



Towards better-informed consent: Research with livestock-keepers and informal traders in East Africa



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ABSTRACT

With the rise of the One Health paradigm, ethicists have called for new research approaches, considering the interdependent relationships of humans, animals, and their environment. These relationships can be particularly complex within resource-poor, smallholder livestock systems, necessitating a rigorous informed-consent process. Little has been published on informed consent beyond human-subject research. This paper outlines two studies on informed consent, for research identifying diseases of animal and human importance, within smallholder livestock value chains.

Firstly, a randomized independent-group study compared three communication tools (written, cartoons, and photographs) for informing 22 Tanzanian livestock-keepers before seeking their consent. A significant difference in comprehension and engagement in the informed-consent process was found between tools, and cartoons had the highest (i.e. best combined comprehension and engagement) scores. Most (21 out of 22) farmers answered half or more the questions correctly, but none were able to answer all questions. Comprehension testing allowed identification of common misunderstandings, such as immediate benefits the farmers would receive and the process to be used for relaying research results. Dialogue stimulated by cartoons and photographs allowed researchers to determine and respond to participants' varied relationships with their livestock.

The second study assessed preferred methods for indicating consent among informal-sector milk vendors in Nairobi, Kenya. Of consenting participants, 61% (140/230) indicated consent verbally, 39% (90/230) signed consent and none chose thumbprint. There was a significant enumerator-effect on both overall consent and the methods chosen.

Several of these findings echo those published in human-medical research. Additionally, highlighted here is the importance of facilitating dialogue during the informed-consent process in One Health research, for a more nuanced understanding of relationships between humans, animals, and their environment. Also discussed is how a requirement to sign consent forms might limit consent among workers in informal markets, which are commonly studied in One Health research. We suggest expansion of these, and development of further, studies towards improving consent processes in One Health research.

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1. Introduction

An estimated 600 million smallholder livestock-keepers, many of them women (McDermott et al., 2010), live in resource-poor countries; globally, livestock chains employ around 1.3 billion

people (Thornton, 2010). Historically, livestock-development initiatives focused on increasing the productivity of smallholder farmers and, more recently, on improving the performance of agri-food value chains. However, the recognition that the health and wellbeing of livestock, humans, and the environment are inextricably linked has led to calls for a new One Health approach to livestock research. With the rise of the One Health paradigm, there is growing emphasis on the need for broader ethical frameworks in research (Goldberg and Patz, 2015), which respond to the moral complexity introduced from considering human relationships with animals and their environments (Rock and Degeling, 2015).

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Smallholder livestock-keepers place great economic, cultural, spiritual, and companionship importance on their animals. Accordingly, ethical clearances for research involving livestock need to not only address animal welfare (Seth and Saguti, 2013) but also the concerns and interests of livestock-keepers. A One Health ethic would demand that in livestock research, the universal ethical principle of Respect for Persons (U.S., 1978) be fostered through a robust informed-consent process (ICP), treating livestock-keepers as autonomous agents. Additionally, care should be taken when conducting research within livestock value chains in resource-poor countries. Characterised by informal, small-scale businesses, these production systems and associated animal-source foods are well-known contributors to outbreaks of zoonotic disease and therefore, are intensively studied in One Health research. Workers in these businesses are often heavily dependent on the income they generate. This dependency, coupled with the fact that practices may be of questionable legality or advisability, means potential risk to research participant livelihoods may be significant. Thus, in this research context also, care must be taken to ensure a rigorous ICP.

Informed consent has received much attention in human-health research, especially in the challenging context of cross-cultural research (Dawson and Kass, 2005; Marshall, 2007; Durham, 2014). The Declaration of Helsinki (W.M.A., 2013) set standards for the process of informed consent and urges researchers to pay special attention to the methods used to convey information to prospective participants. It is essential to ensure information presented is understood. Various researchers have evaluated, with the use of questions and quizzes, the degree of comprehension derived from different types of information-giving processes. Bhansali et al. (2009) and Fitzgerald et al. (2002) found that participants exposed to the same information exhibited a wide range of comprehension levels. Penn and Evans (2010) found that not just the content but also the process used for giving information was influential and could be modified to improve comprehension test results.

