## **A failed method? Reflections on using audio diaries in Uganda with young people growing up with HIV in the Breather Trial**

Sarah Bernays, School of Public Health, University of Sydney

Sara Paparini, Anthropology and Sociology of Development, Graduate Institute of International and Development Studies, Geneva, Switzerland

Stella Namukwaya, Medical Research Council (MRC), Uganda Virus Research Institute, Entebbe, Uganda

Janet Seeley, Faculty of Public Health and Policy, London School of Hygiene & Tropical Medicine, London & MRC/UVRI and LSHTM Uganda Research Unit, Entebbe

Keywords: Qualitative methods, Randomised control trials, audio diaries, HIV, adolescents, young people, participatory research

## **A failed method? Reflections on using audio diaries in Uganda with young people growing up with HIV in the Breather Trial**

**Abstract**

In this article we present a case study in which we consider our use of the audio diary method with young people (aged 10-24) living with HIV in Uganda in a longitudinal qualitative study conducted in a clinical randomised control trial. Despite initial enthusiasm for the method amongst participants to capture accounts of participants’ experiences outside of the confines of the HIV clinic, the constraints the young people encountered in accessing sufficient privacy to confidently make recordings meant that no one elected to use them again in the study. Despite the insights the use of the method generated, the lack of acceptability led to its relative failure. This demonstrates that despite the call for innovation, there is an unwavering necessity when selecting methods that they align with the needs and preferences of our participants and with an attentive assessment of the local context in which illness narratives are produced.

**Introduction**

The relationship between qualitative methodologies and the randomised control trial (RCT) within clinical research is evolving. There has been a shift from qualitative research being done alongside trials ([Lewin, Glenton, & Oxman, 2009](#_ENREF_22)), for example in formative research in advance of the trial beginning ([Bond et al., 2016](#_ENREF_8)) or in understanding how to maximise recruitment and improve retention of participants in trials ([Elliott, Husbands, Hamdy, Holmberg, & Donovan, 2017](#_ENREF_13)), towards the integration of qualitative research within trials ([Rapport et al., 2013](#_ENREF_32); [Snowdon, 2015](#_ENREF_35)). One of the primary drivers for this has been the recognition that although the effectiveness of many interventions may be assessed on clinical terms, the success of these interventions may be intricately bound up in participant behaviour ([Piot et al., 2015](#_ENREF_30)). So an essential dimension of the research question relates to understanding how the intervention is understood and used by individuals within their particular social contexts ([Bernays, Paparini, Seeley, Namukwaya Kihika, et al., 2017](#_ENREF_3); [Camlin & Seeley, 2018](#_ENREF_11)).

Qualitative research provides a valuable set of tools to understand the messiness of human behaviour which may not comply to the neat and controlled categorisation which underpins the methodological principles of an RCT ([Montgomery & Pool, 2011](#_ENREF_27)). For example, a clinical RCT could be assessing the safety and efficacy of a novel treatment in the form of a pill, but this pill needs to be ingested by participants exactly as prescribed. In such cases qualitative research conducted within trials can investigate how individuals are interacting with the intervention to generate a more informed understanding of why a clinical intervention may or may not be working as anticipated ([Colvin, 2015](#_ENREF_12)). By broadening the focus of an intervention’s effectiveness, beyond that which can be measured narrowly against clinical endpoints, qualitative research with its attentiveness to what people are doing within situated contexts provides insights that should inform the adaptation of interventions to facilitate their increased chance of success outside of trial conditions ([Rosengarten & Savransky, 2018](#_ENREF_34)).

When clinical RCTs are trialling interventions which rely on behaviour they may be collecting within the clinic, but the site of the intervention itself is likely to be almost wholly outside of the clinic. Despite the growing recognition of the value of understanding how this intervention is used and integrated (or not) into the daily lives of participants through qualitative methods, attempting to explore experiences of the intervention outside of the clinic provides particular challenges for qualitative methods. This is further complicated by the diffuse manifestations of the Hawthorne effect, through the monitoring effect of trials on behaviour. As the risk is that qualitative research extends the scope and depth of the surveillance that accompanies being part of clinical trials ([MacNeill, Foley, Quirk, & McCambridge, 2016](#_ENREF_23)). There may be further reasons why it is inappropriate for qualitative methods to follow the experience of the intervention into spaces outside of the clinic, particularly if the intervention being trialled relates to sexual practices or a stigmatised health condition. There is a delicate balance to be negotiated in the selection of methods which provides access to experiences in their situated context but avoids harm through invasiveness.

*Case study: rationale for selecting audio diaries as a method*

In this article we present a case study of an integrated qualitative research study within a clinical RCT in Uganda([Bernays, Paparini, Seeley, Namukwaya Kihika, et al., 2017](#_ENREF_3)). Our research question was to explore the HIV treatment adherence behaviour of young people living with HIV (YPHIV) and the acceptability of an intervention designed to support their adherence. Our research ([Bernays, Paparini, Gibb, & Seeley, 2016](#_ENREF_2); [Bernays, Paparini, Seeley, & Rhodes, 2017](#_ENREF_4); [Bernays, Seeley, Rhodes, & Mupambireyi, 2015](#_ENREF_6); [Kawuma, Bernays, Siu, Rhodes, & Seeley, 2014](#_ENREF_20)) and that of others ([Kajubi, Whyte, Muhumuza, Kyaddondo, & Katahoire, 2014](#_ENREF_18)) on the topic of adherence behaviour amongst YPLHIV in Uganda has demonstrated the governing effects of young people’s relationships within the clinic on their adherence accounts. Young people tended to adhere to articulating a script of near- perfect adherence when reporting their experience of taking HIV treatment when asked in the clinic ([Bernays et al., 2016](#_ENREF_2); [Bernays, Paparini, Seeley, & Rhodes, 2017](#_ENREF_4)). There was a well-understood expectation amongst YPLHIV that revealing missed doses would provoke a scolding or worse. Young people learnt not to tell about the oscillation of their adherence behaviour, believing that it would not be understood in context nor provide any useful support ([Kawuma et al., 2014](#_ENREF_20)). This presented a methodological challenge to us in our study because we wanted and needed to understand their adherence challenges and to appreciate the complex relational context and reasons underpinning the missing of doses.

