improve **implementation**
- ..answer questions about **technology-in-use**

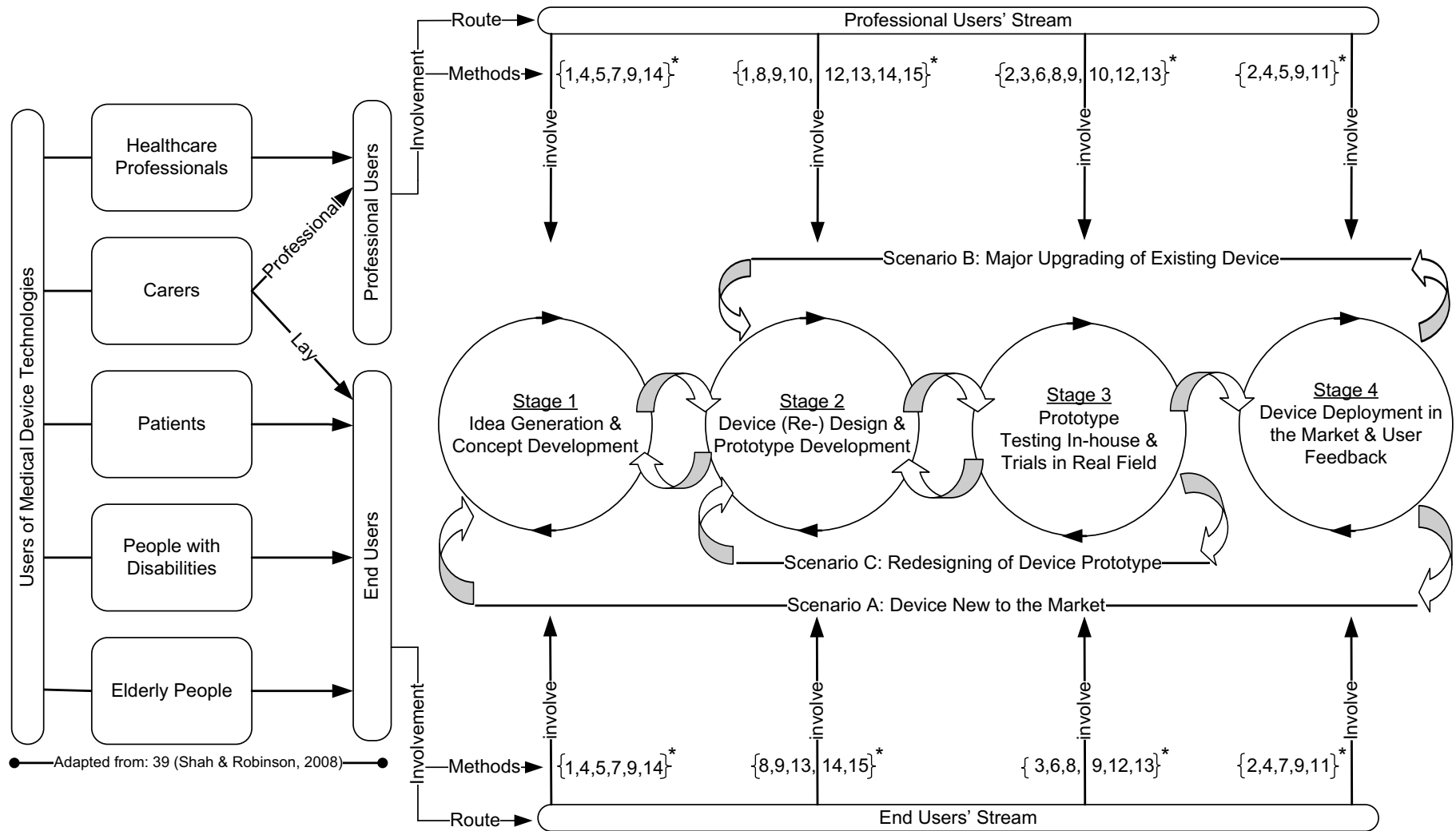
# Qualitative methods in medical device design (Shah et al 2009)

- End-users discard devices that do not fulfill their personal expectations
- Competing perspectives of developers, users, manufacturers, regulators

User involvement necessary:

- Concept stage: interviews, focus groups, brainstorming sessions & users-producers seminars
- Design stage: interviews, usability tests, & users' feedback
- Trials stage: usability tests, interviews, & discussion at testing
- Deployment stage: ethnography, interviews & surveys

