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BMJ Open 'I'm here to save my life': a qualitative study of experiences navigating a cryotherapy referral system for human papillomavirus-positive women in western Kenya

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ABSTRACT

Background We sought to understand the beliefs, social norms and logistical factors that affect human papillomavirus (HPV)-positive women's uptake of cryotherapy treatment as part of a two-part cervical cancer screening strategy in rural Kenya.

Methods In-depth interviews within a parent clusterrandomised trial.

Setting Government-run county hospital in western

Participants 273 of 372 (73.4%) HPV-positive women who underwent cryotherapy

Results Many women feared that an HPV infection meant they would develop cancer. Almost all women reported initial fear of the treatment procedure, followed by a more positive experience than anticipated. Lacking funds for transportation to the treatment site was the most common barrier. Women felt that decentralised treatment would be the most important facilitator of greater access. Spousal encouragement and financial support were key facilitators of treatment access, however many women felt that other husbands in the community would not be supportive. Women described successfully acquiring treatment as empowering, and almost all would recommend seeking cryotherapy to other women who test HPV-positive. Most felt eager to share their own experiences with others to encourage treatment.

Conclusions The main facilitators of treatment access were understanding of the health risks and sense of empowerment. A decentralised treatment model or transportation support may facilitate access, along with improved health messaging about HPV infection, cancer and the treatment process. Focusing on women's personal feelings of empowerment may further improve uptake and satisfaction. These data will be used to design a strategy to improve linkage to treatment.

Trial Registration NCT02124252.

INTRODUCTION

Cervical cancer, despite being one of the most preventable cancers through vaccination and screening, remains the fourth most common cancer among women worldwide. Now rare

Strengths and limitations of the study

- ➤ This study provides insight into women's experience obtaining cryotherapy after a receiving positive human papillomavirus test result in western Kenya.
- The perspectives provided will allow for improved contextualisation of cervical cancer prevention programmes in similar settings.
- These qualitative findings are exploratory, and may not be reflective of larger patterns or associations.
- Women were interviewed by trained study staff, so there may have been social desirability bias.
- We did not interview women who were lost to follow-up, and may therefore have had even more barriers than those identified in this study.

in wealthier countries due to the success of the cytology-based prevention programme, cervical cancer continues to be a major public health issue in low-income and middle-income countries (LMICs). Effective population-based screening, coupled with linkage to treatment for screen-positive women, is critical to preventing the development of cervical cancer. In Kenya, where screening rates range between 3% and 14%, and vaccination for human papillomavirus (HPV) is not yet available, cervical cancer is the second most common cancer in women, and the leading cause of cancer-related mortality.²

Strategies to address the lack of a screening programme in LMICs include simpler screening techniques coupled with cryotherapy for women who screen positive. Cryotherapy is relatively inexpensive, can be performed by non-physician providers and does not require electricity. It has been promoted along with visual inspection with acetic acid (VIA) as part of a same day 'see & treat' strategy, although the expense and



logistical challenges of maintaining supplies, space and personnel for cryotherapy in remote settings make single-visit strategies impossible in most settings.³⁴

Another simple screening technique is low-cost HPV testing.^{5 6} The WHO incorporated the growing body of evidence supporting HPV testing into recommendations for a screening programme in low resource settings.⁷ The current guidelines include HPV primary screening as the preferred modality, followed by cryotherapy. As HPV testing has become more widely available and the evidence for its use more convincing, the programme is starting to move from 'see & treat' to 'screen & treat,' referring women for treatment based on a positive HPV result. While this may be more effective at decreasing cervical precancer and cancer, there are no currently available HPV tests that allow for same-visit results. Therefore, the programme must take into consideration how to deliver HPV test results and counselling in a way that fosters understanding and facilitates women's uptake of the appropriate follow-up. An effective HPV-based screening programme must take into account the multitude of sociocultural factors such as stigma, fear and misperceptions, along with the logistical and health systems factors that affect a woman's decision-making and ability to seek screening, understand her results and obtain treatment if needed.

