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# Retention in the *Bukhali* trial in Soweto, South Africa: a qualitative analysis using self-determination theory

Catherine E Draper ,[1] Nosibusiso Tshetu,[1] Nokuthula Nkosi,[1] Stephen Lye,[2,3] Shane A Norris[1,4]

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[1]SAMRC Developmental Pathways for Health Research Unit, University of the Witwatersrand, Johannesburg, South Africa
[2]Lunenfeld-Tanenbaum Research Institute, Toronto, Ontario, Canada
[3]Departments of Obstetrics and Gynecology, Physiology and Medicine, University of Toronto, Toronto, Ontario, Canada
[4]School of Human Development and Health, University of Southampton, Southampton, UK

**Correspondence to**
Professor Catherine E Draper; catherine.draper@wits.ac.za

## ABSTRACT

**Introduction** There is limited research on applying theory to retention in complex intervention trials. To address this gap, this study aimed to qualitatively examine retention in the *Bukhali* randomised controlled trial, from the perspective of trial participants and staff, through the lens of self-determination theory (SDT). The *Bukhali* trial is part of the Healthy Life Trajectories Initiative in Soweto, South Africa, with young women.

**Methods** Nine focus group discussions were used to generate data from *Bukhali* trial staff (n=45, 23–64 years), and participants, including those currently enrolled (n=16, 25–31 years) and those who had withdrawn from the trial (n=20, 24–32 years). A codebook thematic approach was taken to data analysis; SDT was used to develop a conceptual model to analyse the data in context. The main themes identified were external influences on the trial, trial implementing environment, controlled motivation and intrinsic autonomous motivation.

**Results** Our findings highlighted the contextual issues influencing the trial, including participants' socioeconomic circumstances, and the presence or absence of social support, the trial complexity and participant burden. Issues related to controlled motivation comprised challenges of staying in contact, financial incentives and food, health services provided and other incentives. We also identified aspects of the trial supporting participants' psychological needs of autonomy, competence and relatedness, which in turn contributed to their intrinsic autonomous motivation. These included participants' interest in the trial and its relevance to them; participants' sense of agency, meaning and purpose through their involvement; the building of their knowledge and awareness about their health; relating to other participants and the relationships built with staff and being treated well.

**Conclusion** SDT provides a helpful frame for a contextualised understanding of the complexity of retention of *Bukhali* trial participants (longitudinal study and intervention). These findings have relevance for trials in under-resourced settings.

### WHAT IS ALREADY KNOWN ON THIS TOPIC

⇒ Retention of participants is crucial in randomised controlled trials, but there is little application of theoretical understandings to retention.

### WHAT THIS STUDY ADDS

⇒ Using self-determination theory, this study highlights the combination of retention approaches in the *Bukhali* trial that promote controlled and intrinsic autonomous motivation of participants, within their specific context.

### HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

⇒ These findings provide insight into the consideration of the complexity of retention within complex trials conducted in under-resourced settings.

## INTRODUCTION

Retention of participants is crucial in randomised controlled trials (RCTs), as poor retention can detrimentally impact the validity, reliability and usability of trial results.[1 2] However, despite its importance, retention is often not given the attention it deserves in the design and planning of trials, and can be overshadowed by an emphasis on recruitment.[3 4] There is also little application of theoretical understandings to retention.[5 6]

The role of financial incentives has been highlighted as a measure to boost retention in trials,[1 2 7] along with the importance of relationships between trial staff and participants.[4 6] Focussing on low- and middle-income country (LMIC) settings, Poongothai *et al*[8] emphasised these relational factors for retention, including building trust and listening well. They maintain the importance of 'participant-centric' approaches to retention, without necessarily neglecting tangible incentives like food, money and healthcare services.[8] Related to this, others have noted the underutilisation of strategies to support intrinsic motivation of trial participants, warning against the reliance on controlled motivation strategies, such as financial incentives and other rewards.[6] It has been suggested that strategies such as building relationships

and rapport between trial staff and participants are less frequently reported in trial protocols, as they are often seen as informal strategies that might be harder to plan, report and evaluate.[3]

In South Africa, an LMIC, studies investigating factors influence retention have reported that participants' multiple obligations, inability to take time off work, relocating or travelling out of the area and lengthy in-person trial visits have impacted retention,[9 10] along with challenges of staying in contact with participants.[10 11]

### Healthy Life Trajectories Initiative—*Bukhali* trial

The Healthy Life Trajectories Initiative (HeLTI) is an international consortium developed in partnership with WHO in Canada, India, China and South Africa. HeLTI hypothesises that an integrated complex intervention, comprising a continuum of care from preconception, through pregnancy, infancy and early childhood will promote young women's physical and mental health, in order to establish healthier trajectories for themselves and future children. For HeLTI South Africa, the *Bukhali* RCT is being conducted with women aged 18–28 years in Soweto[12] (trial components and process included as online supplemental material). Soweto is a predominantly low-income, densely populated, urban setting in Johannesburg, and young women face multiple risks to their physical and mental health.[13]

The *Bukhali* complex intervention is delivered by trained community health workers, referred to as 'health helpers' (HHs). HHs provide health literacy support, conduct risk screening referral and management support, provide multimicronutrient supplementation and support health behaviour change through Healthy Conversation Skills.[14 15] During a mix of monthly either telephonic or in-person sessions (at the research site in Soweto), they cover topics related to young women's physical and mental health, as well as early childhood health and development up to the age of 5 years.[13] For the non-intervention (control) arm, standard of care 'plus' is delivered telephonically by call centre agents (CCAs), covering non-health-specific topics, related mostly to practical life skills.[13] After recruitment, participants come to the research site for a baseline testing visit, and an exit testing visit after 18 months if they have not become pregnant. If they do become pregnant, they have two testing visits during pregnancy, and further testing visits at delivery, 6, 12, 24 and 60 months.[12]

Across the HeLTI sites, a set of potential retention strategies was harmonised, including strategies to (1) reduce barriers to participation, (2) create a project community, (3) follow-up and remind participants and (4) implement tracing strategies. These strategies, and comments on their implementation in the HeLTI South Africa site were documented (provided as online supplemental material) through a consensus exercise with HeLTI South Africa researchers and trial staff, indicating which strategies are being implemented, which are not being implemented and which are not applicable (either not relevant or feasible for the South African context). The *Bukhali* process evaluation has thus far explored trial implementation,[16–19] as well as participants' perceptions and experiences,[20–23] and HHs' perspectives.[24 25] While issues related to retention have been implied in this previous work, retention has not been specifically investigated, considering the retention of participants in a longitudinal study, as well as the retention of participants in a long-term intervention. Therefore, the aim of this study was to qualitatively examine retention in the *Bukhali* trial (longitudinal study and intervention), from the perspective of trial participants and staff, through the lens of self-determination theory.