# User involvement in medical device design (Shah et al., 2009)



\*{User Involvement Methods}

1. Brainstorming sessions 2. Cognitive walkthrough 3. Discussion with users 4. Ethnography 5. Expert users meetings

6. First human use 7. Focus groups 8. In vitro tests 9. Interviews 10. Observations 11. Surveys 12. Think aloud method

13. Usability tests 14. Users - producers seminars 15. User feedback

Original Paper

Example study using  
Shah et al. framework of  
user involvement

## The Development of a Mobile Monitoring and Feedback Tool to Stimulate Physical Activity of People With a Chronic Disease in Primary Care: A User-Centered Design

Sanne van der Weegen<sup>1</sup>, MSc; Renée Verwey<sup>1,2</sup>, RN, MSc; Marieke Spreeuwenberg<sup>1</sup>, PhD; Huibert Tange<sup>3</sup>, MD, PhD; Trudy van der Weijden<sup>3</sup>, MD, PhD; Luc de Witte<sup>1,2</sup>, MD, PhD

<sup>1</sup>CAPHRI School for Public Health and Primary Care, Department of Health Services Research, Maastricht University, Maastricht, Netherlands

<sup>2</sup>Research Centre Technology in Care, Zuyd University of Applied Sciences, Heerlen, Netherlands

<sup>3</sup>CAPHRI School for Public Health and Primary Care, Department of General Practice, Maastricht University, Maastricht, Netherlands

Martin and Barnett *BMC Medical Informatics and Decision Making* 2012, **12**:74  
<http://www.biomedcentral.com/1472-6947/12/74>



Medical Informatics & Decision Making

**RESEARCH ARTICLE****Open Access**

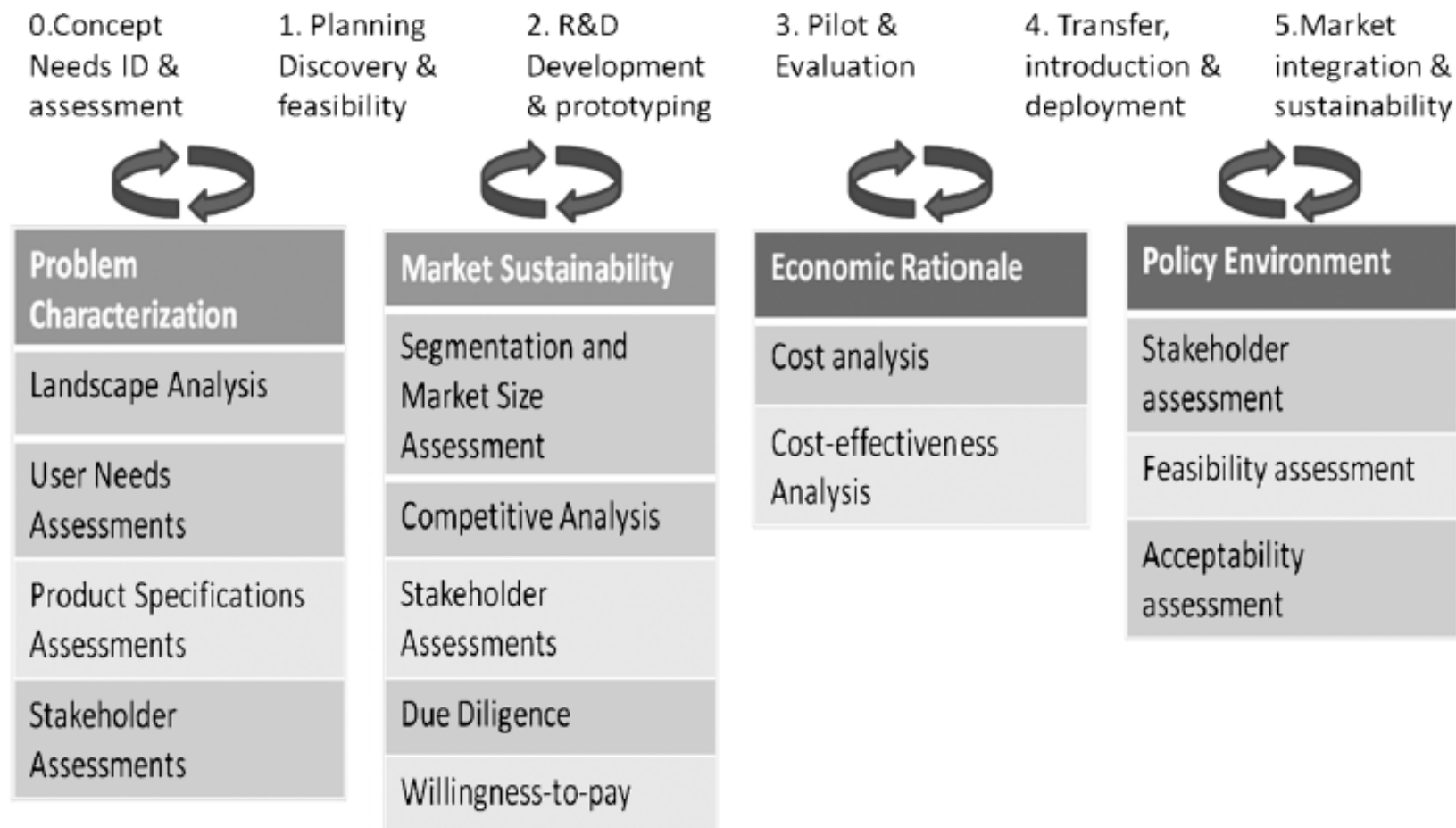
## Integrating the results of user research into medical device development: insights from a case study

