Developing and evaluating a video to engage the lay public about biobanks and biobanking

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Biobanking in health research is leveraging on technological advancement to provide rapid turnaround of research findings. The KEMRI Wellcome Trust Research Programme (KWTRP) has over 1.5 million samples stored in its biobank. Meaningfully engaging sample donors and their communities is widely accepted as an ethical imperative. However, key concepts of biobanking are challenging to explain in lay terms. A study conducted at KWTRP on ethical issues in biobanking showed the need for innovative engagement approaches. While animations are widely used for complex concepts, there is little literature on their effectiveness. This study aimed to develop, use, and evaluate a biobank animation video to engage the lay public about biobanks. A mixed method approach was used. The video was shown to and evaluated with 203 participants: 141 students from 5 secondary schools, 57 community representatives and 5 community facilitators. A 10-question tool was administered pre and post watching the video. The questions had 3 choices (agree, disagree and unsure). Discussions were held with the community representatives and the community facilitators after watching the video. Quantitative data was analyzed using Stata, while NVivo software was used to organize the qualitative data and thematic analysis framework was used. The quantitative results showed a mixed understanding on the pre and post evaluation results. For example 60% pre and 39% post (P=0.009) participants could remove their samples from biobank which was not true, 18% pre and 76% post (p<0.001) agreed that samples in a biobank have got no identifiers which was true. Other aspects: permissions, access rights had no significant changes. The qualitative data showed participants understood key concepts of biobanking and many found the video relatable. The Kiswahili video was preferred by the community representatives while the English version of the same by the students. There was a mixed understanding of key biobank(-ing) concepts on the quantitative results however some concepts such as sample access was well understood. However, the qualitative results showed a good understanding of biobank concepts, but we think it’s because misunderstandings were clarified during the discussions. Animation videos are valuable engagement tool but should be tailored to issue and context.