



Eh!woza: intersection of art and science to engage youth on tuberculosis

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Abstract

Despite substantial expenditure by national tuberculosis (TB) programmes, significant efforts by advocacy groups, and heavy investment in clinical and biomedical research, TB remains a health emergency disproportionately impacting the poorest and most vulnerable in southern Africa and other endemic regions. Personal experiences of TB are varying and contrasting in these areas where misconception, stigma and taboo are commonplace. An urgent need therefore exists for projects that engage community members as active partners in reducing the impact of TB and other diseases. Eh!woza aims to address this need by fostering collaborative interactions between biomedical TB researchers, a conceptual artist, a non-governmental organization, and young people living in Khayelitsha, a township outside Cape Town. In a series of workshops, the project engages high-school learners with biomedical TB research and provides space, guidance and equipment for participants to produce documentaries about personal experiences of TB. Here, we describe the project's growth, the results of a formal evaluation which suggest that Eh!woza is responsive to changing dynamics within the study setting, and preliminary findings from anthropological research investigating how knowledge is configured within the project. Finally, we consider prospects for expanding the project and briefly discuss challenges whose resolution could ensure long-term sustainability.

Keywords: tuberculosis; public engagement; engaged scholarship; health education; film

Introduction

Public engagement has enjoyed increasing investment and interest over the past 20-30 years. In healthcare, there has been an intensifying acknowledgement from funding bodies, regulatory agencies, and researchers that inclusive participation from the public in decision making and knowledge production should lead to more effective implementation of healthcare interventions (Filipe, Renedo & Marston, 2017). As public engagement initiatives are more widely implemented, the methodologies adopted and the motivations for this work evolve and become increasingly developed (Marris & Rose, 2010; Devonshire & Hathaway, 2014) so that public engagement is now broadly defined as (National Centre for Coordinating Public Engagement, 2018):

[T]he myriad of ways in which the activity and benefits of higher education and research can be shared with the public. Engagement is by definition a two-way process, involving interaction and listening, with the goal of generating mutual benefit.

While there are challenges (Devonshire & Hathaway, 2014), public engagement has the potential to combine collaborative, consultative and democratic approaches with traditionally didactic means of knowledge production, facilitating the provision of accurate information as well as frank debates around taboo issues surrounding health and disease (Marris & Rose, 2010; How to get public engagement right, 2018).

The public engagement programme described here seeks to engage with communities in South Africa that are significantly affected by tuberculosis (TB). Approximately 25% of the 10.4 million new cases of TB that arose globally in 2016 occurred in Africa, with 50% of all HIV-associated cases of TB occurring in southern Africa (World Health Organization, 2017). Khayelitsha, a township just outside Cape Town, South Africa, and the main setting for the project, has among the highest TB rates in the world, with a notification rate of 1000/100 000 per year (Cox et al., 2010). This converges with elevated rates of poverty – 16.5% of the population is estimated to have no income (City of Cape Town, 2016) – as well as HIV prevalence in antenatal clinics of 34% (South African National AIDS Council, 2016). While there has been significant investment both in biomedical research and health service provision, TB – driven by overcrowding, poverty and malnutrition (Richardson et al., 2016) – continues to place a heavy burden

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on impoverished communities and is a significant cause of morbidity and mortality amongst the young and economically active (Karim et al., 2009). This highlights a critical need for public engagement initiatives that disseminate accurate and in-depth information about TB but, more importantly, that engage participants as active partners in generating knowledge (Filipe, Renedo & Marston, 2017) and in reducing the social and public health burden of TB.

Eh!woza (www.ehwoza.com) was conceived as a once-off public engagement initiative, and has subsequently developed into an ongoing project that operates at the intersection of public engagement, engaged scholarship (University of Cape Town, 2012), education, advocacy and youth activism. The project does not focus explicitly on the generation of material for entertainment nor for informational purposes, but rather facilitates a space for participants to produce their own documentary films about personal experiences of TB. This enables participants to progress from being passive recipients of biomedical information, to active knowledge producers. This article discusses the project's context, its methodology, lessons from its early development, and future directions.