Jennifer L Martin<sup>1\*</sup> and Julie Barnett<sup>2</sup>

Provides recommendations on  
how to overcome challenges in  
integrating user research

# Clinical Needs Assessment for POC R&D (Weigl et al., 2012)

## CNA-Guided Product Development



Needs assessment through FGDs with clinicians, opinion leaders, and public health professionals on STI POCs

# Perceptions of an Ideal Point-of-Care Test for Sexually Transmitted Infections – A Qualitative Study of Focus Group Discussions with Medical Providers

Yu-Hsiang Hsieh<sup>1\*</sup>, M. Terry Hogan<sup>2</sup>, Mathilda Barnes<sup>2</sup>, Mary Jett-Goheen<sup>2</sup>, Jill Huppert<sup>3,4</sup>, Anne M. Rompalo<sup>2</sup>, Charlotte A. Gaydos<sup>2</sup>

**1** Department of Emergency Medicine, Johns Hopkins University School of Medicine, Baltimore, Maryland, United States of America, **2** Division of Infectious Diseases, Johns Hopkins University School of Medicine, Baltimore, Maryland, United States of America, **3** Division of Adolescent Medicine, Cincinnati Children's Hospital Medical Center, Cincinnati, Ohio, United States of America, **4** Division of Adolescent Medicine, the University of Cincinnati College of Medicine, Cincinnati, Ohio, United States of America



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*Sex Health*. 2013 December ; 10(6): 541–545. doi:10.1071/SH13047.

## Point-of-care tests for sexually transmissible infections: what do 'end users' want?

Anne M. Rompalo<sup>A,D</sup>, Yu-Hsiang Hsieh<sup>B</sup>, Terry Hogan<sup>A</sup>, Mathilda Barnes<sup>A</sup>, Mary Jett-Goheen<sup>A</sup>, Jill S. Huppert<sup>C</sup>, and Charlotte A. Gaydos<sup>A</sup>

<sup>A</sup>Department of Medicine, Johns Hopkins School of Medicine, Baltimore, MD 21287, USA

<sup>B</sup>Department of Emergency Medicine, The Johns Hopkins School of Medicine, Baltimore, MD 21287, USA

<sup>C</sup>Division of Pediatric and Adolescent Gynecology, Cincinnati Children's Hospital Medical Center, Cincinnati, OH 45229, USA

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Needs assessment through FGDs with patients

# Design ethnography

- Observation of device in use
- identify challenges, discover latent needs, document usability, workflow, collect design criteria inputs, time metrics, personnel interaction, and emotional state (Hägen, 2012; Ball & Omerod, 2000)
- Challenge: to translate observational analysis into actionable design criteria (Kjeldskov & Stage, 2012)

## Participatory Design

- Enable participation of users through collaborative design processes (Simonson & Robertson 2013: Lucy Suchman; Maggie Mort)



Source: [www.farmpd.com](http://www.farmpd.com)

# Qualitative methods in Health Technology Assessment

(Reuzel & van der Wilt, 2000)



‘Is this diagnostic technology better than the technology currently used?’

- usually with **accuracy studies**
- some argue experience and clinical judgment should also be evaluated (decision analysis) and impact on patient outcome (Mrus, 2004)

→ strong **focus on cost-effectiveness & effects** (does the technology live up to my expectations?)

→ **less attention to *how* intervention works: complex context, organizational & support systems, legal, ethical, psychological, societal aspects**

→ → **qual methods can help: answer how & why questions**

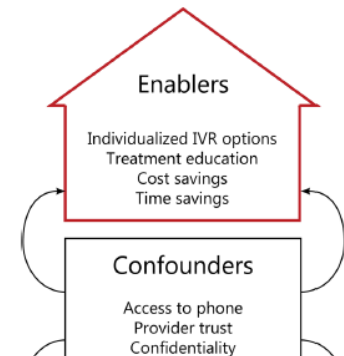
(f.ex. goal-free evaluation, responsive evaluation, illuminative evaluation, pluralistic evaluation, fourth generation evaluation) (Murphy et al 1998)

