

# Family–Based Index Testing for HIV: a qualitative study of barriers and challenges among clients in Cape Coast, Ghana

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## Research article

### Keywords:

DOI: <https://doi.org/10.21203/rs.3.rs-35726/v1>

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# Abstract

## Background

Family-based Index HIV Testing, (FBIT) approach is known to be associated with a relatively higher testing yield compared to Provider-Initiated Testing and Counseling. The implementation of this strategy in several countries has exposed some barriers to optimal FBIT outcomes. With the scale up of FBIT in Ghana, stakeholders' engagement is key in identifying and addressing all barrier to implementation. This study explored index clients' perspective of barriers and challenges of FBIT.

## Methods

Using an exploratory descriptive qualitative design, 17 individual in-depth interviews were conducted among seventeen purposively selected clients who had been offered FBIT at the Cape Coast Teaching Hospital (CCTH) utilizing a semi-structured interview guide. Each interview lasted between 45–60 minutes and the transcripts were transcribed verbatim and analyzed using qualitative content analysis procedure. Themes and sub-themes from the transcripts were generated and supported with verbatim texts to provide a rich understanding of the barriers and challenges.

## Results

Age of participants ranged between 24–71 years, majority of whom were females. Themes and sub-themes emerged on barriers and challenges and these related to good understanding of the benefits of FBIT by index clients, challenge with getting family members to accept testing opportunities, fear and uncertainty of reaction of family members to a positive status, and issues of confidentiality and privacy related to health facility service provision. Key findings were: 1. Index clients perceived FBIT as a good approach to reach family members for testing. 2. Stigmatization, lack of confidentiality and privacy at service centers and 3. Inadequate information on FBIT were identified as barriers that can affect the uptake of FBIT. Getting listed family members to agree to be tested was perceived as a challenge.

## Conclusions

Despite the acceptance of FBIT as a good strategy to reach family members of index clients for testing, there are barriers of stigmatization, fear and uncertainty of reaction of family members to a positive status, lack of confidentiality and privacy, and inadequate information on FBIT. Efforts should be made to address these barriers and challenges. Index clients and their families need tailored support to improve acceptance of this strategy.

## Background

Ghana, like other sub-Saharan African countries, continues to depict a generalized Human Immunodeficiency Virus (HIV) epidemic, with prevalence consistently greater than 1% in the general population over the last decade. Though there has been a lot of strides with HIV control in the country, there are still significant gaps to be addressed for the country to attain the 90-90-90 targets set by the Joint United Nations Programme on HIV and AIDS (UNAIDS) to help the world achieve epidemic control of HIV by 2030 [1]. Family-Based Index HIV Testing, (FBIT) has been identified as a priority global strategy to help bridge the country-wide testing gap and to the attainment of the first 90; the entry point for the other 90 s. As captured in the Ghana HIV acceleration matrix, there is the need to augment the pace of attaining these targets by using innovative and targeted testing, such as the FBIT approach [2].

FBIT is a voluntary, consensual and confidential process where healthcare providers ask index HIV positive clients to list all their sexual partners and children. If the index client agrees, each listed person is contacted and offered HIV Testing and Counselling Services (HTS) [3]. The FBIT approach is associated with a high coverage of HTS for hard-to-reach groups including children, adolescents, adult sexual partners and key populations who are usually missed using only the routine facility-based Voluntary Counselling and Testing (VCT) approaches [4].

The family unit has been noted as an important resource for identifying potential HIV positive patients once a member tests positive. It is estimated that for each HIV positive indexed patient, one or more family members may be HIV positive or have a high risk of getting infected [5]. Research from Kenya to support the effectiveness of FBIT in increasing the diagnosis of paediatric cases indicated a 7.4% yield over the use of Early Infant Diagnosis (EID) strategies. Even with a decline yield from 2009 (18%) and 2015 (5.4%), FBIT still provided higher yield for identification of cases than through Provider-Initiated Testing and Counseling PICT [6].

