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## Challenges of developing a district child welfare plan in South Africa: lessons from a community-engaged HIV/AIDS research project

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### Abstract

The Amajuba Child Health and Wellbeing Research Project measured the impact of orphaning due to HIV/AIDS on South African households between 2004 and 2007. Community engagement was a central component of the project and extended through 2010. We describe researcher engagement with the community to recruit participants, build local buy-in, stimulate interest in study findings, and promote integration of government social welfare services for families and children affected by HIV/AIDS. This narrative documents the experience of researchers, drawing also on project reports, public documents, and published articles, with the objective of documenting lessons learned in this collaboration between researchers from two universities and a community in South Africa during a period that spanned seven years. This experience is then analyzed within the context of an applied research, community-engagement framework.

### Keywords

HIV/AIDS; orphans; community engagement; child welfare policy; South Africa; global health

### Introduction

The community-engaged research approach, also known as ‘community-based participatory research’ or ‘collaborative partnership’, has gained acceptance and advocacy among global health researchers as an ethical requirement for working in vulnerable communities (1–5).

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Community engagement is central to applied public health research, as research questions and evidence generated must, by definition, be of practical value. Stakeholders include local, regional and national government officials and policy makers; donors; program staff from non-governmental, community, and faith-based organizations; community leaders; and the media. Such expectations are also generated by ethics review committees as criteria for approval of study protocols, citing the principles of ‘do no harm’ and ‘empowerment’ of research subjects (6). National and local governments may provide access to a study site contingent on researchers agreeing to report findings to the community quickly and in a format readily understandable to the general public.

The academic literature recommends guidelines for handling ethical, social and cultural challenges while working with community partners to achieve common objectives (1,4,7–10). These guidelines emphasize the need for examples documenting community-engaged research projects, and several researchers have published lessons learned from past or ongoing attempts at community engagement (5,9–11). One key message from these examples is that community-engaged research is a messy, often serendipitous process dependent on opportunity and the shifting priorities of various actors. It also faces administrative, logistical, and ethical challenges.

We offer an analytical narrative of the Amajuba Child Health and Wellbeing Research Project (ACHWRP). ACHWRP was a longitudinal study of the impact of HIV/AIDS and orphaning on household welfare in South Africa that also set out to work closely with the community at each stage of the research and dissemination process between 2003 and 2010. This seven-year period included all stages of the project during which study staff were resident in the community: one year of study preparation; three of data collection; and three of community service and advocacy toward the goal of facilitating a district child welfare policy.

### **Research and policy objectives of ACHWRP**

In 2003, our team set out to document the consequences of parental deaths from AIDS on orphans and other children in foster households in Amajuba District, KwaZulu-Natal, South Africa. The study was undertaken by Boston University School of Public Health (BU) and University of KwaZulu Natal Health Economics and HIV/AIDS Research Division (HEARD) with support from the US National Institutes of Health (NIH) Africa Partnership program, and had both research and policy objectives. The *research objective* was to measure the impact of high levels of orphaning and foster care on households, and to compare the welfare of orphans and non-orphans in foster households vs. that of non-orphans living in non-orphan households. Detailed study methods and findings have been described elsewhere (11–18).

The *policy objective* was to facilitate development of a district-level child welfare management plan by embedding the research within a community-engagement framework. This entailed engaging with government departments, non-governmental and community-based organizations (NGOs and CBOs) from the start, with the goal of developing detailed knowledge of the community, sharing study findings at multiple time points, and catalyzing community partners to advance child welfare. The project encountered administrative,

logistical, and ethical challenges throughout the process. The ethical challenges resulted in the greatest concrete community impact (an improved referral system and child welfare plan process), yet the nature of externally funded research and funding limitations ultimately defined and, arguably, undermined our attempts to place equal priority on community engagement.

### **Amajuba District, KwaZulu-Natal: profile of the study site and population**

Situated in northern KwaZulu-Natal, Amajuba District represents a broad cross-section of urban, peri-urban, and rural areas. Its population is just under 500,000 (20). Newcastle is the commercial hub where housing, health, education, and road infrastructure are well-developed in the central business district, but poorly developed in peripheral areas. When ACHWRP began in 2003, the district was confronting an all-time high unemployment rate of 47% (21). Since then, the economic situation has improved somewhat, with unemployment dropping to 41% in 2011 (20), and those living on less than one US dollar per day falling from 12.9% in 2002 to 4.1 in 2011 (22). Poverty is unevenly distributed across the municipalities with extreme poverty ranging from 2.6% in Newcastle to 8.6% in eMadlangeni and 7.5% in Dannhauser (22). HIV prevalence among pregnant women attending antenatal clinics has remained high in KwaZulu-Natal for the last decade, at 37.5% in 2011 (22). Prevalence at antenatal clinics in Amajuba was the highest in the province in 2006 at 46%, but by 2011 had decreased to 35.3%.

