

STORYTELLING AS A MEANS OF OBTAINING INFORMED CONSENT IN AN ADULT EDUCATIONAL ENQUIRY

Stanley Mukhola
Tshwane University of Technology, Tshwane
(Pretoria), South Africa
dupreez.m@tng.ac.za

Ruth Brown
London South Bank University, United Kingdom
ruth.brown@lsbu.ac.uk

Gillian Godsell
University of Johannesburg
godsell@icon.co.za

Elizabeth Henning
University of Johannesburg
eh@rau.ac.za

Nicholas Lotz
University of Johannesburg
nlotz@ananzi.co.za

Hugo van Rooyen
University of Johannesburg
hgvr@rau.ac.za

Introduction:

The difficulty of obtaining informed consent was graphically illustrated some years ago, when a photograph of a group of tribal initiates appeared on the magazine cover of a leading South African Sunday newspaper. The photographer responded to the storm of criticism by saying that the initiates and elders had given him permission to take photographs. But what did those who agreed to the photography know about what would happen to those photographs? Even the photographer could not have known that one of his pictures would be chosen as a

cover picture. What did those initiates feel as they saw themselves displayed to the nation, faces painted and bodies uncovered? Did they feel that this was a process to which they had given their informed consent?

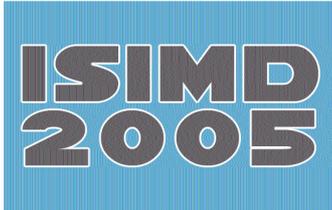
Whether on the physical periphery of the rural area or squatter settlement, the educational margins of illiteracy, or the edges of commercial activity occupied by microenterprise, it is the right of the participant to be fully informed before consenting to take part in a research project. With reference to existing literature and institutional norms, this paper traces the journey of one doctoral student as he sought to inform the participants in his research project of the purpose of his study, the protection of their rights, and the probable uses of the findings of the project, with integrity. In discussion with his doctoral committee, it became apparent that ensuring that consent was honestly informed would be a challenge of groundbreaking proportions.

The doctoral student – a bridge builder

Stanley Mukhola is a man whose roots are in the far north of South Africa: Limpopo province. Brought up in a rural setting in the traditions of his people, his memories are clearly influenced by his extended family, in particular his maternal grandfather and uncles. The advantages of education have not erased the needs or the knowledge of his people from his heart. Uniquely positioned with his head in academia and a heart for his own, he is able to face the challenge of obtaining informed consent with integrity; neither the rigours of academic ethics nor the indigenous knowledge of his people will be abandoned.

The participants in the study

The interviewees of this study are all entrepreneurs who have chosen to ply their trade, street-food vending, in locations in and around the capital of South Africa's Limpopo province, Polokwane. The doctoral student, Stanley Mukhola, did research for his Master's degree among similarly self-employed people and the field of study for his doctorate was elected as a result of this first study. His earlier findings revealed that almost 65% of the participants



3RD INTERNATIONAL SYMPOSIUM OF INTERACTIVE MEDIA DESIGN

JANUARY 5 - 7, 2005

of that study had no more than one year's schooling (2000). The regional statistics for the province reveal that 34.4% of the population is illiterate (Statistics SA, 2001). The large discrepancy in the regional figures, as well as the researcher's own findings, is evidence of the difficulty of the illiterate in obtaining work in the formal sector: in order to earn a living, they are forced into the informal sector. A high level of illiteracy in the province, however, is more than offset by a verbal tradition that is embodied in the story-telling handed down from generation to generation.

The journey to informed consent

As is often the case with challenges, it was the dynamic of the group – in this case the doctoral committee – which broke the deadlock of how to address the matter of informed consent. While it was apparent that the conventional means of obtaining a signature was inappropriate for the greater number of participants, it was in the unconventional thinking of the group that the breakthrough came.

The committee on human research at the University of California, San Francisco (UCSF), have addressed the matter of obtaining informed consent from both non-mother tongue English speakers and from illiterate participants (2003). The population of Stanley Mukhola's survey is not only largely illiterate, but also comprises solely of non-mother tongue speakers of English. Both the USCF guidelines and procedures followed at the University of Washington (n.d) point out that it is essential for the matter of informed consent to be dealt with in the participant's mother tongue. Mr Mukhola has employed the services of a translator who speaks the same dialect as the participants, since consent should be at least as much informed as in the case of literate participants who can simply read and sign a form (UCSF, 2003). The translator will serve as the story-teller of the participants' oral tradition. What the group found unsatisfactory, however, was that both the Washington and the USCF guidelines relied on the intervention of relatives to mediate the consent process. The procedure recommended in these guidelines emphasised the illiterate individual's handicap by suggesting the use of a cross as a means of consenting to participation in the research.

