



STEPSSA 50+ PROJECT

SA Partners: Dissemination Report

Strengthening Prevention, Treatment, and Psychosocial Support Needs of OPHIV Aged 50+ to reduce morbidity and mortality in the era of HIV Test and Treat All in SA (STEPSSA 50_Plus): MY LIFE MATTERS_ Aging with Value”.

SA Partners, a non-profit company registered under Section 21 (A.1) in SA & US, implemented a 6-month pilot project to determine the coverage, scope, and extent to which the Treatment and Psychosocial Support Needs of the 50-plus age group, Older Persons Living with HIV (OPLHIV), are addressed and experienced within the Health System in South Africa (SA).

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A. ABSTRACT:

The project titled Strengthening Prevention, Treatment and Psychosocial Support Needs of OPLHIV Aged 50+ to reduce morbidity and mortality in the era of HIV Test and Treat All in South Africa: MY LIFE MATTERS_ “Aging with Value” (STEPSSA 50+) aimed to gauge the availability, and access to, HIV prevention, treatment, psychosocial support, and non-communicable disease services in communities in South Africa. Using a mixed method approach to conduct a scoping exercise encompassed listening sessions, focus group discussions, story gathering, and a questionnaire. Policy, Programmes, HIV and Comorbidity literature reviews were conducted. It is through these activities that the project has produced comprehensive information emanating from the communities in nine Provinces of South Africa providing a roadmap for future initiatives. The findings highlight the compounded healthcare and support disparities stemming from both HIV status and age of participants. The project outcome has presented the urgency created by challenges experienced by the intersectionality of aging, living with HIV and the complications added by co-morbidities. The unique challenges require tailored attention and support as highlighted in this report’s future work section.

KEY WORDS: 50+, Aging, HIV, Co-Morbidities, Psychosocial, Healthy Aging, Dignity,



Picture 1: STEPSSA 50+ Project Focus Group Discussion in Soweto, Dlamini Methodist Church, City of Jo'burg - Gauteng

1. Acronyms

- **AIDS:** Acquired Immune Deficiency Syndrome
- **ART.:** Antiretroviral Therapy
- **ARV.:** Antiretroviral
- **CCEP:** Community Capacity Enhancement Program
- **CCMDD:** Centralised Chronic Medication Dispensing and Distribution
- **C.E.M.:** Community Empowerment Model
- **CP:** Community Pharmacy
- **C.P.M.:** Community Pharmacy Model
- **D.D.:** Decentralized Distribution
- **DMOC:** Differentiated Models of Care
- **D.S.D.:** Differentiated Service Delivery
- **DSD.:** Department of Social Development
- **GBVF:** Gender-Based Violence and Femicide
- **HIV.:** Human Immunodeficiency Virus
- **HTS.:** H.I.V. Testing Services
- **I ACT:** Integrated Access to Care and Treatment
- **LGBTQIA+:** Lesbian, Gay, Bisexual, Transgender, Queer/Questioning, Intersex, Asexual, and other sexual orientations and gender identities
- **NAPWA:** National Association of People with H.I.V. or AIDS
- **NCDs:** Non-Communicable Diseases
- **NDOH:** National Department of Health
- **NSP:** National Strategic Plan on HIV., TB., and STI.s 2023-2028
- **NSP on GBVF:** National Strategic Plan on Gender-Based Violence and Femicide
- **OPLHIV:** Older People Living with HIV aged 50 and above.
- **P.A.C.:** Positive Action Campaign
- **P.E.P.** Post-Exposure Prophylaxis
- **PLHIV:** People Living with HIV
- **PMTCT:** Prevention of vertical Mother-to-Child Transmission of HIV
- **PrEP:** Pre-Exposure Prophylaxis
- **PWN:** Positive Women's Network
- **SABSSM:** South African National HIV Prevalence, Incidence, Behaviour and Communication Survey
- **SAMRC:** South African Medical Research Council of South Africa
- **SANAC:** South African National AIDS Council
- **SANARELA:** South African Network of Religious Leaders Living with or Personally Affected by HIV & AIDS
- **SDG:** Sustainable Development Goals
- **STEPS:** Strengthening Prevention Services in Correctional Centres.
- **STEPSSA 50+ Project:** Scoping Project for Strengthening Prevention, Treatment, and Psychosocial Support Needs of OPLHIV Aged 50+ to reduce morbidity and mortality in the era of HIV Test and Treat All in South Africa
- **TAC:** Treatment Action Campaign
- **UN. Women:** United Nations Entity for Gender Equality and the Empowerment of Women
- **UNAIDS:** Joint United Nations Programme on HIV/AIDS.
- **UNDP:** United Nations Development Programme
- **UNFPA:** United Nations Population Fund
- **WHO:** World Health Organization

B. The STEPSSA 50+ Project

2. Introduction

	<p>The increase in life expectancy, as described by Mathers et al. (2015)¹, has not been evenly distributed globally. In South Africa 7,8 million people have been reported to be living with HIV. 4.7 million people in the country are on Antiretroviral treatment combinations (ART). The South African Medical Research Council (SAMRC) SABBSM (2022)² report stated that 1,5 million of PLHIV on treatment are aged 50 and above. This brings to the forefront the need to address the health and social care needs of an aging population living with HIV and non-communicable disease (NCD). These diseases are syndemic within sub-Saharan Africa. The two epidemics (HIV and NCDs) negatively interact with one another, especially within a context of poverty, inequality, and inequitable access to healthcare, resulting in those aged 50 and older living with HIV and experiencing an increase in NCD comorbidity. OPLHIV aged 50 years and above have four times the risk of developing Hypertension, Diabetes and Renal Insufficiency³.</p>
	<p>The intersectionality of HIV, Aging and comorbidities calls for the reimagining of HIV service delivery, as advocated by Grimsrud et al. (2016)⁴, to create a continuum of care that addresses the unique needs of this population. The care should be provided from prevention to suppression of HIV. Individuals who participated in the project have conveyed their desire for a comprehensive healthcare approach that includes preventive measures, screenings for non-communicable diseases (NCDs), effective management of comorbidities, and adherence to HIV treatment to achieve viral suppression. In the midst of all, prevention of transmission becomes critical in averting new infections in the older age group. The latest evidence has shown low usage of condoms ages 50+ (29% Females and 28% males) with females older than 50 years having double the risk of HIV acquisition compared to their male counterparts⁵.</p>
 <p>Picture 3: Greater Taung People Living with HIV/AIDS Organisation's Banner at the STEPSSA 50+ Project session in Diphitsing, Magogong Village – North West Province RSA</p>	 <p>Picture 4: STEPSSA 50+ Project District Team members preparing for a Listening Session using Isizinda Sempilo Orgniksation Branding at Monsievile, Mogale City in West Rand – Gauteng Province RSA</p>

¹ Mathers, C.D., Stevens, G.A., Boerma, T., White, R.A. and Tobias, M.I., 2015. Causes of international increases in older age life expectancy. *The Lancet*, 385(9967), pp.540-548.

² <https://sahivsoc.org/Files/SABSSM-FINAL-LAUNCH-presentation-27 November2023-1.pdf>

³ Roomaney RA, van Wyk B, Pillay-van Wyk V. Aging with HIV: Increased Risk of HIV Comorbidities in Older Adults. *International Journal of Environmental Research and Public Health*. 2022; 19(4):2359. <https://doi.org/10.3390/ijerph19042359>

⁴ Grimsrud, A., Bygrave, H., Doherty, M., Ehrenkranz, P., Ellman, T., Ferris, R., Ford, N., Killingo, B., Mabote, L., Mansell, T. and Reinisch, A., 2016. Reimagining HIV service delivery: the role of differentiated care from prevention to suppression. *African Journal of Reproduction and Gynaecological Endoscopy*, 19(1).

⁵ Gómez-Olivé FX, Houle B, Rosenberg M, Kabudula C, Mojola S, Rohr JK, Clark S, Angotti N, Schatz E, Kahn K, Bärnighausen T, Menken J. Brief Report: HIV Incidence Among Older Adults in a Rural South African Setting: 2010-2015. *J Acquir Immune Defic Syndr*. 2020 Sep 1;85(1):18-22. doi: 10.1097/QAI.0000000000002404. PMID: 32516151; PMCID: PMC7417014.



Picture 5: Listening session discussion commission in Nelson Mandela Bay - Gqeberha Eastern Cape Province RSA

This project titled Strengthening Prevention, Treatment and Psychosocial Support Needs of OPLHIV Aged 50+ to reduce morbidity and mortality in the era of Test and Treat All & HIV in South Africa (STEPSSA 50_Plus) was funded through Gilead Sciences Africa. The aim was to conduct a scoping exercise in SA to assess the prevention, treatment and psychosocial needs of people living with HIV Aged 50 and above in SA. Older persons who were HIV negative also participated as they wished to gain knowledge and share their experiences of living with NCDs and challenges of being part of the public healthcare system.

SA Partners has a long-standing history of working with the Department of Health, both at the national and provincial levels. They have collaborated on successful programmes in the past such as the Integrated Access to Care and Treatment (IACT), Strengthening Preventions Services in Correctional Centres (STEPS), Albertina Sisulu Leadership Programme in Public Health (ASELPH) and the LinkCARE programme that resulted in the development of the National Adherence Guidelines for HIV, TB, and other chronic diseases. Using their expertise and experience, SA Partners was interested in exploring the needs of the OPLHIV, specifically those who were part of the I ACT support groups. The main motivation behind this exploration was to gather feedback on these individuals' current state and to better understand any comorbidities they might have faced historically. SA Partners recognizes the importance of continuous improvement and tailoring programmes to meet the changing needs of PLHIV. This inquiry aimed to inform the development of targeted interventions that address the past and present challenges faced by the community of OPLHIV.

