Development and pilot testing of an optimized conversational agent or "chatbot" for Peruvian adolescents living with HIV to facilitate mental health screening, education, self-help, and linkage to care: Protocol for a mixed-methods, community-engaged study

Jerome T. Galea, Diego H. Vasquez, Neil Rupani, Moya B. Gordon, Milagros Tapia, Karah Y. Greene, Lenka Kolevic, Molly Franke, Carmen Contreras

Submitted to: JMIR Research Protocols
on: December 15, 2023

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Abstract

Background: Adolescents living with HIV are disproportionally affected by depression which in turn worsens their adherence to HIV antiretrovirals (ART), increases viral load, and doubles their risk of mortality. Because most adolescents living with HIV live in low- and middle-income countries (LMIC), few receive depression treatment due to a lack of mental health services and specialists in low-resource settings. Chatbot technology, used increasingly in health service delivery, could be a promising avenue for delivering low-intensity mental health care to adolescents living with HIV in resource-constrained settings.

Objective: The goal of our study is to develop and pilot test for feasibility and acceptability a prototype, optimized conversational agent (chatbot) to provide mental health education, self-help skills, and care linkage for adolescents living with HIV.

Methods: The development of the chatbot comprises three phases conducted over 2 years. In the first phase (year 1), we will conduct formative research to understand the views, opinions, and preferences of up to N=48 adolescents aged 11-19 (6 focus groups of up to N=8 adolescents living with HIV per group), their caregivers (N=5 in-depth interviews), and HIV program personnel (N=5 in-depth interviews) regarding depression among adolescents living with HIV. We will also investigate the perceived acceptability of a mental health chatbot, including barriers and facilitators to accessing and using a chatbot for depression care by adolescents living with HIV. In the second phase (year 1), we will iteratively program a chatbot with successive versions (0.1, 0.2, 0.3), meeting regularly with a Youth Advisory Board comprised of adolescents living with HIV who will guide and inform the chatbot development and content to arrive at a prototype version (version 1.0) for pilot testing. In the third phase (year 2), we will pilot test for feasibility and acceptability the prototype chatbot among N=50 adolescents living with HIV naïve to its development. Data will be collected on the acceptability of the chatbot-delivered education and self-help strategies, depression knowledge changes, and intention to seek care linkage.

Results: By the completion of study phases 1 and 2, we expect our chatbot to incorporate key needs and preferences gathered from focus groups and interviews for managing mental health among adolescents living with HIV. By the completion of study phase 3, we will have assessed the feasibility and acceptability of the prototype chatbot. The study commenced in January 2023,

and study phase 3 is planned to begin by March 2024. Final results are expected by January 2025.

Conclusions: The study will produce a prototype mental health chatbot developed with and for adolescents living with HIV that will be ready for efficacy testing in a subsequent, larger study. Clinical Trial: N/A – This study is not an RCT.

(JMIR Preprints 15/12/2023:55559)
DOI: https://doi.org/10.2196/preprints.55559

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Abstract

Background: Adolescents living with HIV are disproportionally affected by depression which in turn worsens their adherence to HIV antiretrovirals (ART), increases viral load, and doubles their risk of mortality. Because most adolescents living with HIV live in low- and middle-income countries (LMIC), few receive depression treatment due to a lack of mental health services and specialists in low-resource settings. Chatbot technology, used increasingly in health service delivery, could be a promising avenue for delivering low-intensity mental health care to adolescents living with HIV in resource-constrained settings.

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Conclusions: The study will produce a prototype mental health chatbot developed with and for adolescents living with HIV that will be ready for efficacy testing in a subsequent, larger study.

Trial Registration: N/A – This study is not an RCT.

Keywords: Chatbot, Virtual assistant, Depression, HIV, Adolescents

Introduction

At the end of 2022, among the global population of children under the age of 15, approximately 1.5 million were living with HIV, 130,000 new cases of HIV were reported, and 84,000 died from HIV-related causes [1]. AIDS remains the second leading cause of death among adolescents globally [2]. Lower adherence to antiretroviral therapy (ART) is the primary culprit of AIDS mortality among people living with HIV across the lifespan; however, relative to children and adults, adolescents living with HIV are less likely to achieve viral suppression, a precursor to HIV treatment failure [3,4]. While many factors negatively affect ART adherence, depression disproportionately affects adolescents living with HIV compared to other age groups [5-7] and is associated with worse HIV treatment outcomes [8,9]. Left untreated, adolescents living with HIV and depression often face mounting problems, including poorer quality of life, more rapid progression of HIV, and premature death [10,11]. Moreover, depression complicates the transition from pediatric to adult HIV care in which adolescents living with HIV already face reduced retention in care, reduced ART adherence, and lower CD4 cell counts HIV viral load suppression [3,8].