This led to discussion around the real meaning behind the ethics of informed consent.

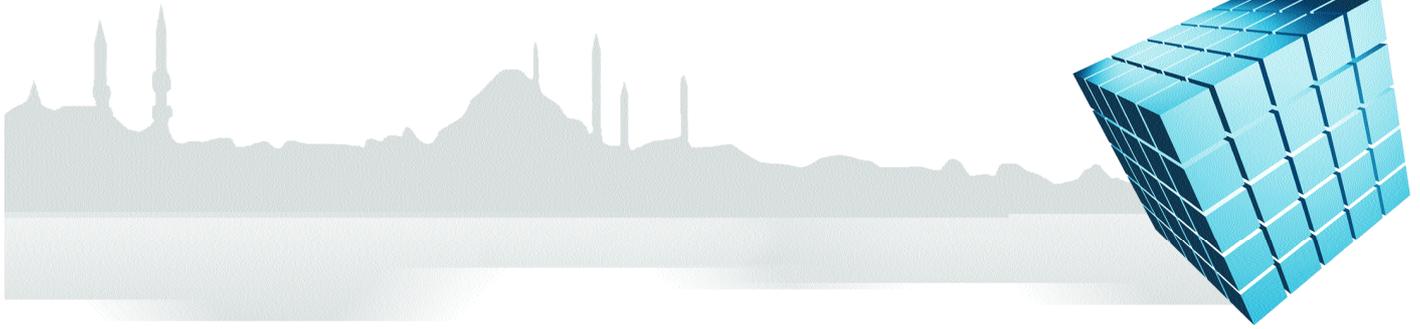
What does informed consent really stand for?

On examining generic artefacts used by students at the Rand Afrikaans University for obtaining informed consent (see appendices), it became apparent that consent is informed when the participants are in possession of the facts concerning why the research is being carried out; who the researcher is and what will be studied; how the rights of the participants will be protected and where the results of the research will be made public. This information is at the heart of the consent and the group debated the necessity of the specious "cross" on a piece of paper in view of the opportunity offered by technology to record the agreement between the researcher and the participant, both visually and aurally, by means of videotape. A "thumbs-up" from a participant on videotape after an in-depth explanation of the purpose of the research carries far greater meaning than the "cross" on a piece of paper.

Explaining the research to the participants

Recognising the strong verbal tradition of the community from which the participants come, and drawing on the custom of story-telling, the group became convinced that explaining the research to the participants would best be achieved by using graphic illustrations coupled with the story-teller's account of why and how the research was being done. The University of Washington emphasises that the language of informed consent must be "readily understandable to potential subjects" (n.d.), and why should the language not be visual (graphics), rather than verbal? As Gleick explains it, visual language is quite as complex in its syntax of images as the words of verbal language (quoted in Burke, 2001). The criterion for its use in the obtaining of informed consent is that the participants should understand it.

To enhance this understanding, it was decided to draw on the example of Paulo Freire (quoted in Cunningham, Duffy & Knuth, 1993) and to replace the letter of academic orthodoxy with a poster, depicting the information needed to lead to informed consent. The poster would use graphics, signs and



symbols that would be readily recognised by the participants. The translator would then tell the story of the poster to each of the participants. The process would be recorded on videotape and the participant would be asked to give a “thumbs up” sign as an indication that he or she understands what is being requested and consents to participating in the research.

The story of the poster

It was important in designing the poster to be used in the obtaining of informed consent that abstract academic ideas are translated into visual material that carries the meaning of these concepts in a way that is readily understood by the participants. The group viewed it as crucial that the closest possible meaning of the academic concept be reflected in the contextualised visual material. We have already said that Stanley Mukhola’s background positions him uniquely to interpret the abstract of the ivory tower into the experience of the research subjects; to attempt to bring the participants to a clear and distinct understanding of what might otherwise be obscure and confused conceptions (Peirce, 1972). At every opportunity the question was asked, “What in the life of the community most closely resembles the concept we are trying to illustrate?” and “How best can we depict this aspect of community life using graphics, signs and symbols that have meaning in the experience of the community?” In this way we sought to interpret the theoretical with the practical.

The story of the poster draws on the practical life experience of the participants. It starts with a background to the researcher (a cartoon of Stanley Mukhola) who leaves the village to go to university, which is represented by the bush school attended by tribal initiates. There he learns many things under the guidance of the academic supervisors, represented as indunas, and he realises that his newfound knowledge could be put to practical use to help the villagers (participants). He sees their need and asks them to tell him their stories (interviews), while all the time he notes their practices (observes) to ensure

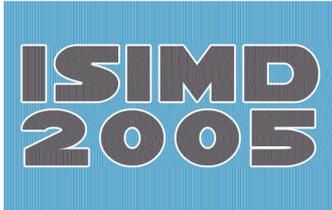
that he understands the whole story. At initiation school, he has learnt to use a tape recorder, a camera and a video recorder, which he puts to use to make sure that none of their story is forgotten.