## METHODS

This qualitative study used focus group discussions to generate data from trial participants and staff from the testing, intervention and non-intervention arms of the trial.

### Sample and recruitment

Trial participants were purposively sampled for this study, including both those who were enrolled (n=16, 25–31 years) and those who had withdrawn (n=20, 24–32 years) from the trial. This was done to obtain a wide range of responses and to mitigate bias that might arise from only including participants who had been retained in the trial. Participants were contacted telephonically to recruit them for the focus group discussions. Enrolled participants were individuals who had been recently recruited to form participant advisory groups for the infancy phase of the trial, and from the 20 enrolled participants invited for the focus groups, four did not arrive on the day. From the withdrawn participants who were able to be contacted with the details available, seven participants were not interested in participating, and out of the 40 participants booked for the focus groups, 20 did not arrive on the day. All staff from the trial testing team (n=17, three males, 29–64 years), and the CCAs (n=8, 23–38 years), HHs, drivers and trial dietitian (n=20, 3 male, 24–52 years) were requested to participate in a focus group with their respective teams, and all agreed. Further details of participants are provided in the online supplemental material.

### Patient and public involvement

The public was involved in the design, conduct and dissemination plans of Bukhali. Intervention development was guided by formative work conducted with community members. Engagement with trial stakeholders (eg, representatives from the South African government, WHO and UNICEF) is ongoing, and a participant advisory group has been involved in the qualitative research strategy.

### Data collection

Nine focus groups were conducted between March and May 2024 at the research site—three groups with staff, two with enrolled participants (one intervention, one

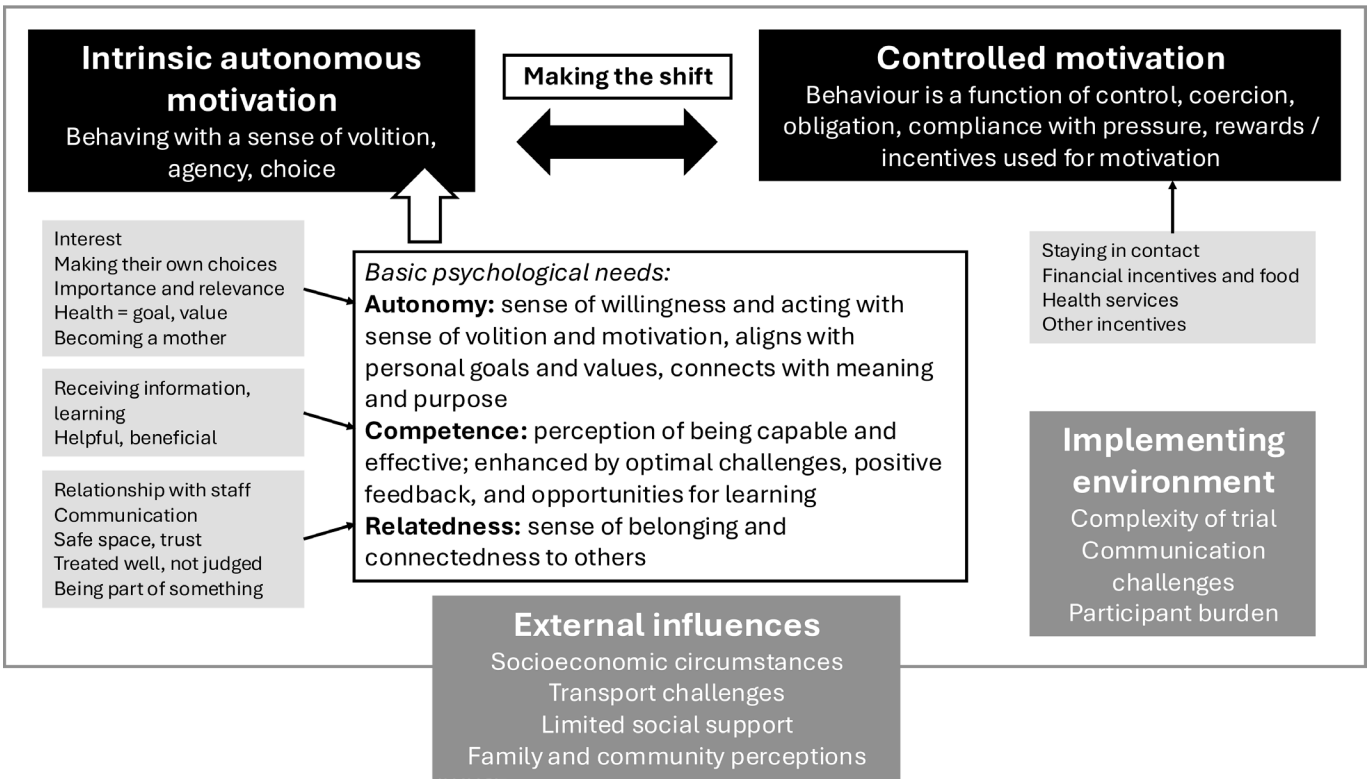


**Figure 1** Conceptual model of self-determination theory applied to retention.

non-intervention) and four with withdrawn participants (two intervention, two non-intervention). The discussions ranged between 1 hour 45 min and 2 hours 18 min for enrolled participants and staff, and between 56 min and 1 hour 33 min for withdrawn participants in length. Refreshments were provided for all groups, and transport costs were reimbursed for participants. For all focus groups, discussion guides were developed by coauthors and are included in the online supplemental material. The focus groups were facilitated by NT and NN, while the discussion guides were developed in English, facilitators were able to converse in local languages when necessary. The discussions were audio recorded, and translated into English and transcribed verbatim.

### Data analysis

A codebook thematic approach was taken to the descriptive and exploratory process of data analysis (led by CED).[26–28] The analysis process began with the discussion guide, which generated some initial ideas for organisation and interpretation of the data in relation to issues of retention and participants' motivations to stay in the trial. Consultation with relevant literature on retention pointed to the usefulness of self-determination theory as a framework for understanding the topic.[6] After reviewing all the transcripts, a conceptual model was developed using self-determination theory, as applicable to the *Bukhali* trial, and is presented in figure 1. This model shows the distinction between controlled motivation and intrinsic autonomous motivation, along with the basic psychological needs (autonomy, competence and relatedness) that contribute to intrinsic autonomous motivation. Intrinsic motivation relates to behaving with a sense of volition, agency and choice, whereas controlled motivation is associated with behaving due to control, coercion, obligation or compliance.[6]

Various aspects of the *Bukhali* trial and its retention strategies were then mapped onto these types of motivation, and drawing on our previous work to contextualise the *Bukhali* trial,[16–25] a range of other contextual factors were identified that characterise the implementing environment, and the external influences of the trial; these are all included in the conceptual model. This conceptual model was shared with coauthors for their input, as well as with trial staff to assess its resonance with their experiences, and they agreed that it provided a meaningful framework for understanding retention and motivation in the *Bukhali* trial.

