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Participatory video making for research and health promotion in remote Australian Aboriginal communities: Methodological and ethical implications

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Abstract

This paper describes the participatory video (PV) method as a means of engaging children in remote Aboriginal communities as participants in health research.

The PV method was piloted in two remote communities in the Goldfields region of Western Australia. There was widespread community acceptance of this approach and preliminary findings are discussed with reference to the key themes of perspectives on health, benefits to participants and benefits to communities. The PV method has a number of strengths, including flexibility to respond to community priorities, a lack of dependence on verbal or written data collection and the capacity to generate immediate benefits for participants.

While not without methodological problems, these pilot projects suggest that the PV method is well suited to the remote Aboriginal communities who participated. The ethical implications of the PV method are discussed with specific reference to published ethical guidelines.



Introduction

Across the world, colonisation has led to the systematic oppression of Indigenous peoples through racial discrimination, dispossession of traditional lands and the fracturing of cultural, linguistic and familial connections (Daniel et al. 2011). In Australia, this has resulted in complex inter-generational effects, including socioeconomic disadvantage (Daly and Smith 1996), poorer educational outcomes (Johnston et al. 2009), increased morbidity and reduced life expectancy (Australian Institute of Health and Welfare 2011) among Aboriginal and Torres Strait Islander people.

Successive governments have prioritised research and health promotion aimed at addressing these disparities. However, the 'Western' approach to research has proven problematic in Aboriginal and Torres Strait Islander communities (Humphery 2001). The implicit valuing of Western worldviews and ways of knowing has led to culturally inappropriate research methods, which have further marginalised communities (Getty 2010, Smith 1999). The resultant mistrust among Aboriginal and Torres Strait Islander communities of institutions responsible for research and health promotion has slowed progress in addressing health disparities (Lowell et al. 2012, Trudgen 2000).

Recognition of these problems and consultation with Aboriginal and Torres Strait Islander communities has led to a revised research agenda, which demands that researchers acknowledge holistic perspectives on health, commit to partnering with communities to identify areas for research (Bull 2010) and deliver benefits to communities (Saggers and Gray 2007). The National Health and Medical Research Council (NHMRC) 'Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research' states that the core values of 'reciprocity', 'respect', 'equality', 'responsibility', 'survival and protection' and 'spirit and integrity' should underpin research involving Aboriginal people (National Health & Medical Research Council 2003).

In the field of health promotion, researchers have progressively recognised the importance of adopting community-based, participatory approaches, which partner with Aboriginal and Torres Strait Islander communities to identify priority areas, and involve local people as collaborators in the generation of relevant and culturally appropriate health promotion resources (Barnett and Kendall 2011, Davis et al. 2004, Hunter et al. 2009). The need for effective health promotion to improve child health has come with a recognition of the importance of understanding children's representations of health and the contexts in which health is experienced (Docherty and Sandelowski 1999) and has led to a search for appropriate methods that enable children to participate as collaborators in research (Jacquez et al. 2013). Alongside this, advances in technology and broader access to digital recording devices have enabled innovative methods for achieving health promotion goals, including the use of visual media (Kindon 2003). The PhotoVoice method was first described in rural China (Wang, 1999) and has since been employed as a participatory research tool in a number of health promotion settings (Castleden et al. 2008, Martin et al. 2010, Wilkin and Liamputtong 2010). Participatory video (PV) has also emerged as a method of enabling community members (including children) to develop and share their own perspectives in community-based health promotion through the creation of films (Kindon 2003, Stewart et al. 2008). The PV method typically involves researchers working collaboratively with community members, using iterative cycles of action (i.e., film-making) and reflection. Research 'data' is yielded from both the creative process and participant reflections on this process and is ideally interpreted collaboratively by participants and researchers (Kindon 2003). The final product is one or more videos that exist as a community-controlled resource, archiving the research process and enabling communication to a broader audience (Parr 2007). Importantly, the participant-directed nature of the process is proposed to privilege issues and perspectives that are valued by participants.