Regardless of the success of the FBIT strategy, there are some barriers that impede the upscale of the strategy. These include the difficulty of disclosure to family especially partners and fear of emotional and psychological harm especially when children are involved [5, 7–9]. Thus, it has been noticed that not all index clients counselled on family screening accepted to link their family for testing. Although there is evidence of some barriers and challenges related to the FBIT from other countries in Africa, not much is known from Ghana and the region where the study was conducted regarding barriers and challenges of FBIT from the perspective of index client. From the socio-cultural context of Ghana, there is limited knowledge of the implications of FBIT on the 'index' client and the family unit. Therefore, with the progressive rolling-out of FBIT in Ghana, there is a need to engage stakeholders including the clients and providers in the identification of opportunities for improving the implementation. This study therefore aimed at providing evidence of the barriers and challenges of FBIT for HIV among index clients seeking care at a tertiary facility in Cape Coast, Ghana.

## Methods

The study was guided by a framework adapted from the Consolidated Framework for the Implementation Research (CFIR) [10, 11]. The original CFIR framework presents five domains that may influence the implementation of an intervention. For the purposes of this study, four out of the five domains of framework: Intervention Characteristics, Outer Settings, Inner Setting and Characteristics of Individuals, were maintained while the constructs were modified to capture information on barriers and challenges of FBIT as can be seen in Fig. 1.

## **Study Design And Setting**

The study employed an exploratory descriptive design to explore the barriers and challenges to FBIT among adults ( $\geq 18$  years) living with HIV attending antiretroviral (ART) Clinic at the Cape Coast Teaching Hospital (CCTH) in the Central Region of Ghana. CCTH is the first facility to initiate antiretroviral therapy in the region in 2006 and still has oversight of all such clinics opened in the region. Data was collected between October and December 2019.

## **Sampling And Data Collection**

Clients were purposively selected using maximum variation type of sampling to allow participants with diverse backgrounds and perspectives to provide rich information and capture core experiences. Clients who had prior to this study received counseling on FBIT formed the sample size for the study. Clinicians at the clinic were used as gatekeepers to identify the eligible clients.

Face to face in-depth interviews were conducted among the participants using a semi-structured interview guide developed for this study. The content of the interview guide was finalized after 3 pilot interviews were conducted using clients who were then excluded from the actual study. Participants were given the opportunity to decide place and time for the tape-recorded interviews after they had been given detailed information about the study and they had consented to be part of the study. Each tape-recorded interview session lasted approximately between 45–60 minutes and were conducted in Fante or English based on the preference of the respondent. Two experienced interviewers who were fluent in both Fante and English were recruited by the research team for the interviews.

The interview guide had open ended questions which explored client's awareness, perception, experiences and suggestions for improvement as far as the FBIT approach was concerned (Supplementary document 1). Specific probes were used to cover relevant areas where necessary. Participant's reactions both verbal and nonverbal were also documented as field notes. In all, seventeen adults with HIV participated in the study.

## **Data Management And Analysis**

Data analysis was done alongside data collection using the qualitative content analysis procedure. The data analysis was guided by the four domains of the adapted conceptual framework discussed earlier. The interviews were then transcribed verbatim by the 2 interviewers independently and any disparity were resolved following further review by the PI. All audio files were removed from the recorder and saved on password protected computer accessible to only the authorized research team members.

The researchers listened to the tape-recorded interviews over and over to familiarize themselves with the data. The transcripts were read several times and also listened to the audio version a number of times. Notes were made on the left-hand margin of the transcripts on significant statements, and also comments on any connections, differences, similarities and contradictions found in the initial interpretations. The emergent themes and subthemes were then listed in order of appearance and connections between them were sort for leading to the creation of theme clusters. This process was repeated several times with themes built progressively. Finally, a list of themes and sub-themes for all participants were then generated to provide understanding of the barriers and challenges as shared by the participants. Then verbatim texts from the interview were extracted and these were used to support the themes. The link between existing literature, theories and the themes were explored.

Themes identified were on the potential benefits, barriers and challenges related to FBIT which were: 1. Understanding of the benefits of FBIT by indexed client. 2. Challenge of getting family members to accept testing opportunities. 3. Fear and uncertainty of reaction of family members to a positive status. 4. Issues of confidentiality and privacy related to health facilities service provision. The findings and discussions are presented under the four selected pillars from the adapted Consolidated Framework for Implementation Research (CFIR).

## Results

Seventeen face to face in-depth interviews were conducted, with 17 participants, consisting of 13 females and 4 males. The ages of participants ranged from 24 to 71 years of age, majority of whom were married. (Table 1).