Securing the grant from Gilead Sciences enabled the collaboration with OPLHIV representatives, organizations, activists, and Community Based Organisations (CBO)s. The STEPSSA 50+ Project was started in October 2023 and ran to April 2024 with this funding, and then taken further to June 2024 through additional funding received from SA Partners.

2.2. Objectives

- Design a comprehensive prevention, treatment, and psychosocial support programme for PLHIV Aged 50+ with a focus on new and OPLHIV on long-term ART to reduce morbidity and mortality in the era of HIV and Aging.
- Review Literature on HIV & Aging including current HIV Programmes and Policies to gauge the alignment and commitment of the health system in addressing HIV & Aging.
- Facilitate engagements with stakeholders, document OPLHIV patients' experiences regarding medication journeys, experiences, health, and psychosocial needs, and develop an implementation framework.
- Pilot a comprehensive prevention, treatment, and psychosocial support program for PLHIV Aged 50+ with a focus on new and OPLHIV on long-term ART to reduce morbidity and mortality in the era of HIV and Aging



Picture 6: Listening Session in City of Cape Town – Western Cape Province RSA

The project aimed to find ways to enhance prevention, treatment, and psychosocial support needs for Older People Living with HIV (OPLHIV) as they age and to lower morbidity and mortality rates in the context of HIV testing and treatment in South Africa. You will notice that findings of the STEPSSA 50+ Project resonate well with South African Government's broader policy commitments, particularly within the context of health⁶ and development goals⁷ notably the National Development Plan (NDP) 2023 and South Africa National Strategic Plan (NSP) for HIV/TB/STIs 2023-2028 including the global Sustainable Development Goals (SDG) 2030⁸.

⁶ National Strategic Plan on HIV, TB and STI's 2023 - 2028

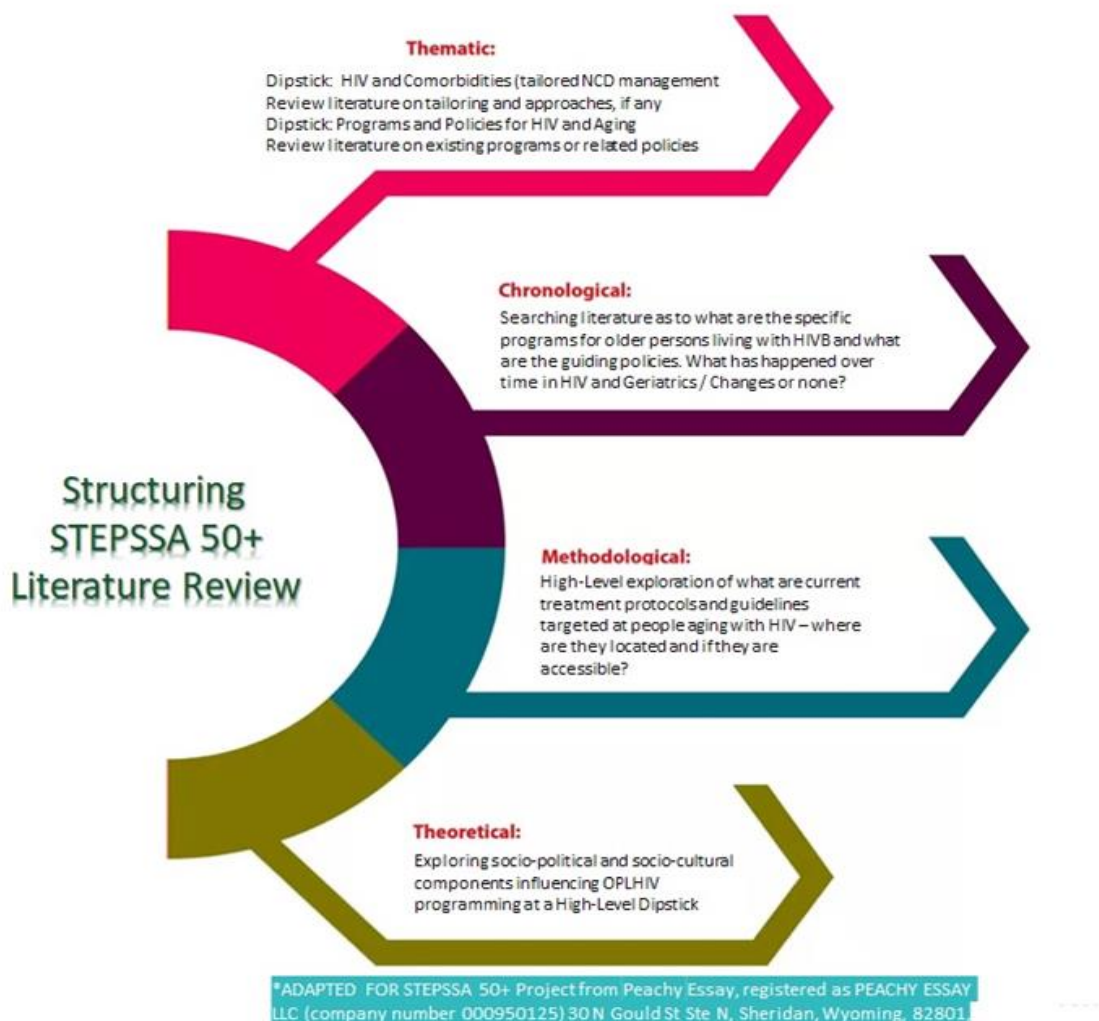
<https://sanac.org.za/wp-content/uploads/2023/05/SANAC-NSP-2023-2028-Web-Version.pdf>

⁷ National Development Plan (NDP): Vision 2030 – “Our future – make it work” - adopted in 2012

⁸ Sustainable Development Goals (SDGs): SDGs_Country_Report_2019_South_Africa.pdf (statssa.gov.za)

3. Literature Review

5.1. Policies and Programmes in South Africa



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Figure 1: Literature Review Thematic areas

Adaption for STEPSSA 50+ Project drawn from the July 8, 2021 Peachy Essay Blog on “How to design and write a Literature Review using 5 easy steps and thematic areas” - Structuring a Literature Review

⁹ How to Write a Literature Review in 5 Simple Steps (peachyessay.com) www.peachyessay.com/blogs/writing-literature-review-in-5-easy-steps/approaches-to-the-structuring-of-literature-review/



The literature review focused on prevention, treatment, and psychosocial support policies and programmes and their alignment with HIV and Aging. Although the South African government's response to HIV has been multifaceted, encompassing a range of policies and programmes aimed at different aspects of the epidemic, we found that tailored healthcare programmes that cater specifically to the older HIV-positive population and address the dual challenge of aging and HIV management were limited¹⁰.

This was further complicated by social and economic¹¹ factors such as stigma, discrimination, and changing societal roles, as well as poverty, unemployment, challenges like financial instability and access support services.

The STEPSSA 50+ Project's literature review offers an insightful exploration of the challenges faced by elderly individuals living with HIV in South Africa. It provides a detailed analysis of the epidemiological shifts¹², healthcare requirements, and cultural perceptions that contribute to the complex nature of these challenges. With the HIV epidemic affecting an aging demographic, it becomes increasingly vital to understand and address the unique difficulties faced by the elderly population. Although antiretroviral therapy has notably improved the lifespan of HIV-positive individuals, it also presents new challenges. Elderly populations living with HIV must navigate not only the virus, but also age-related health concerns¹³. Therefore, it is necessary to develop tailored strategies and interventions that address the interplay between HIV and aging. The review underscores the urgency of addressing these issues and the need for a comprehensive approach to improve the quality of life for elderly individuals living with HIV.

There is therefore a need for:

- More integrated healthcare policies that cater specifically to the older HIV-positive which would involve not only providing ART but also managing age-related comorbidities and ensuring mental health support.
- Enforcement and strengthening of anti-discrimination laws to protect older individuals living with HIV from stigma and social exclusion. This includes discrimination in healthcare, social services, and employment.
- Development and implementation of policies that provide economic support to older individuals living with HIV, recognizing the financial challenges they face due to health care costs (distance and travel), and potential loss of income. This could include pension schemes, disability benefits, and subsidies for medications and health services. Ensuring financial stability is crucial for this demographic, as they navigate the complexities of living with a chronic condition in their older years¹⁴.