From this conceptual model, a coding framework was developed made up of the following main themes: external influences on the trial, trial implementing environment, controlled motivation and intrinsic autonomous motivation. The coding framework was then applied to the transcripts to identify relevant portions of the text that corresponded to these codes using MAXQDA data analysis software. Coded sections were then exported and summarised, and illustrative quotes were selected. The order in which the themes are presented is intended to first characterise the context of participants' experiences and to highlight extrinsic factors influencing motivation and retention, and then to move to controlled

motivation and intrinsic autonomous motivation related to retention. Illustrative quotes are provided in in the results section.

### Reflexivity

We acknowledge that our training, roles, lived experiences, identities and values have influenced the research process. Positionality statements for all authors are included in the online supplemental material.

## RESULTS

### External influences on the trial

#### Socioeconomic circumstances

The challenges of unemployment, poverty and food insecurity mentioned by participants and trial staff provide a backdrop for the contextual realities experienced by young women in Soweto. These challenges likely influence their perceptions of the trial incentives (discussed further on), and hence their motivation for staying in a trial like *Bukhali*.

Due to socioeconomic circumstances, participants seldom have access to a car and rely on transport to the research site, usually by private 'mini-bus taxis' that are ubiquitous in lower-income South African communities, including Soweto. The costs of using taxis are often not affordable for those who have minimal income, and the prices have increased with increased fuel prices in recent years. Due to the size of Soweto, transport challenges were frequently cited as a challenge. While participants are provided a financial incentive to come to the site, this is only received once they come in; many participants reported finding it difficult to afford the taxi fare to get to the site, and would have to borrow money. Some participants would then walk a long distance to the site, but this is not ideal if they are coming with their child, and safety is also a concern. And as the child becomes older, they are required to pay for the child on the taxi.

To encourage retention, where possible, participants are collected by drivers from the trial team, and many participants appreciated this service. However, offering this service to all participants (in all phases of the trial) is not feasible, but participants and staff felt it would be ideal if it was available for all participants.

**Box 1 External influences—quotes**

**Socioeconomic circumstances**

"It's because we receive money, sometimes you come here and find that you don't have anything, you only have money to come here and go back, so coming here you know that you will go back with some money to buy bread for the kids. (Enrolled participant—intervention) I think not getting proper food and some they come from very poor family background and when they get here, they are already hungry. Some of them come here with the child and not having food for the child. You know you would ask them, did you bring anything for the baby and they said, and not because they didn't want to but because they don't have anything where she comes from. So I think so". (Staff—testing)

**Transport challenges**

"The change is that since the baby is now grown, I am able to come by myself, sometimes I don't have money for transport, and so I have to walk from home to here, and it's far, but I try sometimes to make it…I try to leave together with those that are going to work because there are some places that are a bit scary to walk alone on, so I get my baby and come with her. It is difficult and sometimes when I have money I take a taxi. (Enrolled participant—intervention) It was nice, really nice, starting with the transport that you guys offer for us, it made us feel special being picked up from home". (Withdrawn participant—non-intervention)

**Social support**

"Because I felt like when I speak to my family members, like they were judging me or wanted to tell me how to go about doing things, even if I wanted to do the things the way I wanted to, so that I can make my own mistakes, learn from my mistakes. (Withdrawn participant—non-intervention) And when it is known that they are coming to the study, when they get home, they will demand that they give them the money they got here. (Enrolled participant—non-intervention) Family support, you know, when you speak about physical activity and they can do it to keep fit, sometimes they will tell you, no, at home, this is how we live, this is how we do things, and it is going to be hard for me or for me to implement the change if I don't have support near me, I don't have a friend who is going to help me or family who is going to support me, so yeah". (Staff—intervention)

#### Limited social support

The absence of social support was mentioned by some participants, which negatively influenced their ability to stay involved in the trial, and are therefore relevant to retention. This was to do with not having someone to take care of their other child/children when attending the research site (or not being able to pay someone to look after their child), expectations of family members to receive some or all of the financial incentive that participants receive (mentioned above) or family members not being supportive of the health behavioural changes encouraged by the trial HHs. Conversely, participants reported receiving social support from trial staff, which helped make up for the lack of support at home.

#### Family and community perceptions

Related to this, some participants spoke about the perceptions of family and community members about various issues relevant to the trial. This included the supplements provided to intervention participants, which some thought was causing pregnancy, or was being given because the participant was ill, often with HIV, which was stigmatised. Conversely, some participants said that community members would come and ask them for the supplements. Stigma around mental health, and participants' choice to terminate their pregnancy were also mentioned by a few participants.

Relevant quotes for this theme are provided in Box 1.

## Trial implementing environment

### Complexity of trial

Responses from participants and staff indicated that the complexity of trial (online supplemental material) has likely contributed to various challenges that have impacted negatively on retention. While these components are explained to participants during the informed consent process, and reiterated by trial staff at other times, there appears to be room for misunderstanding on the part of the participants, as well as for improvement in these explanations. Adding to this complexity are the measures taken within the trial to boost retention (eg, additional financial incentives for attending pregnancy visits), which also have the potential to create confusion if not explained extremely clearly to participants.

Some participants' comments suggested that the mass recruitment of participants at community level may have meant that not all study details were explained at the point of recruitment, and given that the recruitment team was separate to the testing, intervention and non-intervention teams, there may have been room for miscommunication at the recruitment stage of the trial. Without a comprehensive explanation of the full extent of the trial, participants' expectations were possibly not managed well, and the financial incentive would have been attractive; this was possibly emphasised in recruitment knowing it would attract participants.

While different teams within the trial are required to focus on specific aspects (ie, research testing, delivering the intervention or non-intervention arms), and to uphold blinding within the trial, there is an inherent risk of communication challenges between teams, and this was picked up by participants. This was particularly obvious when it came to booking participants to come in for research visits and in-person intervention sessions at the site, and staff mentioned measures that had been put in place to facilitate better communication between teams, and emphasised the importance of teamwork and consistency. From the staff's perspectives, it was also evident that they did not necessarily know the detail of what other teams were doing. While this detailed knowledge would be beneficial for staff (and ultimately participants), it is not always feasible, given the time pressure teams are already under to deliver their component of the trial.