Official orphan prevalence data for Amajuba District are not available. South Africa has about 3.1 million orphans due to all causes, with half orphaned by HIV/AIDS. In KwaZulu-Natal, 22% of children are orphans due to all causes, compared to 17% in South Africa as a whole (23). According to unpublished ACHWRP sampling data, annual orphan incidence in Amajuba was 10% among school children aged 9–15 years.

ACHWRP's quantitative study documented the longitudinal household and child-level impacts of parental death on a cohort of school-going youth aged 9–15. The study consisted of a case-control design, embedded within a prospective longitudinal cohort. Three annual rounds of demographic, economic, health, and psychosocial data were collected from 637 households between 2004 and 2006. Caretakers and children were interviewed in their homes by local research assistants (RAs) trained in field research methodology. The BU and HEARD institutional review boards (IRBs) approved the study.

### **ACHWRP'S multi-layered engagement with the community**

As the project was starting in 2003, an initial review of civil society organizations, government departments, and other stakeholders identified numerous organizations and government departments providing services to orphans and families affected by HIV/AIDS. These services were largely uncoordinated, with only half of the 15 civil society organizations identified reporting interacting with other organizations or being aware of what others were doing for vulnerable children and families (24). By the end of ACHWRP's seven years, collaboration and coordination among local social service organizations had increased substantially. To some extent, ACHWRP facilitated this by creating a community

board to advise the study and conducting a number of outreach activities and public events. Table 1 presents an inventory of key community partners engaged over the life of the project.

Developing a deep understanding of the context of the study site and building relationships within the community were central to the ACHWRP community-engagement framework. HEARD researchers had previous experience working in Amajuba District collaborating with the KwaZulu-Natal Department of Education (DoE) to pilot the District Education Management Information System, which collected monthly enrollment, absenteeism, and staffing information and numbers of newly orphaned children from schools (25). HEARD's knowledge of the district and relationship with the local DoE and school administrators were chief rationales for locating the study in Amajuba District.

ACHWRP maintained an office in Newcastle from 2003 to 2010, with BU and HEARD research staff living in the district during their tenure with the project. In their role as newcomers, the senior members of the research team had the simultaneous benefit of outside objectivity and challenge of gaining acceptance as researchers and new community members. All RAs and office staff were recent high school or college graduates and district residents. While data collection ended in July 2007, the team remained through March 2010 working with local stakeholders to link study findings with district policy responses as a first step toward devising and implementing collaborative, evidence-based interventions. Through formal and informal relationships with stakeholders, the team initiated and facilitated collaborations between government child welfare agencies, CBOs, and other stakeholders to improve child welfare services.

Unlike the data collection portion of the project, ACHWRP's community engagement framework did not have a clear agenda for reaching its goal. Activities were driven by interaction, opportunity, and changing circumstances, which drove ongoing development and modification of plans. The list of activities and partnerships outlined in Table 2 is illustrative rather than comprehensive, as further details have been reported elsewhere (26–28). Moreover, the partnerships, specific activities, and objectives were not discrete events that took place at single points in time. Rather, they built upon one another toward the common goal of improving integration of child welfare services through establishing partnerships, reducing barriers, and creating administrative efficiencies.

As noted, the RAs who conducted the household interviews were district residents trained in interview techniques and research protocols that stressed objectivity. Despite this training, they often felt an acute tension between their role as researchers and their sense of community obligation and desire to provide assistance to the study participants who had just spent an hour or more explaining their struggles. In some cases, respondents made direct requests to the RAs for assistance. The purpose of the research had been explained to the participants, and they had provided informed consent, which included an explicit statement that they understood they would receive no monetary assistance for their participation in the study. The RAs reminded the respondents about this agreement, and maintained objectivity during interviews and interactions with household members. Nonetheless, they frequently felt disturbed after interviews as they walked away from impoverished families and, in many cases, hungry children.