Despite the disproportionately negative impact of depression on adolescents living with HIV, a recent review of mental health interventions for adolescents with (or at risk of) HIV concluded that "surprisingly little" is known about treatments for this population [12]. Especially scarce are low-cost, evidence-based mental health treatments that could be easily scaled in resource-limited settings [13], including much of Latin America and the Caribbean, home to approximately 42,000 youth aged <15 years living with HIV and where, in 2022, there were approximately 5,300 new HIV infections and 3,570 deaths among this population [14]. Emerging research has begun to demonstrate the benefit of treating comorbid depression and HIV [15, 16], especially among adolescents [12]. Increasingly emphasized are integrated care models that simultaneously treat both HIV and depression to achieve better outcomes at the individual and programmatic levels for both morbidities [17-20]. The integration of mental health services into common priority healthcare platforms, including HIV, is part of a broader movement to increase access to mental health services for all people [21]. However, for young people, existing literature largely focuses on pathways to care for severe mental illnesses, leaving a gap in knowledge for other mental health conditions [22]. The scarcity of mental health resources is further exacerbated in low- and middle-income countries, where interventions are often reserved for only the most severe cases.

In Lima, Peru, we found evidence that depression care for adolescents living with HIV is an unmet health need unless symptoms are severe (e.g., depression with psychosis, suicidal ideation) [23]. At the same time, we also observed in a small pilot study that the majority (92%) of adolescents living with HIV with depression did not have severe symptoms [24]. Adolescents living with HIV with mild-to-moderate depression do not receive support services (education, self-help strategies to develop coping skills and community bonding, low-intensity care) as part of routine care that could help cushion the escalation to more severe depression and thereby sustain their commitment to HIV care. As a result, these young people may miss an early opportunity to attenuate depressive symptoms and their potential impact on adherence to ART, resulting in suboptimal individual and programmatic outcomes.

To address this gap, this project aims to use chatbot technology to provide education, self-help, and care linkage for adolescents living with HIV and depression. Chatbots—conversational agents that use text or voice in a human-like way to deliver information—allow users to receive information through multiple existing platforms such as SMS text messages, websites, WhatsApp, and Facebook Messenger without users needing special software and are ideal for low-resource environments. Furthermore, chatbots are already widely used in consumer environments due to their ability to

quickly provide personalized information and increase the probability of purchase. In the health sector, the use of chatbots is less frequent but has been applied to providing mental health interventions [25, 26] and, more recently, to link people with information and testing related to COVID-19 [27]. In Peru, during the COVID-19 pandemic, we observed that adolescents living with HIV had mobile devices and were able and amenable to receiving health information using technology [28]. In addition, the mental health team at *Socios En Salud Sucursal Peru* (the performance site for the present study) developed and deployed mental health chatbots to screen for depression among adults during the first year of COVID-19, reaching >40,000 people in the country [29, 30]. Building on our experience with adolescents living with HIV, mental health, and chatbot technology, we aim to create a novel chatbot dedicated to the unique mental health needs of adolescents living with HIV.

This project aims first to develop a chatbot, optimized to provide education, self-help skills, and care linkage for depression in adolescents living with HIV. Once a prototype chatbot is programmed, it will then be tested for feasibility and acceptability among adolescents living with HIV in Peru. We hypothesize that the chatbot will be feasible and acceptable to adolescents living with HIV to access depression education, self-help skills, and care linkage.

Methods

Study Overview

Using a mixed method, qualitative-quantitative design, we will develop (study phases 1 and 2), and pilot test (study phase 3) a chatbot to deliver depression education, self-help skills, and care linkage for Peruvian adolescents living with HIV. All research instruments and the design of the chatbot will be done in close, ongoing collaboration with a youth advisory board (YAB) comprised of adolescents living with HIV in Peru. Chatbot development will follow a human-centered approach whereby feedback from the YAB (potential users of a future mental health chatbot) is solicited early and repeatedly during the development process to minimize design errors and maximize the fit of the chatbot to the preferences of the target population before pilot testing. Figure 1 displays the study timeline and key milestones.

