PARTICIPATORY PUBLIC HEALTH RESEARCH: THE PROCESS OF COMMUNITY ENGAGEMENT IN RESEARCH PARTNERSHIPS

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1. INTRODUCTION

There is growing recognition of the appropriateness, importance, and value of Community-based Participatory Research (CBPR) in the field of public health. Implemented rigorously, CBPR enhances the relevance and use of the data (Israel et al., 2005; Viswanathan et al., 2004; Minkler and Wallerstein, 2003). This paper describes a design which engaged, from the outset and in all phases of the research process, members from migrant communities (the target communities) and key stakeholders from multiple sectors, representing and serving them in a research partnership with academic researchers. This paper draws on the findings (minutes of meetings, qualitative observation, stakeholder discussion, and evaluative data) of a two-year research study of structural influences on *Mycobacterium tuberculosis* (TB) in migrant African communities in London, the results of which have been published elsewhere (Marais, 2007).

This study used a multi-method CBPR design, combining quantitative and qualitative methods with an integrated framework to evaluate the process and outcome of the research partnership. The emphasis here is on the pivotal components of the design — the engagement of community participants (members from the target communities) as Community Advisory Panel (CAP) partners and/or Community Research Fieldworkers (CRFs).

2. RATIONALE

The process described in this paper is an extension of the Participatory Action Research literature. It describes a public health research design engaging community participants as full partners in pivotal leadership roles. The concept of engagement — a position of consistent shared responsibility for, guidance and management of, and participation in, the research from the outset — strongly emphasizes the following:

a. equal partnership for each participant;
b. integration of research and intervention contexts, however complex;
c. cultural protocols and procedures at the core of the research process, rather than add-ons or barriers;
d. regular opportunities, throughout the research process, for knowledge to cascade into (and from) the communities, rather than dissemination of findings at the end;
e. mutual learning for all partners (not expert-driven);

f. corrective and appropriate change in the research process, as necessary, to maximize results, inclusivity, and cultural appropriateness;

g. negotiated ethical principles, accepted by all partners at the outset, to guide the entire research process;

h. findings reviewed in cultural context;

i. whenever possible, immediate public health interventions developed and prioritized, throughout the research process, in response to expressed community needs;

j. recommendations for future appropriate public health interventions (policies, services, and programmatic responses), beneficial to communities;

k. appropriate methods and modes of dissemination of new knowledge and the study findings;

l. co-ownership for the CAP of the data and study findings.

In public health research, *engagement* fosters a long-term commitment between partners, investing in, and building mutual capacity for, sustained community participation. The ultimate goal is for communities to identify and instigate their own timely and beneficial research, according and in response to their contexts and needs.

3. THE STUDY

As a professional in the field of TB care and control, Frederick Marais, the Principal Investigator (PI) wanted to investigate why some migrant populations are increasingly and disproportionately affected by TB. Medical explanations of this discriminate public health situation are inadequate. The heterogeneous and diverse nature of the affected cultural groups suggested that this disease pattern was beyond cultural explanations. Accordingly, the study used the concept of "structural violence" (Farmer, 1999; 1997; 1996) to examine structural influences determined at, and operating across, community and sector levels affecting TB in migrant African communities in London, UK. The study findings, published elsewhere (Marais, 2007), suggest several structural influences, with complex interplay, including: social, economic, legal, political, and organizational (including institutional). These influences are beyond the direct control of individuals but impede and/or facilitate health and positive outcomes of TB control measures.

4. THE CBPR DESIGN ADOPTED FOR THE STUDY

The multimethod CBPR design adopted for the study was implemented in several interrelated phases as shown in Figure 1.

4.1 INITIAL STAKEHOLDER CONSULTATIONS: THE FIRST STEP

The first step in the study was to consult stakeholders identified from existing databases and through snowball sampling. These stakeholders originated from:

a. multiple sectors, including healthcare providers and policy makers from both statutory and nonstatutory sectors, and

b. the target communities, including community-based organizations (CBOs), refugee organizations (ROs), and self-help groups, both formal and informal.

The consultations were undertaken as qualitative interviews with the following themes:

a. organizational and community perceptions of TB as a health issue;

b. identification of pertinent research questions;

c. organizational and community views, experiences, and interests in participatory research;

d. possible benefits of CAP membership;

e. factors which could impede participation in the study, including any gender-based barriers;

f. existing capacity to participate;

g. identification of participatory goals to evaluate the process of participation.

Further purposes of these consultations were to:

a. build trusting working relationships with CBOs by regarding and consulting them as community experts,

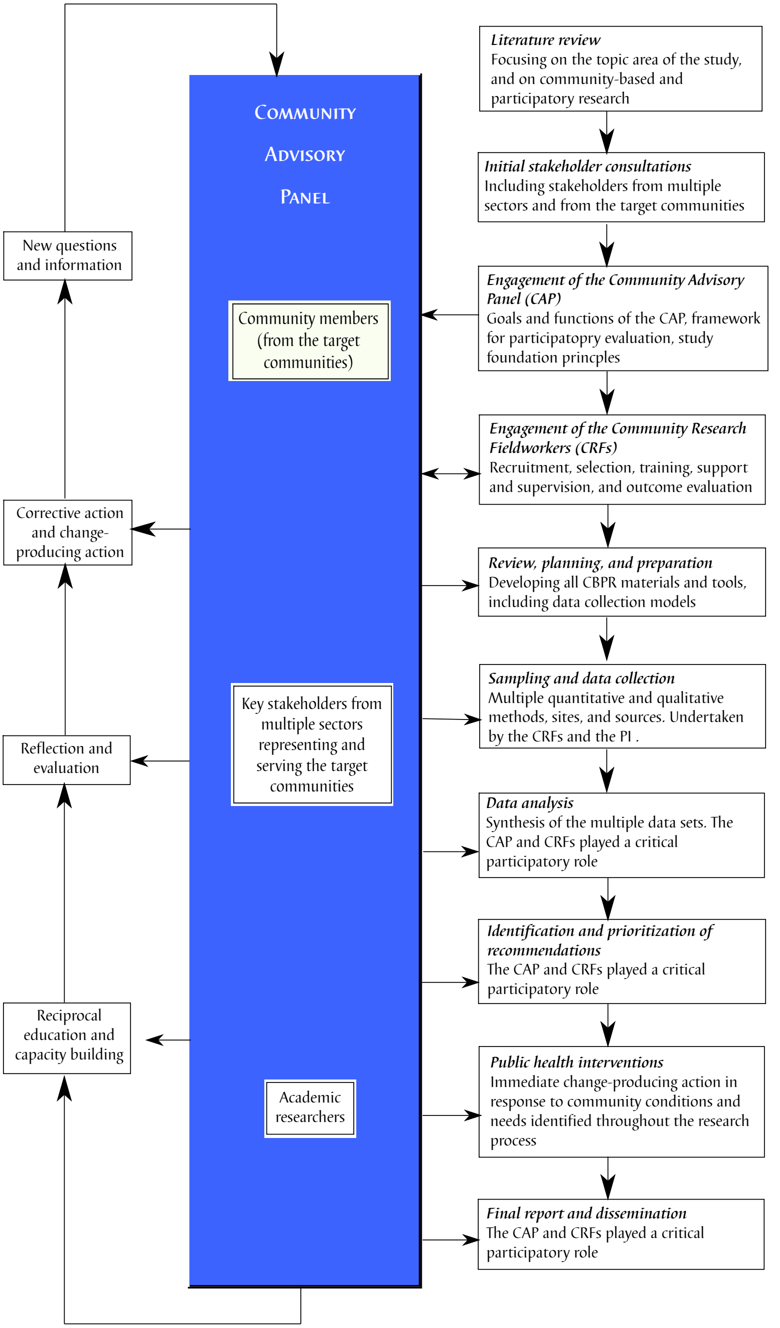
b. demonstrate a real regard for community health development,