Senior researchers and other project personnel attending community meetings with service providers occasionally received a similar message: ‘You’re in these homes and have the resources to gather data; so why can’t you do more?’ The ethical obligation that researchers must make clinical referrals was something the ACHWRP staff thought about frequently. As one senior researcher explained: ‘We were always struggling with the question: where does our role as researcher end and the role of citizen begin?’

During interviews, families frequently explained that they were not able to receive government grants due to missing birth records or other paperwork, and some were simply not aware of available grants. The research team ultimately created and implemented a referral system to help study families obtain services to which they were legally entitled but unable to access due to incomplete paperwork or lack of knowledge about their eligibility.

### **Development and implementation of child/household referral system**

ACHWRP collaborated with the Department of Social Development (DoSD) and DoE to implement the referral scheme in 2004 (during baseline data collection) and ultimately handed it over to these government partners. Study participants were referred for services in two categories: 1) those eligible for childcare, foster, disability and old age grants but unable to access assistance; and 2) those reporting difficulty accessing education for children in their care due to financial constraints, mental or physical illness, or behavioral problems. Cases meeting referral criterion #1 were referred to local DoSD offices; those meeting criterion #2 were referred to the local DoE. Each department designated a focal person to process the referrals, ensure accountability, and facilitate continuity and follow-up. Each also agreed to respond to ACHWRP within two weeks of a referral application being filed. By the time data collection ended in 2007, several dozen cases had been successfully processed.

### **Shift from research to social marketing**

In 2008, the ACHWRP team shifted from research to advocacy. In this phase, the team stepped back from the referral system and focused on strengthening the capacity of CBOs to link households in need with government service providers. ACHWRP staff worked with organizations to improve their ability to conduct an accurate and thorough needs assessment of vulnerable children and document relevant information on the referral card to share with government service providers. Ten CBOs in three wards piloted the referral system and, by April 2010, had connected 1850 children with government services.

Designed as a small pilot study, this second phase of the referral system created an opportunity for the district to scale up the program incrementally as resources and CBO training allowed. The referral cards also provided a means for collecting baseline data on vulnerable children. The referral system was a primary component of the District Child Welfare Management Plan submitted for inclusion in Amajuba’s 2010–2011 Integrated Development Plan. The proposal was submitted to the district in January 2010 and was scheduled for ratification in June of the same year.

## **Challenges of turning evidence into policy and policy into improved services**

While the relationship researchers developed with the community had many positive features, the ACHWRP objective to work with local stakeholders to develop and implement an integrated child welfare plan faced a number of challenges.

### **Tensions posed by university-community partnership**

BU and HEARD were equal intellectual partners in the study design; however, the community was not a third, equal partner in determining study questions or methods. Rather, the research portion of the project more readily fit the definition of ‘community-placed research’, which involves the community in recruitment and on advisory boards (3). Study staff did, however, actively engage with the community to define advocacy objectives and strategies.

While staff were increasingly seen as community insiders, their role and that of the project became blurred as they began receiving requests for support and advice on a variety of problems, a challenge noted frequently in the literature on community-engaged research (2,3,5). ACHWRP was seen by some as an intervention project, a development that both demonstrated the trust the Newcastle Field Office (NFO) staff had built and complicated the job of staff who had to respond to requests for assistance in a way that was compassionate but clear about the limitations of research (26). The referral system is one example of the researchers’ attempt to address this difference in perception by creating an assistance program that would not jeopardize the study and could eventually be taken over by local government and service providers. As Tindana *et al.* note in their case study on the Navrongo Health Research Center in northern Ghana (9), gaining trust through demonstrated community benefit is critical (4). Yet trust takes many years to develop. The social marketing phase of ACHWRP ended and the field office closed just as the child welfare plan began wending its way through the ratification process, making continued facilitation and advocacy difficult.

### **Communicating study results in a timely and audience-appropriate manner**

Sharing study findings with local stakeholders and promoting evidence-based policy and programming were key ACHWRP objectives. Research findings, however, can be complex and difficult to distill into readily understandable language and action points. Early in 2005, cross-sectional baseline findings presented at a community conference indicated that orphans were generally doing no worse than other children and that effort should focus on addressing vulnerable children more holistically. Longitudinal findings suggesting the picture was more complicated over time were later presented during a 2007 community meeting marking the end of data collection. Presenting findings to community stakeholders representing a variety of backgrounds, educational levels, and advocacy objectives created confusion among staff about which and how much data to present, and how to do so in a way that was meaningful.