¹⁰ <https://hsr.ac.za/news/latest-news/sabssm-vi-highlights-progress-and-ongoing-disparities-in-south-africas-hiv-epidemic/> (November 2023 - SABSSM VI highlights progress and ongoing disparities in South Africa's HIV epidemic)

¹¹ Simbayi, L.C.Z.K., Zuma, K., Zungu, N., Moyo, S., Marinda, E., Jooste, S., Mabaso, M., Ramlagan, S., North, A., Van Zyl, J. and Mohlabane, N., 2019. South African national HIV prevalence, incidence, behaviour and communication survey, 2017: towards achieving the UNAIDS 90-90-90 targets

¹² <https://hsr.ac.za/press-releases/hsc/new-hiv-survey-highlights-progress-and-ongoing-disparities-in-south-africas-hiv-epidemic/>

¹³ March 2023: Long-term success for people living with HIV: A framework to guide practice. Jeffrey V. Lazarus, David A. Wohl, Mario Cascio, Giovanni Guaraldi, Jürgen Rockstroh, Matthew Hodson, Bruce Richman, Gina Brown, Jane Anderson, Maria J. Fuster-Ruiz de Apodaca - Long-term success for people living with HIV: A framework to guide practice - Lazarus - 2023 - HIV Medicine - Wiley Online Library

¹⁴ Lombard, A., Kruger, E. Older Persons: the Case of South Africa. *Ageing Int.* **34**, 119–135 (2009). <https://doi.org/10.1007/s12126-009-9044-5>

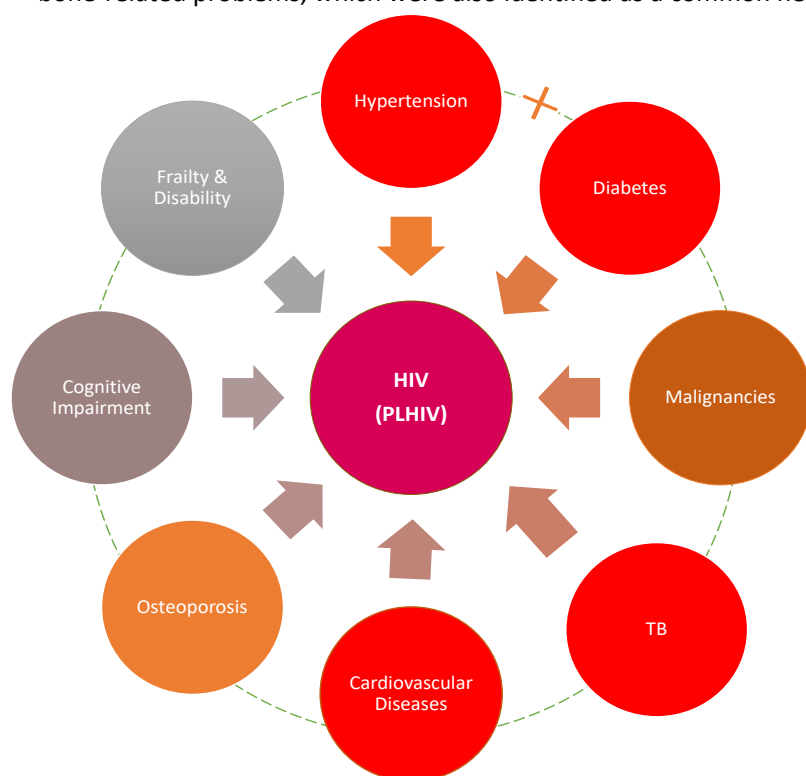
5.2. HIV and Comorbidities

The literature search was conducted using key words:

HIV, AIDS, older adults, 50+, aging, South Africa using PubMed, Google Scholar, and EBSCOhost Databases. Prevalent HIV Comorbidities and emerging themes were summed up as follows:

- Accessing ART & treatment for other conditions is a challenge – services are either physically or administratively separate.
- Older persons forgetting appointments- multiple appointments for different conditions.
- Siloed provision of HIV & NCD care within the SA health system.
- Physical barriers to care: associated with weakness, difficulty walking.
- Financial barriers to care: Social grant (old age pension insufficient to overcome barriers to access)
- Overcrowding, long queues, and time-consuming waiting times.
- Tiredness, pain, and hunger- time spent waiting at the facility.

The STEPSSA 50+ Project conducted an in-depth literature review that shed light on several critical health concerns faced by elderly individuals who are living with HIV in South Africa. The literature review highlighted two particular health conditions, hypertension and diabetes¹⁵, which have been dubbed as the "terrible twins" due to their high prevalence among aging population. Other common health issues identified in the review included tuberculosis, cardiovascular diseases, osteoporosis, cognitive impairment, frailty, and disability¹⁶. While arthritis was mentioned intermittently, participants commonly used traditional terms such as "amathambo" or "marapo" when describing bone-related problems, which were also identified as a common health concern.



From the literature reviewed, the issue of hypertension was also associated with older people living with HIV who developed Type 2 DM¹⁷.

The findings of this literature review will help healthcare providers better understand the health issues of elderly individuals living with HIV and enable them to provide more targeted interventions to improve their health outcomes

Figure 2: Comorbidities Cycle

¹⁵ Nongiwe L. Mhlanga and Thinavhuyo R. Netangaheni, May 2023. Risks of Type 2 diabetes among older people living with HIV: A scoping review - PMC (nih.gov)

¹⁶ Rifqah Abeeda Roomaney, Brian van Wyk, and Victoria Pillay-van Wyk, Feb 2022. Aging with HIV: Increased Risk of HIV Comorbidities in Older Adults - PMC (nih.gov)

¹⁷ Nongiwe L. Mhlanga and Thinavhuyo R. Netangaheni, May 2023. [Risks of Type 2 diabetes among older people living with HIV: A scoping review - PMC \(nih.gov\)](#)

5.3. Methodology

	<p>The project's primary goal of the scoping exercise was to review the experiences of older individuals living with HIV. Our aim was to check the availability and accessibility of prevention, treatment, psychosocial support, and non-communicable disease services in communities. Data collection activities included a combination of listening sessions, focus group discussions, story gathering, literature review including a HIV & Comorbidity questionnaires. Our findings highlighted the compounded healthcare disparities stemming from both age and HIV status. The intersectionality of aging and living with HIV presents unique challenges that require tailored attention and support.</p>
	<p>On completion of the activities in the nine Provinces we then conducted semi-structured interview with other professionals in the HIV/AIDS Field; Chief Executive Officer for Quadcare Clinics, Senior Lecturer focusing Nutrition and Comorbidities and Director Health Care Services in one of the provinces. Consultative meetings were held with Directorate HIV/AIDS Department of Social Development and its divisions, a PLHIV who is a Long-term Survivor, OPLHIV who is a professional and the South African National PLHIV Sector comprised of the National Association of People Living with HIV, Treatment Action Campaign, South African Network of African Religious Leaders living with and affected by HIV/AIDS, Positive Women's Network and Positive Action Campaign. These were not expert interviews but rather opinion-seeking engagements with individuals directly working with people living with HIV (PLHIV), those involved in health provision, and individuals who have been living with HIV long-term.</p>
	<p>The scoping period was followed by a Demonstration Project implemented in collaboration with Isizinda Sempilo CBO, based in Soweto and EPOC (recruitment of facilitators from the LGBTQIA+ organisation) in Ekurhuleni to host the Training of Support Group Facilitators aged 50+ on Integrated Access to Care and Treatment (IACT) Content and Skills as well as Sensitisation and this was finalised by hosting a Health Jamboree targeting the Communities aged 50+ with screening for HIV/TB/STIs, and Information Dissemination. The Health Jamboree served as a platform to mentor SG Facilitators on IACT content and facilitation sessions.</p>
	<p>The following section will briefly narrate the activities and outputs for the Scoping Exercises (Listening Sessions, FGDs, Story Gathering, HIV and Comorbidity Survey, HIV Programs and Policies and HIV Comorbidity Literature Review) and Demonstration Project (IACT and Sensitisation and Content Training, including the Health Jamboree. A Health Jamboree in the context of the Demonstration Project meant a service delivery-oriented programme, bringing a combination (jamboree) of health screening services and testing for HIV and AIDS, STIs and TB. It is a community event open to the general public and usually utilizes makeshift (tented or in Gazebo) clinics / counselling booths, NCD screenings, BMI and health advisory services. Various safer sex packs that contain empowerment skills brochures and other health literature, as well as femidoms, dental derms and condoms are distributed to attendee communities.</p>

5.3.1. Mixed Method Approach

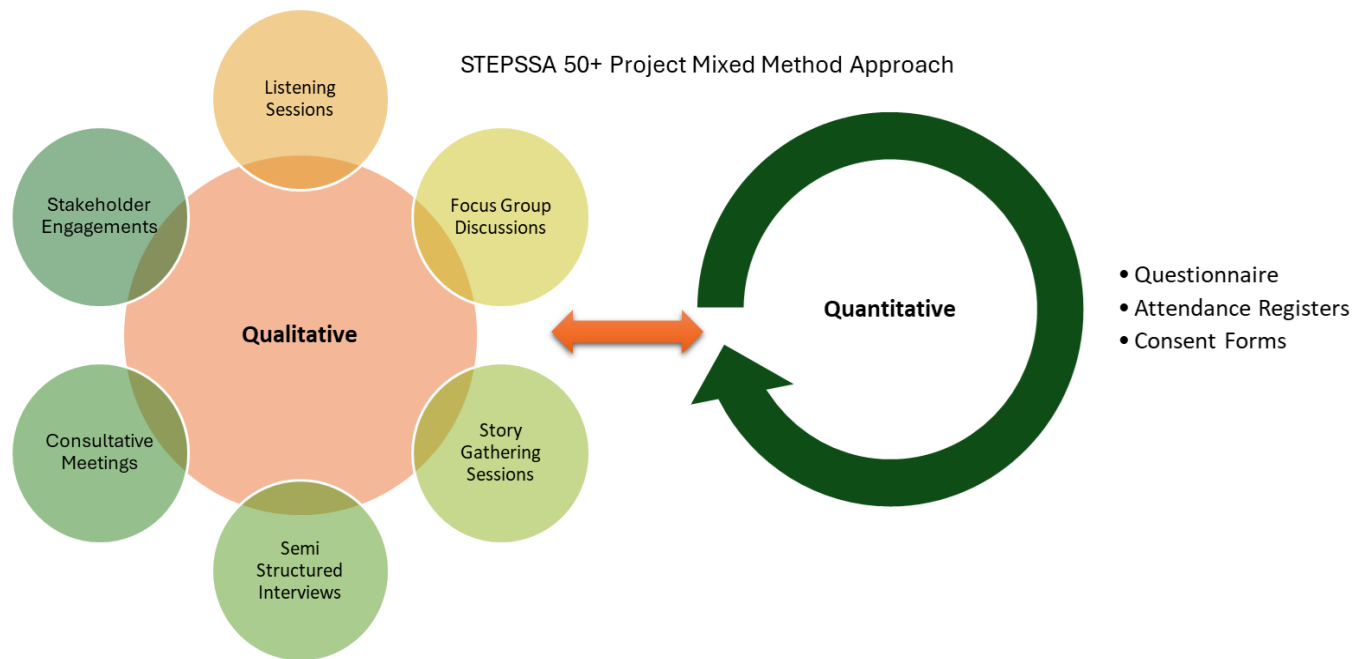


Figure 3: Mix Model Scoping Illustration

- The utilisation of the mixed method approach ¹⁸ depicted above aligned with current practices in peer-reviewed health sciences literature, reflecting the growing integration of qualitative and quantitative data. Deliberate collection and analyses of both qualitative and quantitative data facilitated a more comprehensive understanding of health issues and potential resolutions; moreover, integration of quantitative and qualitative approaches maximizes strengths and minimizes weaknesses of each type of data.