Relatively little has been published on the design of ICPs outside research on human subjects. The authors, with many years' cumulative experience of livestock research in low-income countries, have observed that study participants in those settings do not always comprehend all information provided in written consent forms and are not always comfortable with providing signatures on consent forms. Moreover, the fact that consent to participate in research is seldom refused by rural participants also raises questions about the validity of the consent process.

This paper aims to contribute to the literature around ICPs in cross-cultural, One Health research. Two case studies are presented, on seeking consent for research from livestock-keepers and agri-food workers in resource-poor communities. The first study compared three communication tools used to provide project information prior to seeking consent, comparing comprehension and engagement among rural livestock-keepers in Tanzania. The second study assessed which type of consent (verbal, signed, or finger-print) was preferred by small-scale, informal-sector milk vendors in Nairobi, the capital of Kenya.

2. Methods

2.1. Testing communication tools, for improved informed consent: Tanzania, cattle owners

This study took place in a pastoralist community in Morogoro Region, Tanzania, as part of the pilot phase of a large field survey of cattle diseases. Twenty-two adult cattle owners, including 21 males and one female (in place of her absent husband), were recruited by a local extension officer to partake in the pilot. The number was limited by both the size of the community and time constraints

associated with the pilot activities. All 22 of these farmers were invited to participate in the informed-consent study. The recruitment process involved a group information session (including time for questions and answers) before consent was sought. In this way, all participants received the same description of this study before it commenced.

Four enumerators (one female and three males) fluent in the national language (Kiswahili), were trained to take participants through a mock ICP, using one of three alternative communication tools. The enumerators were trained to provide the same project information irrespective of which communication tool they used. This included information on field activities, which would involve administering a questionnaire and sampling blood and milk from cattle. In addition, the process was designed to include all elements of informed consent as per the Declaration of Helsinki (W.M.A., 2013).

The three different tools and associated ICPs were:

A. Written: A written document in the national language (Kiswahili). A copy was given to the participant and another was used as a script, read out by the enumerator.

Photographic: A poster with 6 photographs on the front (Fig. 1), which visually represented the different elements contained in the written document. The reverse of the poster contained bullet points used as prompts by the enumerator, to cover all of the necessary information. The participant listened to the enumerator's explanation of the project, whilst freely looking at the images.

B. Cartoon: A poster with 6 cartoons conveying the same information as the photographs (Fig. 1). The prompts and process were the same as for the photographic tool.

The tools for the ICP were chosen according to their relevance and practicality in the context where they were to be used. The written tool was chosen because this is a very commonly-used style of communication and documentation in ICPs. Given the remote nature of the field work, communication tools requiring electricity had to be avoided (e.g. video or voice recordings). Posters were practical, easily transported, durable, and allowed prompts to be written on the back to minimize the risk of enumerators omitting information. A media and design consultant was recruited, working with the research team to convey research methods through cartoons, and design the posters.

Three mock ICP stations were set up and enumerators took it in turns to conduct the mock ICP. The remaining enumerator in each round filled the role of silent observer, along with one additional male and female researcher. Thus, each station had one enumerator and one silent observer for each round. The allocation of participants to stations involved participants' sitting in a group, away from the stations. As a station became available, the group nominated the next participant to move to it. The enumerators alternated between the three communication tools and each participant was exposed to only one tool.

Levels of comprehension of project information and engagement in the ICP were measured. The silent observer recorded the time from the start of the ICP until the participant gave consent, including any time for questions the participant had. The observer also made notes on the content of the questions. Throughout the process, the observer also made qualitative observations related to engagement (such as the degree of eye-contact they perceived) between enumerator and participant. As part of the process, each participant was provided with a contact card, so that they could contact the research team if any concerns or questions arose during or after the research activities.

On completion of the consent process, each participant completed a quiz designed to capture their level of comprehension of the information presented (Appendix A). The quiz included eight open questions: five factual questions on different aspects of the sampling activities; two questions on the benefits of participat-

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