Using the Drama of DNA approach to community engagement in genomic research in South Africa: experiences and lessons learnt [version 1; peer review: 1 approved, 1 approved with reservations]

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Abstract
In the context of African genomics research, community engagement has emerged as a powerful means to enhance genomic education of the public and anticipate ethical challenges in relation to increasing genomic research on the African continent. We report our experiences of using narrative genomics, a drama-based community engagement method, to engage scientific and lay communities about ethical and social challenges related to the return of individual genetic research results in genomic research. The method uses set scripts, which audience members act out and thereafter engage in a series of ethical dilemmas presented in the script. In this paper, we describe the steps we took to change the original scripts to make them more suitable for a South African audience. We found the method to be relatively effective at engaging audiences in South Africa. While the changes in the South African versions appear minor, through our experience in trying to change the scripts to make them relatable to a South African audience, we observed that there were limits to how much of the script we could change if the narrative was still to be effective as a community engagement method. While this method and the original scripts are incredibly helpful, new scripts must be developed for African audiences, and these could potentially be more impactful as a community engagement tool in different local contexts.

Keywords
Community engagement, genetic research, Drama of DNA, narrative genomics, South Africa

This article is included in the African Society of Human Genetics gateway.
Introduction
Genomic research and rapidly evolving related technologies, such as next-generation sequencing and genome editing, raise important questions relating to their ethical, legal and social dimensions. In the context of African genomics research, community engagement has emerged as a powerful means to enhance genomic education of the public, anticipate ethical challenges, and also in helping to develop ways of addressing these. Yet whilst there is a myriad of tools available to facilitate community engagement around the science of genomics, far less attention has been paid to how to engage participant communities in the ethical aspects of such research. This was particularly challenging in the conduct of our H3Africa ELSI Collaborative Centre, which focuses on building an evidence base for the return of individual genetic findings in African genomics research. In the context of that work, we wanted to engage communities of participants in genomics research about issues around the return of results but struggled to identify approaches that would allow us to do so.

One method that uses drama to engage people around ethical challenges of genomics research is the Drama of DNA approach which was developed by Karen Rothenberg and Lyn Bush. The approach involves several set scripts dealing with different ethical issues related to genomic research and technology. It relies on audience members to act out these scripts – with or without having prepared their roles – and to follow the plays with a group discussion stimulating audience members to engage with particular ethical issues woven into the scripts. Whilst the method context of the scripts is published in their book, the Drama of DNA: Narrative Genomics, all the scripts are publicly available. The scripts deal with a range of ethical issues pertinent to genomics research and clinical genetic practice, including, for instance, informed consent, return of incidental findings, autonomy and issues related confidentiality. Importantly, these scripts and the challenges they elicit are embedded within specific contexts related to geography, language, culture and economic contexts. Once we had settled on using this approach for our community engagement work, we undertook to work with the original scripts to improve how they fit in the context of South African research. In this paper, we report on the steps we took to explore how clinical genetic findings are currently communicated to South African patients, and the jargon and colloquialisms used by both healthcare professionals and patients in this domain.

The plays
Because we wanted to specifically engage lay people on issues relating to the return of individual genetic research results, we selected two plays by Bush and Rothenberg that specifically revolve around this topic. They were “It’s not that simple” and its sequel “It’s so complicated!” These scripts involve a family that is recruited into a new genetic study by their physician and that eventually learns about the results from the research project. Two of the three siblings have a debilitating genetic condition. The first script revolves around their enrolment and the consent process and describes how the family grapples with various ethical challenges related to their potential participation in the proposed genomics research project. The second instalment sees the family return to the doctor’s office for the results of the study. Whilst there are no general study results to report, the medical team did identify a range of pertinent and incidental findings for all the family members including genetic predispositions to breast cancer, cardiomyopathy and Alzheimer’s disease.

Whilst we felt that this approach would resonate with South African research participants and would offer a meaningful way of engaging lay people around some of its ethical challenges, we were also concerned that the scripts were quite clearly positioned in a US clinical context and that we should try to make the scripts more relevant to the South African context. To do this, we employed three methods: observations of genetic counselling sessions; observations during recruitment of participants into a genetic study; and interviews with clinicians and researchers currently involved in genomics research.

As part of the process of making the scripts more suitable to a South African audience, we conducted a number of observations at various genetic clinics at Groote Schuur Hospital. We also conducted observations of participants enrolling in genetic study.

These combined observation sessions allowed us to understand how ideas relating to genetics, disease, risk and social implications were explained to patients or participants in South African clinical and research contexts. The observations also helped us identify the kinds of questions participants or patients asked, and the power dynamics typically at play in these clinical or research encounters.

Following these observations, we then also organised a series of discussions with clinicians and researchers involved in genetic medicine in clinical and research contexts. These discussions helped form a broader understanding of genetic research in South Africa, and the day-to-day experience of working in a context which serves a similar population as the one we were hoping to engage. We made the changes to the scripts as we received feedback.

Adjusting the Scripts to the South African context
From these methods, we learnt that there were three primary areas where the scripts needed adjusting, namely: language, culture and disease, and issues of privacy and confidentiality.