Table 1  
Sociodemographic Characteristics of Participants (N = 17)

Characteristics	Frequency (n)	Percentage (%)
<b>Age (years)</b>		
24–35	1	5.9
36–45	3	17.6
46 and above	11	64.7
Missing value	2	11.8
<b>Gender</b>		
Female	13	76.5
Male	4	23.5
<b>Marital Status</b>		
Married	10	58.8
Cohabiting	1	5.9
Single	1	5.9
Divorced	2	11.8
widowed	3	17.6
<b>Education</b>		
No formal education	4	23.5
Primary to Junior high	8	47.0
Senior high	1	5.9
Tertiary	3	17.6
Missed value	1	5.9

## Intervention Characteristics: Fbit As A Good And Beneficial Strategy

Participants' perception of the FBIT was explored to understand how they perceived the testing approach, its benefits, complexity or simplicity and whether or not they accept FBIT as a good approach. All participants described the FBIT as a potentially good strategy. They were optimistic that it would lead to early detection and prompt intervention.

*"I think this will help reduce the spread of the infection to others. Because it's even an opportunity for families to know their status."* [Participant 02, Female]

*"It is a good strategy to help trace people who are not yet diagnosed."*

*I don't think there is anything bad with helping people know their HIV status."* [Participant 01, Male]

*"It is good for people to know their status because if your immune system becomes weak, any sickness that attacks you, makes you very weak."* [Participant 04, Female]

Participants however, anticipated some challenges associated with getting their family members to be tested. Some of these were related to lack of understanding of the strategy and perceived complexity of the process.

*"some people may not easily understand the whole concept (of FBIT strategy) and may understand the exercise differently."* [Participant 02 Female]

*"My report (in client's clinic folder) indicates that I agreed to bring them (family members) but I have tried severally to bring them for the test but they will not come. I have tried about six times but they are not coming. They are executives (white color workers) so they will not come. They don't see the need for them to get tested."* [Participant 08, Male]

However, it was suggested by some that the possibility of getting family members tested outside the hospital facility should be considered as some family members would not like to come to the clinic for fear of being stigmatized, or spending too much time.

*".....But encouraging them to come to the health facility to come and get tested, they will not come. They won't come to the health facility but going to them to take the blood samples to the hospitals to check in my view will help get a lot of people to know their status."* [Participant 06, Female]

*"If there is a way you can do it to avoid making the people anxious or worried, it will be better. You can be going to their houses to educate them instead"* [Participant 02, Female]

### **Outer Setting: Challenges due to lack of understanding of FBIT and misconception**

The questions under this section explored sociocultural factors that may influence the success or otherwise of the FBIT strategy. The perception that people generally would prefer not to know their status was expressed by some participants as a hindrance when their families are contacted. All participants were optimistic that with some more education of the general public on HIV, people will come to understand and embrace it.

*"People think that if they don't know their status, they will be better than knowing their status. A guy once told me that, he will be willing to give me every amount I need to do anything to survive but to donate*

*blood for me will mean that, he would know his HIV status. So people don't want to know."* [Participant 04, Female]

*"Some people too think when you get this problem (found to be HIV positive) this is the end of your life".* [Participant 12, Female]

Another major hinderance identified by participants was stigma and discrimination related to people's perception about persons living with HIV (PLHIV) after they have been disclosed to. Some participants were of the view that in spite of public education on HIV, there is still the notion that people living with HIV are promiscuous. This unfortunate notion could serve as a barrier and deter others from accepting to get tested. They recognized that this would also hinder some index clients from accepting FBIT despite acknowledging that the strategy is good and worth promoting.

*"I had like five boyfriends before marrying my husband, they (those disclosed to) would look at you and say what! People don't like to open up. Our educational system, the way we were brought up does not allow us to open up to issues. Even saying you have one boyfriend alone is also a challenge."* [Participant 15, Female]

*"It is the fear of testing positive. This may prevent people from coming for the test."* [Participant 14, Female]

*"This may prevent people from availing themselves to be tested..... The moment people hear that you have got this condition, they think you got through prostitution."* [Participant 13, Male]

Irrespective of the anticipated sociocultural challenges, participants were hopeful that there are opportunities to get the wider population to accept the FBIT strategy. Public education and the availability of social support options were identified as resources that could increase acceptance.