### Participant burden

The time burden on participants was another frequently discussed issue that influenced participants' motivation to stay involved in the trial. For some testing visits, participants would be required to be at the site for a whole day, and even though this is explained to participants, many participants were not happy with this. With regard to the blood tests conducted, a number of participants wanted to know more about their results (although they should receive basic feedback on certain risk factors, eg, glucose control, iron levels and a referral to a health facility if necessary), and felt that they did not receive sufficient information. Participants spoke less about the various questionnaires that were administered to them by the testing team, although a few mentioned sensitivity of some questions, and highlighted the importance of asking these in a way (and a private space) that recognised this sensitivity, and was easy to understand. Participants' levels of literacy and comprehension of the questions were mentioned by some staff as an issue to be aware of.

Relevant quotes for this theme are provided in Box 2.

## Controlled motivation

### Staying in contact

The multiple contact attempts made by trial staff to stay in contact with participants could be seen as putting pressure on participants to stay in the trial, thus contributing to controlled motivation. Participants did not express feelings of necessarily being pressured, coerced or controlled to stay in the trial, but this pressure to retain participants and for them to comply with the requirements of the trial was more implied, particularly by staff.

The challenges of staying in contact with participants was mentioned in all staff groups, and that the trial drivers play a critical role in tracing participants. There were various explanations given for these challenges related to participants' contextual realities and external influences mentioned earlier. Explanations included: poor network connectivity that is exacerbated by electricity blackouts ('load shedding'), which can also make it difficult for participants to keep their phones charged; participants not having a functional phone, or losing their phones, sometimes due to theft; participants changing cell phone numbers and alternative contact numbers not working; participants not being available at home and/or moving within (and sometimes out of) Soweto and having to contact a participant through a partner (eg, boyfriend) who may or may not be supportive of her involvement in the trial, or may not still be in a relationship with the participant. Although not mentioned frequently, the high costs of data and airtime also contribute to participants' challenges with staying in contact with staff.

Some participants spoke about not hearing from the trial staff, and given the challenges mentioned above, it is possible that staff's attempts to reach them were not successful. This was more of an issue for participants who had withdrawn—most not necessarily due to no longer wanting to participate in the trial.

### Financial incentives and food

In relation to controlled motivation, financial incentives for participants were by far the most frequently discussed topic across all groups when it came to the incentives or rewards used for motivating participants to stay in the trial. These discussions highlighted that the money received is greatly appreciated and motivates them to stay in the trial, particularly in the context of socioeconomic challenges mentioned earlier; some participants seem to rely on this money as a source of income. A number of participants cited challenges they had with accessing

**Box 2 Implementing environment—quotes**

**Complexity of trial**

"So my overall, so I would say participants are still interested and still want to come, it's just that there is a communication misunderstanding at some point between us, they feel like it's a lot of arms and they are not told, they don't understand that if I came for a session, is it really my last session or am I supposed to come again. So there is no really clear communication from different teams and arms in terms of they are going to come this side and go to the next, so they never really get it". (Staff—testing)

"Yes, I agree with everything that my colleagues have said, so, so far our retention strategy has been working well but more can be done. As they said again, in between when the participants have given birth, they expect us to be the ones to book with them because we are the ones that they are interacting with from the beginning of the study. We are the ones that call them every month, so they expect us to be the ones to book them even after they have had children. So now when you tell them that I will not be the one to book you anymore, there is someone else from another team that will be booking you with the baby, then they become less interested". (Staff—non-intervention)

"I think, being able to work together, as a team motivates the participant, to say, sometimes, when participants, come, right, and you are not there, they still get the same treatment you would have given them, from your fellow teammate, so, I think if that's what they get, even if you are not there, I think it still motivates them to stay". (Staff—intervention)

"Somehow I think they see that we get along, so I think that's what motivates them most of the time, because they can see that this one is not grumpy or this one, everybody is talking to everybody and no one is saying I am not talking to this one, I think that's what motivates them, they see that we are in a happy place all of us, and we are willing to help, team work". (Staff—testing)

"We become consistent because consistency is key in everything. The same way we are consistent with the R150, can we be that if it's going to be implemented as their asking, maybe they are wanting to try and find a way to retain more participant. If we are saying these and whatever they choose they should be consistent with it. Consistency is key when it comes to retaining people". (Staff—non-intervention)

**Participant burden**

"I think time is the only thing. For an example I stay with my kids and they are still young, so for me coming here, I had to get someone to look after my kids, and sometimes you find that I tell a person that I am going to be gone for so long, but I end up taking much longer time here, which will then prevent the person to help me the next time when I ask for help". (Withdrawn participant—non-intervention)

"And sometimes by 14:00 is only then that we are doing DXA, and the mother has been here, mother and child from 08:00. So that time and the food and the reimbursement of just reimbursing the mother, is not enough. And we need to consider reimbursing both of them, but also having something, I mean if they had a proper meal, I believe that can last longer than bread, especially when they have to wait for that long, for the other procedure, especially DXA because all the kids, from delivery up to five years, they have to have DXA". (Staff—testing)

"Another reason is what she has mentioned that we do blood tests, but we do not get our results. When we first came here, we were told that we are going to know more about our health but now they are just taking the blood tests and not giving us the feedback". (Enrolled participant—non-intervention)

"They don't make it easy for me to understand. It may happen that you can ask a question, but it then becomes difficult for me to understand that question, so I will be ashamed to ask, tell you to explain it to me in vernacular, so things like that". (Enrolled participant—intervention)

the financial incentive provided through the 'e-wallet' system instead of cash, since they need airtime to access the funds via their phone, which they do not always have (and possibly not a functional phone). Linked to this, the food provided for participants was also mentioned often as a motivation, and while some participants were happy with what is currently provided (sandwiches, snack for the child), others preferred the hot meal that was previously provided.

In all groups, the prevailing opinion was that the financial incentives and food were not enough for participants, particularly in light of the time spent visiting the research site. Many pointed out that the financial incentive had remained the same since the beginning of the trial, despite other costs (eg, transport, food) have increased. Both participants and staff agreed that this incentive and the food provided should be more when the child was brought to the site, particularly if both of them are being tested. And there was acknowledgement across groups that mothers felt additional financial pressure with a new baby since the financial incentive needs to go further.

An additional factor contributing to the dissatisfaction about the incentive amount was the comparisons participants made with other research studies that pay higher incentives—some more than double what they were receiving for the *Bukhali* trial. Despite this, some participants chose to stay with the trial because of its perceived benefits.

### Health services

Another valued incentive discussed in all groups was the two free ultrasound scans provided for participants in the pregnancy phase (to which they could invite the father of the baby), free HIV and pregnancy testing offered to all participants and multimicronutrient supplements provided for intervention participants. The scans were especially appreciated since these are not routinely provided in the public health sector, and they are not affordable for most participants if accessed privately. Some discussions highlighted how the scans helped to promote bonding between the mother and baby, while others mentioned that the scan could be a difficult experience if the mother was not yet sure how she felt about the pregnancy or was considering termination. A few participants were grateful that the scans helped to pick up pregnancy complications, facilitating a referral for the help they needed. In addition, participants frequently

commented on how the health services they received as part of the trial was better than the services they received in the public sector, particularly in terms of how they were treated by staff, and about the information they receive from the trial.