¹⁸ 2018 (2nd ed). Bethesda: National Institutes of Health.: [Best Practices for Mixed Methods Research in the Health Sciences](https://www.implementationscience-gacd.org/) ([implementationscience-gacd.org](https://www.implementationscience-gacd.org/))

6. Stakeholder Engagements, Listening Sessions and Focus Groups

6.1. Stakeholder Engagements

The stakeholder engagements for STEPSSA 50+ Project yielded substantive reach, enabling the project to cover all nine (9) provinces of South Africa. The coverage encompassed fifteen (15) districts and reached more than twenty-eight (28) local areas spanning over forty (40) communities.



Figure 4: Stakeholder Synoptic box

Table 1 below summarises the activity outputs based on the target group and the activities conducted and completed in the nine provinces.

Table 1: Target group and activity reach for the STEPSSA 50+				
Target Group	Expected	Actual achieved	% proportion	Activities
Primary Target Population (PLHIV)	700	991	142%	Engagement and Listening Sessions
Secondary Target Population (Aging adults over 50)	300	287	96%	Attendance in both sessions for all 50+ HIV-negative and positive including children born with HIV
Tertiary Target Population (PLHIV aged 50 plus)	300	368	123%	Focus Group attendance of participants aged 50+

SA Partners was able to gather information on HIV and Aging in the communities through 15 listening sessions, 15 Focus Group Discussions, and 36 individual stories collected on camera. A data transcriber transcribed voice and Video data into English, and the experience shared by the people is also reflected under the HIV and Comorbidity Survey Findings Consent for the stories, pictures, and participants were from a mix of urban and rural districts.

6.2. Focus Group Discussions

The FGD served as a platform to gather information through smaller group engagement and for the FG Facilitator to solicit OPLHIV experiences on prevention, treatment, and psychosocial needs. Four hundred and twenty-two (422) questionnaires were completed by OPLHIV aged 50 plus who were part of the FGD.

The survey questionnaire covered various data elements for collection and analysis. This included information on demographics, HIV status, year of ART initiation, history of comorbidities, access to grants, types of grants received, knowledge of nutrition, anxiety, depression, and aspects related to sex and sexuality. It's worth noting that the Focus Group Discussion questionnaire completion included participants who were aged 50+ and HIV-negative but experienced comorbidities, as well as adults. This ensured a complete representation of people aging with NCDs.



Picture 2: Listening Session Held in King Sabata Dalindyebo Municipality, in Qunu - Eastern Cape RSA

Participants utilised the opportunity to share and connect as PLHIV under the new subject of HIV, Aging, and Comorbidities.

Participants also reflected that the sessions were re-traumatising, and this was also evident that sessions were emotionally draining for the project team as they were reflective of individual journeys compounded by the underlying Post Traumatic Stress Disorder (PTSD). Global estimates of the prevalence of PTSD among adults living with HIV have been reported to be at 28 % which requires routine screening and management. So our participants felt that the two day sessions were a safe space for them. The feeling is encompassed in the what's app message sent to the Coordinator for KZN:

"Thank you for everything you did for us as the uMgungundlovu District PLHIV Sector. Discussions, information sharing, and you and your team make us remember where we came from as support groups, NAPWA, TAC, etc. We miss those old times, and we survived through all the circumstances that were meant to kill us. SIYABONGA. "A female PLHIV participant in Harry Gwala District, uMgungundlovu Municipality, KwaZulu Natal

Participants further shared that they faced several frustrations due to both structural and behavioral barriers in that:

- Structural barriers were often related to the systemic issues within healthcare systems, societal norms, and the ongoing discrimination within the legal framework that hindered their access to care and support.
- We also asked if participants understood what was meant by psychosocial support needs for OPLHIV and if they felt these needs were in their language and spaces.
- We also asked if they thought that the circles of support and care existed or were lacking in their environments. And our LGBTQIA+ participants responded as follows:

“If we are to enhance universal test and treat (UTT) archetypal, promote safer sexual practices, and reduce stigma, the needs and experiences of middle-aged and older adults need prioritization. We have forever been forgotten. Some of us are “unpensionable pensioners” because we are not youth, and neither are we at old age to receive social support grant of SASSA. We are above 35 and below 60 and caught in the bitter struggle of daily fighting for your rights, poverty, hunger and living in traumatised community that forever traumatizes you too” **Trans participant – Ekurhuleni - Kwa-Thema**

The consensus was that psychosocial support must be holistic and address the psychological and social needs of OPLHIV. This includes counseling services that provide a continuum of care to help individuals cope with the emotional impact of living with HIV, such as depression, anxiety, grief, and stigma.



Picture 3: Listening Session and Focus Group Participants. Ekurhuleni LGBTQIA+ Organization (EPOC), Gauteng Province RSA

6.3. Semi Structured Interviews

The SSI yielded a wealth of diverse perspectives and insights, especially when exploring a topic as multifaceted as Aging and OPLHIV. However, at some point it felt like the same challenges were reemphasized from the community and SSI's. We interviewed different professionals in the field inclusive of the following: Director Health Service, Western Cape, Senior Lecture, University of Western Cape, Chief Executive Officer Quadcare Clinics and Director, Clinical Services Clinical Services, SA HIV Clinicians Society.

6.4. Consultative Meetings

We consulted with the PLHIV Sector and presented interim findings of the STEPSSA 50+ Project and challenges faced by OPLHIV. Moving forward we agreed that collaboration, inclusivity, and advocacy will drive the process of our future engagement. These three pillars are critical in addressing the needs of Older People Living with HIV (OPLHIV) and promoting the well-being of People Living with HIV in SA. PLHIV Sector advocacy efforts can help raise awareness, reduce stigma, and mobilize support for the program.



Picture 4: Focus Group Discussion in Gert Sibande District, Ermelo - Mpumalanga Province RSA

6.5. Data collection and Analysis

Understanding the Intersection of HIV, Comorbidities, Mental Health, and Socio-Economic Factors:	STEPSSA 50+ Project data collection highlighted the complex relationship between HIV, mental health, and socio-economic dynamics in maturing adults of participating communities. The mix of story gathering, listening sessions and focus group discussion helped the project to understand experiences of OPLHIV, gain insights into their access to chronic medication, mental health struggles, and socio-economic contexts. This commentary synthesizes our findings to offer insights into the complex interplay of these factors and underscores the necessity for comprehensive support frameworks.
Prevalence of HIV and Chronic Medication Usage:	The questionnaire responses from 422 participants who took part in Focus Group Discussions, revealed a significant prevalence of HIV within the sample population, with 75% of respondents identifying as HIV positive. Remarkably, 73.1% of older people living with HIV (OPLHIV) reported being on chronic medication. However, a concerning subset of 105 OPLHIV indicated not taking prescribed chronic medication, highlighting potential gaps in treatment adherence. Furthermore, among participants on Antiretroviral therapy, a vast majority (307 out of 313) were also on chronic medication, emphasizing the need to recognize HIV as a chronic disease meriting consistent medical attention.
Gender and HIV Status:	STEPSSA 50+ Project showcased the diversity of gender identities among participants and their corresponding HIV status. While 249 female participants formed a substantial portion of the sample, a few did not specify their gender. Markedly, one non-binary individual and one Transgender individual reported living with HIV, illustrating the inclusivity of our approach. Also, the distribution of HIV prevalence across gender lines revealed varied experiences and challenges faced by male and female participants, highlighting the intersectionality of gender and health outcomes.
Clear Understanding of Chronic Illnesses:	The captured data on chronic illnesses and comorbidities in the questionnaire yielded clear and insightful responses. Among HIV-positive participants, the most self-reported comorbidity emerged as Hypertension, constituting 24% of the reported cases. Conspicuously, Hypertension often presented alongside other chronic conditions such as Diabetes, Arthritis, osteoporosis, and forgetfulness, among others. This constellation of health challenges underscores the multifaceted nature of comorbidities and the intricate interplay between various chronic conditions.
Complex Medication Regimens:	Another striking revelation from our questionnaire data analysis was the complexity of medication regimens being taken by participants. Many individuals reported taking more than two pills a day, with some navigating through the daunting task of consuming up to 16 pills daily to manage a myriad of illnesses, therefore clinically facing polypharmacy. This poignant insight stresses the significant burden on individuals living with HIV as they grapple with not only HIV by itself but also the intricate web of comorbidities demanding diligent medication adherence.
Comorbidities Conundrum:	The prevalence of comorbidities among HIV-positive individuals paints a vivid picture of the intricate health landscape faced by OPLHIV. Hypertension emerges as a prominent and often accompanied by a constellation of other chronic conditions. Likewise, the arduous task of managing medication regimens pointing to the everyday battles and resilience of individuals at the intersection of HIV, aging and multiple chronic illnesses.
Understanding of Social Grants:	Among surveyed individuals, 198 reported access to social grants, indicating a potential avenue for socio-economic support. However, a discrepancy emerged

