

## Sigma Theta Tau International's 29th International Nursing Research Congress

### Informing an mHealth Intervention to Improve the HIV Care Continuum in South Africa

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**Purpose:** South Africa has over 7 million people living with HIV, the most of any country worldwide (UNAIDS, 2017). Recent changes to the South African National Guidelines has increased the number of people eligible to receive ART, making theirs the largest government-supported ART program in the world and accounting for 20% of people receiving ART globally (National Department of Health, 2014; UNAIDS, 2017). However, high rates of attrition at all stages of the HIV care continuum are a major challenge, underscoring an urgent need for novel interventions to improve retention in care (Fox et al., 2014; Nkala et al., 2015; SANAC, 2017). In recent years, numerous mobile health (mHealth) interventions to improve HIV treatment outcomes in low- and middle-income countries have been explored, such as sending medication adherence and appointment reminders (Georgette et al., 2016; Hall, Fottrell, Wilkinson, & Byass, 2014; Siedner, Santorino, Haberer, & Bangsberg, 2015). However, the potential for improving retention in care by sending specific HIV test results to patients outside of a clinical setting has not been adequately explored. We conducted formative research within the South African context to identify: (i) barriers to entering and remaining in the HIV care continuum and (ii) perceived benefits and concerns of a novel mHealth system to provide HIV laboratory test results to patients through their cell phones.

**Methods:** We conducted in-depth interviews with a convenience sample of 28 providers (nurses and doctors) and 11 patients in 17 government clinics and one tertiary hospital between June 2015 and November 2016 in Klerksdorp (North West province), South Africa. Two analysts reviewed all transcripts and developed a codebook. Inter-coder reliability was assessed to be 0.75, and codes were discussed and the codebook was revised. Analysts coded all transcripts and carried out a thematic analysis using a social-ecological framework.

**Results:** Individual level barriers to seeking HIV care included demographic factors such as gender (women were more open to seeking and receiving treatment than men), denial and fear, and financial difficulties. Dyadic barriers included sexual partners' differing willingness to seek and remain on treatment, and fears over disclosing HIV status to sexual partners. Community level barriers included stigma, with patients fearing mistreatment and discrimination by health workers and neighbors and friends. Health system barriers included resource shortages at government clinics, and absence of a robust system to process and communicate laboratory results and monitor whether patients returned for follow-up visits.

According to providers, perceived benefits of the mHealth system were reduced workload for clinicians and reduced wait time for patients, potential for expanded uses of the system beyond HIV care, and patient empowerment. Providers raised concerns about the confidentiality of delivering test results via cell phone and breaking potentially distressing results through text messages. They also expressed doubts over whether patients would be able to understand their test results without a clinician's interpretation, and doubts as to the proportion of their community with regular access to cell phones. Compared to providers, patients did not view confidentiality or cell phone access to be as large of a concern. Patients were open to receiving test results via SMS but also indicated that they would like a face-to-face explanation of their results.

**Conclusion:** Using a social-ecological framework, we found that barriers to entering and remaining in the HIV care continuum were present at the individual, dyadic, community, and health system levels. Given the magnitude of the HIV epidemic in South Africa, no single intervention can adequately address all these barriers and a multi-pronged approach is necessary to improve retention in care. However, through interviews with providers and patients, we found that an mHealth program that provides test results directly to patients outside of the clinical setting has the potential to address several key barriers, particularly at the health system level, that make it difficult for patients to initiate and remain engaged in care.

For patients who do not require treatment changes, receiving results through cell phone could preclude the need for unnecessary trips to the clinic, saving them long wait times, lost wages, transportation costs and exposure to other sick patients. For patients with an actionable result, receiving their test results through cell phone could encourage them to return to the clinic and be seen by a clinician as soon as possible, therefore reducing delays in initiation or adjustment of ART. This would result in a reduced workload for clinicians. Providers also highlighted the potential of the mHealth system to empower patients as an important benefit. Receiving their test results to their phone without a trip to the clinic could allow patients can take a more active role in understanding and acting on their health status. Ultimately, such a system could be expanded to provide a variety of test results and health information, leading to improved integration with other health services such as those for cancer, heart disease, or diabetes.