Advocates of PV propose that the collaborative research relationships destabilise traditional power imbalances between 'researcher' and 'researched' (Kindon 2003). Others have asserted that the collaborative framework of PV is, in itself, empowering for participants, citing Freire's notion of 'transformative change towards critical consciousness' (Freire 1998) as an achievable outcome for participants within the PV paradigm (Mistry and Berardi 2012, Stewart et al. 2008). It has been suggested that, in comparison to traditional research techniques, the visual and performative emphasis of the PV approach is more accessible for young and/or non-literate participants. PV has also been endorsed as a way of documenting and celebrating the oral traditions prevalent in many Indigenous communities (Hunter et al. 2009, Mistry and Berardi 2012, Stewart et al. 2008).

Some critics of participatory research methods have questioned whether they are truly participatory (Gallacher and Gallagher 2008, Jacquez et al. 2013). Others have challenged the implicit assumption that knowledge generated in collaborative or participant-directed ways is inherently superior (Gallacher and Gallagher 2008). Pointed critiques have emerged in response to the use of PV with children, with some suggesting that power imbalances, resource limitations and ethical constraints can lead to participatory research techniques defaulting to a tightly managed and bounded research relationship in which equal collaboration is difficult or impossible (Jacquez et al. 2013, Lomax, 2012). This has led to recognition that the positionality and motivations of those initiating PV, and those who participate, are of prime importance in evaluating whether participatory research methods truly achieve their collaborative goals (Jacquez et al. 2013). In research involving Indigenous communities, it is also important to acknowledge the ways that relationships and positionalities are racialised and to understand how this might impact the use of PV methods.

In this context, it is interesting to consider whether participatory research methods, and PV in particular, might play a role as part of a revised agenda for research with, rather than on Aboriginal and Torres Strait Islander communities. As a research method, PV appears to satisfy the ethical principles for studies involving Aboriginal and Torres Strait Islander communities. The generation of collaborative knowledge, through iterative cycles of action and reflection, requires commitment, close relationships and reciprocity (Tobias et al. 2013). Previous PV projects have documented practical benefits for participants associated with skill development and self-confidence (Kindon 2003, Stewart et al. 2008). The production of community-controlled resources that can be shared between communities or used in advocacy to governing bodies might enable a more equitable distribution of the benefits of research for Aboriginal and Torres Strait Islander communities.

This paper describes the PV methodology as a way of engaging children in two remote Aboriginal communities as partners in health promotion research. We describe our use of the PV technique and present empirical data (participant and facilitator reflections, and thematic analysis of completed films) yielded from two field trips to trial the method. An evaluation of the methodological and ethical implications of using PV as a research tool, and its feasibility in remote Aboriginal communities, is presented with reference to existing literature and established ethical frameworks for research involving Aboriginal and Torres Strait Islander peoples (National Health & Medical Research Council 2003).

Methods

Study setting

The PV project described in this article was part of a broader project to evaluate the impact of the Western Desert Kidney Health Project (WDKHP 2011), an innovative arts/health intervention aimed at reducing diabetes and kidney disease in ten (predominantly Aboriginal) communities in the Goldfields region of Western Australia http://westerndesertkidney.org.au. The Western Australian Aboriginal Health Information Ethics Committee (287: 05/10), and the University of Western Australia Human Research Ethics Committee (RA/4/1/5401) approved the study methods. Representatives from two of the participating communities were approached by the research team in May 2012 and agreed to partner with researchers and assist in planning for field trips in September 2012. A third remote community was also identified, however, the withdrawal of services and ongoing problems with availability of basic infrastructure meant that the community was almost completely empty during the time available for conducting the PV project.

The two participating communities are small, remote settlements in arid environments, situated 360km and 500km from the nearest regional centre. They both have fluctuating populations of between 30 and 100 people and occasional access difficulties due to flooding of unsealed roads. One community was established by missionaries during the 1920s, while the other was founded in the 1980s following negotiation between local Elders and government officials to occupy and maintain traditional Aboriginal homelands. Community infrastructure is minimal, with no shops, health clinics or rubbish collection. Running water is sourced from bores and electricity is generated locally. Each community has a small school providing early childhood and primary education, while access to high school education requires commuting or relocating to a nearby regional township.

Importantly, both of the communities have a positive history of engagement with the broader Western Desert Kidney Health Project research team, with ongoing contact over several years. The team of researchers facilitating the specific PV projects in each community consisted of an Aboriginal health worker with family ties into the participating communities (Samuel Stokes), a (non-Aboriginal) health researcher (Craig Sinclair) and a (non-Aboriginal) community artist with skills in film and music production (Peter Keelan). A non-Aboriginal paediatrician (Christine Jeffries-Stokes) and an Aboriginal health researcher (Annette Stokes) also provided input into project design and assisted with the initial engagement of the partnering communities.