The deliberate and strategic editing of accounts within clinics is clearly not specific to this condition and context and has been widely reported elsewhere ([Riessman, 2005](#_ENREF_33)). However our consciousness of its significance to our research question and the restrictions that we had as researchers to engage with participants outside of the clinic explicitly shaped our methodological approach. We were concerned that relying solely on in-depth interviews and focus group discussions, which would need to take place within the clinic, might be an impediment to young people talking openly in their interviews with us. However, the options of observations or taking the interviews outside of the clinic, for example to their school or household, carried substantial disclosure risks. Almost without exception our participants were living with the secret of their HIV. For some this was not just a secret that they had to keep from their community, but also even from some of those with whom they shared a home. So in an attempt to access accounts of their daily behaviour as they occurred outside of the clinic we tried using audio diaries to capture their experiences.

The diary method has been described as an opportunity to access “a unique window on human phenomenology” ([Bolger, Davis, & Rafaeli, 2003, p. 610](#_ENREF_7)) and is well placed to capture the ongoing processes and “the particulars of everyday life” ([Williamson, Leeming, Lyttle, & Johnson, 2015](#_ENREF_36)) within the spaces in which days are *ordinarily lived*. A development of this method has been audio diaries, in which participants speak into an audio recorder rather than write the detail of each diary entry. Although their use remains relatively unusual in qualitative longitudinal studies and within clinical RCTs, this method is considered to be particularly pertinent in studies with individuals affected by chronic illness to ameliorate fatigue and for people with limited literacy skills ([Markham & Couldry, 2007](#_ENREF_24)).

The combination of the relative autonomy that participants have in their decisions over when, how and what to record in their diaries and the comparative ease of recording has led researchers to suggest that ‘diaries spoken into voice recorders tended to be less structured ...and often the diarist reflects on his or her relation to a particular issue in great depth’ (Markham & Couldry, 2007, p. 684). Bernays et al (2014) found that continuous availability of the diary to capture reflections meant that recordings were often recorded at ‘antisocial’ hours, for example in the middle of the night, providing insights into the dynamic significance that an illness is given in individuals’ lives and the fluctuating nature of coping. In their study they also showed that audio diaries captured experiences which were often difficult to articulate in an in-depth interview, a forum which may be more explicitly constrained by the speaker’s social considerations to the listener (ibid). Despite the solitary conditions in which audio diaries are often recorded, researchers have often found that participants still tend to direct their accounts to the specific researcher as the eventual listener ([Monrouxe, 2009](#_ENREF_26)). The deliberate performative elements of a diary, shaped by the relational construction of identities and narratives, remain a pertinent feature of audio diaries as it is within any qualitative account ([Frank, 2000](#_ENREF_14)). However the participatory nature of the method with both the subject selection and editing in the relative control of the participant ([Bernays, Rhodes, & Jankovic Terzic, 2014](#_ENREF_5); [Latham, 2003](#_ENREF_21)), potentially makes it a valuable qualitative method within RCTs to navigate the tricky balance between monitoring participants’ behaviour and accessing only what participants are comfortable to share as part of the research. This enables the researcher a temporal and tempered experiential access to these lived environments, access which is theoretically provided through a relatively discreet method.

Our choice to include the audio diary as a method within our research was based on the hypothesis that it would enable young people to speak more freely outside of the narrative confines of ‘near perfect adherence’ so commonly reported within the walls of the clinic and without the physical intrusiveness of home visits. We reflect on whether the presumed promise of this method was realised in our study.

**Methods**

**Study design**

We conducted a longitudinal study using mixed qualitative methods embedded within the Breather trial. BREATHER is a global, phase II, randomised, multicentre, non-inferiority trial testing the efficacy of Short Cycle Therapy (SCT) (5 days on /2 days off) for YPLHIV (aged 8–24) on an efavirenz (EFV)-based combination. SCT is a behavioural intervention relying on self-administered HIV treatment and self-reported adherence. Among the inclusion criteria for the BREATHER trial were: having an undetectable viral load and being on an EFV-based combination for the prior 12 months. Treatment interruption interventions, including SCT, aim to encourage long-term adherence by offering patients regulated time off medication. The trial design to test having the weekends off treatment was informed by anecdotal evidence suggesting that managed interruptions can ameliorate the challenges of adhering continuously.

The qualitative study, conducted in 2011-2016, aimed to explore the experiences of SCT and its interaction with adherence behaviour among a sample of trial participants (aged 10–24). We used qualitative methods of repeat in-depth interviews, focus groups discussions and audio diaries to elucidate whether SCT was an acceptable intervention to the target patient group to inform any potential subsequent roll-out. Our exploration of the acceptability of this intervention pivoted around understanding participants’ adherence behaviour. We report on the use of audio diaries in Uganda.

**Data collection and sample**

The Ugandan study was conducted in a paediatric clinic within a specialist HIV hospital in the country’s largest city. There are currently about 20,000 receiving care there annually, 2255 of whom are children. 33 young people participating in the Ugandan trial site were recruited purposively for the qualitative study. We used a combination of repeat in-depth interviews, focus group discussions and audio diaries. Young people were eligible to participate in the study if they were aged 10-24 years and had full knowledge of their HIV status for at least 6 months prior to being enrolled in the trial. We adopted a purposive sampling strategy to increase the likelihood of capturing a variety of experiences. We placed primary emphasis on sole, shared or carer responsibility for medication, and secondary dimensions of age, gender, ethnicity, membership of HIV youth support groups, current living arrangements and school attendance.