Setting

Geopolitically, Khayelitsha exemplifies apartheid's segregational design and associated structural violence, which is intricately linked with TB and related social factors (Macdonald et al., 2015). Mpfu-Walsh (2017: iv) proposes that today, "two decades of rainbow mythology have soothed South Africa into a state of chronic complacency". Consequently, areas such as Khayelitsha exist as impoverished and under-served with increasing overcrowding. Khayelitsha is isiXhosa for "Our New Home" – an apt moniker given that it was one of many areas set up by the apartheid regime as a living area in which to house migrant workers primarily relocating from the Eastern Cape (then Transkei). Today, Khayelitsha is considered Cape Town's largest and densest township, having grown to a population size of approximately 500 000¹ (Cox et al., 2010) in an area originally designed to accommodate 200,000 according to the Affordable Land & Housing Centre (2018).

A contributing factor to overpopulation and, in turn, the redistribution of diseases such as TB, is situated in apartheid's forced removals as a method of "cleansing" the inner cities under the Group Areas Act, effectively rendering townships as human "dumping grounds" to serve primarily as labour resource to the inner cities and surrounding industrial hubs². Richardson et al. (2016:13) suggest forced removals as a major contributor to the Cape Town TB epidemic:

One underexplored determinant [contributing to TB] has been forced removals, that is, the policies and often violent processes involved in the massive, state-sponsored displacement of people (almost all of them black) from one area to another in South Africa. Starting well before apartheid with the Public Health Act of 1897, the Native Reserve Location Act of 1902, and the Native Urban Areas Act of 1923 – and consolidated in the Group Areas Acts of the 1950's and 60's – forced removals uprooted millions of individuals from both developed urban and rural areas to underdeveloped and poorly resourced peri-urban and rural areas resulting in widespread poverty, disease, and starvation.

Forced removals, together with the influx of migrant labour, contributed to an underserved and overpopulated living environment in Khayelitsha. In a 1963 interview with the Florida Forum, James Baldwin reflects the fictional reality of the lives of workers in the mind of the persecutor (Baldwin & Peck, 2017:40):

[T]he question is really a kind of apathy and ignorance, which is the price we pay for segregation. That's what segregation means. You don't know what's happening on the other side of the wall, because you don't want to know.

Khayelitsha is the township where learners who participate in Eh!woza and their families live, attend school and go about daily routines. It is also the community in which Eh!woza participants decide on issues to investigate and document in the films produced, exposing hardships affecting the daily lives of people confronted with extreme poverty and overcrowded conditions. Within this context, it is essential to de-fictionalise people's living environments and how participants relate to experiences of, and responses to, TB disease, and bring social conditions that contribute to the TB problem to the fore (Mason et al., 2016).

Genesis

Eh!woza was established in 2013 as collaboration between a South African contemporary artist and a group of biomedical PhD students at the Institute of Infectious Disease and Molecular Medicine (IDM), University of Cape Town (UCT). The students, working in the fields of TB and HIV, were planning a health workshop to be held with high-school learners during the annual winter school of IkamvaYouth, a Khayelitsha-based non-governmental organization whose mandate is to empower youth through education (IkamvaYouth, 2018). The possibility of filming the workshop as a tool to enhance the learning experience was discussed.

With an artist on board, a 20-minute documentary was produced, the primary focus of which was to capture how TB is understood and experienced by learners (14-18 years old) from IkamvaYouth. The film investigated stigma and other issues relating to TB and was made available freely online and broadcast via Mindset TV and its OpenHD network.

Eh!woza was born out of the desire of postgraduate students to engage with communities affected by the diseases forming the focus

¹The precise population of Khayelitsha is difficult to measure. Accurate data will only be available after the next national census in 2021.