Study Population

Adolescent participants will be youth aged 10-19 years living with HIV in Lima, Peru. We will purposely recruit a diverse population of participants, including males and females; adolescents that acquired HIV at or near birth and adolescents that acquired HIV recently in life; pregnant adolescents; sexual and gender minorities (transgender, gay and bisexual identifying); and adolescents who have lost a parent(s) to HIV. Adult participants (caregivers and HIV care personnel) will 18 years of age or older. Caregivers may be the adolescent's parents, family member or other legal guardian providing care to an adolescent living with HIV. HIV care personnel will be persons currently working in the Peruvian National HIV care system with adolescents aged 10-19 years and living with HIV.

Youth Advisory Board (YAB)

We will invite up to 10 adolescents aged 10-19 years living with HIV and residing in Lima, Peru to participate in a Youth Advisory Board (YAB). To ensure a heterogeneous group in terms of sex, sexual orientation, age, and HIV acquisition type, the adolescents will be recruited in collaboration with the infectious disease department of Peru's *Instituto Nacional de Salud del Niño* (National Institute of Children's Health), which cares for children and adolescents up to 18 years of age. Additionally, up to 2 adolescents between 18 and 19 years of age will be recruited through other national services of care for adults living with HIV. The YAB will review and provide feedback on

all research documents (consents, instruments) and multiple versions of the chatbot while in the development phase (study phase 1).

Ethics Approvals

All study procedures have been approved by the *Comité Institucional de Bioética (CIB) de VÍA LIBRE* (study CIPHER), which is an IRB of record for the performance site, *Socios En Salud Sucursal, Peru*. The Institutional Review Board at the University of South Florida formally agreed to rely on *VÍA LIBRE* for the review, approval, and continuing oversight of the research project under an interagency Institutional Review Board Authorization Agreement (University of South Florida IRB Study # 005124). For study phases 1 and 2, the data are deidentified and any participant names or other identifying information will be deleted from interview transcripts; only a study ID will be used for identification purposes. For phase 3, participant names and phone numbers will be stored on a password-protected computer only accessible to the study staff in Peru and participants will be identified by a study ID for research purposes. All study participants (Phases 1-3) and YAB members (for each meeting attended) will be compensated PEN 100 (approximately USD 26.50) in vouchers redeemable at multiple local grocery stores. Transportation will be provided for in-person study visits.

Development of a prototype chatbot to provide depression education, self-help, and care linkage

Phase 1: Formative data collection to inform chatbot development

We will conduct up to six focus groups: three with adolescents aged 10-14 years living with HIV and three with adolescents aged 15-19 years living with HIV and residing in Lima, Peru. Additionally, up to ten interviews will be conducted with key informants: five with caregivers of adolescents living with HIV and five with HIV care personnel. A semi-structured interview guide for the focus groups and key informant interviews will be used to identify thoughts, views, and consequences of depression in adolescents living with HIV. Participants will also be asked about their perceived acceptability of the proposed mental health chatbot for adolescents living with HIV using open-ended questions derived from seven core intervention acceptability constructs: affective attitude, ethics, burden, coherence of intervention, opportunity costs, perceived effectiveness, and self-efficacy [31]. Focus groups and key informant interviews will be audio recorded, transcribed verbatim, and analyzed using Dedoose qualitative data analysis software [32].

Eligibility Inclusion Criteria

- Adolescents: 10 ≥ and ≤ 19 years of age, living with HIV, aware of HIV diagnosis.
- Caregivers: ≥18 years old and currently caring for an adolescent living with HIV.
- HIV care personnel: ≥18 years old and currently working in the Peruvian National HIV care system with adolescents aged 10-19 years and living with HIV.

Eligibility Exclusion Criteria: Adolescents, caregivers, and HIV care personnel

- Any acute condition (emotional, physical, social) that, by decision of the investigator, could place the participant at significant risk due to participation in the study.