*Repeat in-depth interviews*

We conducted interviews at repeated times during the trial, for approximately 1–2 hours per interview. Baseline interviews covered life with HIV on ART as described by young people and included participants’ perceptions of the trial and SCT. The second interview reconstructed the life and treatment trajectory of participants since the start of the trial, focusing on adherence and their reflections on intervention and trial acceptability. The third interview was conducted as participants moved into the follow-up stage of the clinical trial and explored changes in their relationships with their treatment and their attitudes towards continuing in the intervention or control arm.

*Focus group discussions*

We also conducted four focus group discussions (FGDs) with 24 YPLHIV after the trial findings had been explained to participants by clinicians. The groups were divided by age, but not by gender (13-15 year olds, 15-17 year olds and two groups of 18-23 year olds). In addition to including a theoretically informed subsample of the interview sample (18), we invited six further trial participants, who had not previously been involved in the qualitative study, to take part in the FGDs to broaden our understanding of the acceptability of SCT across the trial patient group.

*Audio diaries*

15 participants of the 26 taking part in the first in-depth interview were invited to keep an audio diary. This involved being given a tape recorder after the first interview and recording their experiences of taking HIV treatment within the context of their daily lives. They were asked to keep an audio diary for two fortnight periods (after the first interview and then again approximately 36 weeks later. To manage the volume of data that we would collect, transcribe and translate, we only asked the first 15 participants if they would like to keep an audio diary. We used Sony compact tape recorders TCM-150 as our recorders. This phase of the study was conducted in 2011/12. Even at the time there were digital devices available, which would have meant there were no need for the use of cassette tapes. However, they were comparatively expensive. In addition given that the proliferation of smartphone and similar android devices were still relatively rare at this stage, we deliberately chose to use a technologically simple device to minimise the attention the objects may provoke and to reduce the chances of theft. The instructions were deliberately not detailed but were clear. They were asked to record their experiences of and feeling about taking treatment and living with HIV in their daily lives. They were given autonomy over how often they recorded their entries over this two week period and the only limitation was the battery life and only having two tapes of 90 minutes each. Although there was an option of getting more tapes or batteries this was not taken up by any of the participants.

**Data analysis**

The qualitative study received all necessary ethical approvals in each site. Data from all three methods were audio-recorded, subject to consent and assent (for 10-17 year olds) from all eligible participants and their caregivers. We treated informed consent as a process, reminding participants at each stage what the qualitative study was about, answering any related questions, providing information and reiterating that participants could withdraw at any time.

Extensive field notes were also collected by all researchers for each meeting, describing the encounter between researcher and participants, interview environment, and conversations prior and after the interview. Observations were also carried out at study meetings. These were held at the clinic to which all participants and their caregivers were invited. The first was held midway through the trial between the phase 1 and phase 2 in-depth interviews. The second was convened at the end of the trial to support the dissemination of the study findings. At these meetings participants were told about the progress of the qualitative study and ongoing plans, encouraged to ask questions and given the opportunity to meet each other. Despite the clinic being a specialised HIV centre most participants did not know anyone else attending the paediatric clinic prior to these study meetings. So they also served a preparatory purpose for young people to feel comfortable joining and talking within the focus group.

Data were transcribed verbatim and, when appropriate, translated into English by researchers, with personal identifying details removed. We adopted a grounded analytic approach to thematic analysis, using systematic case comparison and negative case analysis throughout. We orientated analyses by themes emerging within/across individual accounts, exploring the acceptability of the trial; the potential value of SCT; and barriers to adherence as it converges with changing priorities during adolescence. In line with our iterative approach, we analysed data as we collected it to inform the direction of subsequent interviews, further coding and case selection([Green & Thorogood, 2018](#_ENREF_17)). We maintained an audit trail of the analytical process. This included the developments of analytical memos and how case comparisons and attention to emerging ‘negative’ cases, for example ensuring that the exceptional accounts can be explained within our overarching theory, has informed our ongoing analysis ([Braun & Clarke, 2006](#_ENREF_9); [Glaser & Strauss, 2017](#_ENREF_16)).

**Results**

**Using the audio diaries: what worked?**

Fourteen out of the 15 participants invited to keep an audio diary expressed an interest in doing so and took a tape recorder with them after the first interview. Only 11 out of the 14 were returned. When asked at week 36 if they would like to use them again, no one took up the offer. This method had great potential in theory, but its execution suggested the flaws in its suitability to access the experiences of those growing up with HIV in this particular context. We report how these audio diaries were used in the first phase and what tempered their acceptability. We will compare this to our use of the same method with other younger people (11-13 year olds) growing up with HIV in Zimbabwe in another RCT ([Mupambireyi & Bernays, 2018](#_ENREF_29)), which appears to have worked more effectively. We then reflect on what other methods did work within this context to demonstrate how the success of methods does not lie in their novelty but in their appropriate application to enable participants to engage with them in an open, insightful and empowering manner.

The first phase of interviews were conducted between screening for the trial and randomisation. The rationale behind this was that interviewing them within this period would allow us to capture their attitudes towards the intervention arm prior to having experienced it. One of the participants was screened by the clinicians, interviewed by our team and given an audio diary but upon the later receipt of his screening test results he was found to have a detectable viral load and so was not randomised into the trial and therefore as he was not a trial participant he became ineligible to participate in the qualitative study. Two of the other participants told the researcher that they did not feel comfortable returning the diaries as they had used it to record entries that they now felt were too personal to share, so they returned the recorder and retained the tapes. A point that we will return to below. Table 1 summarises the characteristics of the 14 participants who took an audio diary in Phase 1:

Table 1: Sample of participants who took an audio diary at Phase 1

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **Age range (years)** | **Gender** | **Trial arm** | **Returned diary** | **Examples of who they lived with** |
|  | **Male** | **Female** | **Continuous Therapy (CT)** | **Short Cycle Therapy (SCT)** | **Screening failure** | **Yes** | **No** |  |
| 11-15 | 2 | 2 | 3 | 1 | 0 | 4 | 0 | Father, Grandmother, Mother, Paternal aunt |
| 16-18 | 3 | 4 | 3 | 3 | 1 | 4 | 3 | Father, Mother, Maternal Uncle, Cousin  |
| 19-20 | 2 | 1 | 1 | 2 | 0 | 3 | 0 | Paternal Uncle, Step- mother |

Of the eleven diary accounts that were returned, the majority of the data recorded indicated that they were not used as intended. Participants rarely used them to reflect on their adherence experiences nor of growing up with HIV. Instead they were a mixture of recordings of television or radio shows, an opportunity to test their own karaoke skills or snippets of seemingly random conversations at the marketplace or other public spaces. A fun insight into the liveliness of young people’s lives, but not generating the data that we had hoped for which were reflections on the constraints and challenges in adhering to treatment.