²Displacement pre-dates apartheid to late colonial undertakings such as Cecil John Rhodes' Glen Grey Act, which introduced a labour tax to force-feed migrant labour to the mining and agricultural industries (South African History Online, 2018).

of their doctoral research, and the determination of a conceptual artist to effect social change. The participating South African artist describes the start of the project:

It started at a bar. The project was unintentionally established at one of Cape Town's lesser-known art crowd hangouts on the corner of Roeland and Buitenkant Streets in Cape Town. [The bar] is also frequented by some of the city's finest biomedical researchers, which provided the opportunity for these disciplines to intersect. Eh!woza was thus conceived and the title owes its legacy to collaborators' rather juvenile attempt at combining the six founding members' initials to combine as a single word (Eh!woza loosely translates from isiXhosa as Hey! Come with us). It was decided that we would replace this at a later stage with something a bit catchier. We never did.

Methodology and Growth

Although conceived as a one-off effort, the achievements of the initial workshop and film (which can now be regarded as a pilot project) and the enthusiasm of IkamvaYouth learners prompted a successful application for a Wellcome Trust International Engagement Award in 2014. This was essential in enabling the extension and formalisation of the project, allowing participants to produce short documentaries, and encouraging agency and a localised response to social environments rather than an external interpretation of how the developed world reads disease in vulnerable areas.

Participants

Participants are selected from the IkamvaYouth pool of learners through an inclusive process that prioritises enthusiasm for the subject and personal commitment to the programme over academic achievement. In April of each year, recruitment is aided by a screening of the previous year's films and a closing ceremony for previous participants (approximately 80 - 100 learners attend). Learners are invited to apply to the project via a simple application form, and consent is obtained from parents for learners to participate and to appear on camera. The collaboration with IkamvaYouth is critical to Eh!woza and the organisation continues to provide key input into the wellbeing and academic progress of the participating learners. Since its inception, 56 learners between the ages of 14 and 20 years have taken part in the Eh!woza programme (Table 1).

Table 1: Learner profile

Year	No. of learners	Age in years: median; mean; range	Gender ^a breakdown	% of applicants accepted
2014	12	16; 15.9; 15-18	8 female, 4 male	100.0%
2015	15	16; 16.1; 15-18	15 female, 1 male	100.0%
2016	15	17; 16.8; 15-18	12 female, 3 male	25.0%
2017	14	17; 16.2; 14-9	12 female, 1 male	17.5%

^aAs self-identified by learners on project application forms.

Approach

Agency through health-seeking and health-promoting behaviour has been investigated in relation to HIV and to a lesser extent, TB (Mason et al., 2016). The development of Eh!woza was predicated on the impression from the pilot film that learners expressed a sense of responsibility towards particular communities and an awareness of the ability to promote change. A young man emphasized this by saying, "I am a growing person, so I have to take responsibility... for myself, for my studies... for my community". Similarly, a young woman suggested that, while there was a lot of TB information available, the same message delivered by young people might be received differently: "Everywhere they talk about TB... TB everywhere... in pamphlets, in the newspapers, on TV, but I think this might be different, because we're young and maybe they'll listen better to us...". Promotion of agency is one of Eh!woza's primary aims, casting participants into the double role of direct beneficiaries on one hand, and advocates for change on the other.

Content

The Eh!woza programme structure is shown in Figure 1. After recruitment, the science workshop phase of the project begins. Over a series of six science workshops, learners are encouraged to engage with biomedical research and to merge the biology of TB with its social implications. The workshops are 3-4 hours long, held on a Saturday afternoons. The content of the science workshops is shown in Table 2. Each workshop is facilitated by 8-12 junior and senior members of research groups based at the IDM, and typically consists of a seminar delivered by a senior research member of the research group facilitating the session followed by a practical experiment in the laboratory with PhD students and postdoctoral research fellows assisting the learners. While there have been minor tweaks, the basic format of the workshops has remained unchanged since 2014.