While multiple studies have evaluated effective screening methods for women in western Kenya, there remains a gap in understanding effective strategies to link women who screen positive for HPV to appropriate follow-up and treatment. Series are relatively new to LMICs, there are very little qualitative data exploring women's experience with treatment. Understanding the knowledge, beliefs, social norms and logistical factors that affect women's decision and ability to seek treatment is essential in the design of effective context-specific treatment strategies. We used the Consolidated Framework for Implementation Research (CFIR) to explore the contextual factors that may have facilitated HPV-positive women's access to appropriate treatment within a community-based screening programme. 13

MATERIALS AND METHODS Study design

We used qualitative data to explore the barriers and facilitators of treatment access for women who tested HPV-positive as part of a two-phase cluster-randomised trial in rural western Kenya. ¹⁴ In the first phase, 12 communities in Migori County were randomised to screening using self-collected HPV tests either through community health campaigns in central locations in the villages (CHCs) or in health facilities. In both the CHC and health facility arms, education and outreach was led by community health volunteers, and women who tested HPV-positive were notified of their results and referred to the Migori County Hospital for treatment with cryotherapy. ¹⁵ After

treatment, women were invited to participant in an in-depth interview (IDI) regarding their experience.

The distance between Migori County Hospital and the 12 study communities ranged from 11 km to 94 km. Transport around the county was available via motorcycles, public buses and private taxis. In the hospital compound, treatment was provided by nurses who had undergone additional training in both cryotherapy and study procedures prior to study initiation. The medical superintendent and an experienced nurse facilitator provided supervision as needed. Women underwent VIA prior to treatment, followed by cryotherapy, unless the cervical anatomy was abnormal, the lesion was too large for the probe or there was suspicion for cancer. In the first two cases, the woman would be referred for a loop electrosurgical excision procedure (LEEP) within the same hospital. If there was suspicion for cancer, she was offered a biopsy and referred for management of cancer. All costs associated with cryotherapy or LEEP were covered by the study. Women did not receive compensation for transport or monetary incentives for participation in the study.

Data sources

IDI guides were developed using selected CFIR constructs to elicit responses about the client-sided experience and perceptions of treatment (table 1). Selected constructs included adaptability, patient needs and resources and complexity of proposed intervention methods.

IDI guides were developed in English and translated and conducted in the most common local languages (Dholuo and Kiswahili) by researchers fluent in those languages. The first part of the IDIs consisted of closedended questions about sociodemographic characteristics, sexual behaviour, gynaecological history, HIV status, cervical cancer screening and HPV. Interviewers entered these data directly into Open Data Kit installed onto study tablets. The second part of the interviews consisted of open-ended questions that probed women on what they understood about HPV and treatment for HPV, their feelings and experience with treatment, barriers and facilitators to treatment, stigma and desire for privacy, and male and community leader roles in facilitating cervical cancer prevention. Interviews lasted between 15 min and 25 min. These data were recorded on the tablets, and then transcribed and translated. All translations were reviewed with the audio by the study coordinator for accuracy.

Data analysis

Using thematic analysis, one member of the research team created the codebook using both the IDI guide for structure and four sample interviews to identify additional themes that together facilitated a more nuanced interpretation of the data. ¹⁶ The codebook was then reviewed and revised by the entire team, followed by a round in which all four researchers sample coded 10 interviews to test and revise the codebook. All analysis and codebook development was done using NVivo V.11 software (QSR International, London, UK). The team then met

Refined CFIR constructs and key findings regarding HPV-positive women's experiences with a referral-based

cryotherapy treatment strategy		
Construct	Topics covered	Key findings
Intervention characteristics		
Relative advantage	What are the advantages of the proposed treatment model?	► Offered free of charge, outpatient
Adaptability	 What are other models of treatment that would facilitate increased access? What are factors of the current treatment model that could be improved? 	 Decentralised treatment or transportation support would improve the model
Complexity	 Perceptions of treatment feasibility and sustainability What is the participant's understanding of the screening and treatment cascade? 	 Women had unanswered questions after treatment regarding follow-up, need for medication or potential impact on fertility
Outer setting		
Patient needs and resources	What can the health facilities do to facilitate patient treatment acquisition?	► Provider respect was high
Inner setting		
Culture	 What is the level and impact of male support? How could community leader involvement facilitate treatment? 	 Male financial and moral support were important to treatment acquisition Many were concerned about post-treatment abstinence or re-infection Ambivalence about community leader involvement
Access to knowledge and information	 How can outreach and education strategies be improved? How does peer education and support impact treatment acquisition? 	► Peer education noted in both educating about screening and encouraging treatment
Characteristics of individuals		
Knowledge and beliefs about the intervention	 Did women understand the meaning of a positive HPV result? Did women understand the process and availability of treatment? Do women understand the importance of treatment for their health? 	 Role of HPV in development of cancer was well understood, however some women equated an HPV-positive result with cancer Women knew that early treatment would be simpler than treatment for advanced disease
Self-efficacy	 Do women prioritise accessing treatment for their health? How do health beliefs and self-efficacy impact women's ability to overcome barriers to treatment? 	 Women felt knowing HPV status allowed them to move on a health action (treatment) Treatment had an empowering influence Post-treatment, women felt that they could/ should be role models
Individual stage of change	 What role do peer networks or social support play in treatment access? What role do individual health beliefs play in reactions or decisions about treatment for a positive HPV test? 	 Women felt relief at knowing HPV status Fear surrounding HPV result and association with cancer led to some inaction