### Other incentives

Other incentives offered to participants that were discussed favourably included the free wifi and *curriculum vitae* printing service provided to participants at the research site (which supports the non-intervention arm content on job readiness), as well as the sanitary pads provided to participants at in-person sessions. A few mentioned the participation certificate they receive at exit (if not pregnant), which they felt would be helpful when looking for employment. Through the expectations voiced by some participants, some additional incentives that could be considered are the provision of on-site mental health services (eg, counselling, support groups), as well as other medical services and medication. A few participants mentioned wanting additional educational sessions, and access to employment opportunities at the research site.

Relevant quotes for this theme are provided in Box 3.

## Intrinsic autonomous motivation

Across all groups, it was evident that aspects of the trial (eg, content, delivery, staff) were supporting participants' psychological needs of autonomy, competence and relatedness, which in turn contributed to their intrinsic autonomous motivation (sense of volition, agency and choice) for staying involved in the trial.

### Autonomy

The first indicator of participants' autonomy was the interest they expressed in the trial, suggesting that they were acting with a sense of volition and exercising their agency and choice to be involved. Staff highlighted the critical importance of this interest in participants' motivation to stay in the trial. Conversely, participants who were not interested in the trial were seen to be much harder to motivate to stay, and some of the withdrawn participants spoke about other commitments that make it difficult to stay, such as employment (or focus on seeking employment), studies. Some participants' and staff members' comments specifically pointed towards participants' sense of agency, where they spoke about positive decisions or actions they had taken in their lives and the skills they had exercised, such as 'prioritising', goal setting, communication and social skills. Others also spoke of how the trial had built their self-confidence and self-awareness, and gave them a sense of meaning and purpose, knowing that they are doing something positive with their lives, and sometimes to escape their circumstances at home.

It was very clear from most participants' responses that they found the trial (for intervention and non-intervention participants) important and relevant, both

**Box 3 Controlled motivation—quotes**

**Staying in contact**

"I think for me and most of the challenges that I have realised, I have faced with the participants, is staying in contact…I might contact your mom and dad, but I still I can't get in touch with you because half the time your mom and dad are not around, and they come back around 17:00 or 18:00 and at that I am not available…They give you a number today, call this number, it's unreachable". (Staff—non-intervention)

"Electricity, load shedding. Remember we are dealing with participants that are residents of Soweto. Soweto that has problems with Eskom and not paying for electricity. So sometimes they cut off their electricity and then when the electricity is off, somehow even the network is affected, so then we can't get hold of the participants because of that". (Staff—non-intervention)

"They lose them, they get stolen, they break, or it's not a conducive phone, always breaking, it works but not all the time. But mostly it's the crime, most of them get mugged and their phones gets taken away from them". (Staff—non-intervention)

"The lady that recruited me had said that she would call me, but she didn't call me. She called me after some months after I had not been here and she wanted to know if I was no longer interested in the study, I told her that I was interested but I wasn't getting any communication from her, and she said that she had been calling me but was not getting through, so maybe I had not charged the phone". (Withdrawn participant—non-intervention)

**Financial incentives and food**

"If the money was not there, I don't think any of us would be interested. Though we need it, you understand. So I am saying that it does make a difference, and if it was more, then you would be very busy". (Enrolled participant—intervention)

"The money is too little, but it motivated us to come. Even right now I do not have it and when I think of that R150 it make a difference". (Enrolled participant—non-intervention)

"If you ask them, that's what they say that that is what actually attracted them to the study. They will tell you that the R150 and food. They get food when they come for first time visit's, they give them food, so those two things says a lot about a person's situation, you understand. If a person is saying to you that I was attracted to this study because I was told that I was going to get R150 and later found out that I was also going to get food, they expect every visit to have food, together with the R150…we cannot emphasise enough to say that R150 plays a huge role in retaining and being a motivation to our participants". (Staff—non-intervention)

"Yes, it should be what you are giving them, you know the little that we give them is what keeps them in the trial. Sandwiches because they don't have food, R150 so that they can buy airtime, what else, ultra scan as they have mentioned that it's expensive to pay for, to go for scans, so those are other advantages, that's it". (Staff—testing)

"The time that we spend here we could have used it for something else, but we are coming here thinking that would get money which is not enough. So we rather stay at home and not come". (Enrolled participant—non-intervention)

"And I think most participants after they give birth, it's like they think that they will be getting more things, more benefits, double the transport money, like double everything. So when they realise that you are still giving them R150, they are like wow, it's still the same". (Staff—testing)

Continued

**Box 3 Continued**

**Health services**

"When we are here in Bukhali, you feel so privileged that at least I am getting something like a sonar, especially if you fall pregnant and you know that your situation is not that good to the point that you can take your own money and go for it, some of us are unemployed and then you get here and you get that, that's why I am saying that it feels like you are at a private hospital of some sort… we are the same level as the private hospital, we don't feel left out. At least you can feel that warmth that in health facilities are like this, unlike at local clinics". (Enrolled participant—intervention)

"And the things that makes them stay in our study is the services that they get from us, which is your HIV test, your pregnancy test, the supplements that we give them, but when you go somewhere, you have to buy them, so I think that is what influences them, that over here, they get things for free". (Staff—intervention)

"Most of them fast, so they are already moody because of the hunger and everything. But the minute they start seeing their babies, they just bubble up and I didn't see any challenges through them through ultrasound scans because it just somehow changes their moods to happiness as they get to bond with their babies and see their babies, being able to see their babies' gender, they just lighten up". (Staff—testing)

"You get a lot of information which is more than what you would get from the clinic because they used to give breast feeding pamphlets and I didn't know how to because I started breast feeding with my second baby because my first baby was taking a bottle, I learned that here". (Enrolled participant—intervention)

"The service that we get here is very good and people are very friendly. There has never been a time where I was treated badly. Unlike at the clinic where you get shouted at by the nurses. Here it is one-on-one consultation, and the staff is very friendly and polite". (Enrolled participant—non-intervention)

in terms of what was delivered, and how it was delivered. The topic of health—both physical and mental—was important to these participants, with many emphasising mental health more strongly than physical health, which could indicate that the trial has raised their awareness around mental health. This was echoed by the staff, and some of them spoke about how participants could be more motivated to stay in the trial if they were experiencing mental health challenges, while for others these challenges would make their participation difficult. This seemed to be exacerbated by the lack of available mental health services to which they could refer participants, and that telephonic counselling services were not sufficient.