HEARD historically has approached this challenge of timely dissemination of results by doing secondary data analysis and publishing data through reports and white papers. BU, on the other hand, has focused on sharing evidence with the broader public health community by publishing in peer-reviewed journals, and its researchers are also quickly pulled into other studies after their official time on a given project ends. The long process of analyzing the longitudinal data, writing and submitting articles to journals, revision, and publication came to fruition five years after data collection ended with eight articles published in peer-reviewed journals (11–18). While ACHWRP presented immediate preliminary findings to the community, direct communication of findings to the community over time has been limited by the lack of continued funding and local presence.

## Discussion

There is a question mark at the end of the ACHWRP community engagement story. HEARD researchers maintained their connection with the district, but staff who were based in Newcastle have moved to other projects. They are no longer community members able to conduct direct advocacy and follow-up with their neighbors. This unsatisfying lacuna illustrates the gap between the best intentions of researchers-cum-activists and measurable outcomes. Once research funding is expended, organizations planning to continue advocacy must find additional resources or stop, regardless of the intensity of their commitment to and integration with the community. BU project staff left in 2007 after the end of data collection. HEARD closed the Newcastle office in 2010 after securing supplementary funding for two years of social marketing to publicize the need for an integrated child welfare system. Without a continued community presence, the ratification and implementation of the District Child Welfare Management Plan has been difficult to track.

### Challenges of measuring success in community-engaged health research

We cannot declare success in the project's initial policy objective to facilitate the implementation of a child welfare plan in Amajuba, unlike Nakibinge *et al.* (5), who documented the community engagement experience of their decades-long HIV epidemiology research in rural southwest Uganda. One of the key differences between the Uganda and Amajuba narratives is continuity. The Uganda team has been in the community for 20 years. The seven years spent by BU and HEARD in Amajuba District allowed us to begin to build relationships and mobilize stakeholders to fight for policy change and service implementation, but were insufficient to continue to push processes that often take years to unfold.

As noted by the Uganda team and others, there is no accepted methodology for measuring success of community-engaged research projects (1,4,5,7,8). In the absence of standard measures, Nakibinge *et al.* chart their accomplishments loosely by criteria of longevity, acceptance, scientific output, and community involvement in the project (5). By this yardstick, we argue that the ACHWRP project was strong in terms of scientific output and developing community acceptance and involvement. Despite HEARD's best efforts to remain in the community—and success in doing so for three years after the NIH grant ended

— the eventual closure due to inadequate funding limited our ability to continue engagement after 2010.

Likewise, our experiences and insights align with the framework for effective community engagement in health research outlined by Lavery *et al.* (10), including early initiation of engagement activities; careful characterization of the community and its changing needs; establishment of trust with stakeholders; and development of community assets (10). Throughout the process, the ACHWRP team was transparent about study goals and communicated frequently with community collaborators to understand local concerns about the research and engaged in ongoing review and modification of engagement strategies. The project was less successful in maximizing opportunities for stewardship and shared control by the community.

### **Suggestions for future community-engaged research endeavors**

We offer the following suggestions based on experiences of the Amajuba Project and guidance from the scholarly literature:

*Communicate, align, and manage expectations for all partners throughout the process* (29,30). In hindsight, it is easy to see that both academic partners entered into the research project with great passion but different goals. First, the NIH Africa Partnership grant funding the research had a primary objective of strengthening research capacity of African institutions. The NIH proposal was planned and written collaboratively by both academic partners, but each had different expectations for the capacity-strengthening goals. BU was focused on transferring longitudinal research skills to junior investigators from HEARD. HEARD was focused on transferring data, knowledge, and skills to community partners who would use the research findings to create a child welfare policy. Both objectives were important and to varying degrees successful, but the difference caused a tension we struggled to identify and navigate at the time.

*Communicate and collaborate with community from start of planning to articulate short and long-term research and policy goals* (10,29,31). Amajuba District was chosen as the research site in part because HEARD had already built relationships there. This early identification of the research community and collaborative intention did not, however, translate into engaging the community in developing the funding proposal, the IRB protocol, or the instruments. Early planning between academic and community partners would have improved our ability to prioritize communication of study findings to various community stakeholders with emphasis on utility. These community presentations and publications could have been organized in a way that contributed to planning for longer, more time-consuming academic manuscripts for dissemination to a global public health audience.