c. establish trusting and ongoing working partnerships with the target communities beyond the life of this specific research study, and

d. build mutual capacity toward improved TB control and participatory research at community, healthcare, and academic level.

Interest was expressed in the research initiative; all the stakeholders per-

Figure 1. Community-based Participatory Research (CBPR) Design Adopted for the Study



ceived TB as an issue for their respective communities and identified related research questions. They agreed that being an integral part of the research process was appropriate to the culture of their groups and would allow them an active voice to influence their own health and development. Potential factors which could impede participation were identified as geographical accessibility of meeting locations, travel and indirect costs, time/scheduling, and opportunities for women with competing domestic and family responsibilities. Existing information and data sets were identified and accessed. The findings also provided information about new community groups, which were all consulted individually by the PI. To reduce potential selection bias, prevent inadvertent exclusion of any new or unknown groups and networks, and optimize inclusiveness and opportunity for community engagement, the study was advertised, with invitations for CAP partners, via all stakeholder forums, meetings, communication networks, and other organizational and cultural events. Advertising was in multiple languages, in oral and written format, and in multimedia, including leaflets, posters, newsletters, and oral presentations. This multimethod approach acknowledged the oral histories and traditions of some migrant African communities. Advertising by word-of-mouth was encouraged via CBOs and individual community members. Additional CBOs were identified and added to the evolving database of local key stakeholders, all of whom were approached individually by the PI.

4.1.1 Community advisory panel (CAP) partner inclusion criteria

Additional aims of the initial stakeholder consultations were to obtain opinions on a proposed set of CAP partner inclusion criteria, and individual commitment for the establishment of a CAP research partnership. All agreed to the appropriateness of the inclusion criteria. Different studies employ different criteria, including:

a. purposive (Chinouya and Davidson, 2003; Weatherburn et al. 2003);

b. convenience (Chinouya et al., 2000);

c. site-based (Arcury and Quandt, 1999).

The combined findings of the initial stakeholder consultations, coupled with the objectives of the study, specified individual requirements for the inclusion of CAP partners. This improved operational productivity and quality by ensuring the genuine interest, expertise, and commitment of CAP participants. The agreed inclusion criteria were:

a. a good understanding of the needs and assets of the target communities;

b. a commitment to the aims and objectives of the study, and to community health and development in its broadest sense;
c. relevant experience, e.g., community development, networking, public health, disease control, and/or issues relating to refugees, asylum seekers, and undocumented entrants;
d. trust and confidence of their respective migrant African communities;
e. ability to speak and read English (and, as an advantage, one African language);
f. capacity to sustain attendance at CAP meetings.

In addition, attempts were made to obtain balanced representation for age, gender, ethnic origin, and sector representation.

The commitment of each key stakeholder following the consultation marked the establishment of the CAP research partnership. Each stakeholder organization nominated, as representative, the person most appropriate to be engaged in the research, based on the CAP partner selection criteria. These people represented various levels of their organizations, not homogenous. All these prospective research partners were invited to the first CAP meeting, marking the first phase in implementing the study's CBPR design.

4.2 ENGAGEMENT OF THE COMMUNITY ADVISORY PANEL (CAP) RESEARCH PARTNERSHIP: BECOMING A RESEARCH TEAM

The first meeting was deliberately held at a local teaching hospital, an initiating partner in the study. Traditionally, the perception is that communities are not accepted in the institutions; holding the first meeting at the hospital confirmed the commitment of the health professionals on the team. There were fifteen people at that meeting, 100 percent of those invited. It was agreed that CAP membership would be emergent, encouraging new partners at any stage. During the course of the study, there were six additional CAP members, including three community members who enhanced the cultural representation. This was balanced by six members who withdrew during the course of the study owing to competing work commitments or relocation. A heterogeneous group of fifteen partners sustained participation throughout the study.

At the first meeting, the importance of TB as a public health issue and the appropriateness of a CBPR design were explored once more. The group negotiated its role as an advisory panel. They chose to be called a Community Advisory Panel (CAP) rather than a board, because the acronym CAB

(Community Advisory Board) already had another meaning in the community. It was agreed that the CAP role would evolve throughout the research process, although core goals and functions were identified as explained below in section 4.2.1.

Financial compensation for participation was one of the issues discussed. The group decided that small CBOs deserved some compensation for expenses and their time, while members representing larger organizations were already compensated as part of their paid positions. The level of payment was agreed by all to be £30 (including travel expenses) per meeting (average 2.5 hours per month). There was consensus to rotate future meeting venues to increase opportunities for partners to attend. To accommodate the family responsibilities of women, meetings were held during school hours. For others, the meetings were considered as part of their work-day responsibilities. Other barriers were anticipated but did not arise, such as responsibility for caring for elderly family members.

