

# Participants as community-based peer educators: Impact on a clinical trial site in KwaZulu-Natal

## AUTHORS:

Sarita Naidoo<sup>1</sup>

Neetha S. Morar<sup>1</sup>

Gita Ramjee<sup>1,2</sup>

## AFFILIATIONS:

<sup>1</sup>HIV Prevention Research Unit, South African Medical Research Council, Durban, South Africa

<sup>2</sup>Department of Epidemiology and Population Health, London School of Hygiene & Tropical Medicine, London, UK

## CORRESPONDENCE TO:

Sarita Naidoo

## EMAIL:

sarita.naidoo@mrc.ac.za

## POSTAL ADDRESS:

HIV Prevention Research Unit, South African Medical Research Council, 1st and 2nd floors, Westville Village Market, 123 Jan Hofmeyer Road, Westville 3630, South Africa

## DATES:

**Received:** 05 June 2012

**Revised:** 15 Feb. 2013

**Accepted:** 20 Feb. 2013

## KEYWORDS:

trial participants; peer educators; community; education; recruitment

## HOW TO CITE:

Naidoo S, Morar NS, Ramjee G. Participants as community-based peer educators: Impact on a clinical trial site in KwaZulu-Natal. *S Afr J Sci*. 2013;109(7/8), Art. #0037, 5 pages. <http://dx.doi.org/10.1590/sajs.2013/20130037>

Participant recruitment, retention and product adherence are necessary to measure the efficacy or effectiveness of an intervention in a clinical trial. As part of a Phase III HIV prevention trial in a rural area in Kwazulu-Natal, South Africa, a peer educator programme was initiated to aid in recruitment and retention of trial participants from the community. Enrolled trial participants who had completed at least 6 months of trial participation and who had honoured all of their scheduled trial visits within that period were approached to be peer educators. Following additional selection criteria, 24 participants were eligible to be trained as peer educators. Training topics included HIV/AIDS, sexually transmitted infections, nutrition, antiretrovirals, clinical trials, and methods of disseminating this information to the community. The role of peer educators was to bring interested women from their community to the trial site for comprehensive education and information about the trial and possibly trial participation. A total of 1879 women were educated by peer educators between July 2004 and December 2006. Of these, 553 women visited the trial site for further education and screening for participation in the trial. Peer educators provided continuous education and support to women enrolled in the trial which also promoted retention, ultimately contributing to the site's 94% retention rate. Recruitment and retention efforts of trial participants are likely to be enhanced by involving trial participants as peer educators. Such trial participants are in a better position to understand cultural dynamics and hence capable of engaging the community with appropriate HIV prevention and trial-related messaging.

## Background

Peer education is a useful and effective educational approach to prevention of HIV/AIDS and other sexually transmitted infections (STIs)<sup>1</sup> and has become a popular method for health interventions globally, including in developing countries.<sup>2</sup> Peer education programmes have been widely accepted and implemented in various health promotion areas such as family planning, nutrition, drug use and violence prevention.<sup>3-5</sup> It is a low-cost and sustainable intervention that can facilitate increases in knowledge, and attitude and behavioural changes. Peer education can also enhance HIV prevention efforts.<sup>6-8</sup> Peer educators are perceived by their peers to be trustworthy or socially credible, and thereby effectively gain access to target communities more easily.<sup>9</sup> The education provided by peer educators usually involves supporting or influencing members of a given group to effect change among members of the same group and thus promotes context-specific and acceptable forms of information sharing.<sup>9</sup>

Our aim was to identify and develop trial participants as peer educators and empower them with the necessary skills required to significantly contribute towards community education, HIV/STI awareness, and trial participant recruitment and retention. We also envisaged that these women would continue with HIV/STI awareness and education within their communities when the trial was completed. Enrolled trial participants who were committed to HIV prevention, education and the uptake of HIV Counselling and Testing (HCT) in the communities where they lived were identified to be trained as peer educators. Here we describe the initiation and outcomes of the peer education programme among trial participants and their contribution to the recruitment and retention efforts at the trial site.