Just under half of those who kept audio diaries explicitly referred to HIV or treatment-taking in their recordings. How much emphasis they placed on this varied. Two recounted briefly what should incentivise people to adhere, although did not personalise this in anyway, which may have reflected a caution in their recording of personal details. A third participant also spoke about treatment by describing it in generic terms as ‘the drug’:

“Today I don’t want to talk about the drug so much but what I can talk about it is, I got a boyfriend and I’m so happy.. …but ,… that is all.” 16 year old woman.

This is an interesting example of the insight provided by multi-occasion windows that diaries enable. Here she is explaining that today she is not interested in talking about adherence and treatment, but instead wants to talk about her joy in having a boyfriend. Despite efforts to encourage participants to talk about their priority concerns, the guided discussion of our interviews may not have so readily allowed her to articulate the fluctuating significance of her condition.

Two participants described their own adherence and their contrary experiences of treatment related side effects. For one young man, a switch in drugs related to the trial had brought substantial relief from side effects. The lifting of physical restrictions and visible indicators brought by illness gave him a sense of normalcy:

“I have come a long way in terms of taking my medication because it no longer affects…. I don’t get dizzy so I am happy and that even makes me forget sometimes that I am sick. You can’t believe this but I am so happy. In the past I used to worry and I would ask God why me but now I am so happy because I am able to take my medication with no problems. It has saved me because in school I used to worry about how the other children would see me because I had so many side effects. I have now stopped worrying about the medication and I am like a normal person, okay I act like a normal person but you can never forget your illness in your heart but it is not something I think about a lot now.” 18 year old male

A young woman, who had just begun on SCT, describes how she was developing a skin rash. She queried whether this was an emerging side effect of the treatment, but did not associate it with SCT.

“I just took my tablets as usual during the course of the week except weekends staying out of drugs and by the way am getting a skin reaction I didn’t know if it is a medicine because I have never had one, I don’t know where the skin reaction came from, I think it was a reaction of the medicine. Oh! Ya bye bye.” 20 year old female

Despite the lack of focus given to explicitly describing their adherence behaviour. Two participants did use the diary to bring up sexual health topics. An 18 year old man used it as an opportunity to ask three HIV-related questions about sexual health which he was curious and confused about:

“Let me ask this to whoever will be listening to recording:

1. Why are men being circumcised? Other than reduction in HIV infection? I have not yet been circumcised but I know it reduces HIV infection rates
2. If an HIV positive couple wants to have children, how do the doctors handle this to ensure that they don’t infect the baby with HIV? That is confusing for me
3. Also how is it possible for an HIV infected woman to have sex with an HIV negative man for like 5 years without using protecting but the woman does not get infected? I have heard of people who say that I have been with my husband for 7 years but I don’t have HIV. How is that possible?”

The second participant, aged 15, described how her HIV positive status must not be transmitted on and so she felt she should not marry, “because they say when you love someone you should care about that person and I think I love that person so I should just stay away from him until other notice.”

So although there were uneven contributions in the insights that we gained from the audio diary data, they generated some illuminating examples of young people’s concerns and priorities. Given that discussion about sexual and reproductive health tended to be avoided within the clinic, it may be significant that these participants initiated conversations on this topic when talking on their own outside of the clinic. This ordinarily silenced subject became one that we were able to follow-up with all participants in subsequent interviews. Within our later interviews we learnt that this theme of confusion and limited treatment literacy diluted the incentives to adhere and reflected participants’ lack of awareness of the preventive effects of adherence (Namukwaya, 2018). This enriched our understanding of the context of their adherence behaviour, including the lack of connection made between adherence and its ‘normalising’ consequences. In subsequent topic guides we asked questions about the perceived physical effects of treatment (both good and bad), as well as explored their awareness of the effects of optimal adherence on reducing the changes of onward transmission. So the insights produced by the diary data strengthened the effectiveness of our other methods overall.

It is also important to note the early stage in the study at which we were using these audio diaries. Participants’ confidence in what they revealed to the research team grew incrementally across each phase of data collection and so some of the limitations in the recordings may reflect an emerging but still uncertain trust participants had in what was safe to reveal in the study. The limited nature of the data may in part reflect that this was only the second (indirect) conversation that they had had with the researchers.

**I don’t want to keep it again: an unacceptable method?**

When we asked participants in the second interview about their experiences of keeping an audio diary and whether they would be interested in keeping a second one, their initial enthusiasm was not repeated. Some of them described how they had found it difficult to store the recorders at home where they could trust that the content would be protected. Even those that told us that they had liked keeping the diary the first time did not want to do it again when asked the second time. The fact that no participants chose to keep a second audio diary in the study suggests that there may have been other constraining influences which affected what they chose to include in their accounts. Their primary concern was not, in the majority of cases, what the research team may think when listening to their diary accounts, but instead they were conscious of the risk of their diaries having unintended audiences.

Initially we considered whether it was the attention by having a tape recorder within their possession that might have been contributing to their reticence to take the audio diary again. However, many of the recordings were done in public places and captured group interactions, indicating that they had used them quite publicly. They looked like small transistor radios, which at the time of data collection, were relatively common possessions with many people walking the streets holding one to their ear listening to music. Conversations about what the device was were even captured as snippets in their recordings, with questioners presuming it was a radio, which pertain to a general acceptance of them as a reasonably common device: “What’s that is it a radio?” (13 year old male).