Subsequent meetings, in addition to planning and implementing the various phases of the study, developed several integrated mechanisms which were fundamental to the ongoing maintenance of the CAP research partnership. These mechanisms included:

a. the identification of explicit goals and functions of the CAP;
b. the design and implementation of a framework to evaluate the process and outcome of participation in the CAP;
c. the development of the Study Foundation Principles.

4.2.1 Goals and functions of the CAP

The guiding principles of CBPR (Israel et al., 2005), coupled with findings from the initial stakeholder consultations and the specific objectives of the study, made several CAP goals explicit from the outset. Identifying explicit goals from the outset increases the success of the participatory research process and its relevance to the study population (Gibson et al., 2001). These goals guided the formulation of the initial functions of this panel. The final goals and functions of the CAP, including the individual and collective roles and responsibilities of the various partners, and the frequency of meetings, evolved throughout the research process. An agenda-based evaluation model (Gibson et al., 2001) identified the personal, professional, and organizational goals of each partner. Negotiation achieved group consensus on appropriate and realistic goals for the objectives of the study and the benefit to target communities. Unrealistic and conflicting goals were discussed and renegotiated, achieving shared goals. The agreed goals and functions of the CAP did not include all the goals of each partner, but provided a common agenda focusing on the objectives of the study and offering measures (participatory goals) for evaluation. During the course of the study, further goals and functions were agreed by the CAP and added. Figure 2 shows the final CAP goals and functions. In brief, their engagement was important in order to:

a. ensure responsiveness to the conditions and needs of the migrant African communities;
b. ensure the contextual and cultural appropriateness of the research process and methods;
c. allow better access to and recruitment of study participants;
d. offer socio-cultural and linguistic compatibility with the study participants;
e. foster trust between participants and researchers; all of which would enhance knowledge production by increasing the quantity, quality, and validity of data collected;
f. benefit communities through the dissemination of knowledge gained and through interventions during and following the study;
g. generate recommendations which would be effective, accessible, and beneficial to the migrant African communities.

4.2.2 Framework for the evaluation of the process and outcome of participation in the CAP

From the outset, there was consensus that both the process and level of participation in the CAP would be regularly evaluated to ensure full and active engagement of all partners. A framework for participatory evaluation was adopted in the study (Found, 1997; De Koning and Martin, 1996; Eng and Parker, 1994; Rifkin et al., 1988). Since participatory evaluation, unlike traditional evaluation, is driven by the beneficiaries and not by “external” actors, all CAP partners in this study were engaged in the entire evaluation process. They approved a framework for participatory evaluation which incorporated both internal and external evaluation to compensate for any inherent bias and weaknesses. The CAP determined the participatory goals for evaluation, the evaluation questions, the methods for data collection (qualitative and quantitative measures used as a measure of triangulation for data validation), participated in data collection, identified corrective actions to improve the engagement of all partners and recommendations for future studies.

Figure 2. Goals and Functions of the Community Advisory Panel

Goal 1	*Full and active participation*
Functions	To participate in the development and operation of all phases in the research process. To influence the development and operation of all phases of the research process. To establish study foundation principles; guiding the study through ethical, methodological and operational challenge and decision making. To respond to ongoing CAP evaluation results and to recommendations made by CAP partners and CRFs. To provide support and guidance to CRFs and academic researchers. To contribute to productive CAP meetings.
Goal 2	*Co-ownership and shared responsibility*
Functions	To co-own all phases of the research process throughout the study. To share responsibility for all phases of the research process throughout the study.
Goal 3	*Community appropriateness, sensitivity, and responsiveness*
Functions	To focus the study on the conditions and needs of the study population, as opposed to those of organizations (including institutions). To enable community perspectives (voices) to influence the research process. To develop all data collection methods, ensuring linguistic clarity, cultural appropriateness, and cultural sensitivity. To assist in the recruitment and selection of appropriate community members to be trained as CRFs. To assist in the training of appropriate community members as CRFs. To ensure that the study offers linguistic, sociocultural, and gender compatibility between CRFs and research participants.
Goal 4	*Inclusive and equitable research partnerships*
Functions	To use the personal expertise of all CAP partners. To engage fully and equally all CAP partners in all phases of the research process. To identify additional key stakeholders to join the CAP and for data collection. To facilitate community engagement in data analysis, and prioritizing proposed recommendations.
Goal 5	*Linking communities and organizations*
Functions	To enable access to the study population. To improve working relationships among communities, academic institutions, and health provider organizations. To link health providers with the study population to raise awareness about TB and available services. To link health providers with the study population to increase access to TB services.
Goal 6	*Enhanced interventions and community benefits*
Functions	To facilitate reciprocal education and capacity building among all CAP partners. To ensure the study is mutually beneficial to all CAP partners To facilitate multiway communication of knowledge from and to the communities. To facilitate multiway communication of knowledge to provider organizations. To facilitate multiway communication to implement follow-up activities and action resulting from the research process. To identify and prioritize recommendations for appropriate public health interventions. To provide support and guidance in the development of Community TB Awareness Days.[A] To provide support and guidance in the implementation of Community TB Awareness Days.[A] To provide knowledge which can be passed on to other community members and used in future work.
Goal 7	*Linking and sharing resources*[A]
Functions	To submit joint applications for additional finances, securing the continuation of the study.[A] To submit joint applications for additional finances for the provision of Community TB Awareness Days.[A]
CAP Goal 8	*Enhancement and promotion of participatory research methodology*
Functions	To develop and review all methods for evaluating participation in the CAP. To develop the CRF training program. To develop and review all methods for evaluating the role of the CRF. To promote the achievements and benefits of the CAP, and of the participatory TB study.[A]
CAP Goal 9	*Sustainable research partnerships*
Functions	To identify possible funding sources to sustain the CAP following the completion of the TB study.[A] To identify topics for future community-based participatory research.[A]

A = additional goals and functions, not identified at the outset of the study.

4.2.2.1. Methods for the evaluation of the process of participation in the CAP. A Self-completion Contact Evaluation Questionnaire and an Anonymous Spontaneous Written Feedback Form were used for internal evaluation of the process of CAP participation. The CAP initiated the Anonymous Written Feedback process from the outset to optimize inclusiveness and participation; those who felt uncomfortable speaking in a forum and contributing openly to a critical discussion could submit any comments, suggestions, and ideas in writing at the end of each meeting if they so desired. The questionnaire contained the participatory goals identified by the CAP. These evaluated issues concerning:

a. productivity,
b. co-ownership,
c. individual input,
d. individual influence,
e. community needs assessment,
f. responsiveness to CAP partners,
g. responsiveness to communities,
h. multiway communication,
i. breaking down barriers,
j. reciprocal education and capacity building,
k. joint-decision making, and
l. shared management.