This study was approved by the University of KwaZulu-Natal Biomedical Research Ethics Committee (Ref. E053/05).

## Methods

### *Study area*

The Methods for Improving Reproductive Health in Africa (MIRA) trial was conducted between 2003 and 2006 across five clinic sites in Harare (Zimbabwe) and in Durban and Johannesburg (South Africa), and included a total of 5045 participants.<sup>10</sup> In Durban, the study was undertaken from a peri-urban clinic in Umkomaas and a rural clinic in Botha's Hill. The peer education programme which was initiated and implemented at the Botha's Hill site took place between July 2004 and December 2006.

### *Selection and recruitment of peer educators*

Women enrolled in the MIRA trial who had completed at least 6 months of trial participation and who had honoured all of their scheduled trial visits within that period were selected and approached to be peer educators. Additional eligibility criteria for peer educator selection were: permanent residency within the community, literacy, a good understanding of the trial, the ability to communicate confidently in the local language (isiZulu), availability to conduct peer education activities within their community, voluntary disclosure of their participation in the trial to their communities and encouragement of their local community members to use available HCT services. Reimbursement, of a minimum of R10, was provided to the peer educators for their travel, time and efforts in educating and referring women to the trial site for screening. This reimbursement was approved by the University of KwaZulu-Natal Biomedical Research Ethics Committee.

### *Peer educator training*

Peer educators were provided with formal training annually, through workshops conducted in the local language (isiZulu). The trainers were community liaison officers (CLO), clinical trial counsellors, social scientists, nurses and clinicians who were research team members experienced in the implementation of clinical trials. Trainers discussed the purpose, objectives and expectations of the programme with the peer educators and each trainer facilitated sessions in their area of expertise. The interactive training curriculum included communication skills, clinical trial related information, basic facts about HIV/AIDS and STI transmission, HIV testing, correct use of condoms, nutrition, positive living and antiretrovirals. Peer educators were provided with referral-to-care education and key HIV prevention messages together with methods of disseminating this information in the community.

### *Role play*

Peer educators participated in role play as part of the training. The role plays were based on scenarios which provided the peer educators with the opportunity to practise their education and communication skills.

### *Education material*

Peer educators were given notebooks and a package of educational material developed in the local language, which they could use to aid in their education efforts in their communities. The package included support material such as pamphlets and posters on HIV and STIs and notes on potential responses to questions that they could be asked when conducting education sessions in the community. They were also provided with user-friendly worksheets to assist them to document their peer education activities. A directory of the local community referral structures and health-care services available in the community was also provided to them to share with community members during their education sessions. The referrals included local primary health care, HCT, and prevention of mother-to-child transmission clinics as well as support groups, hospices, hospitals and social-welfare departments.

### *Evaluation of training and understanding*

An evaluation of the peer educators' understanding and opinions of the training was conducted. This assessment took the form of questionnaires, which were completed after each session, and discussions based on the topics presented during the training sessions. There was also a verbal revision session each morning to evaluate the previous day's learning. Peer educators were also asked to complete training evaluation questionnaires at the end of the week's training, which were used to assess the overall training programme. Peer educators were awarded a certificate of attendance which confirmed their participation in the peer education training programme.

In addition to the annual training workshop, the CLO provided monthly on-site refresher training that comprised group and one-on-one information sessions on the role of the peer educator, maintaining confidentiality, trial-related education, key prevention messages, and updates on STIs and HIV/AIDS.

### *Monitoring and assessment of the peer education programme*

Peer education activities were monitored by the CLO by means of direct observation of peer educators' outreach activities in the community and written and verbal reports from the peer educators. Feedback received during interviews and informal discussions with community stakeholders, such as local clinic managers, was also used as an indicator for monitoring the outcomes of the peer educators.

## **Results**

### *Selection and recruitment of peer educators*

Peer educators were recruited from the 754 enrolled participants at the Botha's Hill trial site. The biggest challenge was identifying peer educators who would remain committed to the programme as no salary or consistent financial stipend was provided for the peer educators. Of the enrolled participants, 26 fulfilled the selection criteria and were approached by study staff. Of these 26, 24 verbally consented to be trained in conducting peer educator activities within their communities. Later, 9 peer educators withdrew from the peer education programme due to work-related commitments; however, they continued to participate in the MIRA trial. By the end of 2006, only 15 peer educators remained in the peer education programme.