However, it was finding the space and opportunity to record their reflections privately which posed a more significant hurdle to being able to utilise the opportunity of this qualitative method. They also reported not having anywhere to store it safely, reflecting the cramped living conditions of the young people in our sample who tended to share sleeping accommodation with four or five people. As a 13 year old female explains in her second interview:

“If you stay with children at home, you shouldn’t let them know about it because that can make them come looking for it. … It was hard to find a suitable time to speak to it without others listening.”

For young people, and especially children (those aged 15 years and under), to need and want privacy attracted attention in this context. Seeking out time and space to be on your own and away from others’ appeared to be an unusual activity and not one ordinarily afforded to or taken up by children. So despite the rationale that the audio diary might afford greater autonomy and freedom for them to explain their adherence behaviour when not in the clinic, there was little to no opportunity to do so without attracting unwanted attention. Critically, participants needed to be able to access a conducive environment in which they could record their diaries in private. There were a few notable exceptions amongst the older participants. In general, there was an overarching trend that the contextual constraints meant that young people could not access such an environment.

We found that there was considerable variation in how they were used and it was not necessarily the concept of keeping an audio diary that was unwelcome. Some appreciated the opportunity to share their experiences in an open way, especially given the pressures which accompanied the need to otherwise keep their experiences of being HIV positive a secret. For two participants their audio diaries shifted into serving a more personalised purpose and as such they chose not to return the diaries, instead keeping their own intimate accounts just for themselves. That they chose not to return the diaries is arguably reassuring that the informed consent process was working. One participant, aged 17 years, who was able to find a space in which to record their diary without constraint and remained comfortable to share it with us, reported in the subsequent interview that she had found it cathartic:

“It wasn’t difficult because at times when I could get (let’s say) disappointments or if home people annoyed me, I would start to ask myself that why is it me anyway; so I would start to record as am crying at same time regretting. So I would empty my sorrow.”

Due to the delay in listening to the diaries, as they were only collected at the end of the two week period, this raises important ethical issues about how best to manage such admissions when support cannot be immediately offered.

Given the difficulties, why then had the participants expressed enthusiasm initially to keep an audio diary? Participants reported finding it more difficult than they had expected to identify quiet and safe opportunities to speak into the recorders. We were very attentive to the risks for young people in trying to find somewhere to store the recorder, prior to being able to protect the data once we had collected them back in, and discussed storage plans with each individual at length. However, although this was important what turned out to be impeding the efficacy of this method in our study was young people’s limited access to private spaces and places to *record* their reflections, which undermined participants’ capacity to engage with the method with confidence.

Despite the challenges that the young people appeared to experience in using it as intended, nobody explicitly said that they did not like it. However, it is vital that we appreciate the complex relational context influencing the way such research is being done and do not misinterpret the initial enthusiasm which greeted the prospect of keeping an audio diary with its ongoing appropriateness and acceptability. Although participants displayed a tempered enthusiasm or even ambivalence when asked in the second interview about how it had been keeping the audio diary in the first phase, a number of them did not say that they would not want to keep an audio diary again. Instead when asked if they would like to take the audio diary a second time, they found excuses to postpone collecting it saying that it would be more convenient at the next clinic visit. Despite their reaction to not explicitly stating their discomfort with the audio diary method, their actions articulated their silent refusal. This continued for some time and the research team, noticing a behaviour pattern in the way participants were only partially engaging in the opportunity, decided not to pursue it further. Participants reported enjoying the opportunity to participate in the qualitative study and with the exception of taking up the audio diaries in the second phase, they were consistently attentive and proactive in their engagement with all other dimensions of the study. The relationships the participants were developing with the researcher and the broader project of the qualitative research, in addition to the overarching context of politeness, may have made it more difficult for young people to tell us explicitly about the problems that they faced in using the audio diary.

**Acceptability in Zimbabwe?**

Although it is novel to use the audio diary method with young people in resource-stretched settings to explore their lived experience of chronic illness, it is not unprecedented. We have tested the method with 11-13 year olds in Zimbabwe (article in review in this journal). This qualitative study was also embedded within a large clinical trial, but unlike the Breather qualitative study, its research question was not directly linked to the trial intervention. Instead the trial acted as a recruitment pool through which to explore the experiences of this age group in growing up with HIV and to understand how the social context of their lives shaped their capacity to comply with what they were told at the clinic about how to manage their HIV. Participants were given a very similar explanation about the remit of the audio diary and how to use it. The participants were given a simple digital device to record their audio diaries. Despite the sample being concentrated within a younger age category there was a higher proportion of participants who recorded accounts on the required topic, with several of them clearly being recorded in private spaces and reflecting on very personal concerns in relation to HIV.

It is worth then exploring why it worked relatively well in the Zimbabwean setting and yet played out so differently in the Ugandan study site. Although the two trial clinics through which the qualitative participants were recruited were both located within the broad catchment area of the two nations’ primary cities, the socioeconomic data of the participants would suggest that the Ugandan participants tended to be living in poorer residential conditions than their Zimbabwean counterparts and had less privacy within their physical environments and accommodation. The Zimbabwean capital city of Harare is likely to have had a more rapid exposure to technological advances and as the participants were using digital devices they did not look especially different to available smartphones. Subsequently changing social practices which accompanied this proliferation may have meant that it was already relatively common for individuals, including children, to be sat alone concentrating and absorbed in interacting with similar devices. However, we are unable to substantiate with confidence whether there was an existing or emerging divergence in the social attitudes towards a young person requesting or seeking privacy across the two settings. So it may have also been underpinned by chance that individuals in the Zimbabwean study were more confident in using the method than in our Ugandan study. This comparison draws attention to the specificity of the local and historical context in shaping whether a method will be found to be effective by those being asked to engage in it.