*You can increase public sensitization on the strategy (FBIT) on televisions, or radio stations. This will help people better understand the new strategy.* [Participant 13, Male]

*"All people talk about is that, it is through sexual intercourse. I think what you can do is to educate persons living with HIV on the need to get their relations and partners tested to know their status after the education. That is what I think will help get family members to avail themselves."* [Participant 04, Female]

### **Individual Characteristics: Personal beliefs, lack of knowledge of HIV and uncertainty about family reaction**

All participants displayed a good understanding of the testing strategy. Some of them who had successfully linked their family members or had been tested through this strategy shared their experiences.

*"...my husband went to test for treatment, it was detected that he was HIV positive, they told him to bring all the children including myself for testing, we were all detected to be HIV positive. I wouldn't have gone*



*personally because I thought I was okay, I went in the interest of the children. When I looked at myself, I saw that I was okay. I was very strong...* [Participant 03, Female]

*"They (nurses) told me to bring my wife and children for the test. .... So, I told them that, they say we should come and do some tests at the hospital. When I brought them, the two were also tested to be positive."* [Participant 07, Male]

*"I got pregnant and went to the hospital for checkup and it was detected that I was HIV positive. My husband became worried when he got to know that I was HIV positive after the marriage. Initially, he was worried but he did (get tested) and it was negative".* [Participant 04, Female]

Participants shared the challenges they have with disclosure within the Ghanaian family context. However, they still maintained a positive view of FBIT.

*"When it was detected that I was positive, they requested that I brought my husband and kids for the test. It was not easy at all. Initially I did not know how to do so but I gathered some courage and told him. When he accepted to go for the test, then I became a bit okay. When I brought my husband and he was negative, I brought my two kids who were with me. They were also negative. It is okay for people to know their status."* [Participant 04, Female]

*"All my siblings are negative except me. We are three siblings with different fathers and I don't want the situation where they will be stigmatizing against me one day and tell other people in the vicinity."* [Participant 16, Female]

## **Inner Setting: Confidentiality And Privacy Issues As Potential Barriers**

Considering the important role physical location or place play in every human experience, we asked participants to share experience on how the clinical environment where education on FBIT as well as actual testing and treatment takes place could facilitate or hinder the FBIT. Participants were concerned with issues of privacy, confidentiality and time spent at the clinic.

*"Confidentiality is key. This is what we need to check if this strategy will see the light of day. It will help many out there to know whether they are positive or negative. However, it should not be done in public where people will queue to get tested".* [Participant 06, Female]

*"Some nurses have okro mouth (can't keep confidential information). They will say anything they know about patients. They have to take out those who have okro mouths from the implementation process and use only those who have been well counselled to go and talk to the people in their homes"* [Participant 12, Female]

## **Discussion**

This study explored participants' perspective of the benefits, barriers and challenges for FBIT strategy. The discussion of findings is guided by the CFIR framework in this section. With regards to intervention characteristics, participants expressed optimism of the relevance of the FBIT approach in reaching many more people who may be potentially HIV positive for early diagnosis and prompt treatment. This perceived benefit as expressed by participants, is supported by evidence from a research study in Malawi and Uganda where FBIT was found to account for an increase in the identification of HIV cases compared to other strategies such as PICT [6]. Other studies have revealed similar findings with regards to increased uptake of diagnosis and treatment as a benefit of FBIT [5, 12]. It was clear that participants in this study had good knowledge and understanding of the FBIT with adequate information on the importance and benefits of the strategy.

The study also revealed participants were willing to provide information on their family members. It was evident from participants' account that their acceptance of FBIT was based on their own understanding, and perceived benefit of the strategy. This is very significant for the up scaling of the FBIT since the acceptance of index clients to provide information on their sexual partners, children and other family members has shown to enhance early detection and treatment of HIV especially among children of index clients [13].

Findings from exploring the sociocultural factors under the outer setting domain of the CFIR indicates that, some participants despite their willingness to provide contacts of family members, had to overcome some challenges such as fear of possible stigmatization and discrimination from family members once their status is made known. Similar fear was reported in the study by Obiri-Yeboah et al on disclosure of HIV status to sexual partners [14]. This finding is consistent with other studies where fear of stigmatization and discrimination and other negative outcomes have been found to be major barriers to the upscale of the FBIT [5, 8, 9, 15]. Similarly, a study in Uganda revealed that HIV positive parents had challenges with disclosing their status to their children due to fear of emotional trauma. This indirectly served as a barrier to family testing opportunities [15]. Another study in Burkina Faso indicated that in communities where issues of HIV related stigma were successfully addressed, number of testing increased significantly [16].