### *Peer educator training*

Annual training sessions addressed issues surrounding confidence building of the peer educators and their acceptance within their communities. This training also provided the opportunity to include topics, such as home-based care and information on tuberculosis, that peer educators requested as per the education needs of their communities. Continuous on-site training also assisted in refreshing the skills, knowledge and motivation of the peer educators and formed an important part of the peer education process.

Opinions shared by peer educators during role plays indicated that the majority of them understood HIV-related issues (transmission, risks and prevention) and the factors affecting the community at large. Review of the outcomes of the training evaluation questionnaires completed by peer educators indicated that all peer educators approved of the training content, the information provided and the method of training. Peer educators also highlighted the ease with which they were able to interact with the trainers and felt that the information given to them at the training sessions adequately enabled them to go into their communities and share the same information with others. In addition, during discussions with trainers, peer educators reported that the peer education training workshops provided them with a better understanding of new research on HIV prevention.

### *Monitoring and assessment of the peer education programme*

The CLO supervised, mentored and supported the peer educators by monitoring them during their education and outreach activities in the community. Feedback received from peer educators via written and verbal reports described their activities in the community, the outcomes and challenges, and frequently asked questions. This feedback enabled the CLO to assess the level of outreach as well as the impact of peer education efforts. This information was also used by researchers to provide additional training, support and information to peer educators and to improve future training workshops.

### *Value added to community*

During an interview with the CLO, a community stakeholder from a nearby local HCT clinic reported that peer educators educated patients at the clinic daily which immensely helped to ease the workload of the understaffed clinic. Peer educators provided an additional resource in conveying HIV prevention messages to where it was needed the most. They also developed a good working relationship with patients in the clinic and educated them on the importance of accessing HCT services, as well as on their general health. This community stakeholder also observed that peer educators were personally interested in the well-being of those they educated and also attempted to follow-up with some of the women whom they had educated.

### *Trial-related outcomes of peer education*

#### Education and recruitment

Peer education was conducted at local and mobile clinics and with various groups in the communities. Peer educators educated and encouraged their communities to recognise risk factors and protect themselves against HIV and other STIs, while providing researchers with valuable insight and understanding about clinical trials from the participant's perspective. A total of 982 men, 1879 women and 401 adolescents were educated by the peer educators from August 2004 to December 2006. Of the 1879 women educated, 553 potential participants had come to the trial site seeking further education and screening for participation in the clinical trial. The peer-recruited women ( $n=553$ ) contributed to 31% of the total women screened ( $n=1800$ ) at the Botha's Hill trial site. Peer educators were not informed by trial staff of the reasons for some of the women they referred being ineligible to participate in the trial, thus maintaining confidentiality.

Peer educators faced numerous challenges during their education sessions in the community. These challenges were reported to the CLO by the peer educators during discussions and via written reports. Several community members refused to be educated by peer educators and did not want to be involved in the programme, or take the education seriously. A number of women in the community disclosed to the peer educators that they were afraid of their partners and therefore could not participate in the trial. There was also a general fear of undergoing the Papanicolaou smear. People in the community did not understand reimbursement in the context of a clinical trial and felt that women were being paid for their participation.

Peer educators found the 'fear of knowing one's HIV status' to be a chief concern within their communities. For those who were afraid of 'knowing their HIV status', the fear of being HIV positive could have resulted in them not disclosing their status, for fear of being stigmatised and socially rejected. HIV and study-related fears and misconceptions in the community were addressed by peer educators through education sessions. The peer education programme was instrumental in raising awareness of HIV/AIDS within the target communities, based on anecdotal reports from peer educators and local clinic managers regarding the notable increase in the number of people accessing HCT after being educated by peer educators.