**Effective use of ‘ordinary’ methods**

What did work well, if the criteria for success is defined as generating insightful data and effectively engaging participants in our study, were repeat in-depth interviews participants and focus groups once the trial results had been disseminated to participants. These methods, although not innovative methodologically, were perceived as being so by the participants because they provided a framework through which they could feel comfortable talking about a subject that they had rarely, or in some cases, never spoken about before within or outside of research. As 19 year old male described when he reflected on the experience of participating in the qualitative study:

“I am the one who found out that I was HIV positive, no one told me so it had an effect on me psychologically but I kept quiet and didn’t tell anyone. But when I came to the Breather (qualitative) study and during the interview I told them, because they asked if I had been disclosed to and I said that no one had ever told me. By that time (start of study) I had a lot on my mind and so many questions and okay that was when I opened up everything and since then I have basically been feeling like I am at home.”

The design of repeat waves of face to face data collection conducted by a researcher independent of both the trial and the clinic, in which participants could observe that no information was shared outside of the research team, fostered participants’ developing confidence in the confidentiality of the research process. “We find it easy to talk to you, while the others are tough.” FGD1 (13-15 year olds). The tailored topic guide approach that was adopted in the follow-up phases served to demonstrate the research team’s engagement in understanding the experiences of participants and to situate this within the broader context of their social lives and relational priorities. As such these relatively *ordinary* qualitative methods were applied in a way that was experienced as innovative by the participants because they allowed them the freedom to talk and to also engage with the trial in a way that may not have otherwise occurred.

**Discussion**:

­The enthusiasm for developing novel qualitative methods to access experience within RCTs is encouraging the application of innovative configurations of methods. We invited young people to keep audio diaries, an innovative method, as part of our mixed qualitative methods study. Participants unanimously chose not to keep the audio diaries for a second time. We thus found that although the diary method generated valuable data, we deemed it a relative failure because it was not acceptable to our participants. Our study design also included the combined use of repeat waves of in-depth interviews, regular study meetings for participants and engaging with participants’ post-trial through focus group discussions, which are all fairly standard issues methods within the qualitative researcher’s toolbox. However what may be considered ‘traditional’ at the point of research design (usually in the North), may be completely novel at the point of fieldwork and in the context of research within HIV paediatric trials. The novelty in this case was because they were asked about their own thoughts and feelings in the context of health and illness, by an adult that they did not know and that expressed interest in their views, but also, even more, an adult in an authoritative space such as the clinic, who was not there to instruct their behaviour as such. The unusual nature of these circumstances resonates with Meinert’s research in Uganda where she identifies health as an area where children and young people are not supposed to take lead in discussion with adults ([2009](#_ENREF_25)).

Our experience of using audio diaries illustrates how the substantive context of a particular research study, which in our study was the silenced topic of growing up with HIV and the limited opportunity for privacy afforded to children and young people in the resource-stretched environment of Uganda, must continue to influence the researcher’s choice of methods above all else. Our study deigns should be guided by context so that we have the necessary flexibility to adapt iteratively to best capture and engage with people as their situations reveal themselves.

It is worth noting that the chances of the audio diary working may have been hampered by the execution of the method. The study was deliberately designed so that the audio diaries would be recorded shortly after the first and second interviews, when the task was still fresh in the minds of participants. Once the audio diary was collected and listened to it was planned that there would be a follow-up phone call to discuss any issues that might warrant further support. The subsequent interview would then provide an opportunity to further explore some of the topics discussed. However as every participant chose not to keep it for a second time our diary dataset and subsequent interpretations of the method are based on a singular period of use in the early stages of the study. It is possible that had participants had the opportunity to have developed a more trusting relationship with the research team before using the audio diary some of these effects may have been mitigated. But it is unlikely to have had a profound effect as the restricted access to private places and spaces was an ongoing feature of most of these young people’s lives and would not have been addressed by waiting an additional six months before offering them the diary. A second connected limitation may have been the technology that we were using at the time of the study. We chose not to use more sophisticated technology because of the rarity of digital personal devices at the time. However as we witness an exponential increase in the technological options available for an audio diary method, the situation is quite different now ([García, Welford, & Smith, 2016](#_ENREF_15)). The proliferation of smart phone devices may mean that social practices and norms around individual’s solitary engagement with such devices are changing. This might afford young people more privacy to record their reflections. The available options through various apps would certainly enable participants to send their recordings securely and delete them from their own devices, which would then enhance the confidentiality of their diaries. In combination this may have provoked sufficient change to render the method more acceptable now.

These limitations and emerging opportunities speak to the historical specificity of context in which the deployment of effective methods are inevitably situated. Context is not only important to the understanding of processes of implementation and the effectiveness of interventions, but also to informing the research platforms and more specifically the choice of methods that can foreground these local particularities. The correct selection of methods though may not always be immediately obvious and as Adams et al argue in their call for “slow research” in global health, a commitment to engaging with local contexts requires a responsive attentiveness to the context in which knowledge is produced and used ([2014](#_ENREF_1)), in a form of “dialogic action” ([Montoya & Kent, 2011](#_ENREF_28)) in which methods are adapted to the shifting needs of researchers and participants. Our experience also highlights the subtle forms in which the dissonance between researchers’ expectations and participants’ experiences of a particular method can be made manifest. The dialogue may not always be easy to hear. In our case study, participants’ engagement with the study was shaped by the relational dynamic characterised by both the hierarchy between adult professional researcher and young patient participant and an appreciation for the opportunity to ‘safely’ speak. This may have hindered the capacity of participants to explicitly refuse to take up the diary for the second time. So being attentive to evaluating the efficacy of a method requires us to be able to listen to and recognise the voice of the silent refuser ([Kamuya et al., 2015](#_ENREF_19)).