As with other artist residencies delivered as part of the Western Desert Kidney Health Project, the PV project in each community lasted for two weeks. The researchers arrived in each community a week in advance of the project commencement to enable introductions and build a rapport with community members. Initiation of the PV project began with approvals from the community coordinator, local Elders and (non-Aboriginal) school teachers. In partnership with teachers, young people were invited to join the PV project. Researchers visited the parents or guardians of young people in the community to explain the PV project and seek their consent.

Procedures

The community artist supplied compact, easy to operate, *GoPro* digital cameras and video-editing equipment for community use during the residency and ran introductory film-making workshops for participants in the project. Practical activities illustrated lighting, composition, camera care and ethical conduct in recording video footage. The Aboriginal health worker provided input about culturally appropriate use of cameras, particularly local rules regarding 'out of bounds' places.

Participants were asked to create a short movie about 'being healthy in your community'. Group discussions and community excursions generated ideas, which were refined by planning scenes and shots visually on 'storyboards'. Further refinement of ideas occurred during practical attempts to record and edit video footage. Wherever possible, the research team facilitated participants to develop and execute their own film-making ideas. Periods of active film-making were interspersed with reflection and feedback, during which participants commented on the evolving film. Photographs documented the film-making process, while participant and community member reflections were recorded and collected in field notes by the researcher. These notes and participant reflections were used to inform research team discussions about the films, as not all of the authors were on-site for the entire period of fieldwork. Both films took the form of short (five to seven minutes) documentary style films in which participants narrated stories or descriptions over audio-visual footage, which included landscapes, interviews and acted scenes. With approval from participants, the completed films were screened at community events held at the school and attended by community members. Copies of films were provided to participants and community members in useable formats (typically DVD) and the films were later uploaded to a public website (http://www.westerndesertkidney.org.au/resources) with agreement from community leaders.

Results

The PV projects were well received in both communities, with positive feedback from community members, participants and teachers. The findings extrapolated from participant and community member reflections, and the completed films, are explored with reference to the key themes of 'perspectives on health', 'benefits to participants' and 'benefits to communities'. The methodological and ethical implications for the use of PV as a research tool in remote Aboriginal communities is discussed with reference to existing literature and ethical guidelines.

Perspectives on health

Participants identified and represented health broadly, consistent with the idea of 'holistic' conceptions of health (Boddington and Raisanen 2009). In addition to demonstrating an understanding of individual agency and its impact on health (e.g., exercising for fitness), participants demonstrated a detailed understanding of the role of ecological factors, including their reliance on the local environment (e.g., the right time of year to look for different bush foods) and community infrastructure (e.g., water pumps) to support health. Participants showed pride in their ability to hunt and gather bush foods or to grow their own fruits and vegetables to share with others in the community. Physical prowess, expressed in athletic, sporting or hunting ability was also prized and provided a motivation to exercise and eat healthy foods. There was a notable lack of material relating to Western medications or health services. Instead, participants referred to traditional bush foods or 'healing places' as methods of maintaining their health. This may reflect prevailing community attitudes regarding the health benefits of a traditional cultural lifestyle. However, it is also important to acknowledge that both participating communities exist with minimal contact from mainstream health services.

Benefits to participants

The PV project provided a visual and performative medium in which young people could express their perspectives. Participants took readily to this medium and appreciated the chance to develop skills.

It's really good. Like if you were ever going to make your own film, you'd know what to do. (Participant)

In some cases, the participant-directed process was demonstrably effective in generating transformative change. One male student was initially tentative about contributing his own artistic decisions to the project, instead seeking direction from the community artist; "What should I do? Should I film this now?" With encouragement and mentoring, he demonstrated a greater willingness to contribute his own input into the project and experienced the reward of having his input valued by his peers; "I came up with that idea and the others liked it." While this vignette demonstrates the potential for PV approaches to encourage transformative change within participants, it also illustrates the powerful influence of the peer group on participant responses to the PV method (Lomax 2012).