A 5 part continuum was developed for each of these goals. Each point represented the level of participation, ranging from "very poor" (score=1) to "very good" (score=5). After each evaluation was scored, the mean for each point was calculated. In addition to structured quantitative evaluation, the questionnaire incorporated an open-ended qualitative section, seeking personal perspectives on the process, level of participation, and suggestions for improvement. The combined results of the quantitative and qualitative measures were collated following each meeting and deliberated at the subsequent meeting with appropriate corrective action.

During the first year of the study, CAP meetings were conducted approximately on a two monthly basis and then, in line with CAP recommendations, reduced to quarterly meetings with the option to be increased if needed (which was not required). Each meeting from the second to the fourth was evaluated, then the CAP agreed to evaluate each third meeting for the duration of the study. There were 21 CAP meetings during the course of the study and 7 of these were evaluated. The evaluative results have been published elsewhere (Marais, 2007) but, in general, all participatory goals were evaluated very positively. The overall mean scoring of the achievement of all goals was between "good" (score=4) or "very good" (score=5). During all CAP meetings several partners submitted the Anonymous Spontaneous Written Feedback Form with comments, suggestions, and recommendations for improvement.

4.2.2.2. Methods for the evaluation of the outcome of participation in the CAP. A Final Self-completion Evaluation Guide for internal evaluation and a Group Discussion Evaluation Guide for external evaluation were used to evaluate the overall participation of the CAP. The Self-completion Evaluation Guide contained graded and open-ended questions which mapped onto the CAP goals and functions listed in Figure 2. The questions assessed the overall achievements and failures in meeting these goals and functions. There were 5 gradings, from "very poor" (score=1) to "very good" (score=5). Following completion of the evaluation, the overall mean score of each CAP goal was established. This guide also provided the opportunity for open-ended qualitative feedback concerning possible causes of any failures, recommendations for improvement, and comments or related topics of own choice. Other open-ended questions sought views on personal participation in the study, on the actual evaluation guide itself, and general comments or suggestions relating to the TB study. This was followed by an external evaluation in the form of a focus group discussion facilitated by an expert in participatory evaluation, using a semi-structured Group Discussion Evaluation Guide. The PI was not involved in this group discussion, enabling participants to express opinions freely on their overall experiences of participating in the study, and to provide constructive feedback and recommendations to guide future studies.

The outcome evaluation was undertaken near to completion of the study. The achievements of the goals were evaluated very positively. The evaluative results have been published elsewhere (Marais, 2007) but, the overall mean score in all the goals was very high, ranging from 4.0 to 4.6.

4.2.3 The study foundation principles

Another primary function of the CAP was to establish context-specific foundation principles for the study. These principles, listed in Figure 3, provided a shared vision to navigate the study through ethical, methodological, and operational challenges. The importance of such guiding principles in participatory research is emphasized by several authors (Gibson et al., 2005; 2001; Gibson and Gibson, 1999; Macaulay et al., 1999). Revisiting the study foundation principles to ensure that they were followed throughout the research was part of the routine evaluation process. These principles, together with the jointly agreed goals and functions of the CAP, described in section 4.2.1, formed the basis for negotiating and responding collectively as a research partnership to differing perspectives on issues and concerns with the research process.

Figure 3. The Study Foundation Principles

1. The research process to be entirely inclusive, decisions to be made jointly by the CAP.
2. To recognize that all people have knowledge and expertise to contribute, and given the opportunity, to gather and develop knowledge and skills to improve their health and quality of life.
3. To value the life circumstances, experiences and time commitments of individual CAP partners, community members and participants by acknowledging their contributions (financially or otherwise).
4. To guide decisions and actions by mutual respect and confidentiality.
5. The research study and final report to be co-owned; CAP partners and communities to be able to access, disseminate and use the findings.
6. The research process to be educational for CAP partners, CRFs, community members and participants.
7. The research to be action-orientated and change-producing.
8. To establish trust between communities and formal sectors by ensuring that the study is inclusive of community voices and responsive to community circumstances, needs, and interests.
9. To show sensitivity and responsiveness to the differing cultures, values, priorities, and socioeconomic and legal circumstances of individuals and communities.
10. To provide opportunities for all community members to participate by ensuring the recruitment process is responsive to barriers relating to gender, age, ethnicity, and legal status or other challenges.
11. To show sensitivity and responsiveness to the varying degrees of stigma associated with TB.
12. The research process and recommendations should not cause harm to the communities.
13. To provide regular feedback and sharing of information, findings and knowledge with the communities.
14. To build capacity within the community and formal sectors through training and other health-related educational activities.
15. To maximize engagement by responding to the findings of the ongoing process evaluation of the CAP.
16. To assure communities and participants of anonymity and confidentiality at all times when participating in the study or attending TB services.
17. To inform communities and participants that the ultimate aim of the study is to improve individual and community health and that there is no suggestion they are infected with or spreading TB.
18. The study recommendations must be based on the recommendations proposed by the study participants, the CAP and CRFs.
19. The primary commitment is to participants who might be more at risk of TB, particularly those who demonstrate symptoms suggestive of the disease, and to take prompt action to guide and support them appropriately.
20. To develop sustainable networks for education and research between CBOs, academic, statutory, and other relevant organizations which would help to establish trust, to facilitate research capacity building and community health development, and to promote future collaboration.
21. To advocate for equity and improved health.