ORIGINAL PAPER

## A Qualitative Evaluation of the Acceptability of an Interactive Voice Response System to Enhance Adherence to Isoniazid Preventive Therapy Among People Living with HIV in Ethiopia

Amrita Daftary<sup>1,2,3</sup> • Yael Hirsch-Moverman<sup>1,4</sup> • Getnet M. Kassie<sup>5</sup> • Zenebe Melaku<sup>1</sup> • Tsigereda Gadisa<sup>1</sup> • Suzue Saito<sup>1,4</sup> • Andrea A. Howard<sup>1,4</sup>

30 qual interviews within an implementation science cluster-randomized trial that evaluated interventions to enhance IPT adherence



JMIR MHEALTH AND UHEALTH

Iribarren et al

[Original Paper](#)

### Qualitative Evaluation of a Text Messaging Intervention to Support Patients With Active Tuberculosis: Implementation Considerations

Sarah J Iribarren<sup>1</sup>, RN, PhD; Katherine A Sward<sup>2</sup>, RN, PhD; Susan L Beck<sup>2</sup>, PhD, APRN, FAAN; Patricia F Pearce<sup>3</sup>, MPH, PhD, FNP-BC, FAANP, FNAP; Diana Thurston<sup>4</sup>, PhD, APRN; Cristina Chirico<sup>5</sup>, MD, MPH

Workflow observations over 115d, text message content analysis & stakeholder input to understand issues encountered during pilot-testing to inform future implementation in a larger-scale trial

### 3. Qual research to help inform implementation

# Qualitative research is useful to..

Help inform Dx **product design**:

- ...support **design process** of medical device
- ...help in **explorative** stage of a research project: clarify/set research questions, conceptualize, generate hypotheses
- .. Support **clinical trials** (how trialists **experience** & why they stop to participate, improve trials in real time)
- .. support **interpretation** of quantitative/RCT results → answer **why & how** questions in **evaluation of interventions**

Help inform Dx **implementation**:

- ..understand **social context** of biomedical interventions → improve **implementation**
- ..answer questions about **technology-in-use**

# Barriers to POCT: Major difference in diagnostic process

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## South Africa:

samples/reports/materials/communication travel between laboratories and providers via courier, fax, internet, telephone, paper record, SMS

## India:

patients travel between laboratories and providers as carriers of samples, of reports, communication between providers, history, results

→ Major challenges to POC are linked to this difference

→ → private sector responds to these challenges:

**SA:** optimize transportation of samples & communication between providers

**India:** optimize coordination between providers (opening hours, kick-backs/tie-ups, settings nearby)



Montreal | 21.6.2017

Nora Engel



# Major difference in diagnostic process

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## South Africa:

samples/reports/materials/communication travel between laboratories and providers via courier, fax, internet, telephone, paper record, SMS

## India:

patients travel between laboratories  
reports, communication

→ Qual research helps you to understand the context, meaning and materiality of complex diagnostic eco-system

→ Major challenge to address this difference

→ → private sector responds to these challenges:

**SA:** optimize transportation of samples & communication between providers

**India:** optimize coordination between providers (opening hours, kick-backs/tie-ups, settings nearby)

# Where does POC testing happen in India? (Engel, et al. 2015, BMC

Health Serv)

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- successful POC testing **hardly** occurs in any of the five settings
- Available rapid tests currently **not translated into rapid treatment decisions**
- Most of the rapid tests are used in clinic and hospital labs → too long TAT  
→→ patients have to come back next day
- In settings with shorter TAT, rapid tests are **unavailable** (public) or their **cost is too high** (small private labs)
- Private providers find **alternative measures** to ensure the POC continuum with older testing methods (coordination, kick-backs)

# Diagnosing in the community



**CHWs:** symptom screening, Malaria slide & sputum sample, and referrals;

**ANMs:** pregnancy, glucometer/urine albumine & sugar, HB with Sahli's haemoglobinometer (Malaria RDT if endemic)

- ❖ Stock-outs and shortages of funds
- ❖ Referrals to clinic?: onus is on patient
- ❖ CHWs struggle to convince & support patients → human resources, transportation, safety constraints, poor services at PHC



# Diagnosing at public clinics



**small PHC labs:** Malaria smears, BP, HBsAg card, Dengue NS1 card, Syphilis card, (AFB), glucometer, urine dipstick, pregnancy, HIV, urine sugar (Benedict)

- ❖ Limited funds for rapid tests
- ❖ Available rapid tests done in small labs
- ❖ → too long TAT (docs & labtechs have workload, HR & infrastructure constraints), drives empirical treatment



# Diagnosing at private clinics: ensuring POC continuum with older testing methods (coordination, kick-backs) (Engel, et al. 2015, BMC Health Serv)