CFIR, Consolidated Framework for Implementation Research.

to discuss and make final revisions to the codebook. All interviews were coded twice by two separate members of the research team. Coding reports were then reviewed collaboratively to identify important themes and finalise mapping onto the modified CFIR framework.

Patient and public involvement

The research question and measures were informed by preliminary work done in partnership with the Ministry of Health to evaluate barriers and facilitators of cervical

cancer screening and treatment. Prior to study implementation, we also carried out focus group discussions with women living in Migori to plan and implement phase I of the study (manuscript submitted). For this study, patients were not involved in identification or recruitment of participants, as all women undergoing treatment were asked by a research assistant to participate in an interview after their treatment had been completed. Results have already been disseminated to the participants through

two key stakeholder meetings. In addition, selected participants were invited to participate in a working group to amend the treatment implementation strategy for phase II.

All participants gave their written informed consent to participate in the study prior to data collection. For low-literacy participants, consent was affirmed with thumbprint.

RESULTS

Between February and December 2016, 5898 women underwent cervical cancer screening in both CHC and health facilities and 1043 (17.4%) tested positive for HPV. Out of these women, 399 (38.3%) women presented for treatment at Migori County Hospital and 372 (35.6%) underwent cryotherapy. Three women were referred for LEEP and one for invasive cancer management. Among the 372 treated HPV-positive women, 273 women (73.4%) completed an IDI after their treatment. The average age for participants was 37.3 years, for 216 (79.1%) primary school was the highest education completed, and 206 (75.4%) were married or had a current partner. There was no difference in the clinical or demographic characteristics in the participants from the original study arm, or between those who agreed to an interview and those who declined. Women travelled a mean of 37 kilometres to get to Migori for treatment, and almost all used a paid form of transportation (bus, taxi or motorbike).

Knowledge and perceptions of HPV positivity and treatment value

Many women expressed confidence in their level of knowledge about the relationship between HPV and cervical cancer, and the role of treatment in protecting their health. Specifically, many understood that the recommended treatment was simpler and more effective than it would be if HPV developed into cervical cancer.

I learnt that, having HPV doesn't mean you have the disease, it is just a sign that it may develop in to a disease and when you have the virus and it is detected early enough it can be treated. (Age 41 years)

Although many women were able to make fact-based statements about HPV, and professed confidence in their knowledge, some expressed fear, anxiety and misperceptions about their positive HPV results and the association with cancer. This was reflected in women's feelings around the time they received their results and their concern that the treatment would not 'cure' their cancer.

I felt pain at heart, since I do hear that those with cancer do not survive, even now I still have no assurance of good health. (Age 43 years)

Though some women reported worry or anxiety about their test result, many felt relief that they were now aware of their HPV status and could get treatment.

What came into my mind after I was confirmed HPV positive was just on how I can access treatment my

focus now is how I can be on treatment and that is my key challenge as at now. (Age 47 years)

Treatment experience

Women were almost uniformly positive about provider respect, privacy, adequate explanation of the procedure and recovery, and ability to ask and have their questions answered. Most women also reported minimal pain or cramping, with no reported complications with the procedure. Overall, women expressed relief that the procedure was not as difficult as they had feared, with responses similar to the comment below.