Data Analysis

Qualitative data will be analyzed using the Framework Analysis approach [33], beginning with a preliminary codebook based derived from the focus group and key-informant interview guides. As coding progresses, *de novo* codes will be added for emergent themes. After all transcripts are coded, reports that contain all text segments for each code will be compiled and analyzed for themes within

each code. Emergent themes will be reported using illustrative quotes. The COREQ (Consolidated Criteria for Reporting Qualitative Data) checklist [34] will be completed to enhance data rigor and methodological transparency.

Study Phase 2: Chatbot design and programming with iterative YAB feedback

We will program the chatbot using the platform SmartBot360 [35]. The YAB will participate in ongoing/iterative testing of the chatbot over several months. First, we will develop an initial version of the chatbot with basic functionality (v. 0.1) and convene the YAB to provide early feedback and suggestions which will be incorporated in the chatbot design and programming yielding version 0.2; the process of YAB feedback solicitation and feedback incorporation will be repeated to arrive at version 0.3. During the YAB consultations, in addition to feedback on the chatbot functionality (for example, presentation, navigation, menus, etc.) the YAB will guide the research team on content for up to six educational videos and/or graphics and animations on depression and coping skills (30 to 90 seconds long) to be delivered by the chatbot. Once the YAB reviews and approves version 0.3, we will finalize remaining programming suggestions to arrive at the pilot version of the chatbot, 1.0, for feasibility and acceptability testing.

Assessing the feasibility and acceptability of the chatbot prototype

Study Phase 3: Pilot testing for feasibility and acceptability of chatbot prototype version 1.0

We will recruit up to N=50 adolescents living with HIV naïve to the development phase to test chatbot version 1.0 for feasibility and acceptability. Participants first will complete a survey to collect information on socio-demographics (age, sex, sexual and gender identity, and education level), HIV (HIV acquisition route, current viral load, and frequency of missed HIV care visits), knowledge and history of depression, and previous chatbot use (see Table 2 for all planned measures). Next, participants will interact with the chatbot and then complete a second questionnaire to assess their acquired knowledge about depression and measure the acceptability and feasibility of the chatbot. The acceptability and feasibility questionnaires will include 3 measures: the Acceptability of the Intervention Measure (AIM), the Intervention Adequacy Measure (IAM), and the Intervention Feasibility Measure (IFM) [36]. Finally, participants will be offered the opportunity to use the chatbot on their own for two additional weeks and will receive a follow-up text message to rate their experience. The number of adolescents living with HIV who use the chatbot on their own and the number of acceptances and refusals to use the chatbot will be recorded during these two weeks as further measures of acceptability.

Table 2: Planned pilot testing survey measures, administration point, target, and rationale to assess the feasibility and acceptability of an optimized conversational agent or "chatbot" among N=50 adolescents living with HIV in Peru to facilitate mental health screening, education, self-help, and linkage to care.

Measure or Instrument	Administration Point	Target	Rationale
Sociodemographic	Before chatbot use	Participant characteristics	Describe the study population including HIV/health information and previous chatbot use.
Adolescent Depression Knowledge Questionnaire (ADKQ) [37]		Current understanding of depression.	Measure baseline depression knowledge prior to interacting with the chatbot.

Patient Health Questionnire-9 (PHQ-9) adolescent version [38]		Current depressive symptoms	Measure baseline presence of depression symptoms
General Anxiety Disorder-7 (GAD-7) [39]		Current anxiety symptoms	Measure baseline presence of anxiety symptoms
The Self-Stigma of Seeking Help Scale (SSOH) [40]		Label Avoidance	Aid in providing appropriate services based on stigma measure
Attitudes Towards Mental Health Treatment (ATMHT) [41]		Feelings about getting mental health help	Aid in providing appropriate services based on attitudes toward treatment
Perceived Stress Scale (PSS) [42]		Current stress levels	Aid in providing appropriate services based on stress levels
Adolescent Depression Knowledge Questionnaire (ADKQ) [37]	After chatbot use	Current understanding of depression.	Measure change of depression knowledge after interacting with the chatbot.
Acceptability of Intervention Measure (AIM) [36]		Acceptability of the chatbot	Measures the perception adolescents living with HIV that the chatbot is agreeable, palatable, or satisfactory.
Intervention Appropriateness Measure (IAM) [36]		Appropriateness of the chatbot	Measures the perceived fit, relevance, or compatibility of the chatbot to address depression among adolescents living with HIV.
Feasibility of Intervention Measure (FIM) [36]		Feasibility of the chatbot	Measures the extent to which the chatbot can be successfully used.
Acceptability of mental health information delivered by the chatbot		Acceptability (or perceived acceptability) of mental health information delivered by chatbot and perceived continued use of chatbot.	Measures the extent to which the user believes they would use the mental health information delivered by the chatbot, use the chatbot in the future and recommend to others.
Chatbot feature satisfaction scale		Satisfaction with core chatbot features	Measures the extent to which chatbot features (e.g., graphics, information, self-help tools) are liked.