**GPs:** pregnancy, glucometer

- ❖ Ensure POC with lab nearby (adjusted opening hours, kick-backs)
- ❖ Prefer older methods over rapid tests (too expensive, doubt accuracy)
- ❖ Avoid losing patients, start emp. Rx

**Small labs:** urine dipstick, sugar, typhoid slide, blood grouping, Malaria smear, HB; some Dengue, Syphilis, HEP, Mantoux, renal & lipid function (exp), no AFB

- ❖ cannot afford rapid kits
- ❖ Small volumes → ensure quick TAT with older, cheaper methods



# Diagnosing in hospitals



**Wards:** glucometer, urine dipstick, pregnancy, HIV, ECG;

**Hospital labs:** use many rapid card tests (Malaria, Dengue, HBsAG, Syphilis, pregnancy, HIV (separate labs))

- ❖ Majority of rapid tests in labs → too long TAT (half a day/next day)
- ❖ HIV & TB testing in different locations → potential for loss to follow-up
- ❖ lack of manpower to interact with lab & to act on results (OPD) → delay



# Major barriers to POCT in India

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1. Relationships: Interaction, coordination & patient-initiative
2. Infrastructure: Material, money & human resources
3. Modified behavior & practices: emp. treatment vs. investigation

# Relationships: Interaction, coordination & patient-initiative

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- More interaction/coordination/cooperation → more likely POCT
- Onus always on patient to get tested & follow-through

**Private sector:** tie-ups/kick backs → ensure POCT, but incentivize malpractice

**Public sector:** lack of cooperation & HR shortage → culture of blame,  
Dysfunctional referrals between centres → delays, loss to follow-up

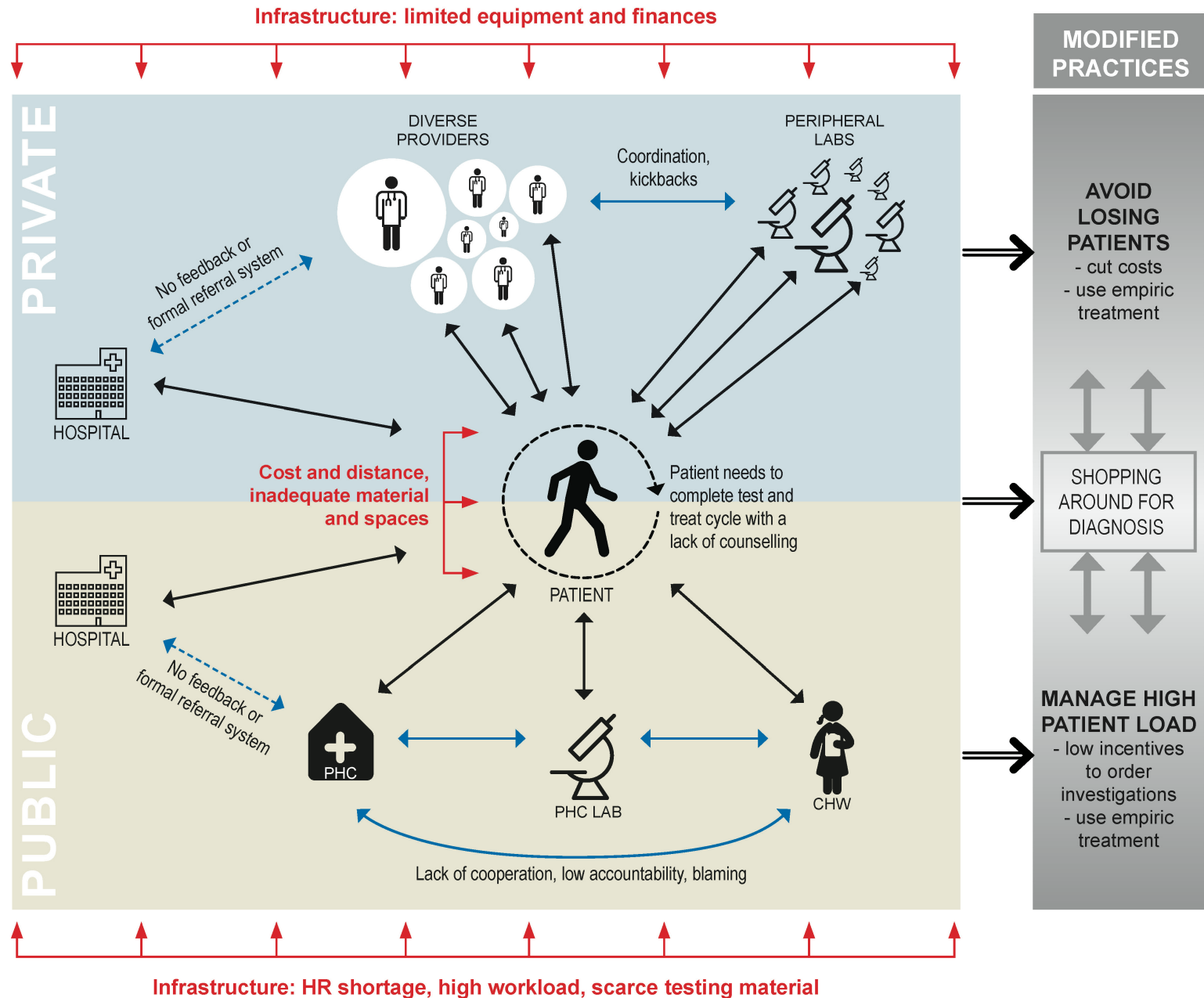
**Patient-provider:** lack of counseling and explaining, neg. results not communicated  
→ patients roam around, lose trust, opt out