For some participants, the trial was able to identify and assist them with a particular health issue, either for them or their child, or an aspect of their child's development. Other participants expressed interest in the trial in the hopes that it could identify health issues in the future. These responses suggest that physical and mental health could be a goal or value for these participants, and the trial thus aligns with these. Furthermore, these views were expressed by both intervention and non-intervention participants, showing that even just the testing done with non-intervention participants has an impact, and can spark an interest in knowing more about their health.

Comments from some participants suggested that this prioritisation increased during pregnancy and infancy, which may have been influenced by participants' realisation of the health services offered through the trial that they could not easily access at public health facilities. A few of the withdrawn participants expressed an interest in rejoining the trial to benefit from this information about pregnancy and infancy. To some extent, this could align with goals and values they have for motherhood, which could also be linked to meaning and purpose that their motherhood role brings to them. However, some participants were not necessarily happy with the shift in focus from them (during preconception) to their baby.

### Competence

Linked to participants' interest in the trial and prioritisation of health, participants (including those who had withdrawn) frequently spoke about the information they received and things they learnt from the trial, which they perceived as relatable, helpful and beneficial. For all participants, this included the information they receive after testing. Intervention participants receive more detailed health information, which some reported sharing with family members to help improve their health, whereas non-intervention participants receive information related to life skills. This contributes to their feelings of competence, especially opportunities for learning, and how the information they received can make them feel more capable to deal with their health. Furthermore, the extent to which trial staff helped participants to understand things they did not know could be seen as positive feedback.

### Relatedness

Staff and participants' responses indicated that the trial was providing a sense of belonging and connectedness for many participants, both in terms of other participants as well as to the trial staff. Some participants spoke about the way in which the trial has helped them to engage with other young women, and that they were appreciative of the support they could gain from each other, even when participating in focus group discussions such as these. The focus groups helped them to feel that they were not alone in their experiences, and could have a safe space to talk about relevant topics. Some participants were eager for more activities as part of the trial, such as support groups, and activities that could involve their children, suggesting that they see themselves and the trial staff as a community.

In terms of connectedness, numerous participants spoke about the way in which they were treated well by trial staff, and it was evident that this motivated them to stay in the trial, even in the midst of challenges like long waiting times previously raised. Apart from the communication challenges mentioned earlier, the communication between participants and staff seemed to contribute

positively to these interpersonal interactions. Staff were described as welcoming, friendly, non-judgemental, caring, loving, easy to talk to and trustworthy; participants commented that staff made them feel comfortable, were willing to answer questions and explained things to them as highlighted earlier—all in contrast to the service they receive at public health facilities. HHs and CCAs were often described as supportive and encouraging, and participants appreciated how they were available to them for questions, sometimes even from other family members. HHs and CCAs emphasised the importance of providing a safe space for building trust with participants, recognising that for many participants they are providing support they do not get at home, as previously highlighted. Due to the positive nature of these interactions, in some groups it was suggested that participants have more in-person visits. Related to this, the relationships formed can be difficult when staff resign or are not available on a particular day, and participants do not want to be moved to a different HH or CCA, and this could affect their motivation to stay in the trial.

Staff affirmed the importance of how participants are treated and providing quality service as important motivating factors. There were a few instances shared by participants when they did not feel like they received quality service, but these seemed to be in the minority compared with the positive reports.

### Making the shift

For the retention of participants over the long-term in the trial, it is important that intrinsic autonomous motivation plays a stronger role than controlled motivation for participants, given that it is not feasible to meet all expectations in terms of increasing incentives and services, and the challenges of staying in contact with participants are likely to persist. While financial incentives and food will continue to remain contextually appropriate and, indeed, necessary for most participants, it would be ideal to see a shift where these are no longer the most important motivators for their participation. Encouragingly, there were some participants who specifically spoke about making this shift over time, and it was articulated particularly well by this intervention participant (enrolled):

> I started the study before I fell pregnant, so I started with the mentality of getting money, so I was after the money. And when I got to be aware that I have to know about my health, that I need to exercise and eat healthy, up until I fell pregnant…I am able to ask questions about whatever issues that I have, and they are able to put me in a sonar. So that's where you get motivation because you now know that you will be informed about anything, no matter how small it is, you will be able to know what bothers you. And that is what motivates me and made me realise that it's not only about the money, but rather that your health is more important. The money is just for you to be able to come here and also to buy yourself something to eat if you were not happy with what they served. But the most important thing is your health. And also when it comes to babies, you get to learn a lot about the baby as well…when you come here you get to understand your baby's growth in each stage. So yes, that's what motivates me to stay here because you now realise that it's not just about the money.

Relevant quotes for this theme are provided in Box 4.

## DISCUSSION

The aim of this study was to qualitatively examine retention in the *Bukhali* trial (longitudinal study and intervention), from the perspective of trial participants and staff, through the lens of self-determination theory. A key finding from this study is that the *Bukhali* trial is using retention methods that are meeting participants' psychological needs of autonomy, competence and relatedness, and hence encouraging intrinsic autonomous motivation. Contributing to these needs and motivation are participants' interest in the trial and its relevance to them; their sense of agency and purpose; the development of their competence, particularly their knowledge and awareness of their health; being treated well; their relationships with trial staff and other participants and their sense of being part of something.

Another key finding is that controlled motivation plays a critical role in the *Bukhali* retention strategy, especially financial incentives, according to both staff and participants. This is not surprising given participants' socioeconomic circumstances, social vulnerability and food insecurity,[17 29 30] which could also contribute to the challenges of staff staying in contact with participants, which have already been documented for the trial.[31] These findings align with previous research on strategies that boost retention, including financial incentives,[1 2 7] and building good relationships between trial staff and participants.[4 6] Furthermore, they affirm the importance of balancing these relational factors with the realities of participants needing tangible incentives in under-resourced settings.[8] These findings provide a theoretical understanding of how these motivations co-exist within a complex intervention trial—and the complex context of Soweto—and how participants' motivations can shift over time. Many of the contextual challenges related to retention that came up in this study have emerged in other trials as well, such as the push for recruitment,[3 4] managing participant burden, staying in contact with participants and participants relocating and/or juggling multiple obligations.[9–11]

Figure 2 presents a mapping of controlled motivation and intrinsic autonomous motivation factors for *Bukhali* that have been identified in this study, related to retention according to whether these (based on the data presented) could be seen to be associated with promoting retention in longitudinal studies or interventions, or both. Our findings and this mapping highlight that in this, and potentially other under-resourced settings, controlled motivation strategies are necessary to boost retention in longitudinal studies, but these may not be sufficient for retaining participants in interventions; strategies targeting intrinsic motivation are essential. Applying self-determination theory, these strategies can

**Box 4 Intrinsic autonomous motivation—quotes**

### Autonomy

"Their motivation on being part of the study, actually, it depends on the participants, on how their interest is, I could say, those participants who are really interested in the study, actually don't give us any problem, when it comes to attending sessions, doing face to face sessions, and also coming here to the sessions". (Staff—intervention)