#### Retention

Peer educators provided on-going education to women enrolled in the trial which promoted retention. On-going education included the requirement of enrolled participants to attend all study visits. Peer educators were requested to assist with retention of women referred by them to the study only if the enrolled women provided them as a contact in their locator form, once again to ensure participant confidentiality. CLOs contacted peer educators to assist them with locating women who had missed their scheduled study visits and discussed various reasons why participants were not returning for their scheduled visits. During the final trial close-out, peer educators were instrumental in contacting women they had recruited in order to honour their final study exit visit. Over the period of January 2006 to August 2006, 34 participants were contacted by peer educators to return to the trial site for a final close-out visit which improved the overall retention and contributed to the trial's final retention rate of 94%.<sup>11</sup>

#### *Benefits to the peer educators*

Peer educators informed the researchers that they were not being formally recognised in the community as trained educators. They suggested wearing 'peer educator' t-shirts so that they would be easily identified as peer educators by community members. Peer educators derived great pride and satisfaction in wearing the t-shirts subsequently provided by the researchers.

The peer education programme had a positive impact on the peer educators' knowledge, skills and personal development. Four peer

educators were interviewed by the Medical Research Council (MRC) iThemba Newsletter team on their personal development journey through their involvement in the programme.<sup>12</sup> As study participants, they experienced the trial as a positive impact on their lives. As experienced and educated members of their community, they felt that they were the best people to communicate safe sex education at a grass-roots level. Peer educators also expressed the ease and confidence with which they were able to speak to their communities, friends and families on topics relating to sexual and reproductive health. This confidence also filtered through to their personal lives as they were now not afraid to tell their husbands that they were going out to do 'important work' within the community and that this work was 'important and right' for them.

#### *Dissemination of final trial results*

Peer educators attended two training sessions in July 2007 on the MIRA trial results, ensuring clarity of messaging and dealing with the fears and misconceptions of their targeted audiences. They were trained, by MIRA study managers, on the meaning of the results, correct messaging with respect to the results and the way forward after the MIRA trial. Peer educators worked closely and assisted site managers with potential concerns and questions that could be raised by community members and participants. They also assisted with the translation of these questions into the local language (isiZulu). At study closure, peer educators were given condoms and HIV and STI prevention-related educational resources to distribute during their education sessions in their communities.

#### *Sustainability of the peer education programme*

The peer education programme has been sustained from 2004 until the present and currently has active peer educators at all clinical research sites of the MRC HIV Prevention Research Unit (HPRU). There are currently two active peer educators at the Botha's Hill trial site who have been with the programme since its inception. Since the South African government initiated the HIV counselling and testing programme in 2010, peer educators at Botha's Hill have been conducting awareness campaigns together with the local clinic staff. These peer educators are also currently participating in a Pre-exposure prophylaxis (PrEP) trial and are members of the trial community working group (CWG).

The researchers currently provide peer educators with on-going training and information on treatment, care and HIV prevention research such as PrEP. The role of peer educators within a clinical trial setting and in communities has expanded since its inception, and, in 2009, male peer educators were recruited by female peer educators in the Botha's Hill area. These male peer educators worked closely with the site's CLO to conduct education sessions with men in their areas.

All peer educators, male and female, are part of the MRC HPRU CWG. They attend the monthly CWG meetings and provide the research staff and other CWG members with valuable feedback from current trial participants – community men and women that they recruit for the study. Peer educators also participate in monthly international CWG conference calls. In addition, peer educators have recently participated in protocol review meetings in which they have provided valuable feedback on informed consent documents and procedures from a research participant's point of view.

### **Discussion**

Peer education has been successfully implemented in many countries, as well as in different contexts, because of its role at the ground level. To our knowledge, this study is the first of its kind, worldwide, that describes HIV prevention trial participants being recruited and trained to be peer educators while concurrently enrolled and participating in the trial themselves. Other studies have described training ex-trial participants to be peer educators and recruiters.<sup>13,14</sup>

Peer educators in this study provided HIV-prevention education and support to women in their communities. They were genuinely concerned with promoting awareness of HIV/AIDS and other STIs within their community and provided a valuable and supportive structure to help



make prevention messages and options accessible to the community during the period of the trial. This process involved raising awareness, providing accurate information, encouraging safe sex and reinforcing values required to promote positive change in their community. The peer education programme also benefitted the peer educators themselves, and had a remarkable impact on their self-esteem and confidence. Peer educators learned important skills from trainers, such as how to be empathetic, non-judgemental and actively listen. These skills, combined with the HIV-related information they received at workshops and trainings, proved beneficial and enabled them to communicate with community members effectively.