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*... it is not as if we are one group, the ANMs [auxiliary nurse midwives] are separate, staff nurses are separate, lab separate, everybody is separate. If we request somebody to help us when they are free they say “we are not lab technicians.” There are so many people working but **nobody is ready to support us.**” (Participant 3, FGD 9 lab technicians)*

*In case of such type of patients [where HIV test is required] we will not disclose them you are affected by this. If the patient is illiterate, he does not understand what we do.. there is no meaning in explaining them. Unless it is positive, we do not disclose. **We will do the test, we will not tell the patient.**”(Private practitioner 5)*

## Barriers to POC testing India (Engel et al., PLoS One 2015)



# Infrastructure: Material, money & manpower

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## Material:

- Poorly equipped lab facilities, lack of tests & consumables, inadequate space & insufficient transport infrastructure for samples & staff
- Poor sample quality (targets)  
→ delays or send patients away

## Money:

- Cost of rapid tests (>2USD is too much)
- Cost to patients to get tested (transport, fees, loss of income, assoc. costs)  
→ Long TATs raise costs further

## Manpower:

- does not match workload, lack of training
- CHWs: irregular & low wages, no transport  
→ backlogs, frustrations, discourages ordering investigations

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Often *we do not get those [test] materials*, [so] we have to send them [the patients] away, refer them to another hospital or they go to private. (medical officer 1)

They send samples because they are *target oriented*. So at the end of each month, (...) doctors, staff, field workers, they refer lots of cases, even if it's not a good [valid] case (program officer 3)

They [medical officers] are loaded with programs, financial work, administrative work, that training, this training, so they will *not have time [for testing patients]*... (program officer 3)

# Modified behavior & practices: emp. treatment vs. investigation

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**Lack of infrastructure** drives emp. treatment (no time, no privacy, no lab)

**No functioning referral system/too long TATs** favor emp. treatment (avoid losing patient)

System relies on patient: providers **make it more attractive to patients:**  
no tests/fast results, instant relief (strong medication), secretly conduct HIV tests

# Why does POC testing hardly occur in India?

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onus is often on the patient to ensure completion of test and treat cycles across homes, clinics, labs and hospitals,  
amidst a multitude of uncoordinated providers  
with divergent and often competing practices  
in settings lacking material, money and manpower.

Barriers don't act in isolation!

**material aspects, socio-cultural relations between actors and diagnostic practices  
are inseparably related**

# Results South Africa: strategies to overcome challenges in HIV testing

(Engel et al., BMC Health Serv 2017)

- overcoming constraints in equipment, spaces, human resources and workload
- actively managing diagnostic processes

## Involved...:

- maintaining relationships
- adapting testing guidelines and practices to stock-outs, to physical space, and to different clients
- turning the test into a tool to reach another aim
- turning the testing process into a tool to enhance adherence



## → Adaptive strategies

- Require work by providers & clients
- fragile and not necessarily sustainable, strategic vs reactive
- Testimony to professional commitment but can compound delays, generate frictions/mistrust
- Clients & providers have different aims of testing: Test results take on new meaning for clients and providers
- Tools can aid/trouble these aims

# Implications for POCT

- ❖ Currently: limits to material/money/HR new tests can rely on
- ❖ Successful POCT assumes functioning relationships!
- ❖ Tests can harm/support these relationships
- How to take such complexity into account when designing POCT programmes?
  - Through such studies! **before, during and after** design and implementation
  - Tackle **jointly the relationships** between providers and between patients and providers, **infrastructure**, testing platforms and adaptive **strategies of dealing with constraints**

# Why is qual research important for you?

Qualitative research will..

- ..help you to **develop better products**: create better fit with local contexts, user needs and support scale-up to different contexts,
- ..support **scale-up & introduction** of existing products (implementation)
- ..**evaluate** what products do to the context

→ **reach out to social scientists & qualitative researchers!!**

(f.i. medical anthropologists & sociologists, design ethnographers, science & technology studies scholars, political scientists)

→ **Join the qual methods course next year!**



Thank You!  
Questions?  
Suggestions?