*Plan from the start to raise additional funds to support community initiatives and staff positions for community members tasked with carrying-out action plans* (10,31). HEARD was able to raise *ad hoc* funds to continue pursuing community capacity-strengthening and policy change goals after data collection ended. Clear articulation up-front of these intentions between both academic partners and the community may have allowed all



partners to buy into planning, contribute to fund-raising efforts, and communicate goals and activities.

## Conclusion

The ACHWRP experience confirms some of the promising practices outlined by other researchers as well as the tensions and limitations of community-engaged global health research. Seven years is a relatively short time period in which to enter a community as outsiders, engage local stakeholders in a complex research agenda, gradually gain acceptance as community members, and implement policy change. Even within this short period, the community-engagement approach stimulated a referral system that assisted multiple families. As with most investments of this kind, our team did not have the opportunity to measure long-term consequences of these efforts. Yet anecdotal reports suggest the social welfare and educational benefits were useful to those families and children at the time. Although imperfectly implemented in Amajuba, the long-term benefits of citizens effectively demanding and accessing their legal rights is a model researchers and community partners should strive to replicate elsewhere.

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## References

1. Berndtson K, Daid T, Tracy CS, Bhan A, Cohen ERM, Upshur REG, et al. Grand challenges in global health: ethical, social, and cultural issues based on key informant perspectives. *PLoS Med* 2007; 4: e268. [PubMed: 17850176]
2. Quinlan T, Scogings P. Why bio-physical and social scientists can speak the same language when addressing Sustainable Development. *Environ Sci Policy* 2004; 7: 537–546.
3. Horowitz CR, Robinson M, Seifer S. Community-based participatory research from the margin to the mainstream: are researchers prepared? *Circulation* 2009; 119: 2633–2642. [PubMed: 19451365]
4. Tindana PO, Singh JA, Tracy CS, Upshur REG, Daar AS, Singer PA, et al. Grand challenges in global health: community engagement in research in developing countries. *PLoS Med* 2007; 4: e273. [PubMed: 17850178]
5. Nakibinge S, Maher D, Katende J, Kamali A, Grosskurth H, Seeley J. Community engagement in health research: two decades of experience from a research project on HIV in rural Uganda. *Trop Med Int Health* 2009; 14: 190–195. [PubMed: 19207175]
6. Emanuel EJ, Wendler D, Killen J, Grady C. What makes clinical research in developing countries ethical? The benchmarks of ethical research. *J Infect Dis* 2004; 189: 930–937. [PubMed: 14976611]
7. Bhan A, Singh JA, Upshur REG, Singer PA, Daar AS. Grand Challenges in Global Health: Engaging Civil Society Organizations in Biomedical Research in Developing Countries. *PLoS Med* 2007; 4: e272. [PubMed: 17850177]