Following the science workshops, an intensive two-week, full-day film production programme is held during the school holidays. Despite the majority of learners having limited access to digital technology, the artist employs a hands-on teaching method, which allows for learners to navigate complex software as well as camera and sound equipment. Throughout the film production period, shoot days are arranged to facilitate interviews with local township residents (scientist facilitators attend shoot days), and participants

are encouraged to take cameras home and conduct independent interviews. Learners conceptualise, shoot, and edit films with minimal prescription from the project coordinators other than basic technical guidance aimed at ensuring safe and ethical practices, similar to those described in (Black et al., 2017).

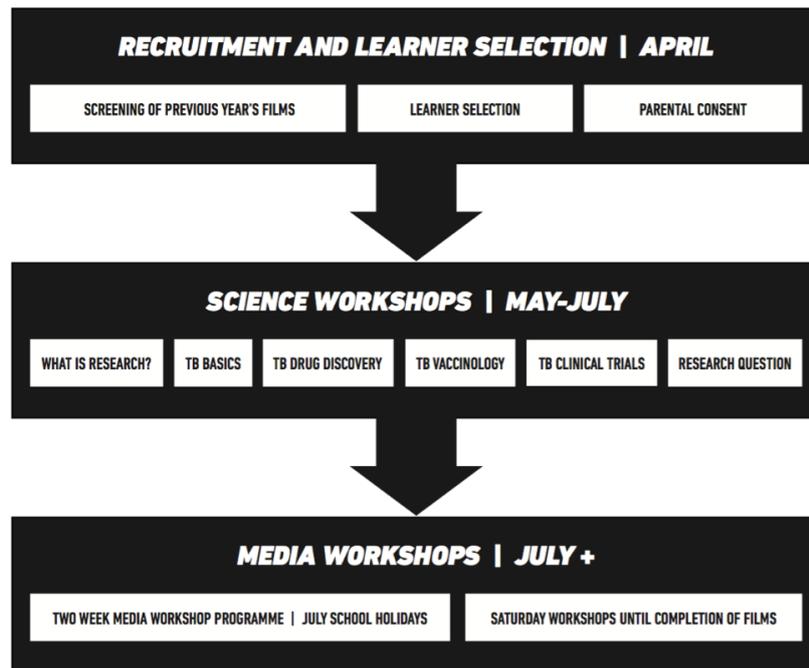


Figure 1. Eh!woza programme structure

Table 2. Science workshop topics

Workshop Title	Facilitating Research Group	Description	Venue
What is research & TB basics	All	To prepare for forthcoming workshops, TB infection and pathogenesis are discussed from a clinical and microbiological perspective. Additionally, the principles of biomedical research are described. To understand hypothesis development and interpretation of experimental results, learners perform an experiment on the number and types of bacteria which exist naturally on different everyday surfaces.	IDM
TB drug discovery	Molecular Mycobacteriology Research Unit (MMRU)	The TB drug discovery process and associated complexities are described during the workshop. In the MMRU BSL2 laboratory, learners conduct experiments to determine the minimum inhibitory concentration of rifampicin, a cornerstone TB drug, against the non-pathogenic <i>Mycobacterium smegmatis</i> .	IDM
TB vaccinology	South African TB Vaccine Initiative (SATVI)	The basics of TB immunology, the history of vaccines and the specificities of TB vaccinology are the focus of this workshop.	IDM
TB clinical trials	Wellcome Centre for Infectious Disease Research in Africa (CIDRI-Africa)	Clinical trial design, the experience of CIDRI-Africa in implementing TB clinical trials, and ethical issues related to clinical trials are discussed. A mock trial to investigate the influence of sugar-free vs. standard soft drinks on simple mathematics performance is conducted to demonstrate principles of randomisation and potential bias.	Ubuntu Clinic, Khayelitsha
Design a research project	All	Learners are asked to come up with a research question related to TB. This includes formulating a hypothesis and a research approach and presenting this to the rest of group as if it were to motivate for funding.	IDM

Insights

Over the years, organisers and collaborators have been informally reflecting on the development of films produced annually, and in the second project year an evaluator was invited to assess formally the project's design, implementation, and early results. In 2015, an anthropology PhD candidate was recruited and has initiated an in-depth qualitative study aimed at generating rich contextual information. Some of the insights gained from these activities and observations are summarised below.