	as only 177 participants could identify the types of grants they received, suggesting either inconsistencies in responses or a lack of understanding regarding available support mechanisms. This finding underlines the importance of enhancing awareness, education and accessibility to social assistance programs among vulnerable populations.
Anxiety and Chronic Fatigue:	Mental health emerged as a significant concern among participants, with 174 individuals reporting enduring Anxiety. Intriguingly, a significant subset (118) experienced both Anxiety and Chronic Fatigue, elucidating the intricate relationship between psychological distress and physical manifestations. The varying responses to questions regarding Anxiety and Chronic Fatigue accentuated the intricate experiences and coping mechanisms applied by older persons living with HIV and grappling with life challenges.
Depression and Chronic Fatigue:	Another huge reveal is the substantial burden of Depression among participants, with 49% reporting suffering from this condition. In addition, a sizable subset of individuals (118) experienced both Depression and Chronic Fatigue. These results highlight the composite relationship between mental health and physical manifestations, elevating the need for wide-ranging support frameworks.
Gender Lens and Socio-Economic Context:	When looking at the findings through a gender lens, we were reminded of the female participants' specific struggles as providers in their families and care-givers. We were also awakened to older women (50+) living with HIV nuanced issues, such as managing their health while having to be sexually active, lead normal lives in abnormal situations be dealing with socio-economic constraints. This shows that people who are already marginalized need tailored support in order to cope with their challenges.
Navigating Multisectoral Burdens in Transgender and LGBTQIA+ Communities Amidst HIV and Aging:	Transgender and LGBTQIA+ people face many challenges due to their identities and experiences, and those challenges become more complex when you add in HIV and aging and comorbidities. These communities struggle with social, economic, and health inequalities that require multidimensional approaches to prevention, treatment psychosocial support, care and services
Multisectoral Burdens:	Discrimination against LGBTQIA+ individuals, particularly transgender people, is a significant issue that affects their well-being and drives disparate outcomes across various areas of life. The LGBTQIA+, and notably Transgender individuals often face heightened structural and interpersonal discrimination because of their sexual orientation, gender identity, race, and socio-economic status creating a unique set of challenges, such as limited access to healthcare, leading to non-adherence and other social ill's. LGBTQIA+ individuals often face significant disparities in physical, mental, and behavioral health due to discrimination, stigma, stereotyping, and violence. These disparities manifest as higher rates of depression, anxiety, substance use, and suicide attempts within this community.
HIV and Aging:	HIV is prevalent in Transgender and LGBTQIA+ communities, which compounds existing vulnerabilities. As people in these communities age, they face new challenges related to managing their HIV, such as taking medication, dealing with other illnesses, and accessing healthcare. This intersection of HIV and aging requires tailored support and care strategies.

Analytical Perspective:

Our analytical approach provided a comprehensive understanding of the complex issues related to HIV, mental health, nutrition knowledge and socio-economic factors in a diverse population. The data we collected through the STEPSSA 50+ Project gives us valuable insights into the experiences of people living with HIV and managing chronic illnesses and comorbidities. Our findings reflect a need for a holistic support system that address all the needs of OPLHIV. We need to prioritize awareness, accessibility, and inclusivity to help people cope with the challenges of HIV and promote individual and community resilience.



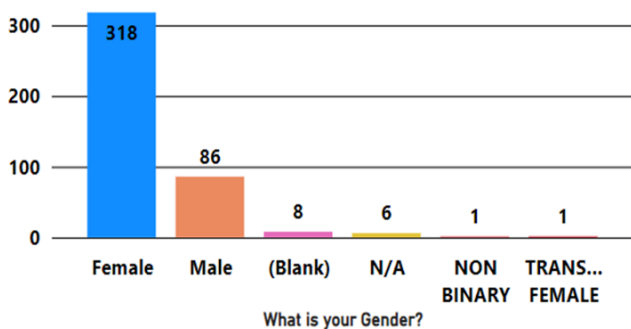
Picture 5: Focus Group Discussion in Diphitsing, Magogong Village, Taung North West Province RSA

7. HIV and Comorbidity Survey Findings

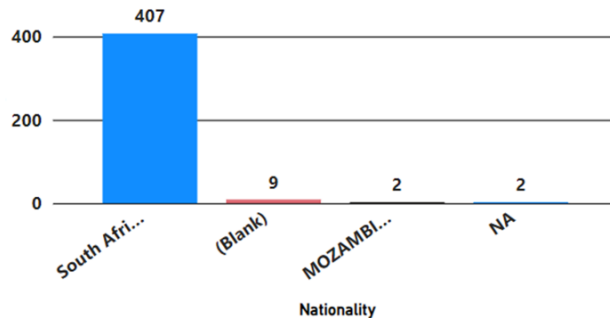
The HIV Comorbidity Survey was completed by 422 FGD Participants who were aged 50 and above. There was an oversupply of Participants in some of the FGD and at the same time it was culturally insensitive to send people away after travelling long distances. So, the implementation Team adapted to the situation, where it was not possible we had commissions discussing topics and voice recorded the sessions.

7.1. Socio-demographic Profile and Health Determinants:

Gender

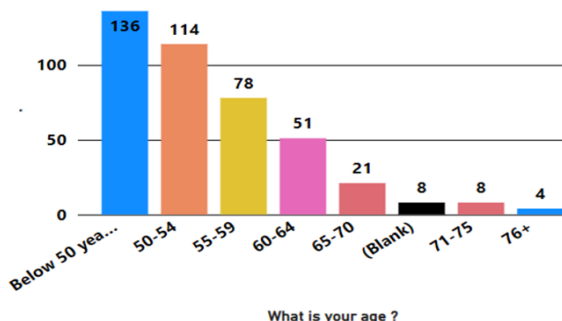


Nationality

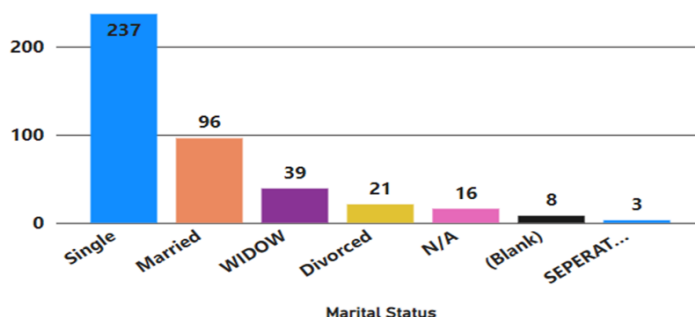


The majority (96%) of participants in our FGD were South Africans, with only 0.4% indicating that they were from Mozambique. Females comprised about 75% (n=318) of the population, while males were at 20.3% (n=86), which is typical for public health programs. Unemployment stood at 33% (n=140) which is closer to the 34% national rate¹⁹, with 24% (n=102) FGD participants indicating that they have already retired. The remaining participants were categorized into full-time employment 13% (n=55) and part-time employment 11.3% (n=48). It was observed that this trend is consistent with the demographics of the 50+ age group, where individuals are often in the process of transitioning towards retirement. In South Africa, the minimum age for retirement is 55 years, while the conventional retirement age is considered to be 65 years. Thus, the data suggests that a significant proportion of the participants were either retired or nearing retirement age, which is in line with the expected age distribution of the 50+ age group.