Benefits to communities

The PV project received strong support from participating communities. Significant creative input from participants, together with oversight from community leaders, contributed to the acceptance of the completed films, with public screenings being well attended by almost the whole community. During both arts residencies, the research team did not receive any indications of concern relating to the PV project. This is likely due to the extensive period of engagement with the broader WDKHP team in the lead up to this residency and the cultural guidance and arts facilitation provided by dedicated staff. Participants expressed enthusiasm about sharing their films with other communities to "show [them] how we keep healthy", while one local elder encouraged

the researchers to "show it to everybody, everywhere you go." This illustrates the ways that the films were perceived by community members to have value, particularly as tools for health promotion. One adult community member reflected on the benefits of the PV process, talking of the children's enjoyment of the film-making and her pride in their participation and social cohesion.

It's pretty good you know. Like... all the kids you know. They're pretty happy when they're doing their little shots. And it makes me proud to see all of them all together you know? Doing their own little bits and pieces for the camera. (Adult community member)

Discussion

The PV methods piloted in these two communities were clearly well accepted, however, it is also important to consider the effectiveness of this process in generating knowledge relevant to improving Aboriginal health. The following section focuses on the methodological and ethical implications associated with this research method, with reference to existing literature and published ethical guidelines.

Methodological implications

Converging sources of evidence support the value of traditional, arts-based approaches in Aboriginal health research (Barnett and Kendall, 2011, Davis et al. 2004, Mikhailovich et al. 2007, Ware, 2014). Others have suggested that discussion centred around an artistic process can facilitate deliberation, potentially resulting in richer data or new insights (Downey et al. 2009). The performative aspects of film-making (Gibson et al. 2011), together with the capacity for the screening of completed films (Kindon 2003), provide innovative methods for building consensus around research findings and disseminating messages further.

Despite these benefits, there are a number of problems associated with the PV method. Perhaps the most pressing concern is the difficulty in being certain that participant perspectives are reflected in the finished films. Some authors have suggested that the themes explored by participants in PV projects can be interpreted as symbolic of their own perspective (Stewart et al. 2008). However, it is hard to be certain as to whether the themes portrayed in each film reflected participant priorities, as opposed to expedient options within the time and resource limitations of the PV project. When communities are engaged in a PV project, it is to be expected that some community members will have 'stronger voices' than others. It is also important to acknowledge the motivations and positionality of both participants and researchers in the research process, particularly when children are involved (Lomax 2012). From an evaluative stance, it is important to acknowledge the positionality from which the WDKHP researchers come to the task of collaborating with community members to conduct evaluation research for a project that they have been instrumental in delivering. These issues suggest the importance of documenting the context in which the research takes place, either through participant observation, participant reflections or by interviewing key informants from within the community.

In the Aboriginal health research context, it has been suggested that the 'processes' of research are at least as important as the 'outcomes' generated from research (Cochran et al. 2008). Acknowledging the ways in which research has previously been deployed as part of a colonial political agenda (Smith 1999), the PV method has potential as a 'decolonising' research method. Community-based participatory research methods, such as PV, allow participants significant input into research conducted in their communities and the method itself relies on developing knowledge within a relational context that accommodates cultural difference (Dudgeon et al. 2010). The existing relationships between the WDKHP Aboriginal health workers and the participating communities is a key component that enables the use of innovative research methods and the brokering of agreements about implementing these methods in culturally appropriate ways (Jeffries-Stokes et al. under review). The design of the WDKHP has placed a central emphasis on the research process, building on the community engagement developed through previous research projects (Wenxing et al. 2011). It may be that 'findings' generated from such research methods are context specific and difficult to generalise. However, the learning that occurs through PV projects, together with the completed films, can deliver immediate benefits to participants and communities. From this perspective, it is the strength of the community engagement in the PV process that provides the strongest evidence of methodological soundness (Gibson et al. 2011).

Ethical Implications

The following section illustrates some of the ethical issues associated with the PV research method, with specific reference to the NHMRC 'Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research' (National Health & Medical Research Council 2003). The guidelines emphasise six core values of 'reciprocity', 'respect', 'equality', 'responsibility', 'survival and protection' and 'spirit and integrity' in research involving Aboriginal and Torres Strait Islander communities.