Language
There were two primary areas requiring change when we considered the original language used in the scripts. The most obvious of these were changing words and phrases which were suited for the American context but that did not resonate with audiences in South Africa. For example, we changed the names of characters to more locally familiar names and

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removed words such as “janitor” and “folks”. We then added more South African colloquialisms such as ‘Haibo wena’, ‘Ag’ and ‘Eish’. We also removed cultural references that do not travel well – for instance, in the original script there was some discussion about the Ashkenazi population which would be meaningless to South African participants. But perhaps the more challenging change in language and tone related to the technical scientific language used in the scripts. The script authors had drawn on existing consent documentation for genomic studies to reflect the significant and confusing use of jargon in genomics consent processes. While we had anticipated that this could be a challenge, during piloting we learnt that even researchers and clinicians (specifically those who had no advanced training in genetics) also found the technical language related to genomic research inaccessible. Furthermore, in the initial script the family which is being recruited into the genetic study is unusually knowledgeable about genomic research. During our different pilots we found that this was often seen as unrealistic for the South African context. For this reason, we decided to simplify some of the scientific jargon used in the scripts and also to show that the family that was being recruited struggled to make sense of that information. When reducing the amount of scientific jargon in the script, we opted to replace terms like ‘autosomal recessive genetic disorder’ for the easier to understand ‘genetic disease’ for instance and removing terms like ‘degenerative symptoms’ with an actual description of what that means for the patients (e.g. ‘he struggles to walk and sometimes uses crutches’).

Culture and disease
We found during our observations and pilots that one important dimension to explore were cultural constructs of disease given that particular diseases can signal different social meanings in different contexts. In our research context, one of those dimensions that merits specific consideration relates to spiritual or supernatural beliefs, which for some African patients are important in explaining disease. This is the case for a range of genetic conditions including for instance Sickle Cell Disease7 and Down’s Syndrome8. During our observations and pilots, we realised that it would be important to integrate such disease causal beliefs in the scripts we used for engagement. We did this by adding the following italics to the script:

**ANDILE:** So, does that mean that everyone will know about our genetic information. Wow, look at this paragraph:

“Breaches in confidentiality involving genetic information could impact future employability, reproduction plans, or have a negative impact on family relationships.”

**THEMBI:** What does that mean? Reproduction plans? Does that mean it hurts my chances of having a baby?

**MOM:** I know it says family, but have they thought about what people in our communities will think? Already people think we are bewitched because you guys are sick. Now what happens when people find out there’s something wrong with our blood? Then they will really believe we are bewitched.

During further piloting, we found that the introduction of this concept not only made the scripts feel more authentic to the experiences of the South Africans present, but participants also found such local parlance humorous and this thus added a light-hearted dimension to an otherwise serious topic. Other small nuances are for instance to do with the family situation. The scripts revolve around a mother who attends a clinic with her children. In the original script, the father was in the picture but lived in another town with his second wife and their child. In South Africa, it is more common for fathers to disappear and not be involved in the rearing of children. For that reason, we changed this to “Their father, Malungisa, left them four years ago, and has moved back to Gauteng.”

Another important aspect of culture that we unearthed during the observations and pilots is that lay people in South Africa tend to have limited health literacy and that the dynamics between healthcare professionals and patients are such that the latter do not feel empowered to ask questions. Playing out the scripts, and particular the second installment which is highly dramatic, we realized that there was an overload of information and that there were too many incidental findings that were fed back to the family. This was too much for our audience to handle, so we decided to cut the number of incidental findings that were reported back in the second installment. This worked to calm down the scripts and helped our audience to better engage with the kinds of findings that were reported.

Privacy and confidentiality
In the original scripts much is made of the individual’s right to privacy and confidentiality. The mother is especially concerned about her family members or other people finding out information about their personal affairs. Whilst emphasis on privacy may make sense in Western contexts, in more communal contexts such as in South Africa, such emphasis may be misguided. During the pilot sessions, some of the feedback we received was that generally people were not concerned with their individual privacy, especially if it meant receiving help. For example, issues around privacy were never raised as issues in any of the observational sessions and research participants often expressed their interest in contributing to research which has the potential to help other people (even in situations when they would not directly benefit from the results). Similarly, in the second script, the doctor insists on speaking with the 16-year-old son alone – something that many of our pilot participants found completely unrealistic in the South African setting, where parents continue to play an important role in decision-making well into adulthood. We made changes to the scripts to reflect that participants were not so worried about their individual privacy, either brushing it away as a matter of concern – ‘I know mama, but I am not worried about that’ – or resisting the doctor’s insistence on seeing the 16-year-old alone – ‘Choice? Haibo, Andile is my child! I can’t leave the room.’