Age



Marital Status

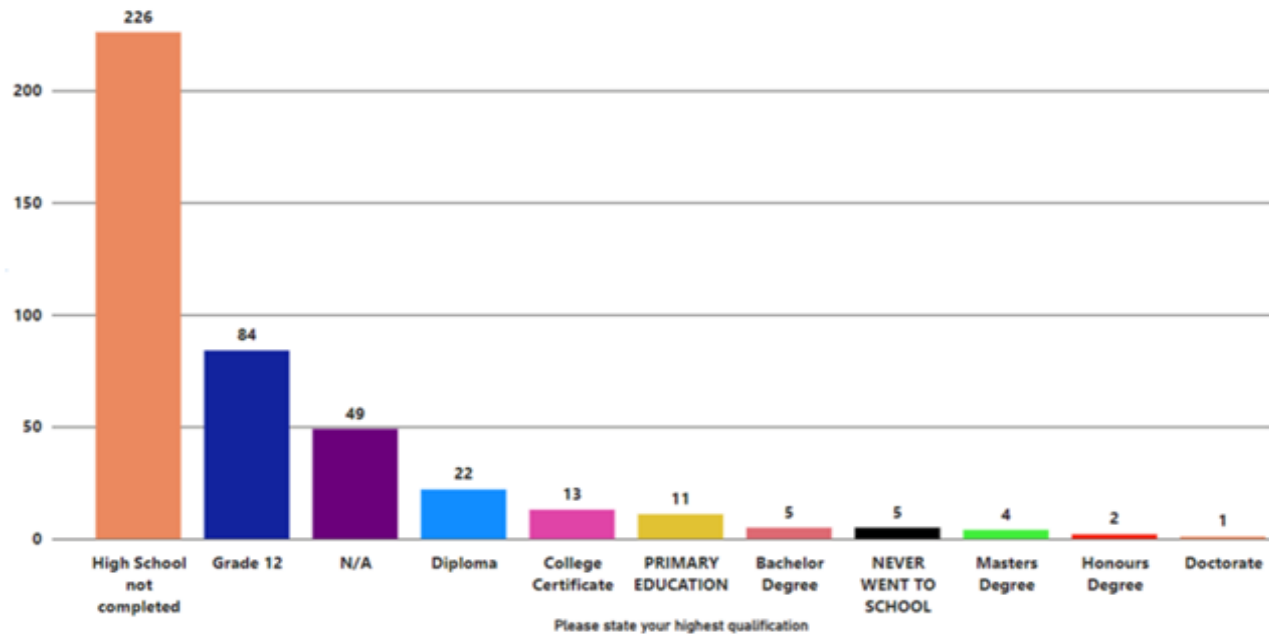


Age was an essential factor in our scoping exercise, with 27% (n = 114) of respondents falling in the 50 – 54 age group and about 18% (n = 78) in the 55 to 59 age group. In South Africa, there is a unique age gap for participants, referred to as un-pensionable pensioners, defined by our OPLHIV participants as the cohort above 35 years (the cut off age for all employment opportunities) and below 60, which is the age at which one can enrol for social support in the country. The oldest respondents were aged 76+ (n = 4). With regards to marital status, 56.1% (n = 237) of the STEPSSA 50+ Project FGD participants were single, which is higher than the national average of 28.4% for legally married males and 26.7% for legally married females, while the number of civil unions registered in South Africa increased by 52.3% (Statistics SA,2023)²⁰, about 23% (n= 96) FGD participants were married. Respondents who reported being widowed were 9.2% (n = 39), and 4.9% were divorced.

¹⁹ <https://www.statista.com/topics/9296/employment-in-south-africa/#topicOverview>

²⁰ Statistics South Africa 2023: General Marriage Rate (GMR). <https://www.statssa.gov.za/?p=16142>

Level of Education



The three major social determinants of health (SDH) in SA are knowledge and education; social protection, employment, housing and infrastructure²¹. The majority 54% (n=226) of our respondents indicated that they did not complete high school, 20% (n=84) completed grade 12, with 2,6% (n=11) and 1,1% (n=5) reporting primary school and no schooling respectively. Lower education and poor health outcomes affect quality of life of individuals²².

One participant reflected as follows:

“Three things I feel are important for us older people living with HIV: exercising is the number one priority because if we do not exercise our health deteriorates; we must get food parcels and lastly, we must get home visits by caregivers because we are staying with children and we do not disclose our status to them and due to aging we sometimes forget to take medication on time. Home-based care workers should do house visits and door-to-door campaigns”. **Participant _ FGD**



The levels of educational attainment are improving across all population groups in South Africa. In 2021: Q4, the largest share of the population aged 25-64 (39.2%) had some secondary as their highest level of education attainment, followed by 31.9% with secondary (Grade 12 or equivalent) as their highest level of education attainment. The distribution of highest education attainment by population group, however, reveals that Coloured and Black African population groups had lower levels of education attainment than their White and Indian/Asian counterparts. For example, less than 4% of the Black African and Coloured population groups had degrees, while close to 30% of the White population had a degree²³.

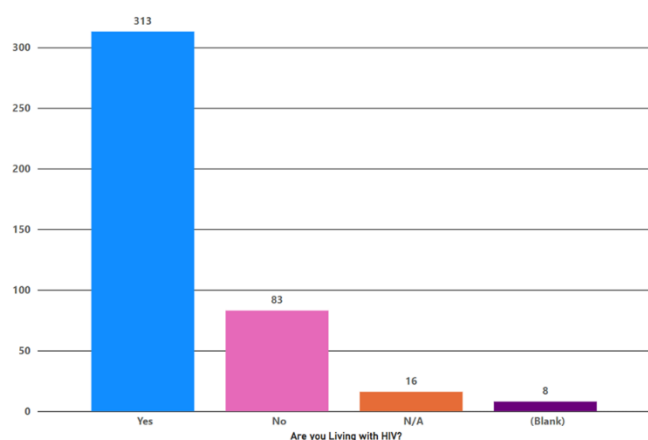
²¹ https://www.ncbi.nlm.nih.gov/books/NBK574228/pdf/Bookshelf_NBK574228.pdf

²² Adults with higher educational attainment have better health and lifespans compared to their less-educated peer

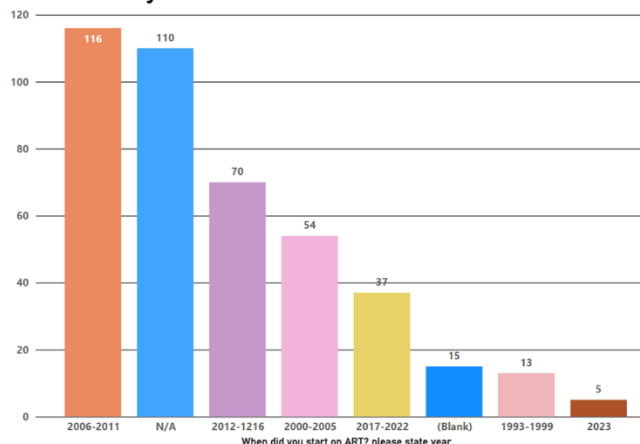
²³ [Khuluvhe, M. and Ganyaupfu, E.M. (2022). Highest Level of Educational Attainment in South Africa. Department of Higher Education and Training, Pretoria.]

7.2. HIV Status and ART Initiation

HIV Status



When did you start ART



A significant number of respondents, 74% (n=313), self-reported that they were HIV positive. When asked about their ART initiation dates, many of the participants, 37.1% (n=116), reported starting ART between 2006 and 2011. This indicates that the ART program has been effective in reaching those who need it. However, the scoping exercise also found that some participants started ART during a time when ARTs were not provided in public health facilities. This is evident from the fact that about 3% (n=13) initiated ART between 1993 and 1999. Over the years, there has been a significant improvement in the availability and accessibility of ART. From 2012 to 2016, 17.3% (n=54) of participants started ART, which shows that more people are accessing the treatment.

Additionally, 9% (n=37) of participants-initiated ART between 2017 and 2022, which suggests that the ART program has continued to be effective over time. Only a small number of participants, 1.1% (n=5), started ART in 2023. Overall, the scoping exercise provides valuable insights into the uptake of ART among HIV-positive individuals and highlights the need for continued efforts to improve ART accessibility and awareness. In addition, we were able to hear experiences of aging intersecting with HIV and the loneliness:

“We are living in silos in our dark corners and not open about our feelings of living with HIV at our ages. Some of us get sick and hide their sickness to their children and family members because of the age and being scared of being discriminated and isolated. Some they come to me for help at night because they don’t want to be seen by families or community members. Some they result in drinking day in and night because of stress and frustrations they are experiencing”. **Participant- Qunu Listening Session; KSD Municipality**

Treatment interruption themes also emerged due to unemployment, travelling distance from home to the clinic, lack of access to social support services or just general fatigue from lifelong treatment.

“From 2002, I stopped collecting my medication in 2018 after I couldn’t go to the hospital to collect my medication after a fallout I had with the doctor because I skipped my collection date. The reason I couldn’t collect my medication was that I didn’t have transport money to go to the hospital and the doctor refused to give me a transfer to the nearest clinic, he said that I was a good example to other patients at his clinic and whenever he had a conversation with them he would tell them how far I’ve come and how long I have been taking medication. I am a perfect example for him to encourage other patients so he didn’t want to lose me. That’s why I stopped taking medication. Now I want to go back to medication and be moved to my nearest clinic”. **Video: MVI_0564 1st participant.**

Sometimes treatment breaks were taken during weekends just to live a little.

“There was a time when I wanted to stop treatment . Yhaaz on Monday to Friday I take my treatment kahle nje but on weekends uyayeka and take a break. This is happened because uyahamba for the whole weekend uyophuza ungabuyi ekhaya uze ubuyele maybe on Sunday or Monday” **Participant- EPOC Ekurhuleni FGD**

Emergence of opportunistic infections and the socio economic conditions resulted in fatigue and a feeling of wanting to opt out as there was no solution:

“I am still on treatment. There was a time when I stopped taking my treatment. I got tired because each and every time I took treatment something new will develop. And remember I am not working. The person who had to pay for all these bills doctors and hospitals was me mother who is also not working just a pensioner. There is a time when I got very sick having so many sicknesses and mouth ulcers on the other side. I started thinking why am I continuing taking this treatment because I don’t see anything coming out right, instead am very sick. So I thought why I don’t die once”. **Participant- EPOC Ekurhuleni FGD**

The intersections of external and internal stigma, coupled with rejection and sexual orientation.