Reciprocity

Reciprocity refers to an inclusive research relationship that ensures that "research outcomes include equitable benefits of value to Aboriginal and Torres Strait Islander communities or individuals" (National Health & Medical Research Council 2003, p.10). Delivering benefits that are valued by research participants, and the community as a whole, requires a commitment to inclusiveness and consultation during project development and flexibility on the part of the research team, expressed by a willingness and capacity to adjust the project based on community feedback. The PV methodology can demonstrate reciprocity by providing opportunities for research participants to work collaboratively with researchers, defining the research agenda and taking control of decisions about how to portray film content. The collaborative relationship not only increases the richness and relevance of the data collected, but also contributes to cultural safety in the relationship between the 'researcher' and the 'researched'. In the longer term, participants report pride and self-confidence associated with developing creative and technical skills (Hunter et al. 2009, Stewart et al. 2008), and the community benefits from the creative products that portray locally relevant issues from a local perspective (Hunter et al. 2009).

Respect

A respectful research relationship promotes the dignity of research participants, particularly by understanding and valuing difference, and provides adequate recognition for the contribution of participants to a research project (National Health & Medical Research Council 2003). The PV methodology is grounded in respect for the knowledge possessed by research participants and relies on respectful relationships as a vehicle for developing shared understandings between researchers and participants, which can then be conveyed to others through the film-making medium. The contribution of research participants is also made explicit by their public acknowledgement as 'film-makers'. However, while public acknowledgement can affirm dignity, the exposure of research participants or the community to negative evaluation can also lead to humiliation or 'shame', particularly in small, tight-knit communities where participants are highly visible. Researchers should be vigilant in this respect, seeking input from participants and community leaders about the appropriateness of films for public presentation. Private screenings of 'rough cuts' can minimise risk in this area (Kindon 2003) and may also be a source of further insights. For some projects, the discussion of rough cuts may constitute valuable research data. In the present project, Aboriginal health workers, community leaders and research team members with cultural authority (acknowledged as such by community members) were consulted for advice regarding preliminary versions of the film. While such relationships minimise risk of harm to communities and constitute important ethical safeguards, it is important to acknowledge how collaborative research can be mediated by the perspectives of senior community members, potentially marginalising the views of research participants.

Equality

Equality in the research relationship is reflected in a commitment to fairness and justice, and a willingness to contest discrimination, while appreciating and respecting the rights of Aboriginal and Torres Strait Islander peoples to be different (National Health & Medical Research Council 2003). This requires valuing the knowledge and wisdom of research participants and distributing the benefits of the research equally between all partners in the research project. As a collaborative endeavour, PV requires that participants are actively engaged in the process of generating shared understandings about the meaning of decisions made during the creative process and researchers resist any temptation to 'objectify' participants. Encouraging ongoing reflection by research participants during the PV process about their perspectives on the meaning of the film can contribute to equitable relationships in drawing conclusions from the films. The provision of equipment and training to enable film-making by Aboriginal and Torres Strait Islander peoples is an example of how this technique can promote equality, particularly by challenging the 'digital divide' experienced by those without the means to develop new media skills (Hunter et al. 2003). However, researchers should also be aware that exposure to PV, without some provision for participants to sustain their participation beyond the conclusion of the project, can highlight existing economic inequities. Our research team chose to use affordable, easily accessible film-making equipment. One community member endorsed this approach, expressing an intention to purchase a similar camera so that the children could continue their film-making beyond the end of the project.

However, for others with less access to financial resources, these measures alone did not enable ongoing participation. One community member spoke of wanting to show the completed film to visiting family members, but not having access to a television. Some have cautioned that participatory research methods conducted without sensitivity to the local contexts may reinforce the very forms of power and inequity that they seek to challenge (Kesby et al. 1997).