Informal Observations: Learner Produced Films and Representation of the Social Conditions Associated with TB

In the first few years of the project, the content of the films was limited and did not reflect personal stories related to TB. Learners were reserved during interviews and interviewees were cautious not to expose limited knowledge of TB as a disease. Camera and sound work was flawed and learners formulated 'safe' questions such as, "So tell me about TB" or, "What do you know about TB?". Respondents generally articulated biomedically inaccurate knowledge. The conclusion from the media outputs of the first two project years is that, despite many people having personal experiences of TB, people living in Khayelitsha (and potentially other South African townships) have limited accurate information about the disease, a problem that is exacerbated by – as well as exacerbates – the stigma and taboo that surround the disease (Macdonald et al., 2015).

During the third year of the project, learners began engaging with more personalised stories and addressing social factors that reflect the lived reality of TB in Khayelitsha (Table 3). Owing to the annual film screenings attended by prospective participants, each year sets a new precedent, and the bar for addressing difficult and personal realities is raised. New participants are encouraged to explore uncharted territory, both through content, production value, and an urgent sense of activism. Moreover, in 2016, previously enrolled learners were invited to join the project for a second year and this is likely to have contributed to the improved quality of the films produced.

In December 2016, an alumni group began producing an independent film exploring the lives of, and violence towards, LGBTIQ+ high-school learners in Khayelitsha. This effort indicates the project's potential to generate a cohort of learners engaged with various forms of activism, utilising film and media as tools for advocacy. It also highlights the benefit of sustained commitment to public engagement initiatives, especially within small and concentrated annual target groups.

Table 3. Films produced by the learner cohort of 2017

Film Title	Description
Isipho Sephepha: the daily experience of our people	Four learners visited the community of Trevor Vilikazi, Khayelitsha. None were familiar with the area, but were aware of it as a vulnerable place and wanted to explore similarities and differences in attitude towards TB compared to Makhaza, where they are based. The group successfully engaged residents with conversations on TB and HIV, and related the information directly to themselves as four young women expressing issues and vulnerabilities affecting their daily lives in their own community.
Ubuthi Wam: my brother	Four learners produced a film highlighting the death of a participant's brother, who contracted TB and HIV and eventually died after defaulting on his medication, hiding the pills under his mattress and ultimately initiating his own death. Suicidal tendencies are hinted at, and what is highlighted is the mental health of the person suffering from near fatal disease as well as the mental health of those caring for him and within his immediate environment.
We're Still Here	Two learners produced a film focussing on ex-mineworkers in Khayelitsha and dealing with silicosis, TB and asthma. Mining-related silicosis, TB and death have been major media topics with an unprecedented class action settlement reached with South Africa's largest gold mines after the completion of the film ³ . The film also investigates corrupt and possible criminal activities in the release of provident and pension funds owed to ex-mineworkers. Again, this provides an example of a cause emanating from, but not solely focused on, TB and the experience of illness by the economically vulnerable.
Why Us?	Four learners portray the life of Pam, a single mother with no job and living with HIV. It is a story about numerous episodes of TB and drug resistant TB, as well as multiple counts of rape and abuse from a very early age. It touches on psychological trauma related to the events of her life, including abandonment by her mother.
This Is Who We Are	Three learners look at Khayelitsha's LGBTIQ+ community, in particular their daily lives, as well as threats and violence against lesbian high school students. Khayelitsha has a history of targeting and killing of members of the LGBTIQ+ community (Evans, 2016) as well as other forms of violence including "corrective rape" and the general assault and beating of lesbian women. (This was an additional film, and not part of the core workshop programme.)

A conclusion that can be drawn from the media output, specifically, is that the strength of Eh!woza lies not only in the diffusion of knowledge about TB and the potential for enhanced biomedical understanding in the communities with which the project engages. Rather, a critical innovation lies in revealing lived and sometimes unspoken realities of people affected by disease within social, economic, and cultural frameworks through the lens of those who live it.