4.3 ENGAGEMENT OF THE COMMUNITY RESEARCH FIELDWORKERS (CRFS): EXPANDING THE RESEARCH TEAM

Once the CAP was comfortable in its initial role, the members developed the process to recruit CRFs, from within the target communities, to collect the data. From the outset, the CAP identified and agreed explicit goals and functions for the CRFs as listed in Figure 4. The CAP suggested that formal employment was inappropriate for CRFs; some community members might be concerned about losing social benefits if they received payment as CRFs, and undocumented migrants might fear identification and deportation if engaged in paid employment. It was decided that CRFs would be reimbursed for travel expenses and personal costs related to recruitment and interview

Figure 4. Goals and Functions of the Community Research Fieldworkers (CRFs) of the Study

Goal 1	*Full and Active Participation*
Functions	To participate in the development of the survey and semi-structured interview questionnaires. To participate in the development of guidelines for research participant recruitment. To develop guidelines for the personal safety of CRFs during fieldwork. To collect research data by administering survey and semi-structured interview questionnaires. To undertake data/information translation and transcription. To participate in data interpretation.
Goal 2	*Community Appropriateness, Sensitivity, and Responsiveness*
Functions	To ensure cultural appropriateness of the survey and semi-structured interview questionnaires. To ensure cultural sensitivity of the survey and semi-structured interview questionnaires. To provide sociocultural, linguistic, and gender compatibility for the study participants. To obtain oral consent from study participants.
Goal 3	*Identification of Diverse Sites and Heterogeneous Community Members for Study Recruitment*
Functions	To identify health organizations, community, organizations, and social venues frequented by the study population. To identify a diverse range of community members for recruitment as study participants.
Goal 4	*Facilitating Access to a Diverse Range of Community Members*
Functions	To facilitate access to migrant workers, refugees, asylum seekers, and failed asylum seekers. To facilitate access to "hidden" community groups and members — those who are from smaller cultural/ethnic communities, and those who do not access community organizations and services.
Goal 5	*Contribution to the Benefit of Communities*
Functions	To provide TB information and other health-promoting information to research participants (pre-prepared materials). To disseminate the results to the study population.

time, telephone calls, and the provision of refreshments for interviewees. In addition to travel expenses, a standard payment of £12.00 per completed questionnaire was agreed by the CAP.

To increase community engagement in the study, the CAP designed a strategy for CRF advertising in various venues and with different methods, including web sites, leaflets, and word-of-mouth. They also designed an application form that was accessible to those with limited skills in English and qualifications. The form maximized the opportunities for community members to become engaged. All CAP partners insisted that CRF selection must be inclusive of as many different cultures, age groups, and genders as possible. Specific individual requirements were used to guide CRF selection. Recognizing the varying levels of capacity and opportunity for education within and across the target communities, these requirements were as broad as possible to prevent discrimination against and exclusion of those who could not meet specialist requirements. This approach reflects the commitment of the adopted CBPR study design to optimize opportunities for capacity building and participation for all. The criteria as agreed by the CAP included:

a. a member of a migrant African community,
b. interested in and concerned about health development issues in own respective migrant African community,
c. enjoy working with people,
d. a willingness to learn, undertake training, and work as part of a team,
e. able to speak, read, and write in English and in at least one African language
f. able to work flexible hours, including evenings and weekends.

Twenty-five applications from a variety of communities were received; interviews were conducted by the PI and three CAP partners, self-selected from within the group. Of these applications, twenty matched the specified criteria and were interviewed. Based on their performance during the interviews, sixteen were selected for CRF training.

4.3.1 CRF training program

The CRFs completed a 5 day training program which provided:

a. project-specific knowledge and skills about TB, general research, and participatory research and CBPR;
b. transferable generic knowledge and skills, which could be disseminated to others in their respective migrant African communities for better in-

teraction toward improved TB control and future research activities.

This reflects the principles of a CBPR design to build capacity and invest in overall community development. CBPR is concerned with research, reciprocal capacity building and community development (Israel et al., 2005; Viswanathan et al., 2004; Minkler and Wallerstein, 2003; Nyden, 2003). Figure 5 provides an outline of the aims and objectives of the study's CRF program. The training program had a strong emphasis on extensive practice with constructive feedback, and on fostering a sense of team membership. During the training sessions the CRFs also critically reviewed the research tools (developed by the CAP over a 5 month period) for content, linguistic clarity, and cultural appropriateness. Many changes in wording were made, some questions were deleted and others added.

A combination of learning approaches was used including structured presentations, interactive group discussions, case studies and scenarios,

Figure 5. Outline of the Community Research Fieldworker (CRF) Training Program of the Study

Overall Aims

The training program aims:

1. To provide participants with the necessary knowledge and skills to participate as CRFs in the community-based TB study within Westminster, London.
2. To provide participants with knowledge and skills which they could use in future community health and development projects.
3. To provide participants with knowledge and skills which could be passed on to others in their communities in order to: (a) improve TB control, and (b) establish a network of community members with research skills to initiate and carry out future health research projects.

Learning Objectives

On completion of this training program, participants will have gained:

1. Awareness of the basic principles, limitations, and potential benefits of CBPR and of the CBPR design adopted for this TB study.
2. Understanding of the importance, role, and responsibility of the CRF in this study.
3. Understanding of the importance and dilemmas of key ethical considerations in research.
4. Understanding of the importance and implications of participant confidentiality and anonymity.
5. Basic knowledge of key research designs and methods, with emphasis on the purpose, strengths, and limitations of surveys and one-to-one semi-structured interviews.
6. Understanding of the social and practical considerations in researching stigmatized and sensitive issues.
7. Knowledge of important health and safety considerations when undertaking fieldwork.
8. Practical skills in undertaking surveys.
9. Basic knowledge of TB and of key methods and challenges for its control.
10. Practical skills in undertaking one-to-one semi-structured interviews.
11. Experience in critically reviewing research questionnaires and related documents for cross-cultural clarity, appropriateness, and sensitivity.
12. Experience in identifying methods and mapping sites for recruiting study participants.
13. Understanding of the procedures and protocols to be used in this TB Study.

small group and pair work, role-play, and individual reflection. Meals were occasions for networking, with culturally appropriate food and music provided. The overall goal of these learning approaches was to relate sessions to practical research issues; integrate participants as experts in order to capture cross-cultural contexts, experiences, and suggestions; and facilitate reciprocal learning. The program was co-facilitated by the PI, TB specialist medical and nursing staff from the local TB Clinic (who were CAP partners), and academic researchers. All CAP partners were encouraged to participate as facilitators but some declined owing to competing work priorities and lack of knowledge and skills in the program topics. However, several attended various sessions both as observers and participants which enriched reciprocal learning.

Of the sixteen invitees, two failed to attend training and one failed to complete the program; all three stated that they withdrew owing to family health problems. Among the thirteen CRFs who completed the training and were engaged in the study, the age range was 22–69, eight women, five men, and five cultural groups. The thirteen CRFs, three of whom were also CAP partners, remained engaged throughout the study, although one died before the outcome evaluation. All were paid £50 for the week of training. They also received £50 upon completion of the data collection, along with a Certificate of Attendance, issued by the College where the PI was based.