8. Singer PA, Taylor AD, Daar AS, Upshur REG, Singh JA, Lavery JV. Grand challenges in global health: the ethical, social and cultural program. *PLoS Med* 2007; 4: e265. [PubMed: 17850175]
9. Tindana PO, Rozmovits L, Boulanger RF, Bandewar SVS, Aborigo RA. Aligning community engagement with traditional authority structures in global health research: a case study from Northern Ghana. *Am J Public Health* 2011; 101: 1857–1867. [PubMed: 21852635]
10. Lavery JV, Tinadana PO, Scott TW, Harrington LC, Ramsey JM, Ytuarte-Núñez C, et al. Towards a framework for community engagement in global health research. *Trends Parasitol* 2010; 26: 279–283. [PubMed: 20299285]
11. Babich LP, Bicknell WJ, Culpepper L, Jack BW. Social responsibility, international development, and institutional commitment: lessons from the Boston University experience. *Acad Med J Assoc Am Med Coll* 2008; 83: 143–147.
12. Parikh A, Bachman DeSilva M, Cakwe M, Quinlan T, Simon JL, Skalicky A, et al. Exploring the Cinderella myth: intrahousehold differences in child wellbeing between orphans and non-orphans in Amajuba District, South Africa. *AIDS* 2007; 21: S95–103.
13. Bachman DeSilva M, Beard J, Cakwe M, McKoy K, Nkosi B, Parikh A, et al. Vulnerability of orphan caregivers vs. non-orphan caregivers in KwaZulu-Natal. *Vulnerable Child Youth Stud* 2008; 3: 102–111.
14. Bachman DeSilva M, Skalicky A, Beard J, Cakwe M, Zhuwau T, Quinlan T, et al. Early impacts of orphaning: Health, nutrition, and food insecurity in a cohort of school-going adolescents in South Africa. *Vulnerable Child Youth Stud* 2012; 7: 75–87.
15. Bachman DeSilva M, Skalicky A, Beard J, Cakwe M, Zhuwau T, Quinlan T, et al. Household dynamics and socioeconomic conditions in the context of incident adolescent orphaning in KwaZulu-Natal, South Africa. *Vulnerable Child Youth Stud* 2013; 8: 1–17.
16. Bachman Desilva M, Skalicky A, Beard J, Cakwe M, Zhuwau T, Simon J. Longitudinal evaluation of the psychosocial well-being of recent orphans compared with non-orphans in a school-attending cohort in KwaZulu-Natal, South Africa. *Int J Ment Health Promot* 2012; 14: 162–182. [PubMed: 23457424]
17. Govender K, Penning S, George G, Quinlan T. Weighing up the burden of care on caregivers of orphan children: the Amajuba District Child Health and Wellbeing Project, South Africa. *AIDS Care* 2012; 24: 712–721. [PubMed: 22106942]
18. George G, Govender K, Bachoo S, Penning S, Quinlan T. Comparative economic positions of orphan, non-orphan and mixed households: Findings from round 3 of the Amajuba District Study in KwaZulu-Natal, South Africa. *Vulnerable Child Youth Stud* 2014; 9: 28–42.
19. Govender K, Reardon C, Quinlan T, George G. Children's psychosocial wellbeing in the context of HIV/AIDS and poverty: a comparative investigation of orphaned and non-orphaned children living in South Africa. *BMC Public Health* 2014; 14: 615. [PubMed: 24938864]
20. Stats SA. Census 2011 municipal report KwaZulu-Natal. Report No. 03–01-53 Statistics South Africa Pretoria; 2012 Available from: [http://www.statssa.gov.za/census/census\\_2011/census\\_products/KZN\\_Municipal\\_Report.pdf](http://www.statssa.gov.za/census/census_2011/census_products/KZN_Municipal_Report.pdf)
21. Amajuba District Municipality. Integrated Development Plan 2010–2011 Amajuba District Municipality Newcastle, South Africa; 2010.
22. Amajuba District Municipality. Integrated Development Plan 2013–2014 Amajuba District Municipality Newcastle, South Africa; 2015 Available from: <http://www.amajuba.gov.za/index.php/access-to-info/idp/category/651-2013-2014-final-idp>
23. Hall K, Sambu W. Demography of South Africa's children. In: Jamieson L, Berry L, Lake L, editors. *South African child gauge 2017* Cape Town, South Africa: Children's Institute; 2017 p. 102–106.
24. Hovedoppdage MJ. Somatic and Psychological Health of Orphans and Vulnerable Children in a Context of the HIV/AIDS Epidemic - A Case Study of Needs and Services in One Locality in South Africa Norwegian University of Science and Technology 2005.
25. Badcock-Walters P, Heard W, Wilson D. Developing district-level early warning and decision support systems to assist in managing and mitigating the impact of HIV/AIDS on education. Proceedings of: XIV International AIDS Conference. Barcelona, Spain: UNESCO HIV and Health Education Clearinghouse; 2002 July 7–12 [accessed 2018 May 11]. Available from: <https://>

[hivhealthclearinghouse.unesco.org/sites/default/files/resources/BarcelonaDEMISPaperFinalJuly2002.pdf](http://hivhealthclearinghouse.unesco.org/sites/default/files/resources/BarcelonaDEMISPaperFinalJuly2002.pdf)

26. Casale M Bridging the Gap between Researchers and Policy Makers: RAPID Report Health Economics and HIV/AIDS Research Division, University of Kwa-Zulu Natal Durban, South Africa; 2006.
27. Potter L, Quinlan T. From Advocacy to Social Marketing: The Amajuba Child Health and Well-Being Research Project Durban, South Africa: ACHWRP; 2009.
28. Potter L, Quinlan T. Newcastle Social Marketing Project: Phase 2 of the Amajuba Child Health and Well-Being Research Project Durban, South Africa: ACHWRP; 2010.
29. Michener L, Cook J, Ahmed SM, Yonas MA, Coyne-Beasley T, Aguilar-Gaxiola S. Aligning the goals of community-engaged research: why and how academic research centers can successfully engage with communities to improve health. *Acad Med* 2012; 29: 997–1003.
30. Parkin RT. Communications with research participants and communities: foundations for best practices. *J Expo Anal Environ Epidemiol* 2004; 14: 516–523. [PubMed: 15316572]
31. Israel BA, Schulz AJ, Parker EA, Becker AB. Review of community based participatory research: assessing partnership approaches to improve public health. *Annu Rev Public Health* 1998; 19: 173–202. [PubMed: 9611617]

**Table 1.**

Community partners involved with ACHWRP, 2003–2010.