"I was also concerned about my health, because I was low on iron, and sometimes I would just sweat when I was sitting with people, so I was concerned about that, so when the ladies, they came, they told us what the study was like and they included the money, and I was like okay, I will join, but it was about my health". (Withdrawn participant—intervention)

"Okay for the fact that they check up on us all the time, you are kept up to date with your health, you know what your health status is, things like HIV, your weight, how to eat, and how to raise your child". (Enrolled participant—intervention)

"I am motivated by the money and also the fact that they make you aware of a lot of things pertaining to your health. So even if you don't get anything, you are still able to contact your helper and speak to them over the phone and speak to them over the phone about what your experience with the child is and they would give you advise on how to deal with the matter, you can talk to them about any issue that you have, so there is a lot of knowledge that you get from them. There is even no need for you to go to the clinic once you have the information". (Enrolled participant—intervention)

"What motivates me the most is my health. When I am just sitting at home, I would not know what diseases I have or infections. If I come here and they discover those they are able to give me a referral letter to go to the clinic". (Enrolled participant—non-intervention)

"Just looking at our economy, it's not okay and a lot of us are unemployed, but the purpose of the study is not about money, I mean we all need it, even if you are working or whatever. Because we get the information, we get the support, we get a lot of things here, so I think in most cases it's not about money. The information that we get here is very helpful and also like the question that you asked, our mental health and stuff". (Enrolled participant—intervention)

"So yes, I think their mental health does influence whether they stay in the study or they don't. I also think that different participants have different reactions to their mental health, you know. So there is participants that stay in the study because of their mental health, and there is also participants that withdraw from the study because of their mental health. They feel, now can I put it, demotivated, you understand, because of what they are going through in their personal life, with unemployment". (Staff—non-intervention)

"I think now that we have children, we want to be more focused and want to know what is going on with your child. For example if it was me without a child I was going to be not motivated but now that I have the child and which is the benefit of the child. I would want to know if my child is developing well". (Enrolled participant—non-intervention)

"The study is an escape for a lot of them, so they come because it's beneficial for them to come rather than being at home, being faced with a lot of things, some of them are being abused, others it's drugs and all those things, so I definitely think that for most of them, the study is a motivation, just to get away from whatever it is that they go through on a daily basis". (Staff—non-intervention)

"Since joining the study I learned and I eventually went back to school, I am even writing exams tomorrow, I am writing matric". (Withdrawn participant—non-intervention)

Continued

**Box 4 Continued**

### Competence

"What stood out for me was the help in getting work, help in applying for work, how to apply for work. They taught us the importance of reporting your cards when you have lost your cards, to go to the police station and report your cards, things like that". (Withdrawn participant—non-intervention)

"For me it was interesting because I learned about things I was not aware of about my body and which food I should not consume. I became very cautious about what I was eating…Things like BMI (body mass index), I did not know that you get measured in order for you to be regarded as being a healthy person. I did not know that they calculate the BMI according to your height and weight". (Withdrawn participant—intervention)

"I get help from the study, they teach me how to look after myself, how to know myself, about the baby and how the baby grows and things like that, and that is why I am still in the study, up until time for me to leave the study comes, I will still be part of it". (Enrolled participant—intervention)

"I am currently not working, so the little information and knowledge that I get here will help me to be able to answer my interview questions when I go for job interviews. Also the certificate is motivating…because sometimes you would be asked during the interviews that during the whole year while you were not working, what were you doing?" (Enrolled participant—non-intervention)

"I think it does influence them in a positive way and it makes them to be more interested because of the information that we share. I feel like the information is very relevant to what the age group is going through". (Staff—non-intervention)

### Relatedness

"Yes, just the time issues, but they are otherwise very good, because even when they are teaching you, they are friendly and ask you if you understand and encourages you to speak if you don't understand, they make you feel free to interact". (Withdrawn participant—non-intervention)

"She has stated a good point because the CCA also asked you how your day was. You get comfortable and start telling them what you are going through and they motivate you by telling you that you get through whatever you are going through". (Enrolled participant—non-intervention)

"The CCAs do not judge us, instead they encourage, motivate and guide us. They will not go around talking about what we have confined to them. It is very painful to find a family member who feels comfortable talk about your confidential matters to other people out there. Here we know that what we discuss with our CCAs will remain confidential". (Enrolled participant—non-intervention)

"I also wanted to say support, because for some participants, we are the only support they have, they don't have someone to talk to at home, a friend, and I think when we support them, we don't judge them, and we let them be themselves around us". (Staff—intervention)

"I think it influences it a lot because them being just comfortable knowing that we have these people, who are the ones who speak to them, ones to hear what they have to say, being comfortable around the entire unit, which is very important. And it's also very important for us just to, something that I always say is always to try and be happy. Just try and smile, it doesn't take a lot just to smile a little. And the smile does a lot, I see it as I walk past a participant. Just me being able at them and then good morning, they are feeling a bit better

Continued

**Box 4 Continued**

now. Okay now you are sitting, you are sitting so long and someone is smiling, they feel a bit better. Just being kind is very important. It encourages them to come back and want to be there". (Staff—testing)

"I think the safe space that we have created for them, and the comfortability of how they can speak anything with us, they trust us a lot, I see with my pregnant participants, when we get to, around 9, 8 months to 9 months of pregnancy, I tell them, okay, when you go deliver, please let me know, or even if you don't feel the baby, let me know, they will panic, even if they are going to deliver, 3 AM, I will see someone was calling, and then I will have to call, no, I was going to the hospital, you said to let you know, so I think that is the comfortability they have with us, and I think it motivates them to stay in the study". (Staff—intervention)

"I think the fact that you know that you are not the only one who is facing a challenge, when we get together as young women speaking about our situations, you now get to that place where you are like, okay I am not the only one who is actually going through this, there is someone who is going through the worst, so you get motivated that okay, it will pass too, because whenever we are sharing our challenges and you hear a person telling you how they overcame their challenge, you also feel that okay, I also overcame this, at least so, yes". (Enrolled participant—intervention)

BMI, body mass index; CCA, call centre agent.

lead to a sense of autonomy, competence and relatedness, which can help participants to act out of a sense of volition, agency and choice. For interventions supporting behaviour change, this can hopefully contribute to increased self-efficacy for behaviour change, commitment to the intervention and the ability to overcome extrinsic challenges that could hamper retention.