When I came from home, people were saying that this treatment is painful but I have not felt any pain. I have found it to be good and the pain that people are talking about is not there. (Age 36 years)

When asked how to improve the treatment experience, women had limited suggestions, or focused on access issues. This may not reflect satisfaction with the treatment model as much as a feeling that it was the role of 'health-care providers' or 'doctors' to 'improve the experience'. 'It is you as healthcare providers to find on ways of making it more comfortable.' (Age 33 years)

Unanswered questions

Despite reporting adequate explanation and overall treatment satisfaction, a number of unanswered questions or misperceptions regarding cervical cancer or follow-up arose throughout the interviews. When asked whether women had unanswered questions at the end of the screening/notification and treatment process, they revealed underlying fears about extent of disease/ outcomes of treatment (future fertility, death from cancer, etc). Many women were under the impression that they would be given drugs to treat HPV, like treatment for malaria or HIV management. I have learnt that in case I will be given drugs then I will have to take them to help prevent the virus from advancing into cervical cancer' (Age 38 years). Women who mentioned drugs recounted that they were told they would be given drugs, although this was not an intended part of the health messaging during screening or treatment.

Some women believed that if they were infected with HPV, they would not be able to give birth, or they should not get pregnant because the fetus would be infected with HPV. Related to the fear of infertility, women reported believing that family planning methods caused their positive HPV result or would cause cervical cancer. 'I thought that I had cervical cancer because since I went for family planning (Intrauterine Device). I have not been feeling okay in the uterus.' (Age 42 years)

Identifying specific barriers and facilitators to treatment access

When women were asked whether they encountered any barriers or difficulty accessing treatment, most answered no. However, when prompted, many confirmed that they had to miss work, struggled to find childcare or transportation funds, or travelled a long distance. Some women expressed the belief that if a woman is sick or valued her health, there were no barriers that could stop her from accessing treatment in statements like the following: 'It can only be far for someone who is not sick but if you are sick, you cannot say that it is far. I'm here to save my life' (Age 46 years).

Lack of access to means of transportation and/or funds to hire transport were the main barriers that resulted in delays in treatment. Women also worried about future transport costs if the disease progressed, explicitly stating that they anticipated missing future appointments.

I do not know what to tell you. If you have money you can access everywhere, but if you do not you cannot make it on foot. The poor will die of even diseases that can be treated unlike the rich. (Age 38 years)

When asked about how to make treatment access easier, many women mentioned that telling their own story of treatment to women who tested positive for HPV would be helpful, suggesting that peer education and social support may play a large role in the decision to get treated. Women wanted to publicise that treatment was free, easy, quick and important for women's long-term health. Examples of these sentiments include the following:

When the (positive) results came I was surprised. I then took time and went to my friends who also were HPV positive and shared with them, we encouraged each other and set dates for coming for treatment. (Age 45 years)

I would tell her it is important for her to know her HPV status because she would be able to know if she is at a high risk of developing cervical cancer... Treatment is good. It is free and very easy. There is no pain, so it is good. That is how I would encourage her. (Age 51 years)

Women suggested two changes in the treatment model that could facilitate treatment for women in the community: (1) A decentralised treatment model that provides treatment in more rural health facilities, closer to homes, or a mobile treatment unit that moves periodically through communities. (2) Transportation provisions or reimbursements, echoing the main barrier to treatment access.

Finally, a substantial number of women felt that greater awareness of or access to *screening* would increase uptake of treatment. Women suggested repeating screening in the communities for those who had missed earlier campaigns and increasing involvement of lay health workers, or community health volunteers, in outreach and education around screening.

Support from peer networks and community leaders

Women wanted to share their diagnosis with others in their community, both to be able to obtain psychological and financial support for treatment and to set an example. Most reported that privacy around their HPV status was not important to them.

I am comfortable with any other person knowing my status because, he or she might be able to support me if am sick or I might be able to encourage and support a person who is sick but is too scared to receive treatment.

A small minority of women who did not want to share their diagnosis with others, apart from their spouse or co-wives, gave reasons including a general desire for privacy about their own health, without specific mention of HPV or cervical cancer related stigma.

The reason why I did not want anyone else to know is because some people tend to exaggerate things, if one hears you have this disease, they may start telling you how you have a very bad disease and that you will die soon.

Women held contradictory opinions regarding the role of community leaders in facilitating treatment. Women who were in favour stated that leaders could 'mobilise women to seek treatment' (Age 33 years), while those opposed feared a loss of privacy, stating that 'community leaders would spread rumours to the community members' (Age 37 years).