**Discussion**
To our knowledge, this is a first attempt to use the Drama of DNA approach for community engagement in genomic research in South Africa. Across the variety of audiences in which we have piloted the Drama of DNA method, it has been received with enthusiasm and excitement. Participants often commented about how the play has elicited ideas and questions they had not previously thought about. Audience members also shared...
how the experience allowed them to reflect on the perspectives of various stakeholders. The discussions following the acting out of the scripts have invariably been lively and have engaged with important ethical issues including issues around consent, the right to know or not, the benefits of research and so forth. Importantly, through discussions audience members themselves started to ask some fundamental questions (for instance, how much information is enough) about the way in which research is conducted, and started to outline the parameters of consent commonly agreed upon in bioethics literature (for instance, that ‘full and technical’ information does not achieve the ambition of consent, which is comprehension). This happened regardless of the knowledge and expertise of the audience we engaged with, and as such we found this to be a meaningful way to engage communities of prospective research participants in the ethics of genomics research.

While the changes in the South African versions appear minor, through our experience in trying to change the scripts to make them relatable to a South African audience, we learnt that there were clear limits to how much of the script we could change, if the narrative was still to be effective as a community engagement method. While this method and the original scripts are incredibly helpful, new scripts must be developed for African audiences, and these could potentially be more impactful as a community engagement tool in local contexts. These scripts can be requested from the authors and will be freely shared.

Data availability
All data underlying the results are available as part of the article and no additional source data are required.

Acknowledgments
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References


Open Peer Review

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The paper 'Using the Drama of DNA approach to community engagement in genomic research in South Africa' forms a unique contribution highlighting the need for a translational approach to genomics engagement tools for ethical issues developed in high resource settings to the culture and context of low income settings - in this case South Africa. The paper explains the rationale for engaging communities of participants in genomics research to further their informed participation but places particular emphasis on the need to ensure they are conversant with the ethical implications of genomic research, practice and technology. It is the latter that forms the basis for the development of theatre scripts suitable for communities in US settings that the authors have translated to the South African setting.

The authors state explicitly that this paper is a report on the steps taken to explore 'how genetic findings are currently communicated to South African patients and the jargon and colloquialisms used by both healthcare professionals and patients'. The authors then set out to detail the steps they took to explore this including observations and discussions with clinicians and researchers involved in genetic medicine. This, they stated, allowed them to make appropriate changes to the scripts before piloting them.

The paper is well written and a relevant and useful addition to the engagement and ethics literature on genomics. Of particular interest was the fact that the feedback highlighted a distinct lack of concern for individual level privacy, particularly if it meant not receiving help. This acutely contrasts the emphasis on privacy as an ethical requirement in US findings, although it is not clear whether this lack of emphasis was related to a lack of rights awareness or whether the lack of privacy was actually a stated preference. This is a key issue for future genomics ethical practice in SSA settings and needs to be explored further. There are some gaps in the reporting of how genetic findings are communicated. Nor is it clear who the piloting was conducted with and nothing is included on the relative success in communicating and building knowledge of genomics research using the scripts as a tool. Perhaps this is reported elsewhere but some reference to the 'results' would have been useful since the adaptation of the script was driven by this ultimate purpose of communicating and creating discourse around ethical issues in genomic research.

Despite this, I thoroughly enjoyed reading this paper as one of a series of important publications on the ethics of developing culturally appropriate and contextually relevant genomics research in SSA.
Is the work clearly and accurately presented and does it cite the current literature?
Yes

Is the study design appropriate and is the work technically sound?
Yes

Are sufficient details of methods and analysis provided to allow replication by others?
Yes

If applicable, is the statistical analysis and its interpretation appropriate?
Not applicable

Are all the source data underlying the results available to ensure full reproducibility?
Yes

Are the conclusions drawn adequately supported by the results?
Yes

Competing Interests: No competing interests were disclosed.

Reviewer Expertise: anthropology, risk, ethics, engagement, behaviour change, treatment seeking, acceptability, technologies, mixed methods, public health

I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard.

Reviewer Report 08 April 2020

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This manuscript demonstrates the importance of adapting research related to genomics to the culture of the community. Rather than designing their own drama-based community engagement activities, the team used the Drama of DNA and adapted to the culture of the South African communities - a very important step in working effectively with different cultures.

Very little information was presented about the specific methods used to gather information related to needed change: observations of genetic counselling sessions; observations during recruitment of participants into a genetic study; and interviews with clinicians and researchers currently involved in genomics research. If presented, this could help others to develop a protocol for adapting materials to fit
the needs of their communities.

Otherwise the manuscript is strong with descriptions of changes, and the changes can help others who want to use the information.

Is the work clearly and accurately presented and does it cite the current literature?
Yes

Is the study design appropriate and is the work technically sound?
Partly

Are sufficient details of methods and analysis provided to allow replication by others?
Partly

If applicable, is the statistical analysis and its interpretation appropriate?
Not applicable

Are all the source data underlying the results available to ensure full reproducibility?
Yes

Are the conclusions drawn adequately supported by the results?
Yes

**Competing Interests:** No competing interests were disclosed.

**Reviewer Expertise:** My expertise is using community engaged research and qualitative research to improve community engagement in improving stroke knowledge and outcomes related to phonemics of stroke. Also I work with communities in US to decrease health disparities related to stroke and diabetes.

I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard, however I have significant reservations, as outlined above.