Although we have portrayed this method as a relative failure in this specific historical and localised context, it is concomitantly revealing about both methodology and our research topic as the reasons underpinning the failure of the diaries tells us about the nature of their adherence experiences. This reflects a similar pattern to what has been observed in the silences within interviews ([Poland & Pederson, 1998](#_ENREF_31)). For example, it tells us about how these YPLHIV are able to live and move publicly, hence they can record in the street, but how the knowledge and management of their condition HIV in being secret and hidden belongs to a private space where recording *about it* thus becomes inhibited. Reflecting on participants’ experiences of using the audio diary tells us about the silencing of their HIV in their lives, and about the fears associated with being found out which underpins the risks of unintended disclosure via the diaries. It also tells us about the nature of adherence behaviour itself by illustrating how difficult it is to keep up adherence because it involves being able to find private time and space in which to take the drugs, to find places to store the drugs and to access them when needed, just as it was difficult with the recording.

This may also tell us about why the trial intervention may be especially valuable to them. The routine of the five day taking treatment and two day rest which makes up short cycle therapy means that young people do not need to take it at the weekends. They enjoyed this because without the need to take treatment for those two days and with the relatively good health afforded by having an undetectable viral load their HIV became temporarily invisible. A sense of normalcy as a young person was attained by not requiring privacy. Their experiences of HIV although felt individually are framed by the structural conditions in which they live. Whether denial is an appropriate coping strategy is beyond the remit of this article, but it reveals the nature of adherence and shows the value of qualitative research within trials by countering the epistemological framing in RCTs which is commonly rooted in an emphasis on the individual rather than the structural level. So by integrating qualitative research into RCTs, with its focus on lived experience it also helps bring the influence of the structural level to the fore as well as that of the individual in the design and refinement of interventions ([Adams et al., 2014](#_ENREF_1)).

In addition, we learnt that the young people struggled to tell us that they did not want to keep the diaries any longer and so were deliberately vague about it. This may also align with why they struggle with talking about non-adherence explicitly because of the risk that this is a failure and a disappointment to the adult, which is revealing about what shapes the lack of communication about non-adherence. Finally, and somewhat contrarily, there is an additional aspect in the nexus of learning from our use of this method, which further reveals the complexity of the experience of living with HIV for these young people. They described in their diaries something other than their HIV-related stories. This points to the possibilities the diary offered them to focus on their lives beyond HIV, and possibly to their wish to communicate to us other aspects of their lives, even when this was not what we had shown interest in. This is potentially an encouraging finding, against the background of a failure of methods that can tell us something about young people’s extraordinary resilience and capacity to live with HIV in often difficult circumstances.

The insights that we gained from using the audio diary although illuminating may inadvertently- and unacceptably- be replicating the constraining structure in which they are negotiating the management of their HIV treatment and care. It serves as a case study for the need for responsive study designs, in which context is not treated as “background static” but a critical variable influencing the effective selection of interacting methods, technologies and techniques ([Adams et al., 2014](#_ENREF_1)). We need to try to resist the pressure that is accompanying the growing enthusiasm for qualitative innovation in clinical trials to deliver qualitative studies on an accelerated timeframe using the favoured methods of funders ([Burke, le May, Kébé, Flink, & van Reeuwijk, 2018](#_ENREF_10)) without having the opportunity to pilot these methods in context, as we can not know a priori what will work where, when and with whom. If we are to innovate towards a more effective arsenal of qualitative methods for integration into RCTs then this must involve the use of flexible social science designs so that methods can be tailored, adapted or even abandoned as necessary. This is vital for the ethical and effective conduct of qualitative research, but will also mean that the endeavour of integrating qualitative research into RCTs does not dilute its credibility and value by overpromising in terms of what rich qualitative data might be collected when moving across different countries in multi-country trials.

**References**

Adams, V., Burke, N. J., & Whitmarsh, I. (2014). Slow research: Thoughts for a movement in global health. *Medical Anthropology, 33*(3), 179-197. doi:doi.org/10.1080/01459740.2013.858335

Bernays, S., Paparini, S., Gibb, D., & Seeley, J. (2016). When information does not suffice: young people living with HIV and communication about ART adherence in the clinic. *Vulnerable Children and Youth Studies, 11*(1), 60-68.

Bernays, S., Paparini, S., Seeley, J., Namukwaya Kihika, S., Gibb, D., & Rhodes, T. (2017). Qualitative study of the BREATHER trial (Short Cycle antiretroviral therapy): is it acceptable to young people living with HIV? *BMJ Open, 7*(2), e012934.

Bernays, S., Paparini, S., Seeley, J., & Rhodes, T. (2017). “Not Taking it Will Just be Like a Sin”: Young People Living with HIV and the Stigmatization of Less-Than-Perfect Adherence to Antiretroviral Therapy. *Medical Anthropology, 36*(5), 485-499.

Bernays, S., Rhodes, T., & Jankovic Terzic, K. (2014). Embodied accounts of HIV and hope: using audio diaries with interviews. *Qual Health Res, 24*(5), 629-640. doi:10.1177/1049732314528812

Bernays, S., Seeley, J., Rhodes, T., & Mupambireyi, Z. (2015). What am I ‘living’with? Growing up with HIV in Uganda and Zimbabwe. *Sociology of Health and Illness, 37*(2), 270-283.

Bolger, N., Davis, A., & Rafaeli, E. (2003). Diary methods: Capturing life as it is lived. *Annual Review of Psychology, 54*(1), 579-616. doi:doi.org/10.1146/annurev.psych.54.101601.145030

Bond, V., Chiti, B., Hoddinott, G., Reynolds, L., Schaap, A., Simuyaba, M., . . . Seeley, J. (2016). “The difference that makes a difference”: highlighting the role of variable contexts within an HIV Prevention Community Randomised Trial (HPTN 071/PopART) in 21 study communities in Zambia and South Africa. *AIDS Care, 28*(sup3), 99-107. doi:10.1080/09540121.2016.1178958

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology *Qualitative Research in Psychology, 3*(2), 77-101. doi:doi:10.1191/1478088706qp06309

Burke, E., le May, A., Kébé, F., Flink, I., & van Reeuwijk, M. (2018). Experiences of being, and working with, young people with disabilities as peer researchers in Senegal: The impact on data quality, analysis, and well-being. *Qualitative Social Work*, 1473325018763515.