[n.engel@maastrichtuniversity.nl](mailto:n.engel@maastrichtuniversity.nl)

# Sources qual. research handbooks

- Silverman, D. (2010) Doing qualitative research: a practical handbook. Los Angeles: Sage
- Polit, D. & Beck, C. (2008) Nursing research: generating and assessing evidence for nursing practice; Philadelphia: Wolters Kluwer – Lippincott Williams & Wilkins; 8<sup>th</sup> edition  
free download of the 2003 edition available: Download Nursing Research: Principles and Methods (Nursing Research: Principles & Practice)  
<http://mihd.net/q0enrc>  
Password: econiches
- Janice M. Morse & Lyn Richards (2002). Readme First for a User's Guide to Qualitative Methods. Thousand Oaks, London, New Delhi: Sage
- Kielmann, K., Cataldo, F., & Seeley, J. (2012). *Introduction to qualitative research methodology: A training manual produced with the support of the Department for International Development (DfID), UK, under the Evidence for Action Research Programme Consortium on HIV Treatment and Care (2006-2011).*  
<https://www.rbfhealth.org/sites/rbf/files/Introduction%20to%20Qualitative%20Research%20Methodology%20-%20A%20Training%20Manual.pdf>

# Sources qual. research design

- Maxwell, J. A. (2005). Qualitative Research Design. An Interactive Approach (2nd ed. Vol. 41). Thousand Oaks, London, New Delhi: Sage Publications.
- Creswell, J. (2009) Research design, Qualitative, Quantitative and mixed method approaches London: Sage 3<sup>rd</sup> edition

# Sources data collection & analysis

- Rubin, H. J., & Rubin, I. S. (2005). Qualitative Interviewing: The Art of Hearing Data (2nd ed.). Thousands Oaks, London, New Delhi: Sage Publications.
- Fetterman, D. M. (1998). Ethnography - Step by Step (2nd ed. Vol. 17). Thousand Oaks: Sage Publications.
- Eisenhardt, K. M. (1989). Building Theories from Case Study Research. Academy of Management Review, 14(4), 532-550.
- Eisenhardt, K. M., & Graebner, M. E. (2007). Theory building from cases: Opportunities and challenges. Academy of Management Journal, 50(1), 25-32.
- Gibbs, G. (2007). Analyzing Qualitative Data. In U. Flick (Ed.), The SAGE Qualitative Research Kit. London, Thousand Oaks, New Delhi: Sage Publications.

# Sources analysis & writing up

- Mays, N., & Pope, C. (1995). Qualitative Research: Rigour and qualitative research. *bmj*, 311(6997), 109-112.
- Pope, C., & Mays, N. (1995). Qualitative Research: Reaching the parts other methods cannot reach: an introduction to qualitative methods in health and health services research. *bmj*, 311(6996), 42-45.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77-101.
- Dierckx de Casterlé, B., Gastmans, C., Bryon, E., & Denier, Y. (2012). QUAGOL: A guide for qualitative data analysis. *International Journal of Nursing Studies*, 49(3), 360-371

# Sources Nvivo

Basics of coding: <http://www.youtube.com/watch?v=O9eTvP3E5TE>

Tutorials from NVivo directly:

[http://www.qsrinternational.com/support\\_tutorials.aspx?productid=18](http://www.qsrinternational.com/support_tutorials.aspx?productid=18)

NVivo Getting Started guide

<http://download.qsrinternational.com/Document/NVivo9/NVivo9-Getting-Started-Guide.pdf> NVivo

9

<http://download.qsrinternational.com/Document/NVivo10/NVivo10-Getting-Started-Guide.pdf>