³On the 3rd of May 2018, a landmark out-of-court settlement was signed, in which mining houses agreed to compensate ex-mineworkers who contracted silicosis and TB, setting aside a total of R5bn (Faku, 2018).

Formal Evaluation

An external evaluation of Eh!woza was conducted in October 2015 to investigate the extent to which the project had been fine-tuning its implementation strategy and expected outcomes in response to shifting needs.

In terms of project implementation, it was noted that an unplanned change in focus from the development of fact-based infographics for health education to a more open cinematographic approach, where an emic and interpretative perspective is favoured, resulted in unforeseen benefits. By eliminating the proposed infographic design component of the project, learners could entirely focus on film production, thereby acquiring more knowledge during the allocated time. Moreover, the move to a more subjective representation of TB deepened the learners' emotional investment in the project. This, in turn, led to the generation of a nuanced and richer description of the social determinants of the disease in Khayelitsha, as well as of the impact that TB has on the area's population.

These insights underscore the necessity to redefine the audience of the films and, ultimately, reflect on the wider aims of Eh!woza's dissemination efforts. If the reception of the videos has been positive, it must be considered in the context of a frequent question voiced by observers, namely "Who are these films produced for?" A clear plan for how to make the most of the wealth of information that they convey is missing. While Eh!woza has potentially raised TB awareness amongst young people nationwide, as shown by its over 30 000 Facebook followers, a dissemination strategy that matches the project's approach to public engagement is yet to be developed.

Preliminary Findings from an Ongoing Anthropological Study

A key area in generating knowledge is doctoral research that seeks to understand the intersection of science and community in understanding TB. It explores how a project such as Eh!woza navigates knowledge about TB and the lived experience of the disease through engaging a community of TB scientists, a community of young people from a TB-burdened setting, and narratives of TB illness shared by affected community members. The work explores understandings of TB as presented by the project, and whether and how the media produced by the young people are reflective of local experiences of health and illness. With fieldwork currently underway, preliminary findings suggest that the manner in which young people participate in the project articulates the role they play in narrating how TB is understood and lived within their social worlds. Moreover, by participating in the work of the project, young people are finding ways to present themselves as active agents within their communities interrogating and shaping local understandings of this infectious disease.

During focus group interviews, a learner suggested that, following her training with Eh!woza, she became more comfortable having conversations with her mother about TB, who was then "able to share this information with her friends and people that she knows", while another described feeling that he had the opportunity to change people's mind-sets and talk openly to individuals about issues generally considered taboo.

These statements echo sentiments expressed in the pilot film, however further work will be required to determine whether the conversations young people are having with their families, peers and close contacts effect change in perceptions of TB. This will be an important topic of investigation as Eh!woza was specifically designed to focus intensively on smaller groups of participants rather than a larger public.

Conclusions and Future Directions

As Eh!woza enters its fifth year, a project that started as an informal once-off event has grown into a sustainable initiative. An early evaluation, informal observations, and preliminary data from ongoing doctoral research indicate that the initiative has been successful in certain respects, specifically in its ability to engage young people in Khayelitsha and – through online dissemination – nationwide. Preliminary findings from an anthropological study suggest Eh!woza participants are more confident and comfortable to discuss TB with family members and peers, potentially enabling the diffusion of scientifically accurate information.

In addition to the core workshop programme, which was initiated in 2014, the project has grown to include engaged scholarship work (University of Cape Town, 2012), including doctoral research investigating how knowledge is reflected within the project, and a public engagement coursework component of the BMedSci (Hons) degree at UCT. Figure 2 illustrates the history of the project as well as new initiatives and future plans.

Eh!woza is expanding through two new initiatives in 2018. The first involves a collaboration with Médecins Sans Frontières (MSF) and aims to bring together teenagers living with drug resistant TB, young musicians, and scientists. The aim is for those affected by this severe form of TB to share personal experiences and to learn about the biomedicine of the disease, as well as to inspire musicians to produce music and videos that move away from the stereotyped representation of disenfranchised South African townships.

