Video-supported Informed Consent in Genetic Research and Biospecimen Collection: experiences from the SPOT-Study in Ghana.

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BACKGROUND:

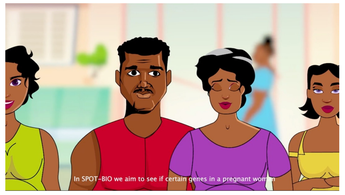
Informed consent (IC) is an ethical principle that involves assisting patients to make cognizant decisions about their healthcare. Biobanks are being set up on many continents, with concerns over the IC process. Empirical evidence shows that most study participants do not understand the important components they have committed. It is imperative to use language that is comprehensible to research participants and to clarify how long data will be stored and the scope of research questions. Informed consent could be a paper-based form, an electronic form, or a multimedia format. Multimedia tools have been shown to support comprehension of study procedures. The SPOT study team developed a comprehensive IC video for genetic research in preeclampsia, requiring broad IC for maternal and neonatal biospecimen collection.

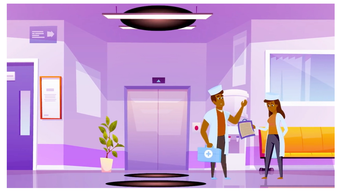
METHODS:

The animation script was generated in English through feedback from animators, Action on Preeclampsia Ghana (APECGH), social science researchers, and health care professionals until the final transcript was approved. Study rationale and conduct aspects were explained in simple terms with appropriate examples, and voice-overs and subtitles were included. The text was also translated into Twi, majority of eligible study participants could speak fluently. The video was evaluated during and post-implementation by asking for research assistants' feedback and experiences.

RESULTS:

A 6-minute 52-second animated video with five characters was found to be more acceptable, understandable, and easier to administer than paper-based methods.





Twi Translation:

Ebia w'ate sɛ yɛ ka 'BP' sɛ moba apemfo hwɛ mu Ansa na yebuhunu sɛ wowɔ Preeclampsia no, Dɔkota bɛ hwɛ 'protein' a ɛwɔ wo dwonso mu, ɔhaw a ɛwɔ wo mmerɛboɔ ho ne ɔhaw a ɛwɔ wo yam neɛma no ho no bi

Ga Translation:

HELATSE: Mami Nɛɛsi, Ofainɛ mɛni baaba kɛdzi misumɔɔ akɛ moko aale akɛ mifata nɛkɛ nikasemɔ nɛɛ he? An oonyɛ okɛ mihewɔŋ sadzi ni baaddze kpo lɛ ato odzogbaŋ

QR Code:

CONCLUSION:

Video-IC can help participants better understand research and is an engaging model that can be easily disseminated, particularly in treatment facilities for hypertensive disorders of pregnancy.