He also explains to them that he may need to investigate their story further by visiting them at home, and tells the villagers that if they don’t want to tell their story, that is their right (voluntary participation). (Although the opportunity to withdraw from the study is explicitly offered at this point, the participants are told that they are not committed to the study until they have heard all that the researcher has to tell them.) If the villagers want to hear how they can help the researcher to help them, they are asked to give a “thumbs up” sign to the camera. If they don’t want to hear any more, they give a “thumbs down” sign.

The storyteller continues by explaining that the researcher carries the villagers in his heart (he understands their needs, rights, values and desires); that the villagers have to be adult to help the researcher (legal capacity); that the researcher will bring video footage of what he learned (feedback) and present it to them at a legotla (tribal gathering); that their faces will be pixellated on the video (anonymity); and that the backup audiotapes will be burned in their presence (security of information – once the video tapes are verified).

The story continues. The researcher will also write in books about what he has learned; he may tell their stories at other magotlas* (conferences); and he won’t stop at the stories. He will devise a way to teach them the things that they want to know (training course) so that what he learned at the initiation school can help everyone to a better life. The story concludes with a tape-recording of ululation (a cultural sign of closing a deal), before the participant is asked to give his (now) informed consent by giving the “thumbs-up” sign to the camera.

* Magotlas is the plural form of legotla.



3RD INTERNATIONAL SYMPOSIUM OF INTERACTIVE MEDIA DESIGN

JANUARY 5 - 7, 2005

Multimedia in this educational setting

In contrast with most other interpretations of multimedia, this method for obtaining informed consent does not make use of a computer (except insofar as the video footage is stored on a compact disc and made available for playback to the participants). Rather, the poster concept comprises drawn graphics, and symbols readily identifiable by the participants, such as a book (for the writing), a cross (for the child who is not old enough to give legal consent) and a tick (for the adult who may agree). Although the participants are illiterate, all of the subjects of Stanley Mukhola's previous study had been to school, where they would have become acquainted with these symbols.

Juxtaposition in drawings – such as the researcher leaving for initiation school and returning to the village – also draws on the syntax of visual language for meaning. The drawing of the researcher with the villagers in his heart is an example of the visual representation of emotive meaning. The use of the “thumbs-up” and “thumbs-down” sign – in action and in graphic representation – is the incorporation of a commonly used sign into the meaning-making of the story. Although illiterate, most of the participants have access to television, and it is assumed that they would understand the implication of anonymity in the act of pixellating facial features. Finally the use of sound – the voice of the story-teller and use of the sound of ululation – serve to reinforce the visual imagery of the poster.

Conclusion

This paper has examined a method of obtaining informed consent from illiterate participants in a research project against a backdrop of existing practice in this regard. Using a multimedia approach, and incorporating a story-telling tradition from the cultural context of the participants, a solution to interpreting the demands of academia at the rock face of practical research is offered. In a country such as South Africa where a part of the advance of education is dependent upon obtaining informed consent from people who do not have the educational background to be able to grasp the finer details of academic abstraction, the derivation of a

practical means of obtaining this consent with integrity is essential.

List of references

- Burke, J. (2001). *Illuminating texts*. Portsmouth, NH: Heinemann.
- Committee on Human Research, University of California, San Francisco. (2003). *Special subject populations: Those who cannot read or speak English or who are illiterate*. Available from http://www.research.ucsf.edu/chr/Guide/chrG_SpSpeakWrite.asp. (Accessed 16 March 2004).
- Cunningham, D.J., Duffy, T.M. & Knuth, R.A. (1993). *The textbook of the future*. In *Hypertext: A psychological perspective*. Edited by McKnight, C., Dillon, A. and Richardson, J. Chichester: Ellis Horwood.
- Human Subjects Division, University of Washington. (n.d.). *Consent form language and readability*. Available from <http://www.depts.washington.edu/hsd/INFO/info13.htm>. (Accessed 16 March 2004).
- Mukhola, M.S. (2000). *Factors influencing the safety and quality of street food in rural areas*. Unpublished thesis. Pretoria: Technikon Pretoria.
- Statistics SA. (2001). *Census 2001*. Available from <http://www.statssa.gov.za/SpecialProjects/Census2001/Census2001.htm>. (Accessed 16 March 2004).