<i>Government partners</i>	<i>Non-government partners</i>
Department of Education (District and Regional)	Newcastle Community Radio
<ul style="list-style-type: none"> <li>Psychological Guidance and Special Education Services</li> </ul>	Amajuba District Youth Council Newcastle & District Child and Family Welfare
<ul style="list-style-type: none"> <li>Principals</li> </ul>	Christelike Maatskap Dienst (Welfare)
<ul style="list-style-type: none"> <li>Teachers</li> </ul>	Khulisa Newcastle (Crime Prevention)
Department of Social Welfare (District and Regional)	Osizwemi Drop-In Centre
Department of Health (District and Regional)	Kwa Hilda Drop-In Centre
Department of Agriculture (District)	Thembelihle Children's Shelter (Orphanage)
Department of Home Affairs (District)	Saint Anthony's Home (Orphanage)
Amajuba District Municipality	Lutheran Church Partnership Program (Education Scholarships)
<ul style="list-style-type: none"> <li>Community Services Department</li> </ul>	Madadeni Catholic Church (Home-Based Care Program)
<ul style="list-style-type: none"> <li>Planning and Development Department</li> </ul>	Rosary Clinic
<ul style="list-style-type: none"> <li>Poverty Alleviation Task Team</li> </ul>	
<ul style="list-style-type: none"> <li>Integrated Development Planning Group</li> </ul>	
<ul style="list-style-type: none"> <li>Forum for Local Economic Development</li> </ul>	
Newcastle District Municipality	
Amajuba District AIDS Council	
Municipal AIDS Councils (Dannhauser, Newcastle, eMadlangeni)	
National Integrated Plan Forum	

**Table 2.**

Chronology of ACHWRP community engagement.

<i>Timing</i>	<i>Objective</i>	<i>Activities/outcome</i>
<b>2002 ACHWRP Startup</b>	Establish community Presence  Engage with local schools to explain study objectives and seek assistance in identifying current and potential orphans	<ul style="list-style-type: none"> <li>Field office opened in Newcastle central business district</li> <li>Community members hired as research assistants and office administrators</li> <li>Principals and teachers assist with identification of orphans and children at-risk of being orphaned</li> <li>Orphans and children at risk of becoming orphans in the near future identified</li> <li>Caretakers of the identified children invited to participate in Study</li> </ul>
	Establish community advisory committee	<ul style="list-style-type: none"> <li>Advice solicited on how best to build a relationship between the community and research project</li> <li>Advisory Committee made up of District Departments of Education (DoE), Health (DoH), and Social Development (DoSD) NGOs; CBOs; local businesses; other private sector stakeholders</li> </ul>
<b>2003–2007 Data collection &amp; ongoing community engagement</b>	Engage community in ongoing discussion about study purpose and procedures	<ul style="list-style-type: none"> <li>ACHWRP attended meetings convened by District AIDS Council and other civil society organizations to promote project visibility and cultivate local ownership</li> <li>Community leaders and other key players informed about study purpose, survey procedures, the need for informed consent, steps taken to ensure confidentiality of data</li> <li>Input elicited on survey instruments prior to initial piloting and between rounds of data collection</li> <li>Advice gathered on how to minimize inconvenience and avoid emotional distress during interviews</li> <li>Activities of ACHWRP team and research findings published in isiZulu and reader-friendly format for general audience</li> <li>Letter to the editor by ACHWRP senior researcher published in the Newcastle Advertiser on World AIDS Day 2005 to draw awareness to HIV’s impact on the community</li> <li>Rumors and misinformation about study purposes and methods responded to, and to the extent possible, dispelled</li> <li>ACHWRP invited to attend Newcastle Municipality AIDS Council meetings</li> <li>ACHWRP invited to present at Damnhouser Municipality AIDS Council meeting</li> <li>ACHWRP invited by DoH to moderate student debate during Sexually Transmitted Infection and Pregnancy Awareness week</li> </ul>