4.3.1.1. Evaluation of CRF training program. Process and outcome evaluation, quantitative and qualitative, of the training program was undertaken. Each training day concluded with a group evaluation which provided the opportunity for questions or clarification — to add further points of interest, to request additional information, and importantly, to identify any problems with the program or the content. This information enabled immediate corrective action. For example, CRFs wanted more information about stigma and TB, and printed material on all the training topics for later reference; this was provided and a handbook was created. Furthermore, in the event of some participants feeling uncomfortable in expressing their opinions in a forum, an Anonymous Spontaneous Written Feedback (similar to that used in the CAP evaluation as described in section 4.2.2.1) was implemented for optional completion at the end of each day. The findings from the process evaluation suggest that all the sessions were regarded as appropriate and invaluable.

Outcome evaluation was undertaken by means of a Training Program Self-completion Evaluation Questionnaire. This contained graded and open-ended questions which measured the overall level of achievement of the specific program aims and objectives, the appropriateness of the different learning approaches, the value of each learning session, and the overall quality and experience of the training program. There were 5 scores, from "very poor" (score=1) to "very good" (score=5). All CRFs completed their questionnaires and the findings suggest that the program was perceived as highly effective; all the measures were scored either "good" or "very good."

Overall, the evaluative results (Marais, 2007), confirm that the CRF training program was extremely positive in terms of increasing their knowledge about TB and research. They felt that they had acquired new knowledge that they could cascade into their communities. They requested further training sessions on the following health topics: general health issues, HIV, female genital mutilation. They also wanted more time together to explore cross-cultural perspectives on health and TB.

4.3.1.2. Follow-up research workshops. Following completion of the training program, the CRFs were given a three-week period to pilot the questionnaire survey interviews. This provided them with practical experience and enabled the identification of problems with the content or administration of the questionnaire. After the practice period, all CRFs attended a research workshop, facilitated by the PI and another academic researcher, to reflect on their experiences, improve their practical skills and, if necessary, amend the questionnaire. Based on the feedback from the CRFs, several changes were made to the layout and wording of the questionnaire. These changes were discussed with the CAP which agreed the final version.

Six CRFs, who showed an interest in and demonstrated basic skills for undertaking semi-structured interviews, attended two further workshops to practice their interviewing skills and improve their confidence and competency. In addition, during the period between the workshops, these CRFs undertook pilot tape-recorded semi-structured interviews which were reviewed by the author with constructive feedback provided to each CRF. Feedback from the CRFs also resulted in minor amendments to the content of the semi-structured interview guides.

4.3.2 Safety guidelines for the CRFs

The study recognized that in their role as CRF, community members working in unfamiliar settings might be exposed to potential risks not encountered in their usual environments. To maximize their personal safety, the CRF training program included a session covering various aspects of safety during fieldwork. These included: assessing and avoiding risk, preserving the anonymity of the interviewee, confidentiality, and dealing with rejection, stigma, and other sensitive issues. This was followed by group exercises during which participants developed and jointly agreed a set of Fieldwork Safety Guidelines to avoid difficult or potentially threatening situations and to respond appropriately in the event of an untoward incident. No such incident was reporting during the study.

4.3.3 CRF contract

Following completion of the follow-up research workshops, and before the commencement of data collection, all CRFs attended a final group meeting to revisit all protocols, procedures and the final amended questionnaires. In line with CAP recommendations, each CRF was asked to sign a Volunteer Community Research Fieldworker Contract. The purpose of this contract was to obtain individual written commitment to fulfill the role and responsibilities of the CRF, to respect at all times the anonymity and confidentiality of the interviewee, and to follow the agreed Fieldwork Safety Guidelines. All CRFs signed this document.

4.3.4 Support and supervision of the CRFs

Training and support to enable community members are essential to foster participation, maintain high motivation and morale, and facilitate community development and empowerment (Israel et al., 2005; Minkler and Wallerstein, 2003; Gibson et al., 2002). The issue of volunteer participation versus paid community health work continues to be debated. In accordance with the recommendations of the CAP, a mixture of financial and other types of support were provided for the volunteer CRFs. These included:

a. the training program and follow-up research workshops in TB and research skills;
b. a Certificate of Attendance on completion of the training program;
c. provision of meals and refreshments during training and meetings;
d. payment of £50 in recognition of personal expenses related to training attendance, such as time and travel;
e. payment of £12 per completed questionnaire, in addition to travel expenses;
f. payment of £50 on completion of the fieldwork in recognition of personal time, input, and undeclared expenses such as telephone and refreshments during data collection;
g. acknowledgement of participation in all printed material.

Additional standard procedures served as a quality-check mechanism to improve data quality (Israel, 2001). These included:

a. periodic and random partnering with CRFs, by the PI, when culturally appropriate, to assess the interview process and to provide immediate feedback to the respective CRF;
b. review of interview data, by the PI, immediately after collection to ensure appropriate content, obtain any missing data, and provide feedback to the CRFs;
c. regular telephone calls to CRFs, by the PI, to monitor progress and resolve any problems;
d. easy telephone access for CRFs to the PI and CAP partners.

The findings from the initial stakeholder interviews, coupled with the recommendations of the CAP, reveal that fieldwork interviewing may be stressful or traumatic for some CRFs, particularly if they share similar experiences and conditions with the interviewees. Others also reported possible distress for insider interviewers (Black and Minority Ethnic Health Forum [BMEHF], 2003; Weiss et al., 2000). Therefore, in addition to the above mentioned procedures, sensitivity to potential emotional consequences was maintained by:

a. easy access to the PI and CAP partners, allowing CRFs to discuss feelings and possible distress as needed;
b. weekly telephone calls and/or personal visits from the PI to all CRFs for debriefing;
c. had any CRFs displayed signs of distress (though none did), they would have been given the opportunity to interrupt, temporarily, their interview schedule and to consider attending counseling services;
d. had any CRFs displayed sustained distress over several days (though none did), they would have been advised to discontinue their participation and referred to counseling services.