With regards to how the inner setting affects the FBIT, we found out that some of the perceived barriers identified by participants were related to the health facilities where counselling and testing is done, and treatment provided. Participants expressed the preference of having home-based service where health care providers would contact family members at home and carry out testing and treatment, rather than family members going to health care facilities. Participants were more concerned about issues of confidentiality and privacy, which they perceived as potential barriers to FBIT if family members are to visit the facilities for testing. Findings from a study conducted in South Africa [13] showed that home-based HIV services lead to high enrollment in care and treatment services due to personal engagement at the household level [10, 12]. Home-based testing was proposed by participants in this study as a preferred option to provide the opportunity to address this potential challenge and enhance the success of FBIT. This aligns with other studies where home counseling and testing was considered as one of the

most effective strategies to reach more people [17] and attend to family preference for home counseling and testing due to issues of privacy and confidentiality [4, 18, 19]. In contrast a study among people living with HIV in this same setting had revealed a fear of accidental disclosure associated with community-based service provision [20]. This is an indication that there is no conclusive evidence of home-based testing being the preferred option over facility-based service. Thus, the need for confidentiality in service provision, be it home- or facility-based is obviously an important consideration that affects HIV testing and must be addressed to improve acceptance of FBIT.

Concerning individual characteristics such as personal beliefs, knowledge of HIV and uncertainty about family reaction, findings from this study revealed that lack of adequate information on FBIT can potentially reduce the willingness of family members to accept testing. Public education is needed to create awareness on FBIT to facilitate the acceptance of the strategy and the willingness of more people to agree to test. Increasing public knowledge and awareness on HIV related issues through public education activities has been found to increase uptake of HIV testing strategies. In a study by Kirakoya-Samadoulougou et al, it revealed that high HIV related knowledge through education and provision of information through social media related sources in Burkina Faso resulted in high HIV testing [16]. Increasing health education on HIV issues in general is vital as part of promoting means to reach more people through FBIT [21, 22].

## Conclusions

To enhance the success of FBIT in Ghana, the barriers posed by stigmatization, lack of confidentiality and privacy should be adequately addressed. Public education that highlights the importance and benefits of FBIT and HIV in general should be intensified as lack of information among family members was found as a challenge to family members accepting testing. Creating awareness on the benefits of FBIT has the potential to influence the acceptance of family members to be tested. It has the potential to increase the willingness of index clients to provide information on family members and link them for testing. The preference for home-based service in this study though contrary to a previous study in that same setting, should be further investigated. It serves as bases to consider offering clients options for preferred testing services.

## Abbreviations

FBIT: Family-based Index Testing

PITC: Provider-Initiated Testing and Counseling

CCTH: Cape Coast Teaching Hospital

HIV: Human Immunodeficiency Virus

AIDS: Acquired Immune Deficiency Syndrome

VCT: Voluntary Counselling and Testing

HTS: HIV Testing and Counselling Services

EID: Early Infant Diagnosis

CFIR: Consolidated Framework for the Implementation Research

ART: Antiretroviral Therapy

UNAIDS: The Joint United Nations Programme on HIV and AIDS

## **Declarations**

### **Ethics approval and consent to participate**

Ethical approval was obtained from the Ethical Review Board of the Cape Coast Teaching Hospital in Cape Coast, Ghana, with ethical clearance number CCTHERC/EC/2019/086. Written informed consent was obtained from all study participants.

### **Consent for publication**

Not applicable

### **Availability of data and materials**

All data and results in this manuscript are based on the study data set which is available upon reasonable request from the corresponding author.

### **Competing interests**

The authors declare no competing interest be it financial or otherwise.

### **Funding**

Funding for this research was provided by the Directorate of Research, Innovation and Consultancy - University of Cape Coast, Ghana (DRIC-UCC). The Research Support Grant identification number for the project is RSG/GRP/CoHAS/2019/107. The funder had no influence on the data collection, analysis and any aspect of this study.

### **Authors' contributions**

EAA, and DOY conceptualized the topic and were involved in the design, data collection analysis and drafting of the manuscript. ICT, EA and NIEE contributed to the design of the topic, data collection and review of the manuscript. RAG and SAA contributed to the study design and review of the manuscript. All authors read and approved the final manuscript.