However, some important concerns remain, such as the ethics surrounding privacy and disseminating potentially distressing results through text messages and patient comprehension of results. These findings recommend that an mHealth intervention address confidentiality issues, for example, by implementing a secure password-enabled system such as USSD. Success of an mHealth intervention would rely on patients' understanding of the messages sent, and therefore messages would need to be carefully crafted and tested. Rather than completely replacing face-to-face communication, an mHealth system should serve as a complement to it, leading to more meaningful interactions between patients and providers. These considerations will need to be addressed for an mHealth system to be successfully integrated with the clinic workflow. This formative research supports delivering HIV laboratory results directly to patients through a secure mHealth system. This type of mHealth intervention will capture those patients who currently do not return for their laboratory results, and may empower patients to know their status and return for treatment, improving engagement and retention in the HIV care continuum.

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**Title:**

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**Keywords:**

Care Continuum, HIV and mHealth

**References:**

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### **Abstract Summary:**

Discuss the multi-level barriers impacting the HIV care continuum and the potential use of an mHealth intervention to improve initiation and retention in HIV treatment in South Africa.

### **Content Outline:**

1. Introduction
  1. South Africa has 7.1 million people living with HIV, the most of any country worldwide
  2. South Africa accounts for 20% of people receiving ART treatment worldwide
  3. Retention across the HIV care continuum is poor, and novel interventions are needed
2. Research Questions
  1. What are the barriers to entering and remaining in the HIV care continuum?
  2. What are perceived benefits and concerns of a novel mHealth system to provide HIV laboratory test results to patients through their cell phones?
3. Methods
  1. Qualitative in-depth interviews completed with 28 clinicians (nurses and doctors) and 11 patients
  2. Two analysts reviewed interviews and conducted thematic analysis
4. Results

1. Individual-level barriers
  1. demographic factors (women more open to treatment than men)
  2. denial and fear
  3. financial difficulties
2. Dyadic-level barriers
  1. partners' differences in seeking and remaining on treatment
  2. fear of disclosure to partners
3. Community-level barriers
  1. stigma
  2. fear of mistreatment and discrimination by neighbors and healthcare workers
4. Health system barriers
  1. resource shortages at government clinics
  2. no robust system to process and communicate laboratory results
  3. no monitoring system of patients' return visits
5. mHealth Perceptions
  1. Benefits
    1. reduced wait times at the clinic (and no return visit if results stable)
    2. reduced workload on clinic providers
    3. potential expanded use beyond HIV care
    4. patient empowerment
  2. Concerns
    1. confidentiality
    2. possible lack of patient understanding of results without a clinician's interpretation
5. Conclusions
  1. mHealth could be an important tool in improving retention in HIV care
  2. Confidentiality concerns could be overcome through use of a USSD (PIN-protected) system
  3. Clinic flow could be improved through allowing stable patients to receive their results outside of the clinic and save them a return visit
  4. Patient understanding remains a concern, and an option for speaking to a provider would be important

First Primary Presenting Author

**Primary Presenting Author**

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 Johns Hopkins University  
 Research Nurse  
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**Professional Experience:** 2009-2011: Peace Corps Volunteer, Mozambique 2012-2013: Completing BSN program 2014-2015: Registered Nurse working in inpatient and community health settings 2015-2016: Completing MSN/MPH program 2016-current: Working with JHU and PHRU to complete the presented research

**Author Summary:** Lisa is a public health nurse interested in international health and infectious disease. For the past two years she has been working with a dedicated team in South Africa and Johns Hopkins to design and implement an mHealth pilot program.

Second Author

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**Professional Experience:** Nandita was part of the project team involved in the implementation of the mHealth intervention to improve the HIV care continuum in South Africa. She is trained in the social and behavioral sciences and has 2 peer-reviewed publications to her credit.

**Author Summary:** Nandita holds a bachelors degree in Public Health and a Masters Degree in International Health from Johns Hopkins University. She has experience working in the technical areas of non-communicable diseases, tobacco control, HIV and mHealth in the United States, India and South Africa. Nandita has also served as a consultant for projects on reproductive health and social norms change. She will begin a PhD in Social and Behavioral Sciences at George Washington University in 2018.

Third Author  
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**Professional Experience:** Dr. Elf is an epidemiologist whose research focuses on the epidemiology, health impacts, and intervention strategies for air pollution and tobacco exposure in the context of tuberculosis and HIV.

**Author Summary:** Dr. Elf is an epidemiologist whose research focuses on the epidemiology, health impacts, and intervention strategies for air pollution and tobacco exposure in the context of tuberculosis and HIV.

Fourth Author  
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**Professional Experience:** Sarah Cox is the Manager of Population Health and Analytics within San Francisco Health Network Primary Care. In 2016, she obtained her MSPH in International Health: Global Disease Epidemiology and Control at Johns Hopkins Bloomberg School of Public Health focusing on infectious disease and vaccine science & policy. Sarah is the co-founder of two non-profit organizations, One Sun Health, Inc. and Science-Corps. She is passionate about population health, analytics, equity, vaccine-preventable diseases, and sustainable development.