“He said to me “eish mntanam udume ngezinto ezimbi in our community”. He said that because; I tested HIV positive, I am gay (homosexual); I am a drug recovering addict; I am homeless. I don’t have time and bond with my family at all. I went to my mom last year to ask her if I can go back home for stability. I even ask her that I will help in the house with house chores because I have been living with friends for a very long time. You know friends when they are tired of you because you are not working and don’t have money. Social changes, challenges are from people in church. It was bad because they find out all about my background and my sexuality. I am a quiet person naturally but I had to create a new persona of “hi hi hi” so that I get with other people. I feel like nobody knows me really. Now nobody wants to hear anything from me because they said am washed out. There was even a time where they wrote about me on the walls in the location saying, “yho uyashona shame”. **Participant- EPOC Ekurhuleni FGD**

Stigma and rejection for some of our participants resulted in feelings of isolation and loneliness:

“There are times where you find yourself sitting alone and feeling very lonely. I thought it’s a phase of getting older. At times you wake up, you take a bath, clean and sit on the couch not doing something. It’s then that you realise that you are really alone and this is not the space or place where you want to be. I kept my friends from being young. As you know that friends are seasonal, they come and go. Friends are one thing you cannot keep for the rest of your life. I don’t do partying anymore.” _ **Participant- EPOC Ekurhuleni FGD**

7.3. Health system challenges.

Stigma and discriminatory practices at health facilities

“The problem I have realized is something that the nurses do and we do not like it. Whenever we are at the clinic we are referred to as “Shabalala’s people” (Shabalala is the person who gives us our medication at the clinic) so if he is not there we will be isolated and told to wait for him, mind you this is said amid other patients, the minute they hear our group being referred to as Shabalala’s people they know we are there for ARVs. Another thing, the nurses do not respect us, and we are human and we deserve respect”. **Video: MV- 4178, 69 year Old Participant**

Distance and waiting times and lack of adherence to DMOC strategies.

“Whenever I go to the clinic I leave the house around six and get there at seven in the morning, I always carry a lunch box because I am going to leave the clinic at half past four when they knock off. We are suffering because of that, and when the collection date approaches we get stressed even our blood pressure rises because we know we are going to spend the whole day without food and collect medication for high blood pressure as well. We would appreciate it if we could get our medication delivered here at the church so that we can collect it closer to our homes. Some older people travel from far away to collect their medication”. **Video: MV- 4178, 69 year Old Participant**

Lack of screening for NCD's (lack of comprehensive health care management)

“Sometimes I feel fatigued and my heart beats faster than normal. When I go collect my treatment, they changed my treatment but didn't explain the reason behind it. At times I would feel like something was burning inside my heart or have swollen legs. When I reported it they said they would call me around twelve on that day but they did not call. Nowadays I don't go to the clinic when I have a fever or a burning episode because I do not get help. I have resorted to home remedies when I feel my heart burning I simply cut a potato and eat it”. **Video: MVI- VID2 Participant**

Insensitivity to health needs of older persons with comorbidities.

“During collection they checked our weight and vitals, they would tell me my blood pressure was too high but they would ask me to step aside and drink water. People ask me if I take medication for high blood pressure and I always say no I would think the nurse will give me blood pressure medication when I collect my ARVs but they would give me ARVs only. They never check if I have high blood pressure. I do not think the health needs of the elderly living with HIV are met. I sometimes think on my own that on the 1st of December, maybe we could have a gathering where we could talk about things relating to us like this program. I did not know it existed. We need safe space where we can talk freely, I still believe that family members are the only people I can share my HIV status with because people from outside might take you somehow when you disclose or want to talk about HIV”. **Video: MVI- VID2 Participant**

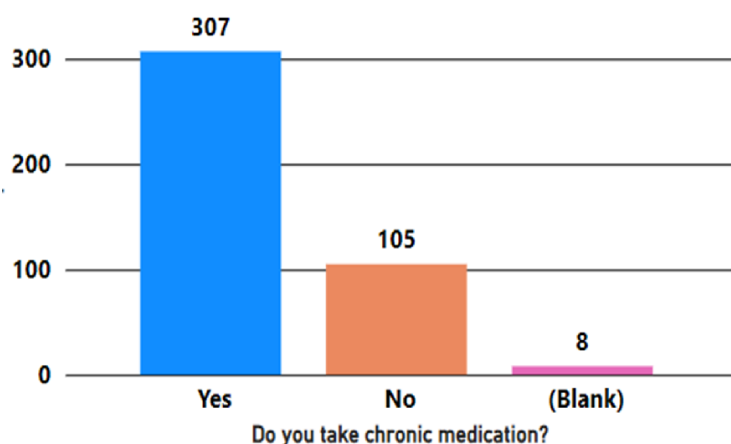


Picture 6: Listening Session Participants in Soweto, Dlamini - City of Johannesburg, Gauteng Province RSA



Picture 7: Focus Group Discussion session in Seoding, Kuruman - Northern Cape Province RSA

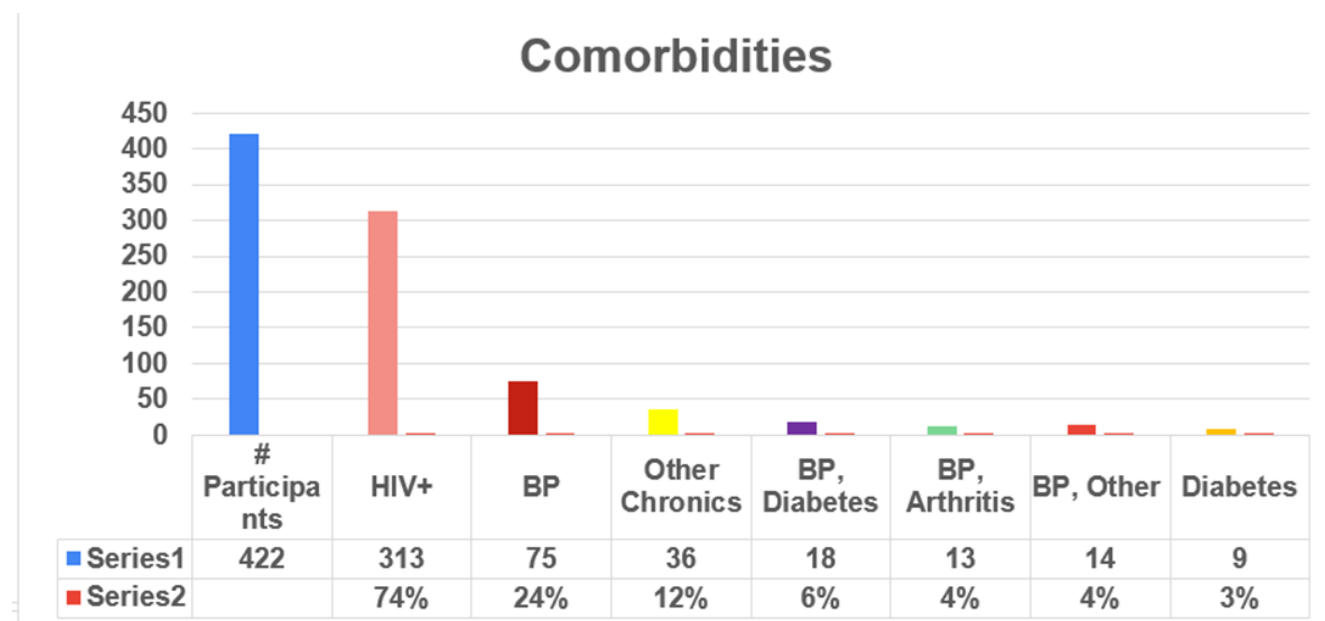
7.4. Chronic Medication, HIV and Comorbidities



About 73% (n= 307) of the HIV positive respondents self-reported that they were on chronic medications. The STEPSSA 50+ Project findings delved into the intersection of multi-morbidity's and polypharmacy within HIV and aging populations. Hypertension + Diabetes emerged as the highest chronic condition, affecting 24% (n=75) of respondents. Other chronic conditions collectively accounted for 12% (n=36) of cases, encompassing a range of non-communicable diseases such as cancer, stroke, gastrointestinal problems, insulin resistance, and Graves' disease.

"I am 53 years old coming from the ghetto. My health status I am on insulin injection and at the moment I started to develop prostate cancer. I just have been told now. I am 33 years on medication. It depends how you live your life. The problem at the moment is that whenever you take this, another thing comes up; continuing with medication is tiring because all the time you take medication, something else comes up. Sometimes they misdiagnosed you and also not taking the right medication. You end up going to stage 4 of the cancer" **Participant- EPOC Ekurhuleni FGD**

The high prevalence of hypertension suggests a complex interplay of factors contributing to its occurrence, including medication types, family medical history, duration of antiretroviral therapy (ART), and lifestyle factors. These findings underscore the syndemic nature of HIV, highlighting the co-occurrence of HIV infection and non-communicable diseases. They emphasize the urgent need for tailored interventions aimed at addressing the dual burden of HIV and non-communicable diseases within aging HIV communities.



Combinations of hypertension + Diabetes with other conditions were also observed, albeit less frequently. Hypertension combined with Diabetes affected 6% (n=18) of respondents, while hypertension paired with arthritis and other unspecified conditions accounted for 4% (n=13) and 4% (n=14) respectively. Diabetes alone represented 9% (n=9) of respondents.

It was also evident that inflammation, bone problems and natural aging process affected the quality of life of OPLHIV. The inflammatory response of an aging body plus geriatric syndromes results in constant pain and falls as reported by the participants.

This summary elucidates the intricate relationship between HIV infection, aging, and the prevalence of multi-morbidities, signalling the importance of comprehensive healthcare strategies that are patient centred and tailored to the unique needs of HIV-positive individuals as they age.