Male partner involvement

Male partner involvement was described as it related to treatment access, post-treatment care and fears of re-infection from their partners. Almost all women interviewed said the decision to seek treatment was theirs alone. However, they did feel like male support or opposition played a role in access of treatment services. Interestingly, most women stated that while men in general would likely not be supportive of their wives obtaining treatment, their own spouse had been. Reasons for other husbands' perceived lack of support were related to a lack of understanding or belief that HPV is a real threat, and low prioritisation of their wives' health. Male support was generally described as financial support for transportation, with a minority naming encouragement or moral support for treatment. Women's comments indicate either a perception about lack of male support for other women in the community, while descriptions of their own experience suggest that male support was a key factor in their ability to obtain treatment (as all the women in this group had successfully obtained treatment).

My husband support(ed) screening so that should I be confirmed positive, I start the treatment in time before it worsens...he provided me with fare and asked me to leave early so I can get to the hospital in time. (Age 42 years)

Some do not understand cervical cancer and some just care less about their wives and cervical cancer hence not becoming supportive. Other men are supportive when they value the lives of their female partners. (Age 33 years)

Standard counselling after cryotherapy includes abstinence for a month, and use of a condom after resumption of sexual activity for 6 months to prevent spread of HPV or reinfection. A few women expressed concern about cultural and social beliefs regarding sexual activity that would prevent their husbands from supporting them through the recovery period, or use of a condom afterwards. Some women even requested that a health provider speak with their husband.

I had a concern with the issue of not having sexual contact with my husband for a month. We built a new house, which we are supposed to enter into in the course of this week. As Luos, we have our customs that we must uphold, what will I do? (Age 35 years)

Concerns about the ability to be abstinent following treatment were echoed in some women's thoughts about the futility of treatment in situations where they perceived little control over possible reinfection. Concerns were raised about safe relations with their husband, inability to negotiate condoms and concerns about (re-)infection among co-wives.

It is said that men are the one who infects us, and us still being a young couple we are bound to have sexual relations, what can be done so to men so that they do not spread the disease? (Age 39 years)

Supposing I have a co-wife, how will I know that she has also been treated so that we can all be free and not use condoms? (Age 34 years)

Treatment and empowerment

Although this group of women who were able to overcome barriers and access treatment for their HPV likely had higher baseline levels of empowerment than women who did not get treatment, many women expressed a sense of personal empowerment from the process of either undergoing treatment or from gaining an understanding of the impact of HPV on their health. This may have been as a key factor in overcoming barriers to treatment.

I have come to seek treatment for a better future; I want a future so that I can continue taking care of [my children] (Age 35 years)

Finally, almost all women said they would recommend treatment to other women who they knew tested HPV-positive, stating that the treatment was easier than they thought, free, quick and almost painless. Importantly, many felt that they had an important role to play as peer educators or advocates to convince other women who tested HPV-positive to get treatment. Often, women expressed that their treatment experience changed their minds about privacy and the importance of sharing their experience.

I never felt like letting anyone know about my treatment, now that I have, I can easily encourage my neighbour to seek for treatment in case she's positive. (Age 36 years)

I would tell her my experience about the treatment. How easy and how painless it is. How the doctors are prepared and how they talk nicely to us. I would tell her she has nothing to fear and she should gather courage and come. (Age 41 years)

DISCUSSION

Appropriate follow-up for HPV-positive women is a critical component in cervical cancer prevention and control; the success of the programme in LMICs is often limited by attrition between screening and treatment. This study used the CFIR framework to explore the contextual factors surrounding women's uptake of treatment after a positive HPV test in rural Kenya. We found that women were generally satisfied and even empowered by their treatment experience. The results also showed that the belief that the treatment they were seeking would have an important and positive impact on their health enabled women to overcome the barriers of fear, lack of transportation funds and distance to the treatment centre. Women's responses were surprisingly consistent throughout the interviews, with some level of disagreement emerging around the importance of male involvement in their own ability to seek treatment compared with their perception of how it impacted other women.

These findings add substantially to a body of work that has primarily focused on structural, financial, and policy-related barriers and facilitators to the implementation of a cervical cancer screening and treatment programme by exploring the patient experience from receiving results to navigating treatment access. ¹⁷¹⁸ The participant perspectives provide important insight into ways the treatment model can be improved. To our knowledge, this is the only study to assess patient-level factors impacting cryotherapy treatment in a low-resource setting using the CFIR framework. The use of a standardised framework is important to developing a sustainable and effective enhanced linkage to treatment strategy with the potential for replication in other settings.