The findings from this study about the prioritisation of health, and especially mental health, are encouraging, since previous *Bukhali* process evaluation work has highlighted that health does not seem to be prioritised, and that health literacy is low among young women in Soweto.[16 17 32–34] These new findings suggest that it is possible for these priorities to change over time, and that health literacy can increase through exposure to an intervention such as *Bukhali*, with a potential positive knock-on effect on retention. In addition, they emphasise the importance of the health services provided through *Bukhali*, not just as incentive in their own right, but the way in which these are provided also contribute to intrinsic motivation, for example, being treated well, which participants frequently contrasted to their treatment in public health facilities.

Regarding the role of time in retention, our findings do not indicate a universal 'sweet spot' for intervention length in terms of how this could influence retention. However, they do suggest that those developing interventions (ideally using community participatory methods) need to balance the tension between participant burden over time, and sufficient time for participants to experience the benefits of the intervention. In the context of behaviour change in vulnerable contexts, such as those with intergenerational trauma like South Africa, adequate time needs to be given to build trust between participants and intervention delivery agents, and to allow participants time to work through cognitively

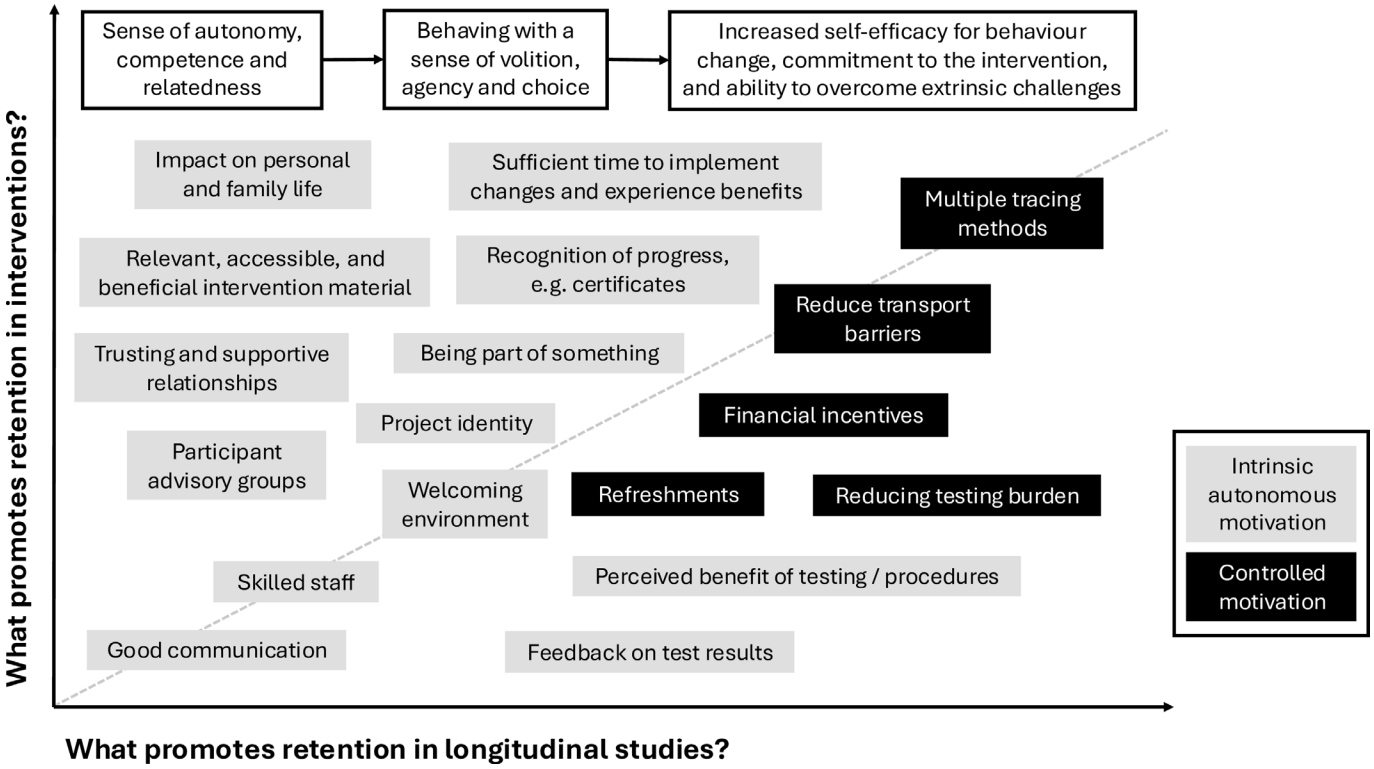


**Figure 2** Factors promoting retention in longitudinal studies and interventions.

**Box 5 Recommendations for retention in complex intervention trials.**

1. Consider retention from the perspective of longitudinal studies and interventions (that involve long-term implementation), recognising different factors influencing retention and different strategies needed.
2. Employ qualitative methods (from early in trial design and planning) to understand nuances of participants' motivations and how these relate to retention.
3. In under-resourced settings especially, be mindful of necessary (but not sufficient) controlled motivation strategies, but understand the lived experiences of participants to put contextually relevant strategies in place to boost intrinsic autonomous motivation.
4. As far as possible, minimize participant burden, and prioritise providing clear and timely feedback to participants on results to help outweigh the burden of participating with the reward of relevant and helpful information.
5. Tangible incentives (e.g. cash, vouchers, food) need to be adequately budgeted for in complex interventions; funders should allow for flexibility in funding allocations for these costs to enable responsiveness to participants' needs and economic challenges.

demanding processes like problem solving, goal setting and planning. In the *Bukhali* trial, we have found that this takes longer than expected, when attempting to understand behaviour change through a trauma-informed lens.[17] Based on our findings, we offer the recommendations related to retention for trials of complex interventions, as presented in box 5.

The application of a theoretical approach, self-determination theory, is a strength of this study, along with the use of qualitative methods to provide in-depth insights into retention in the *Bukhali* trial, especially relational factors, since these are often not reported well.[3] The inclusion of trial staff, as well as enrolled and withdrawn participants to present a range of perspectives is another strength of the study. However, it is still possible that participants who attended focus groups were more positive about the trial, and this should be acknowledged as a potential limitation, although an inherent challenge in this type of implementation research.

In conclusion, self-determination theory provides a helpful frame for a contextualised understanding of the complexity of retention of *Bukhali* trial participants, which is applicable to this trial both as a longitudinal study and a long-term, complex intervention. These findings and recommendations provided have relevance for complex intervention trials in under-resourced settings.

**X** Catherine E Draper @DrCathD

**Contributors** SAN and SL are principal investigators for the HeLTI Bukhali trial. SAN and CED conceptualised this qualitative study, and SAN, CED, NT and NN designed the methodology and developed the interview guides. NT and NN conducted the data collection. CED led the analysis with input from NT, NN and SAN. CED drafted the manuscript, and all other authors provided input on the draft and approved the final version. CED is the guarantor.

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**ORCID iD**

Catherine E Draper http://orcid.org/0000-0002-2885-437X

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