4.3.5 Methods of evaluating the outcome of participation as CRF

The overall participation of the CRFs was evaluated following completion of data collection. Similar methods to those used to evaluate the CAP, described in section 4.2.2.2, were employed to evaluate the overall participation of the CRFs. Internal evaluation was completed using a Final Self-completion Evaluation Guide containing graded questions, with 5 scoring options from "very poor" (score=1) to "very good" (score=5). This was mapped onto the

CRF goals and functions listed in Figure 4. The evaluation guide also provided an opportunity for open-ended feedback concerning possible causes of any failures, recommendations for improvement, and comments or related topics of own choice. Other open-ended questions sought views on personal participation in the study, the actual evaluation guide, and any general comments or suggestions relating to the TB study. This was followed by an external evaluation in a focus group discussion facilitated by the same expert in participatory evaluation, using a semi-structured Group Discussion Evaluation Guide. Once again, the PI was excluded from this focus group discussion in recognition that his triple role as PI, CRF trainer, and CRF supervisor could be a possible cause of any failure in the participatory process. This freed participants to express opinions on their overall positive and negative experiences, and suggest recommendations for future participatory public health research. The achievement of the goals was evaluated very positively (Marais, 2007), with a very high overall mean score, ranging from 4.1–4.6. in all the goals.

4.4 REVIEW, PLANNING, AND PREPARATION

During this phase, the CAP developed all the CBPR materials for the study, including framing the research questions and designing the methods for data collection. All the materials were reviewed by the CAP and CRFs and the final versions agreed, ensuring cultural appropriateness, sensitivity, and linguistic clarity. Following recommendations from both the CAP and CRFs, community consultation was included as an additional contextually appropriate method for data collection. Feedback from the study participants confirmed cross-cultural relevance and acceptance of community consultations.

4.4.1 Data collection methods

The study used both quantitative and qualitative methods for data collection. These included:

a. questionnaire survey interviews with migrant Africans;
b. semi-structured interviews with migrant Africans with no experience of TB treatment;
c. semi-structured interviews with migrant Africans with experience of TB treatment;
d. community consultations with migrant Africans
e. semi-structured interviews with key stakeholders from multiple sectors;
f. qualitative observations (minutes and notes from CAP meetings, and notes from all planned and unplanned discussions and consultations);

g. process and outcome evaluations of CAP and CRF participation.

Before beginning the surveys, four CRFs conducted semi-structured interviews as a pilot exercise to identify other topics that needed to be included in the survey. No new topics emerged from the pilot interviews. The subsequent methods were finalized sequentially. The input from study participants gathered by one method shaped the content of the following methods, ensuring contextual appropriateness and community responsiveness.

4.5 SAMPLING AND DATA COLLECTION

This was the main fieldwork phase during which sampling and data collection were undertaken by the CRFs and the PI. The study comprised two main study samples: migrant Africans and key stakeholders.

The CAP and CRFs informed the development of the sampling strategies which were tailored according to the specific sub-group samples. Awareness of, and community participant recruitment for, the study was achieved at multiple treatment (e.g., TB Clinics) and non-treatment sites (social and commercial venues, social networks) through a variety of methods (e.g., snowball sampling, poster displays and leaflet distribution, feature articles in community newsletters and networks, direct approach by CRFs via social contacts and networks, and purposive sampling at the TB Clinics). Both snowball and purposive sampling were undertaken for the key stakeholders.

4.6 DATA ANALYSIS

The analysis of the quantitative and qualitative data sets involved a number of different systematic steps, encompassing separate and integrated analysis. Quantitative data were analyzed with SPSS 12.0 for Windows statistical software. Qualitative data were analyzed manually, with a thematic approach, based on grounded theory (Strauss and Corbin, 1990), clustering recurring factors into themes and sub-themes. The same procedure was followed for the integrated analysis. The CAP and CRFs participated in the data analysis process. Their participation shaped the interpretation of the data, ensuring valid interpretation, study conclusions, and recommendations based on the data. The study findings have been published elsewhere (Marais, 2007).

4.7 IDENTIFICATION AND PRIORITIZATION OF THE RECOMMENDATIONS

The CAP and CRFs participated in the identification and prioritization of the recommendations for public health interventions toward improved

TB control, and improved implementation of participatory research designs (Marais, 2007). These recommendations are rooted in the findings from all the different data sets, and the input from the CAP and CRFs. During data collection, all migrant African and key stakeholder participants were asked to identify recommendations for improved TB control; many responded spontaneously without probing. Recommendations suggested during the qualitative observations were also recorded. In addition, throughout the entire study, CAP partners and CRFs were asked to identify recommendations for improved participatory public health research. This approach contrasts with more conventional research paradigms in which "outside experts" determine the recommendations. The recommendations of this study arose from a fusion of "internal" (participating migrant African communities) and "external" (participating sectors) contexts. They were extracted from the findings from the different data sets and presented in simplistic written format to all CAP partners and a group of available CRFs. Their perspectives and opinions were sought, not to alter or replace, but to verify and/or expand the explanations of the recommendations.

The final recommendations were prioritized individually by the CAP partners and by the group of CRFs. Following individual prioritization on a scale of "not important" (score=0) to "very important" (score=10), the mean score of each recommendation was calculated. These were very high, ranging from 8–10. These scores were re-visited during a CAP group discussion to agree the final scoring. Group consensus was that all the recommendations were important, and, therefore, required no amendments.

4.7.1 Public health interventions

In addition to the recommendations of the study, the CBPR design also facilitated immediate change-producing action in response to community conditions and needs identified throughout the research process. For example, all study participants were given prepared printed material with information about the signs, symptoms, and treatment of TB; how to access TB screening; and the contact details of organizations, CBOs, and ROs representing and serving migrant African communities. From the outset, study findings and recommendations were considered by the CAP. Whenever possible, the CAP took action directly — providing two community-based TB awareness days in response to study participant requests during data collection, or indirectly — facilitating a link between the local TB Clinic and organizations for the homeless, identified by CRFs during the fieldwork phase of the study.

Direct action was also taken by some CRFs who, after completion of interviews and on request from the migrant Africans, escorted them to the local TB Clinic for screening or treatment follow-up appointments.

4.8 OUTCOME EVALUATION

Using several internal and external methods described in sections 4.2.2 and 4.3.5, evaluations of the outcome of the participation of the CAP and CRFs were undertaken near completion of the study. The purpose of these evaluations was:

a. to establish the overall achievements, weaknesses, and experiences of engagement as CAP partner and/or CRF;
b. to identify recommendations for improved engagement of communities in public health research.