Data Analysis

Data will be cleaned, and summary tables will be generated. Due to the small sample size, tests of association are not planned, and the main analysis is limited to descriptive statistics. For the Adolescent Depression Knowledge Questionnaire (ADKQ), which is applied before and again after interacting with the chatbot (during a single study visit), we will use matched paired t-tests. Using G*Power v3.1 [43, 44], with a medium effect size, a sample size of N=45 would be sufficient to detect effects if they are present using a matched pair t-test.

Results

The study commenced in January 2023, with subsequent regulatory approvals allowing for the

initiation of data collection in March 2023. Study phases 1 and 2 will be complete by January 2024, and study phase 3 will commence by March 2024. Results on the feasibility and acceptability of the chatbot are expected by January 2025.

Discussion

This study tests a pragmatic, inexpensive, adaptable, and highly scalable solution to increase access to a range of depression care services for adolescents living with HIV, beginning with education and self-help skills. Given the global shortage of mental health professionals to deliver depression care, especially in low- and middle-income countries (LMIC) where >90% of people with HIV live [45], we anticipate that our mental health chatbot holds potential to go beyond depression identification and care referral; it could empower adolescents living with HIV by providing depression education and practical self-help coping skill. Moreover, the chatbot may be especially attractive to adolescents not wanting to immediately speak with another person due to the stigma surrounding both depression and HIV.

Our chatbot should meet adolescents living with HIV "where they are at," providing linkage to a mental health specialist as needed but also helping adolescents living with HIV learn healthy coping strategies. Moreover, future versions of our chatbot could be adapted to address other psychosocial issues, including HIV disclosure, sex, sexuality, dating and romantic relationships, stigma, body image, and other common psychosocial issues among adolescents, and could be easily adapted for delivery in multiple languages. As with all health problems, early intervention is associated with improved outcomes both at the individual and programmatic levels. At the individual level, adolescents living with HIV who learn how to recognize depression and enact healthy coping skills may be able to stave off the escalation of depression and associated disengagement with HIV care. At the programmatic level, enhanced mental health support for adolescents living with HIV could ultimately reduce missed clinic appointments, improve ART adherence (and consequently less need for inpatient care), and ultimately lead to better HIV outcomes for this vulnerable population.

Anticipated limitations of this study include the rapid formative and chatbot development period (12 months) with participants from one geographic location (Lima) which may not address experiences of depression by adolescents living in rural areas. Further, the small (convenience) sample of adolescents who will test the chatbot (phase 3) will preclude tests of association. Nonetheless, we expect that some participants (including youth, their caregivers and HIV care professionals) will have previously lived in rural areas and could share insights from those experiences. Although the sample size precludes tests for association, the data collected using a battery of validated instruments from this pilot study should provide a clear indication of the acceptability and feasibility of the chatbot to facilitate mental health screening, education, self-help, and linkage to care among adolescents living with HIV and provide the groundwork for a future, appropriately powered study to determine efficacy of the approach.

This study will contribute to a growing body of literature on the use of chatbots in the health services delivery sector and holds promise for addressing a mental health service gap among adolescents with HIV by providing education, self-help skills and care linkage. If our chatbot is determined to be feasible and acceptable among adolescents in this study, future iterations could be expanded beyond depression (e.g., anxiety; disordered eating and body image; HIV and mental health stigma) and disseminated beyond the single geographic area in this study (i.e., to rural areas and, potentially, other countries in Latin America).

Acknowledgments

Funding for this project was made possible in full by a CIPHER grant from the International AIDS Society. The views expressed in written materials or publications do not necessarily reflect the official policies of the International AIDS Society.

Generative AI was not used in the production of this study protocol nor in any other aspect of the research study described.

Data Availability

The data sets generated and analyzed during this study will be available from the study investigators (JTG and CC) on reasonable request.