## Acknowledgements

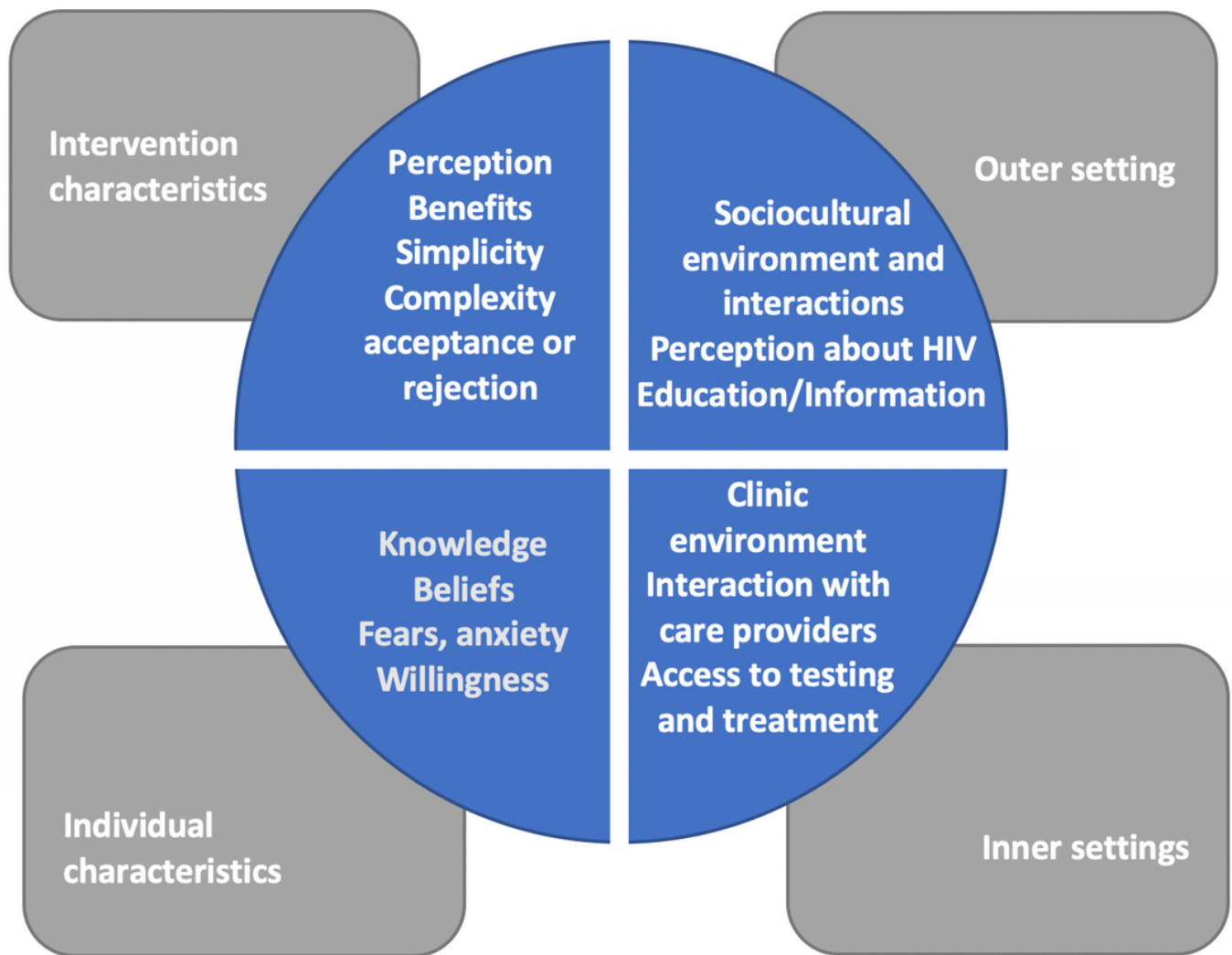
Grant support from DRIC-UCC is gratefully acknowledged. We acknowledge the support of the staff and index patients of the HIV Clinic of the Cape Coast Teaching Hospital. We also sincerely thank Mr. Benjamin Attuah Agyekum and Miss. Sarah Nsawah for helping with data collection.

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## Figures



**Figure 1**

Consolidated Framework for Implementation Research (CFIR)-Adapted from Damschroder et al 2009 [11]; and Naidoo et al 2018 [10].

## Supplementary Files

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