Nvivo 10

# References

- Angotti, N. (2010). Working outside of the box: How HIV counselors in Sub-Saharan Africa adapt Western HIV testing norms. *Social Science & Medicine*, 71, 986-993.
- Ball, L.J., & Ormerod, T.C. (2000). Applying ethnography in the analysis and support of expertise in engineering design. *Design Studies*, 21, 403-421.
- Bennstam, A.L., Strandmark, M., & Diwan, V.K. (2004). Perception of Tuberculosis in the Democratic Republic of Congo: Wali Ya Nkumu in the Mai Ndombe District. *Qualitative Health Research*, 14, 299-312.
- Denzing, N.K., & Lincoln, Y.S. (Eds.) (1994). *The SAGE Handbook of qualitative research*. Thousand Oaks, London, New Delhi, Singapore: Sage Publications. (latest edition 2011).
- Engel, N., Davids, M., Blankvoort, N., Pai, N. P., Dheda, K., & Pai, M. (2015). Compounding diagnostic delays: a qualitative study of point-of-care testing in South Africa. *Tropical medicine & international health*, 20(4), 493-500.
- Engel, N., Ganesh, G., Patil, M., Yellappa, V., Vadnais, C., Pai, N., et al. (2015). Point-of-care testing in India: missed opportunities to realize the true potential of point-of-care testing programs. *BMC Health Services Research*, 15(1), 550.
- Engel, N., Ganesh, G., Patil, M., Yellappa, V., Pant Pai, N., Vadnais, C., et al. (2015). Barriers to Point-of-Care Testing in India: Results from Qualitative Research across Different Settings, Users and Major Diseases. *PLoS ONE*, 10(8), e0135112.
- Engel, N., & Pai, M. (2013). Tuberculosis diagnostics: Why we need more qualitative research. *Journal of Epidemiology and Global Health*, 3, 119-121.
- Jutel, A., & Nettleton, S. (2011). Towards a sociology of diagnosis: Reflections and opportunities. *Social Science & Medicine*, 73, 793-800.
- Kjeldskov, J., & Stage, J. (2012). Combining ethnography and object-orientation for mobile interaction design: Contextual richness and abstract models. *International Journal of Human-Computer Studies*, 70, 197-217.
- Leys, M. (2003). Health care policy: qualitative evidence and health technology assessment. *Health Policy*, 65, 217-226.
- Leys, M. (2003b). HEALTH TECHNOLOGY ASSESSMENT: THE CONTRIBUTION OF QUALITATIVE RESEARCH. *International Journal of Technology Assessment in Health Care*, 19, 317-329.

# References cont

- Meadows & Morse, 2001. Constructing evidence within the qualitative project. In JM Morse, LM Meadow, AJ Kunzel, 2001 (eds). The nature of qualitative evidence. Thousand Oaks: Sage. Pp. 187-200.
- Murphy, E., Dingwall, R., Greatbatch, D., Parker, S., & Watson, P. (1998). Qualitative research methods in health technology assessment: a review of the literature. *Health Technology Assessment*, 2.
- Murray, E. J., Bond, V. A., Marais, B. J., Godfrey-Faussett, P., Ayles, H. M., & Beyers, N. (2013). High levels of vulnerability and anticipated stigma reduce the impetus for tuberculosis diagnosis in Cape Town, South Africa. *Health Policy and Planning*, 28(4), 410-418.
- Nichter, M. (1994). Illness semantics and international health: The weak lungs/TB complex in the Philippines. *Social Science & Medicine*, 38, 649-663.
- Ngamvithayapong-Yanai, J., Winkvist, A., Luangjina, S., & Diwan, V. (2005). "If We Have to Die, We Just Die": Challenges and Opportunities for Tuberculosis and HIV/AIDS Prevention and Care in Northern Thailand. *Qualitative Health Research*, 15, 1164-1179.
- Reuzel, R.P.B., & Van Der Wilt, G.J. (2000). Health Technology Assessment and Evaluation. *Evaluation*, 6, 383-398.
- Rintiswati, N., Mahendradhata, Y., Suharna, Susilawati, Purwanta, Subronto, Y., et al. (2009). Journeys to tuberculosis treatment: a qualitative study of patients, families and communities in Jogjakarta, Indonesia. *BMC Public Health*, 9, 158-158.
- Sagbakken, M., Frich, J.C., & Bjune, G.A. (2008). Perception and Management of Tuberculosis Symptoms in Addis Ababa, Ethiopia. *Qualitative Health Research*, 18, 1356-1366.
- Shah, S.G.S., Robinson, I., & AlShawi, S. (2009). Developing medical device technologies from users' perspectives: A theoretical framework for involving users in the development process. *International Journal of Technology Assessment in Health Care*, 25, 514-521..
- Schumacher, K.L., Koresawa, S., West, C., Dodd, M., Paul, S.M., Tripathy, D., et al. (2005). Qualitative research contribution to a randomized clinical trial. *Research in Nursing & Health*, 28, 268-280.
- Simonson, J., & Robertson, T. (Eds.). (2013). *Routledge International Handbook of Participatory Design*. New York, Oxon: Routledge.
- Weigl, B.H., Gaydos, C.A., Kost, G., Beyette, F.R.J., Sabourin, S., Rompalo, A., et al. (2012). The Value of Clinical Needs Assessments for Point-of-Care Diagnostics. *Point of Care*, 11, 108-113 10.1097/POC.1090b1013e31825a31241e
- Watkins, R.E., & Plant, A.J. (2004). Pathways to Treatment for Tuberculosis in Bali: Patient Perspectives. *Qualitative Health Research*, 14, 691-703.