Conflicts of Interest

None declared.

Abbreviations

ART: antiretroviral therapy
LMIC: Low- and middle-income countries
YAB: Youth Advisory Board

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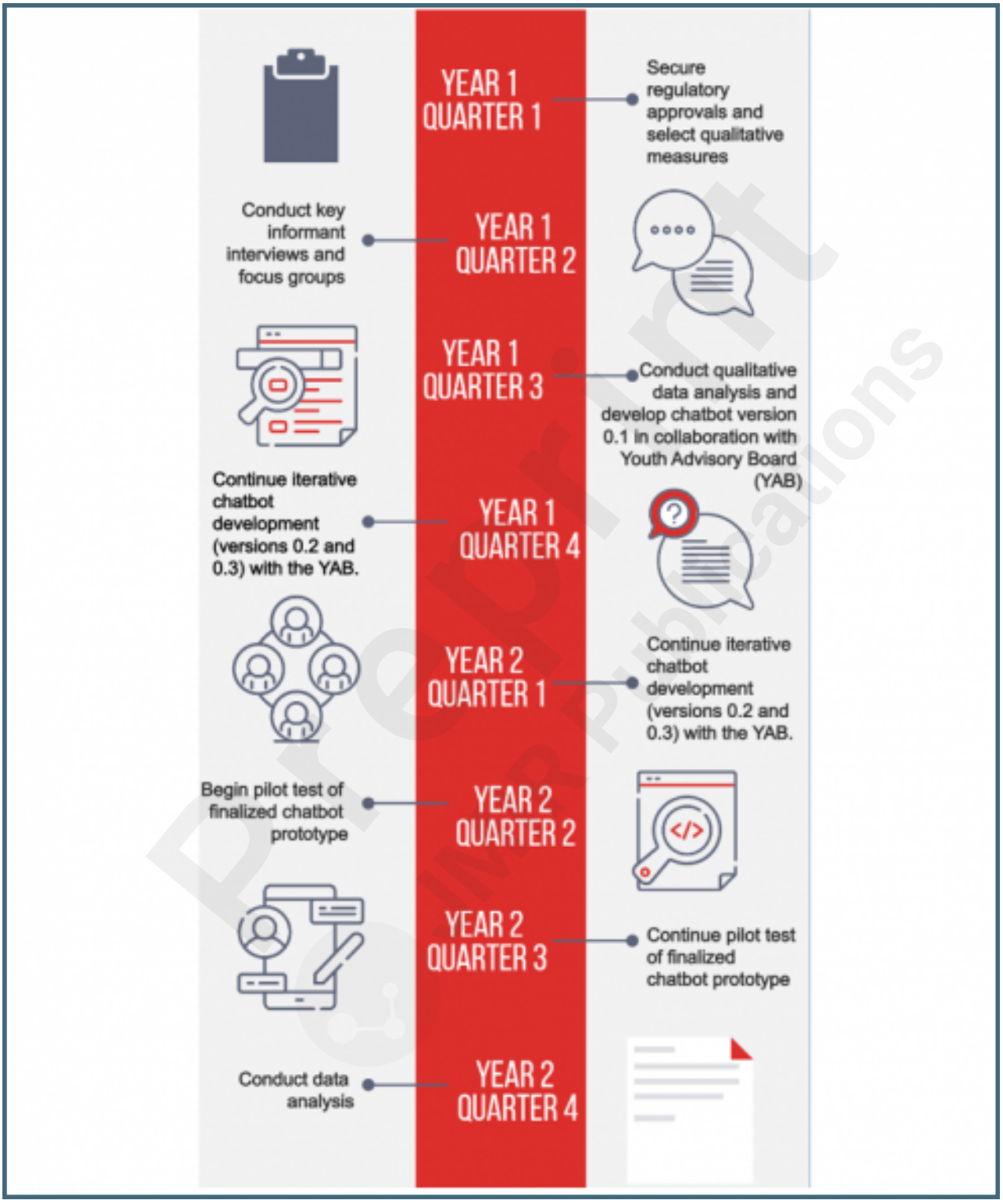
Supplementary Files

Figures

Study aims and process for the development and pilot testing of an optimized conversational agent or "chatbot" for Peruvian adolescents living with HIV to facilitate mental health screening, education, self-help, and linkage to care.



Multimedia Appendixes

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