Camlin, C., & Seeley, J. (2018). Qualitative research on community experience of large HIV research trials: What have we learned? *Journal of the International AIDS Society, 21*(Suppl 7), e25173. . doi:10.1002/jia2.25173

Colvin, C. (2015). Who benefits from research? Ethical dilemmas in compensation in public health and anthropology. In D. Posel & F. C. Ross (Eds.), *Ethical quandaries in social research* (pp. 57-74). Cape Town, South Africa: HSRC Press.

Elliott, D., Husbands, S., Hamdy, F. C., Holmberg, L., & Donovan, J. L. (2017). Understanding and improving recruitment to randomised controlled trials: qualitative research approaches. *European urology, 72*(5), 789-798. doi:doi.org/10.1016/j.eururo.2017.04.036

Frank, A. W. (2000). The standpoint of storyteller. *Qualitative Health Research, 10*(3), 354-365. doi:doi.org/10.1177/104973200129118499

García, B., Welford, J., & Smith, B. (2016). Using a smartphone app in qualitative research: The good, the bad and the ugly. *Qualitative Research, 16*(5), 508-525. doi:doi.org/10.1177/1468794115593335

Glaser, B. G., & Strauss, A. L. (2017). *Discovery of grounded theory: Strategies for qualitative research.*: Routledge.

Green, J., & Thorogood, N. (2018). *Qualitative methods for health research.* : Sage.

Kajubi, P., Whyte, S., Muhumuza, S., Kyaddondo, D., & Katahoire, A. R. (2014). Communication between HIV-infected children and their caregivers about HIV medicines: a cross-sectional study in Jinja district, Uganda. *J Int AIDS Soc, 17*, 19012. doi:10.7448/IAS.17.1.19012

Kamuya, D. M., Theobald, S. J., Marsh, V., Parker, M., Geissler, W. P., & Molyneux, S. C. (2015). “The one who chases you away does not tell you go”: silent refusals and complex power relations in research consent processes in Coastal Kenya. *PloS One, 10*(5), e0126671. doi:doi.org/10.1371/journal.pone.0126671

Kawuma, R., Bernays, S., Siu, G., Rhodes, T., & Seeley, J. (2014). ‘Children will always be children’: Exploring perceptions and experiences of HIV-positive children who may not take their treatment and why they may not tell. *African Journal of AIDS Research, 13*(2), 189-195.

Latham, A. (2003). Research, performance, and doing human geography: Some reflections on the diary-photograph, diary-interview method. *Environment and Planning 35*, 1993-2017. doi:doi:10.1068/a3587

Lewin, S., Glenton, C., & Oxman, A. D. (2009). Use of qualitative methods alongside randomised controlled trials of complex healthcare interventions: methodological study. *Bmj, 339*, b3496.

MacNeill, V., Foley, M., Quirk, A., & McCambridge, J. (2016). Shedding light on research participation effects in behaviour change trials: a qualitative study examining research participant experiences. *BMC Public Health, 16*(1), 91. doi:doi.org/10.1186/s12889-016-2741-6

Markham, T., & Couldry, N. (2007). Tracking the reflexivity of the (dis)engaged citizen: Some methodological reflections. *Qualitative Inquiry, 13*(675-695). doi:doi:10.1177/1077800407301182

Meinert, L. (2009). *Hopes in friction: Schooling, health and everyday life in Uganda*. Charlotte, North Carolina, USA: Information Age Publishing Ltd.

Monrouxe, L. V. (2009). Negotiating professional identities: Dominant and contesting narratives in medical students’ longitudinal audio diaries. *Current Narratives, 1*(41-59). doi:doi:10/1111/j.1365-2923.2009.03440.x

Montgomery, C. M., & Pool, R. (2011). Critically engaging: integrating the social and the biomedical in international microbicides research.

. *Journal of International AIDS Society, 4* (Suppl 2), S4. doi:10.1186/1758-2652-14-S2-S4

Montoya, M. J., & Kent, E. E. (2011). Dialogical action: Moving from community-based to community-driven participatory research. . *Qualitative Health Research, 21*(7), 1000-1010. doi:doi.org/10.1177/1049732311403500

Mupambireyi, Z., & Bernays, S. (2018). Reflections on the Use of Audio Diaries to Access Young People’s Lived Experiences of HIV in Zimbabwe. . *Qualitative Health Research*. doi:<https://doi.org/10.1177/1049732318780684>

Piot, P., Karim, S., Hecht, R., Legido-Quigley, H., Buse, K., Stover, J., . . . Dybul, M. (2015). Defeating AIDS—advancing global health. *The Lancet, 386*(9989), 171-218. doi:[https://doi.org/10.1016/s0140-6736(15)60658-4](https://doi.org/10.1016/s0140-6736%2815%2960658-4)

Poland, B., & Pederson, A. (1998). Reading between the lines: Interpreting silences in qualitative research. *Qualitative inquiry, 4*(2), 293-312. doi:doi.org/10.1177/107780049800400209

Rapport, F., Storey, M., Porter, A., Snooks, H., Jones, K., Peconi, J., . . . Clement, C. (2013). Qualitative research within trials: developing a standard operating procedure for a clinical trials unit. *Trials, 14*(1), 54. doi:<https://doi.org/10.1186/1745-6215-14-54>

Riessman, C. K. (2005). Exporting ethics: A narrative about narrative research in South India. *Health:, 9*(4), 473-490.

Rosengarten, M., & Savransky, M. (2018). A careful biomedicine? Generalization and abstraction in RCTs *Critical Public Health*. doi:10.1080/09581596.2018.1431387

Snowdon, C. (2015). Qualitative and mixed methods research in trials: BioMed Central.

Williamson, I., Leeming, D., Lyttle, S., & Johnson, S. (2015). Evaluating the audio-diary method in qualitative research. *Qualitative Research Journal, 15*(1), 20-34. doi:doi.org/10.1186/s13063-015-1084-4