Timing	Objective	Activities/outcome
Develop and implement referral system to assist study participants in accessing government entitlements and services	<ul style="list-style-type: none"> <li>DoE, DoH, and DoSD identified as main government agencies needed to support work toward integrating child welfare services</li> <li>Children and families referred to social workers within DoE and DoSD for direct assistance accessing government services (e.g., vaccination, birth registration, social welfare grants, school enrollment)</li> <li>School and Psychological Guidance and Special Education Services (PGSES) conversations lead to further development of referral scheme</li> <li>Memorandum of understanding signed with District Department of Social Development</li> <li>Conference Advisory Council initiated</li> <li>Findings from first round of data collection presented</li> <li>Over 500 community participants attend including: regional and district government agencies, NGOs, CBOs, three municipal AIDS councils (Newcastle, Dannhauser, eMadlangeni)</li> <li>Funded jointly by HEARD, DoH, and Amajuba District Municipality; additional support from Department of Agriculture, DoE, and Newcastle Municipality</li> <li>Breakout sessions held for participants to discuss opportunities for and challenges to improving child welfare</li> <li>Media attend; article is published in Newcastle Advertiser</li> <li>Advocacy plan and associated activities developed</li> <li>HEARD newsletter highlighting conference activities published in isiZulu and English</li> <li>ACHWRP staff invited to primary schools to participate in discussion of common problems faced by learners at home and in the classroom.</li> <li>ACHWRP offered office space in DoE offices to provide research support in developing child welfare plan</li> <li>Many respondents praise conference as an important opportunity to meet and to improve relationships with others working with orphans and vulnerable children</li> <li>HEARD management invited to meet with District Director of Community Services to discuss ACHWRP's objectives and promote district ownership of project</li> <li>Database of 400 local CBOs providing services to vulnerable children developed and integrated with government geographic imaging system mapping (documenting location, capacity, needs, funding sources)</li> </ul>	
Convene Amajuba Family and Child Welfare Conference (November 2005, Monte Vista Casino)	<ul style="list-style-type: none"> <li>Seek feedback on conference effectiveness from Conference Advisory Committee, DoE staff, primary school teachers, 23 child and family welfare organizations, and local municipal AIDS councils</li> <li>Improve networking and funding potential between CBOs and NGOs focused on vulnerable children</li> </ul>	



Timing	Objective	Activities/outcome
	<p>Pilot formal referral service in three wards with goal of inclusion in District 2011 Integrated Development Plan and district-wide implementation</p>	<ul style="list-style-type: none"> <li>• Comprehensive referral card developed documenting child demographic and socio-economic details, services required (birth registration, vaccinations, grants) with space to record case history</li> <li>• Card developed in conjunction with district and municipal government and non-government partners</li> <li>• Referral card piloted in 4 wards</li> <li>• 10 CBOs in pilot wards trained to implement referral system</li> <li>• Referral system training manual developed for CBOs</li> <li>• Referral card database developed to capture baseline child needs to monitor implementation and evaluate effectiveness of program</li> </ul>
	<p>Communicate preliminary research findings from three rounds of data collection to general community</p>	<ul style="list-style-type: none"> <li>• Geographic information system mapping of CBOs, saturation, and reach within pilot districts</li> <li>• Closing ceremony for research phase of ACHWRP</li> </ul>
<p><b>2007–2010</b> <b>Shift from research to advocacy and social marketing</b></p>	<p>Produce and distribute advocacy communications to facilitate behavior change at the district level</p>	<ul style="list-style-type: none"> <li>• ‘Keeping the Promises’ film highlights challenges faced by community members when attempting to access health and government services</li> <li>• Three local newspaper articles and two radio programs feature the film and the need for an integrated child welfare management plan</li> <li>• ACHWRP team participates in ‘Community’ Voices’ Newcastle Community Radio call-in show twice a month</li> <li>• Six monthly newsletters produced and distributed</li> <li>• Training workshops provided for local government stakeholders to reduce defensiveness when working with advocacy groups</li> </ul>
	<p>Propose district child welfare management plan to integrated development planning forum</p>	<ul style="list-style-type: none"> <li>• ACHWRP team presents child welfare management proposal to district policy makers</li> </ul>

Acronyms: ACHWRP: Amajuba Child Health and Wellbeing Research Project; CBOs: community-based organizations; DoE: Department of Education; DoH: Department of Health; DoSD: Department of Social Development; NGOs: non-governmental organizations; PGSEs: Psychological Guidance and Special Education Services.