The second initiative is a pilot study in collaboration with Wits Institute for Socio-Economic Research (WiSER) that seeks to combine the Eh!woza-model with biomedical research to investigate notions of sexuality among young people in South Africa and how these might influence the uptake of sexual health programmes. The film, produced by a re-enrolled 2016 learner group, that documents the experiences of LGBTIQI+ people in Khayelitsha's high schools (Table 3), was instrumental in the setting up of this initiative. The activities have included a symposium, held at WiSER, with a programme featuring biomedical researchers, artists, sex-workers, activists and public commentators as well as Eh!woza learner film producers. The second phase of this initiative consisted of a series of Eh!woza-type workshops in Johannesburg and resulted in an online exhibition of creative outputs (www.wellsexuality.com) as well as an anthropological study. This expansion constitutes an important development of Eh!woza

as it suggests the potential of the project model to be applied in a variety of contexts, allowing the gathering of knowledge about traditionally hard-to-reach population segments.

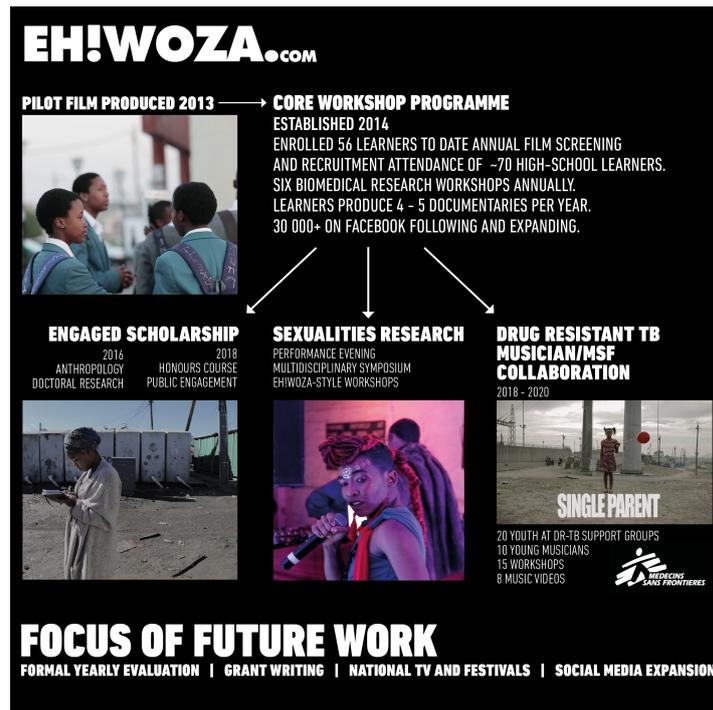


Figure 2. Eh!woza then and now

While Eh!woza has produced progressive and innovative results, certain programmatic areas require strengthening and addressing. Dissemination of films has been improved by yearly screenings, presentations at conferences and symposia and more recently, plans to screen a selection of films on national TV as well as at national and international film festivals. A schools programme for screenings and presentations is also currently under development. However, the aims informing the learner-produced media, and their target audience, need to be better defined to maximise the utility of these outputs. Moreover, given its fast growth, the project has now reached a stage where regular evaluations (yearly) are necessary. Outcomes that could be measured with the appropriate techniques and resources include assessing (i) to what extent to the biomedical knowledge acquired by learners is redistributed to family and other social circles, (ii) the impact and reach of Eh!woza’s social media campaign, (iii) the quality of discussion and debate around TB, biomedical research, and social issues, that occurs at films screenings, and (iv) how sustainable the project is in terms of funding income, management, as well as the changes generated. This kind of evaluation is essential to ensure the project’s growth is useful, strategic, sustainable, and scalable. If Eh!woza is able to address these questions honestly, it has the potential to develop into an independent and sustainable public engagement programme that facilitates dialogue and democratic decision making between biomedical researchers and practitioners, and the various publics impacted by TB and other diseases.

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