



# REACH

## challenging barriers to health care

REACH (Research on Equity and Community Health) is an independent research trust in Malawi conducting multi-disciplinary research to promote equity in health care. A team of 32 local staff works to identify barriers that prevent poor and vulnerable people accessing health care for TB, HIV and AIDS and malaria and identify appropriate interventions. The team includes experts in sociology, clinical sciences, and health economics and uses a range of research methods such as clinical trials, qualitative, operational and action research on gender and equity and participatory approaches. Patient and community perspectives are a major focus. REACH links its research to policy and practice through developing close working relationships with policy makers and practitioners and communicating findings using a range of methods to appropriate audiences.

This policy briefing paper considers the findings of research exploring how poverty and unequal access to healthcare services affect the way people experience diseases at community level. It looks at the range of processes used by REACH to communicate findings into policy and practice so that barriers to health care that exist for poor and vulnerable people are properly addressed.

“Since the illness we stopped buying a whole bag of maize per month, instead we buy a pail of maize. It is now several months since we stopped using the communal public water tap because we could not pay, now we use water from the traditional well.”

*During an in-depth interview a woman in Lilongwe describes how accessing treatment increases poverty for her family.*

### How does poverty affect how people experience disease and ill-health?

- TB, malaria, HIV and AIDS are diseases of poverty. Poor people are more likely to become ill with these diseases but have the least access to diagnosis, treatment and health care services. Evidence from Lilongwe, Malawi's capital city, shows that TB cases are 'missing' from the poorest areas.
- Poverty analyses suggest that for these diseases, poor people experience greater barriers in accessing care and completing treatment than those that are less poor. These barriers can be financial, geographical or social (including stigma) and lack of knowledge of healthcare systems. Health systems may lack responsiveness to the needs of poor and vulnerable people.
- Financial costs are a major barrier to early diagnosis and treatment of TB and HIV and AIDS. The long diagnosis process or lack of proper diagnosis can lead to repeated visits to health clinics and huge costs for patients. Transport costs can be high when patients have to travel long distances or repeatedly to access services.
- The impact of ill health leads to greater impoverishment. In relative terms, poor people spend three times as much as the better off to access TB diagnosis in Malawi. Poor women and men sell assets (such as pots and pans), lose income, take on high interest loans known as 'katapila', miss meals or are unable to purchase water.
- In Malawi, social stigma associated with TB and HIV and AIDS can sometimes act as a barrier to seeking care and adhering to treatment for both women and men. Negative perceptions of these diseases are such that people fear loss of employment, loss of income and social exclusion if they disclose the cause of their ill health.

## How do gender roles and relations affect access to health care?

- Gender roles and access to resources shape the ability of men and women to access health care. Women in Malawi, as in a number of other developing countries, have less power to make decisions about using resources and often have to seek their husband's approval before incurring expense for health care.
- Findings show that women take longer to report to health facilities than men. For example, women took longer to be diagnosed with TB than men and visit health clinics more often. People shop around for different care providers with storekeepers often being the first point of contact for treatment.
- Most TB patients have a guardian who supports them in taking their drugs on a daily basis. Most guardians are women. Women also tend to accompany patients to health care services more than men, incurring travel costs. Women and girls who take up caring roles frequently lose out on educational or income generating opportunities.
- Women often feel the impact of ill health more than men. Female-headed households especially are pushed further into poverty after accessing care. Women suffer more social consequences from TB and HIV and AIDS and disclosure of positive HIV status has led to social isolation and some women being divorced by their husbands.

## Translating poverty and equity research into policy and practice

Substantial obstacles exist to translating research findings into policy and practice. There is no linear or straightforward relationship and there can be no assumption that more research means more evidence based policy-making. REACH has identified a myriad of opportunities and challenges in translating research into policy and practice.

## Working in a participatory way with policy makers, practitioners and community members

REACH is in an advantageous position to make strategic connections between grassroots and policy making levels. REACH has a close research relationship with the National TB Control Programme (NTP). Both organisa-

tions work from the same building and sit on all NTP strategic management groups. Working closely, they jointly identify research gaps, design and implement research projects and discuss the implications of research for policy and practice. Stakeholders for different research projects have included the NTP, the HIV and AIDS unit within the Ministry of Health, the National Malaria Control Programme, district health offices, the city assembly and the Lighthouse, a charitable trust implementing the government supported anti-retroviral therapy programme. The results from working in this collaborative way have been encouraging.

REACH's research findings, approaches and expertise have been used by policy makers at both national and international levels. At the national level, researchers were called upon to incorporate an equity focus in the design of the Sector Wide Approach for the Ministry of Health. At international levels, findings from research were used in forming the Global STOP-TB Partnership's Network for Action on TB and Poverty and the designing of the WHO book, 'Addressing poverty in TB control: Options for TB control programmes'. Due to its broad range of relationships, REACH is also able to bridge the gap between community levels and district and national policy-making levels.