Responsibility

The ethical concept of responsibility requires researchers to recognise the responsibilities held by Aboriginal and Torres Strait Islander peoples to their kinship networks, communities and country, and to not adversely affect these community structures in the conduct of their research. In addition, this principle demands that researchers 'do no harm' and establish processes to guarantee their accountability to the Aboriginal and Torres Strait Islander communities who choose to participate in research (National Health & Medical Research Council 2003). Responsibility begins with the processes by which communities and researchers interact, to discuss the aims and methods of a proposed research project, the conduct of researchers in the community, the process for disseminating results and the distribution of benefits associated with the research. In the development of this PV project, the research team met with community representatives to discuss the proposed methods and seek their approval. Further consultation with community members indicated that they would feel comfortable with the use of video cameras in and around their community provided that there were appropriate controls over the use of the material. One community expressed concern about a previous photography project (conducted approximately 20 years prior) in which some photos had later appeared on commercially produced postcards without community consent. The Aboriginal health worker employed by the project provided ongoing guidance to researchers and participants about the appropriate use of cameras, including culturally significant places that should not be filmed. The Aboriginal health worker had family ties into both communities, meaning a direct system of accountability through traditional kinship networks. Importantly, the non-Aboriginal members of the research team needed to recognise that, within the prevailing cultural norms for this region, the Aboriginal health worker employed as part of the project would be accountable to the community for the actions of the entire research team. Research funders must recognise the burden of these responsibilities when making decisions about appropriate remuneration and professional support for those Aboriginal people who take on cultural stewardship roles within research projects.

Survival and Protection

Traditional approaches to research have led to exploitation and marginalisation of Aboriginal and Torres Strait Islander communities (National Health & Medical Research Council 2003, Humphery 2001, Dudgeon et al. 2010). The ethical principle of survival and protection requires that researchers acknowledge and respect the cultural distinctiveness of Aboriginal and Torres Strait Islander peoples and commit to opposing any further erosion of this distinctive set of values, which, collectively, unite Aboriginal and Torres Strait Islander peoples (National Health & Medical Research Council 2003). A number of authors have suggested that community-based participatory research (CBPR) methods, such as participatory video-making, are

generally consistent with a respect for the cultural distinctiveness and social cohesion of Aboriginal communities (Dudgeon et al. 2010, Cochran et al. 2008). Developing processes by which communities can work collaboratively with researchers to ensure culturally appropriate research methods can make the research process more accountable to Indigenous 'ways of knowing' and less likely to repeat past mistakes in which research has objectified and colonised Indigenous peoples (Cochran et al. 2008). However, it is important to recognise that institutional barriers sometimes limit the extent to which the participatory aims of CBPR are practically achieved (Jacquez et al. 2013).

In the context of this specific PV project, we recognise the importance of adopting whole-community approaches during research design, implementation and dissemination. Trudgen (2000) has documented how even well-intentioned projects can undermine the traditional position of Elders as keepers of knowledge and, hence, destabilise familial and community networks if the projects are targeted at just the children within a community. While children were the main participants in these PV projects, we attempted to engage the broader community wherever possible and Elders were consulted for their approval of the completed films. In addition, these specific PV projects built on extensive whole-community engagement associated with the broader WDKHP. We acknowledge that not all communities will have such pre-existing relationships with research teams and recommend a cautious approach in respect to this ethical principle.

Spirit and Integrity

Spirit and integrity is considered to be an overarching ethical construct, encompassing all of the other ethical concepts. It entails a respect for the cultural inheritance of Aboriginal and Torres Strait Islander peoples, which is exemplified in both motivation and action. From this perspective, we suggest that, in considering 'spirit and integrity', it is imperative that research governance structures enable researchers to deliver positive motivations to work collaboratively with people in Aboriginal communities. Ensuring that adequate time and resources are available to facilitate relationship building and to support participation in research is imperative. Research governance should also ensure that researchers maintain contact with participating communities to facilitate collaborative decision-making regarding the dissemination of research findings. Good ethical practice in these areas may lead to stronger community acceptance of research and greater potential for research findings to be translated into policy and practice to benefit Aboriginal health outcomes.

Conclusion

This paper outlines the PV method as an innovative approach to conducting community-based participatory health research in remote Aboriginal communities. Initial pilot studies of this method have shown promising results, although it is important to note that the outcomes demonstrated here might be partly due to the history of positive engagement between the WDKHP and these communities, built up over a number of years. While this method is not without methodological and ethical challenges, we suggest that PV methods meet the pressing need for greater community control over the Aboriginal health research agenda and align with other principles outlined in published ethical guidelines.

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ⁱ In one community (with a school population of approximately 80 students), teachers identified a small group of five upper primary school students to participate. In another community (with a small school population of approximately 20 students of predominantly primary school age), all of the students participated.