The fact that empowerment associated with treatment emerged so strongly was encouraging and indicated a facilitating culture. However, substantial logistical and financial barriers remain in place for women in this model, despite free screening and treatment. Women travelled an average distance of over 30 km and almost all women required some form of hired transportation. While the majority of women did not recall income loss, or reported a loss of less than 1000 Kenya Shillings (US\$10), the cost of transportation represented a significant burden, even among this group of women who were not lost to follow-up. Partner support was significant, and most often appeared in the form of payment for transportation. While almost all women stated that the decision to seek treatment was their own, their reliance on partners for financial support was crucial and may have important implications for future cervical cancer prevention and treatment initiatives. The role of partner support

needs to be explored among women who were not able to obtain treatment. The frequency at which the costs of transportation to a distant treatment site and the reliance on partners were reported indicates a need to explore the decentralisation of treatment with or without a mobile treatment unit, the use of transportation vouchers or assistance of some type that emphasised transportation.

The use of peer educators to help encourage and facilitate treatment access may also be a strategy to overcome the logistical hurdles using an empowerment framework. While other studies have not shown educational interventions to be as effective as other implementation strategies for cervical cancer prevention, ¹⁹ peer-led counselling has increased perceptions of screening benefits and engagement in screening activities.^{20 21} Peer-to-peer education has played a large role in the success of the HIV programme in this region, so participants were likely to have experience and comfort with this. Importantly, women saw themselves as potential peer educators, using their positive experiences with treatment to convince other women to get treated. In this way, the self-efficacy they displayed in obtaining treatment would be transformed into a sense of personal empowerment through a reflection of their own success and influence on others.

These qualitative data clearly elucidated points of clarification for the educational counselling provided throughout the outreach, screening and treatment activities. Although the current education modules stress that HPV is not cancer, some women continued to believe that a positive HPV result was synonymous with having cancer, which then caused cancer-related fear, sometimes resulting in inaction. Educational content and the mechanisms by which women are notified of their results should be rigorously tested to ensure clarity, as fear of cancer or more invasive procedures may prevent women from seeking appropriate treatment. In addition, these data highlight a need to address the misconceptions about family planning, infertility and the need for medication as part of treatment both during outreach and at the time of screening and treatment. The persistent expectation that treatment would involve long-term medications may reflect an interpretation of medication as synonymous with treatment, as is the case with the more common diseases in the area: HIV, Tuberculosis and malaria. Based on these findings we updated the educational material to include more precise descriptions of the cryotherapy procedure and clarify that treatment does not require medication.

While these data highlighted crucial information that allows us to further understand how and why women are able to access treatment when free treatment is offered, there are limitations inherent to the study design. The current study is missing the voices and experience of women who were unable to access treatment, who were the majority of women screened; this may contribute to the relative homogeneity of observed themes. For example, in this population of women who had successfully accessed treatment, almost all were in a relationship

or married, which was possibly a key factor in their success with navigating treatment. While the qualitative data suggest partner financial support was key in reaching treatment sites, we must identify and work with women who were lost to follow-up to fully begin to understand and address insurmountable barriers. In addition, as these interviews were done by the study team in proximity to treatment sites, there may have been some social desirability bias in responses related to treatment experience and provider respect.

CONCLUSIONS

These data provide valuable insight on the implementation of a community-based cervical cancer screening programme through the perspectives of HPV-positive women who were able to access free treatment through referral to a county government hospital. While many women reported feelings of self-efficacy and empowerment, and were pleased with their experience deciding and accessing treatment, they represent the minority of patients. Despite multiple efforts to counsel women about the importance and availability of treatment, over half of the women who tested HPV-positive in the parent study did not access treatment. We have identified specific barriers and potential facilitators to treatment access that will inform new implementation strategies and ways to intensify efforts to reach the wider population of women who were lost to follow-up and work with healthcare teams to develop a linkage to treatment strategy that ensures greater follow-up with appropriate care.

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Contributors MH is the overall study Principal Investigator (PI). She conceived the study, led the study design, led the coding and analysis, and wrote the manuscript. KA, SO and IS assisted with the coding, analysis and conceptual framework. SO led data collection activities. IS led data management. EB assisted with the manuscript preparation and acts as the site Pl. All authors have read, actively edited and approved the final version of the protocol.

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Competing interests None declared.

Patient consent for publication Not required.

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Provenance and peer review Not commissioned; externally peer reviewed.

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