The findings of these evaluations have been published elsewhere (Marais, 2007) but the sections below describe the main issues which emerged.

4.8.1 Overall experiences of engagement as a CAP partner

Participants reported wide-ranging reasons for becoming a CAP partner in the study, from organizational, community, and personal development to interest in the participatory methodology and working in partnership with multiple sectors, especially with an academic institution. Several factors motivated sustained participation as a CAP partner. These centred around commitment to the participatory methodology, the eradication of TB, an equitable research partnership approach, participation from the outset, reciprocal learning, recognition of personal expertise and input, multisectoral participation, and an interest in and responsibility for community health and development. Work pressure, lack of capacity (time, funding, and staff), and competing priorities were cited as the key factors which sometimes impeded participation.

Overall, participation as a CAP partner was a positive experience for all, contributing to personal, organizational (including institutional) and community development. Participants acquired new and transferable skills (e.g., research, evaluation, participatory approaches, cross-cultural communication) and knowledge (e.g., about TB and methods for its control, and the roles and responsibilities of different organizations). This benefited their personal and organizational interactions with community members and the various sectors, not only in relation to improved TB control and research activities, but to broader community development. They also established new working relationships, contacts, and networks which will further benefit their organizational roles and community development. Several reported that their participation provided a deeper understanding of the range of problems experienced by communities and providers in terms of access to and provision of general healthcare and TB control. Some also gained confidence and practical experience in research, participatory work with different sectors and communities, and providing TB information and advice to community members. All the academic researchers reported increased knowledge, skills, and motivation for participatory research. Participants were inspired by the participatory research experience, the mutual learning and capacity building, and by the multisectoral engagement to combat TB. All partners felt that the CBPR process was highly appropriate and beneficial to migrant African communities. Equitable research partner relationships, engagement from the start of the study, and having an equal say in all discussions and decision making, were highly regarded.

4.8.2 Overall experiences of engagement as a CRF

Similar to the CAP, the reasons for participation as a CRF included personal and community development; interest in participatory research methodology; learning about community perspectives on TB, general living conditions, and needs; and a desire to help fellow community members by raising awareness about TB and other health related issues. Several factors motivated sustained participation as CRFs throughout the study. These centred around commitment to the participatory methodology, fulfilment of interviews with community members, gaining additional knowledge and information, witnessing community benefit, interest in community health and development, and cross-cultural interaction and learning. The difficulty of finding participants who matched the study inclusion criteria was the key factor impeding participation for some.

Overall, participation as a CRF was a rewarding experience, contributing to personal capacity building and empowerment through:

a. increased knowledge about TB and other health care issues;
b. greater confidence, self-esteem, and motivation;
c. acquisition of transferable skills;
d. improved cross-cultural awareness and understanding;
e. enhanced cross-cultural communication skills;
f. improved research and interviewing skills;

g. achievement of skills in TB control and participatory research activities;
h. enhanced employment potential.

Participation as a CRF had a positive impact on community health and development by building good relationships and providing communities with information and motivation.

Several CRFs were of the opinion that they had little direct scope to influence policy, but that the training and engagement of CRFs in research was innovative and important for the development of appropriate public health research and interventions. The CRF approach offered great potential for distributing health information to communities and providers, and empowering community members to demand better access to, and better services from, the National Health Service and other provider or non-responsive and oppressive organizations.

4.9 Final Report and Dissemination

Throughout the research process, the CAP and CRFs facilitated the dissemination of information and knowledge to and from the target communities and multiple sectors representing and serving them. This included word-of-mouth; prepared printed materials about the signs, symptoms, and treatment of TB; services representing and serving migrant Africans; and knowledge about research and methods for TB control by training and participation. CAP partners and CRFs distributed the final study report directly to the target communities, multiple CBOs, statutory and non-statutory organizations, and academic institutions. The report was provided to any research participant who requested a copy.

The CAP submitted several articles about the study to relevant newsletters, and the PI presented various lectures on the adopted CBPR design at academic, healthcare, and CBO levels. The study findings, with accompanying printed study report (Marais, 2007), were presented at several community and provider forums. Several articles are planned for publication in printed formats accessible to migrant African communities, policy makers, health and social care providers, and academics.

5. Conclusions: Implications for Community-based Researchers

The documentation of this process of community engagement in public health research is important. It presents an inclusive model for community engagement in research and defines the process of competent, culturally appropriate, and beneficial community research partnerships.

The CAP focused the study on a group which would otherwise not have engaged in research: the migrant communities. The study findings demonstrate the value of CBPR, for example:

a. research methodology, recommendations, and resulting public health interventions are contextually and culturally appropriate, sustainable, and beneficial to the target communities;
b. a fusion of external and internal expertise bridges the "context-gap" between externally and internally produced knowledge;
c. swift translation of results into effective and relevant interventions, beneficial to the target communities, bridges the "translational-gap."

The findings also demonstrate the potential of CBPR for enhanced research outcomes, community development, and mutual capacity building between insider and outsider research partners for better interactions in health promoting and research activities.

The challenge is that funding guidelines for research do not usually allow for the initial, and essential, phases of the overall CBPR process as outlined here. These include, importantly:

a. initial stakeholder consultations;
b. building mutual trust;
c. establishment and maintenance of the Community Advisory Panel (CAP);
d. Community Research Fieldworker (CRF) training and support;
e. rapid public health interventions, throughout the research process, in response to expressed and identified community needs;
f. community capacity building for and engagement in data analysis;
g. ongoing process and outcome evaluation.

Initial and sustained community research partnerships are currently developed, but not compensated, by self-selected, committed people. The academic research funding model still excludes costs such as start-up salaries, honoraria, and administration expenses prior to the formulation of a research budget. Our purpose is to make this process accessible for our colleagues and to encourage sponsors to consider the ethics of funding the development of the initial research partnerships and other non-conventional but essential phases toward the engagement of communities in public health research. The present study has expanded models for community participation. The possibility of guidance from community members to preclude the conduct of insensitive or untimely research has yet to be explored. There are still many more steps to be taken towards a truly equitable model for engaging communities in participatory public health research — transforming people hitherto regarded as passive research subjects into active co-researchers.

> *When indigenous peoples become the researchers and not merely the researched,*
> *the activity of research is transformed.*
> *Questions are framed differently,*
> *priorities are ranked differently,*
> *problems are defined differently,*
> *people participate on different terms.*
> (Smith 1999: 193)

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