**Author Summary:** Sarah Cox is the Manager of Population Health and Analytics within San Francisco Health Network Primary Care. In 2016, she obtained her MSPH in International Health: Global Disease Epidemiology and Control at Johns Hopkins Bloomberg School of Public Health focusing on infectious disease and vaccine science & policy. Sarah is the co-founder of two non-profit organizations, One Sun Health, Inc. and Science-Corps. She is passionate about population health, analytics, equity, vaccine-preventable diseases, and sustainable development.

Fifth Author  
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**Professional Experience:** Carla received her masters in public health in 2015. She studied infectious disease as well as qualitative and quantitative methods. She currently conducts mixed methods research including qualitative interviewing and analysis.

**Author Summary:** Carla currently conducts STI research in Baltimore City. She is interested in social determinants of health and using research to inform local health department practices.

Sixth Author  
Munei Nthulana, BA  
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**Professional Experience:** Completed BA Degree majoring in welfare science (social work) and psychology, Completed 6 months course in HIV care and counseling, GCP trained and also completed some DAIDS online courses on Quality control. Roles in the study included recruitment of participants, conducting ICF processes, performing in depth interviews, translations and transcription.

**Author Summary:** Munei Nthulana is a BA graduate and is currently registered with the SA council for social services professions, an individual whose passion is to see improvement in the lives of those infected and affected by HIV and other chronic diseases.

Seventh Author  
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**Professional Experience:** Nadine participated in the formative research for the mHealth intervention, conducting fieldwork in local clinics in Jouberton township. She graduated Johns Hopkins University in 2018 with honors and a BA in Anthropology and a minor in Women, Gender, and Sexuality Studies. She currently works as a paralegal at Lanier Law Firm in their pharmaceutical liability department.

**Author Summary:** Nadine participated in the formative research for the mHealth intervention, conducting fieldwork in local clinics in Jouberton township. She graduated Johns Hopkins University in 2018 with honors and a BA in Anthropology and a minor in Women, Gender, and Sexuality Studies. She currently works as a paralegal at Lanier Law Firm in their pharmaceutical liability department.

Eighth Author  
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**Professional Experience:** For this educational activity I made substantial contributions to the conception of the work through my research in South African clinics from June-August 2015. My contributions included analysis and interpretation of data for the work, including a critical revision amongst the additional authors. A final approval of this version of analysis was agreed to be published. As an author I am in agreement to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

**Author Summary:** My name is Elisa Dupuis. My Nurse Practitioner career began in HIV Primary Care with specialization in Hepatitis C and transgender care. The need for dual trained HIV/HCV providers transitioned my career to Hepatology as a Liver Transplant Nurse Practitioner with the Johns Hopkins Comprehensive Transplant Center where we offer greater access to organ transplants to people living with HIV through the HOPE Act.

Ninth Author

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**Professional Experience:** Katlego Motlhaoleng's experience in implementation research includes effective and efficient ethical quality management of TB and HIV patients, and continuously improving program efficiency and promoting staff development. She also has excellent stakeholder management skills and improving communication between implementing organizations, the community and government.

**Author Summary:** Katlego Motlhaoleng (Dip NSc, BA Cur) has ten years working experience in both the public health sector and research field. She is currently working as a Clinical Operations Manager at the Perinatal HIV Research Unit (PHRU) while studying for a Masters in Public Health (MPH) at the University of Pretoria in South Africa. She is actively involved in various Tuberculosis (TB) and HIV prevention and treatment research studies.

Tenth Author  
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**Professional Experience:** Dr. Golub is an epidemiologist at Johns Hopkins University. Dr. Golub's research focuses on the epidemiology, detection and prevention of TB in low and middle income countries, with an emphasis on people with HIV. I also investigate the impact of social determinants on TB risk, mortality and treatment outcomes, including tobacco use, alcohol, indoor air pollution and diabetes. I am experienced in developing and implementing research studies for TB in Brazil, South Africa and India.

**Author Summary:** Dr. Golub is an epidemiologist at Johns Hopkins University. Dr. Golub's research focuses on the epidemiology, detection and prevention of TB in low and middle income countries, with an emphasis on people with HIV. I also investigate the impact of social determinants on TB risk, mortality and treatment outcomes, including tobacco use, alcohol, indoor air pollution and diabetes. I am experienced in developing and implementing research studies for TB in Brazil, South Africa and India.