## case study:

### A community proposal is taken up at national level

Suggestions from a community to improve access to care for TB and malaria were taken up by NTP and the National Malaria Control Programme (NMCP). A joint malaria-TB intervention was developed to address issues of improper advice on home management of malaria and delay in seeking care for TB. Community members received feedback from initial findings about women and men's pathways to seeking care for tuberculosis through participatory approaches including drama. During discussions, community members proposed a community based intervention to shorten the pathway and improve their access to TB services. They suggested this should not be limited to TB but also include malaria as mothers and female carers especially, lose time and money when looking after sick people. They suggested that storekeepers and key community members should be equipped with advisory and health promotion skills, since they are often the first point of

contact when someone falls ill. This proposal was sent to providers and policy makers at district and national level through different forums such as conferences and management meetings for NTP and NMCP. An intervention was agreed upon that involved training store-keepers, volunteers and community members in health promotion and referral skills.

## case study:

### **Integrating gender equity and concerns into NTP core business**

REACH advocated for gender and equity to be included in National TB Programme operations. NTP responded by creating a post in Gender and Equity. NTP also integrated equity and gender within its five year development plan from 2001 to 2006. This included setting aside funding for community based initiatives to address barriers and costs of accessing care. With the current focus in Malawi on decentralisation in the health sector, NTP is using the findings of these community based initiatives to advocate incorporating gender sensitive and equitable community based activities within District Implementation Plans.

These case studies show that working closely with national, district and community levels has created an opportunity for translating research findings into interventions that meet the needs of poor women and men, as well as developing strategies to institutionalise, and hopefully sustain, a gendered approach in NTP's core business. We now turn to a range of other methods that REACH uses to communicate research findings.

### **Advocating research findings at strategic forums**

Findings of studies on access to anti-retroviral therapy (ART) for HIV and AIDS informed the process of developing policy for scaling up ART in Malawi and the development of national policy on equity in access to ART. At the same time that policy discussions were taking place on how to scale up ART, REACH was investigating barriers to accessing and adhering to ART. This was a critical opportunity to input into the new policies being drawn up. REACH presented the findings of its research: that cost is a key barrier and that gender is a critical issue with women in particular struggling to meet the costs required. Through participation at a number of strategic working groups, discussion groups and other



Community members taking a break from focus group discussions in rural Malawi

forums, these findings fed into discussion at the Ministry of Health and were arguably influential in shaping the Malawian policy. There are now free drugs provided on a first come first served basis and a particular emphasis on reaching the most poor and vulnerable people, particularly women.

### **Multi-method approaches**

Using a range of research methods has been central to the strategic approach of REACH. Quantitative methods include questionnaires and gender analysis of pre-existing routinely collected health information. Qualitative approaches include focus group discussions, in-depth critical incidence interviews and participant observation. These methods provide a validated evidence base for advocating for change. There is also scope to address the personal preferences of policy makers, some of whom prefer quantitative methods and others qualitative methods. When methods are combined, a more holistic picture of the situation on the ground appears. For example, analysis of questionnaires can produce statistical significance of the numbers of poor women and men to access services. Qualitative findings can help to explain why this is the case by describing the barriers and obstacles that poor women and men face using their own personal testimonies.

### **Adopting different languages or discourses to discuss research findings**

Also known as 'strategic framing', REACH sometimes situates its research findings within different languages or discourses depending on the audience. For example REACH works within poverty, equity and rights discourse. However, it might be more strategic to frame research



Potential users of health services provided by storekeepers in peri urban Malawi

findings on access to TB services for poor women and men within institutional or technical arguments, to make it more appealing to policy makers. If TB services are not accessible or acceptable to poor people, TB programmes will not meet their case finding and cure rate targets, with negative repercussions for the community of a large number of untreated, infectious TB cases. This threatens the efficiency and sustainability of the entire TB programme. One useful means of communicating findings has been overlaying demographic information with disease control information. For example this was done through linking indicators of poverty (such as the proportion of female headed households) with TB notification data on digitised Geographical Information Systems.

## Capacity building to make research sustainable and relevant

The REACH Trust is an example of how building the capacity of research institutions in the South can lead to effective and relevant operational research and build closer linkages with local policy makers and practitioners. Close working relationships at both community and policy levels mean that changes are likely to happen more quickly and be more relevant to local people. REACH became an independent trust in 2005 and grew out of long established research collaborations between the Malawian National TB Control Programme, the Department of Sociology at the University of Malawi and the Liverpool School of Tropical Medicine (LSTM). The UK Department for International Development (DFID) funded it under the name of the 'TB Equity Project' in 1999 to promote access to TB care particularly for the poor-

est and most vulnerable. With more funding from DFID, this grew into the EQUI-TB Knowledge Programme, a consortium of research organisations led by LSTM, focusing on research to promote equity in TB care.

## Summary

Poverty has a huge influence on equity in access to and adherence to care for TB, malaria and HIV and AIDS. The multiple ways in which poverty and gender intertwine to shape health experiences and outcomes need to be realised and acted upon if health policy and practice is to be equitable, efficient and sustainable. However the path from research to policy making to implementation is not straightforward. It is important to think through strategies and approaches needed to navigate this complex relationship.

### REACH's main strategies have been:

- developing sustained and responsive relationships with policy makers to enhance ownership of the research process and the likelihood of decisions being based upon findings
- having a sustained voice to advocate at policy forums and technical working groups to illustrate the main issues
- presenting findings from multiple research methods and within an appropriate and strategic discourse such as equity, gendered rights, efficiency and sustainability depending on the audience.



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