Women in rural areas are particularly vulnerable to HIV infection and other STIs, as they are constrained by gender roles and associated societal and cultural norms. Consequently, they lack the ability to protect themselves against potentially unsafe sex with their partners, as a result of poor negotiation skills with respect to condom use.<sup>15,16</sup> Women in the community felt comfortable discussing issues such as power dynamics, condom negotiation and so forth with peer educators whom they could identify with and who were empathetic to their situation.

It was integral that community stakeholders formed part of this peer education programme as their involvement resulted in unwavering support and acceptance of peer educators and their outreach and education activities within the communities. This support was achieved through on-going involvement and consultation with community stakeholders by the trial CLO during the planning and implementation of this programme. As a result, the peer educators encountered minimal challenges in gaining the support of local community stakeholders and service providers. Community stakeholders highlighted that the trial researchers provided continuous support and education on HIV/AIDS-related issues via the peer educators who had made a significant impact in their community. Nurses at local clinics supported the peer education programme as peer educators assisted them by educating patients in their local clinics. Church elders and ministers who previously maintained an HIV/AIDS 'denialism' stance,<sup>17</sup> finally acknowledged that the disease existed, after considering the education received from peer educators.

Another outcome of the peer education programme was that peer educators proved to be an important link between the trial team and the community as they reported community rumours related to the research, which they addressed using the training information and material provided to them. Peer educators also assisted with message development and dissemination of final trial results in partnership with researchers, sharing their own experiences with the communities. Ultimately, peer educators served to educate a broader range of individuals in the community where the trial was being conducted and consequently the peer education programme served as a valuable link between the trial and the community. Peer educators in the trial proved to be not only an invaluable resource for recruitment and retention of fellow trial participants but remained a sustainable resource in their community long after the trial had ended.

### *Limitation*

The lack of scientific evaluation of the peer education programme was a limitation in this study, in that it was not possible to quantify the impact of the peer education programme on the target community and the peer educators themselves. The assessment was based purely on observation of peer education activities in the community and on reports from community stakeholders and the peer educators. This limitation is acknowledged and was addressed by a subsequent study using process and outcome evaluations which included in-depth interviews, focus groups and round-table discussions. The outcome of this subsequent study will be presented in a future publication.

### **Conclusion**

Trial participants from this HIV-prevention trial site were successfully trained as peer educators and impacted positively on the outcomes of health education, outreach and recruitment and retention for the trial.

At the same time, the peer educators and women in the community were empowered to take charge of their sexual and reproductive health. Community empowerment through education and capacity development of peer educators facilitates sustainability of HIV awareness within the community. It also ensures that communities are provided with sustainable programmes for HIV prevention. There is a need for continuous support and promotion of peer education activities, given the serious nature of the spread of HIV/AIDS. The peer education programme described in this paper added value to the trial by empowering the community within which the trial was conducted.

### **Acknowledgements**

We thank the study team and the peer educators who participated in this programme and Elizabeth Montgomery for initial comments on the paper. We also thank the sponsor of the MIRA trial: The Bill and Melinda Gates Foundation (grant number 21082) and the MIRA trial team for their support.

### **Authors' contributions**

S.N. was the principal investigator of the Peer Education Study from 2005 to 2006 and drafted the manuscript. N.S.M. is the current principal investigator of the Peer Education Study, provided data on peer educator activities and edited the draft manuscript. G.R. was the Durban site principal investigator of the MIRA Trial and is Director of the HIV Prevention Research Unit. G.R. initiated the concept of the Peer Education Study, oversaw the implementation of the MIRA trial, and reviewed and edited the draft manuscript.

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