“Consideration must be given to the medications individuals are taking and their potential interactions with the liver and other organs. For instance, medications for hypertension and diabetes can have implications for liver and kidney function. Monitoring parameters such as liver function tests and urea and electrolyte levels is essential to assess these impacts. Additionally, adherence to medication regimens is crucial. Patients often prioritize what they perceive as important and may discontinue medications if they believe their conditions are under control. For example, if they haven’t experienced headaches for a while, they might stop taking their blood pressure medication, unaware of the potential risks” **Medical Doctor and CEO of QuadCare Clinics**

The combination of old age, HIV, and socio-economic status underpinned by varying comorbidities’ in the groups represents a future burden on the health system and a need for a systematic program encompassing continuum of care geared towards palliative care and end-of-life for 50+ where the need arises.

“I can only speak for our province - I want to mention that based on the social economic conditions of our patients who are cared for within our services, and the social determinants of health that influence wellbeing, many older persons require support in the form of care homes and frail care facilities”
Emergency and Clinical Services Director _ Department of Health



Older adults had four times greater odds (OR = 4.7 (3.1–7.0)) of having an HIV comorbidity compared to younger adults. Being female (OR = 1.6 (1.1–2.4)) and living in an urban area (OR = 2.6 (1.8–3.7)) increased the odds of HIV comorbidity. Older adults with HIV require comprehensive health care to deal with multi-morbidity, to maximize the benefits gained by advances in HIV therapies²⁴.



In South Africa, palliative care is being broadened from a concept of end of life care to encompass a palliative approach to all life limiting illnesses and to those who need support and care while suffering from a chronic illness. Different local needs and situations will require different models of care. Each province and district may adopt a model or combination of models that best suit their needs.²⁵

²⁴ [Roomaney, R.A.; van Wyk, B.; Pillay-van Wyk, V. Aging with HIV: Increased Risk of HIV Comorbidities in Older Adults. Int. J. Environ. Res. Public Health 2022 |

https://repository.uwc.ac.za/bitstream/handle/10566/7566/roomaney_aging%20with%20hiv_2022.pdf?sequence=1&isAllowed=y

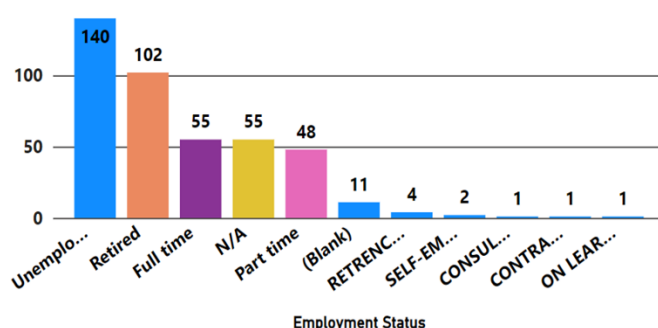
²⁵ National Department of Health - National Policy Framework and Strategy for Palliative Care 2017 to 2022

7.5. Recommendations for future programming for OPLHIV

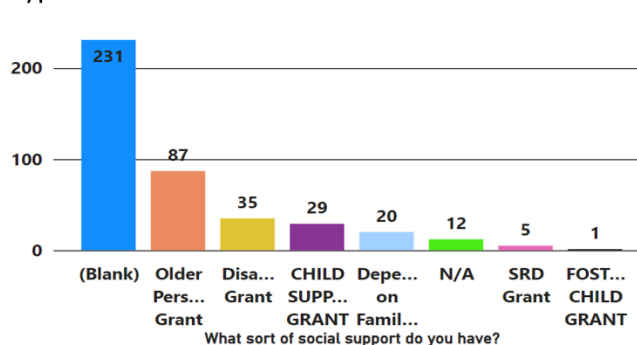
“Let there be research on this; I’d like to propose a program for this. Long-term patients more especially those over 50 years have been forgotten and to think this Virus was found through them now, how are they supposed to live and make a living because they can’t work? There should be some aid they get and job opportunities so that they can make a living. One of the reasons they stop taking medication is due to lack of money to buy food, so they decide to stop taking medication because they cannot take them on an empty stomach. Plus, stress and depression and children need to be cared for. Last word, support systems government should subsidize and support them because they are helpful, even those who are in hiding can come out and join the support groups”. **FGD Participant Gert Sibande District_ Mpumalanga**

7.6. Access to Social Support, Dependents, and Nutrition

Employment Status



Types of Grants



Around 42% (n=177) of participants received social support grants. A significant number of participants were supporting 1-5 dependents equalling 57% (n=242) and 6-10 dependents equalling 27% (n=115) respectively. The type of grants received were: Older person grants: 21% (n = 87) Disability grants: 8.2% (n = 35), Child Support 6.8% (n = 29) R350 & Social Relief of Distress grant at 7% (n = 20) respectively.

Lack of access to good nutrition was reported by 38% (n= 162) of participants, and they shared that lack of access to food had sometimes resulted in interruption of ART due to financial strain and lack of support. It is important to also to note that nutrition is not just food it forms part of the continuum of care in particular when one is on treatment.

With SA battling the issue of NCDS there is a need to address access to correct, affordable and accessible nutrition. The focus on prevention of NCDS and HIV metabolic complications like lipodystrophy and increased triglycerides should focus on increasing awareness and application of nutrition education:

“Firstly, let us understand that good nutrition for all South Africans should be pro- moted as a basic human right and as an integral com- ponent and outcome measure of social and economic development.” **Senior Lecturer _ SSI Interviewee.**

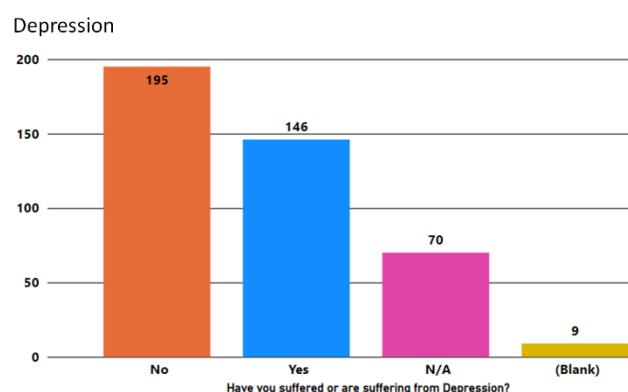
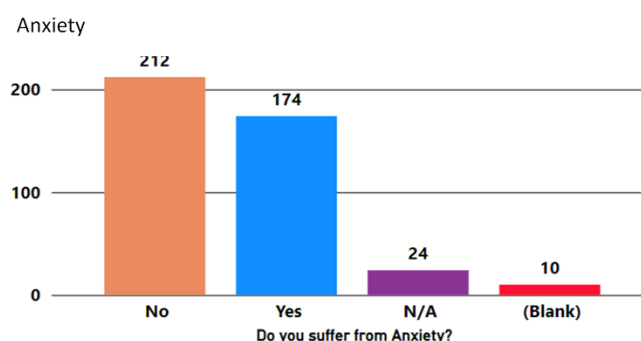
The above-mentioned approach should include knowledge of food groups, preparation and portion skills transfer for both HIV negative and positive individuals. This will assist to alleviate gastric and other metabolic complications.

Availability of food was also a concern for some participants as some were dependent on family members or reported having no financial means to buy food which leads to treatment interruption and disengagement from health service. Even efforts to seek support from local structures sometimes yielded no results:

"Hunger is painful when you are on medication and because we are trying to take care of our health we try to get something to eat so that we can take our treatment. The new contractors don't care about us, we have written to them asking for assistance, even those who are building RDPs in the township we approached them and asked that whatever they may have left after their project must be given to us and they said we would get feedback from the Councilor to date we haven't heard from them". FGD Participant Gert Sibande District_ Mpumalanga

"The challenges in life generally is that when I take medication, I have to eat something before I take my medication. Now things are difficult for me because I don't work. Sometimes I take that medication without food. I don't have friend any more. Participant- EPOC Ekurhuleni FGD

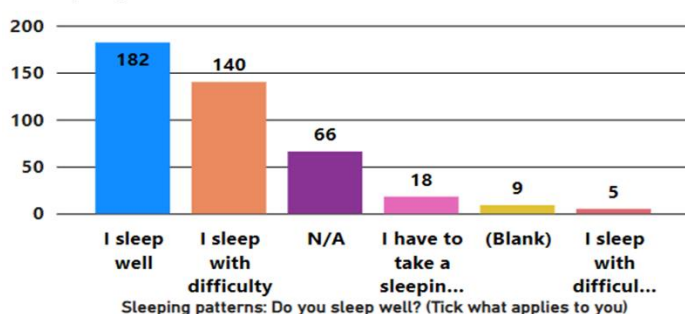
7.7. Anxiety and Depression



Out of the total number of respondents, 50% (n=212) stated that they did not have anxiety, while 41% (n=174) self-reported anxiety. About 46% (n=195) responded 'No' to having depression whilst 35% (n=146) responded 'Yes' to depression, which negatively affects their sleeping patterns and quality of life. The mental health burden compounds with the socioeconomic status, adding to the burden of disease. Anxiety and depression remain major concerns for people living with HIV, despite advances in treatment and awareness.

7.8. Sleeping Patterns

Sleeping Patterns



Only 43% (n=182) of respondents reported that they were sleeping well, while 33% (n=140) reported sleeping with difficulty, often relying on sleeping tablets, which accounted for only 4.2% (n=18) of the total respondents.

"I have a problem of sleeping these days. Two days now passing without me having some good sleep. I refused to take medication to sleep. So now with that be it causes anxiety on me and I get out of bed because I start to think what am I going to do tomorrow. What am I going to eat tomorrow? Where am I going to get my next plate for the next coming day. It's very difficult for me. What I know now is that we should be prepared for the future but because I was very young at the time when I started to be sick. I did not have any savings and at the moment I don't have anything". Participant- EPOC Ekurhuleni FGD

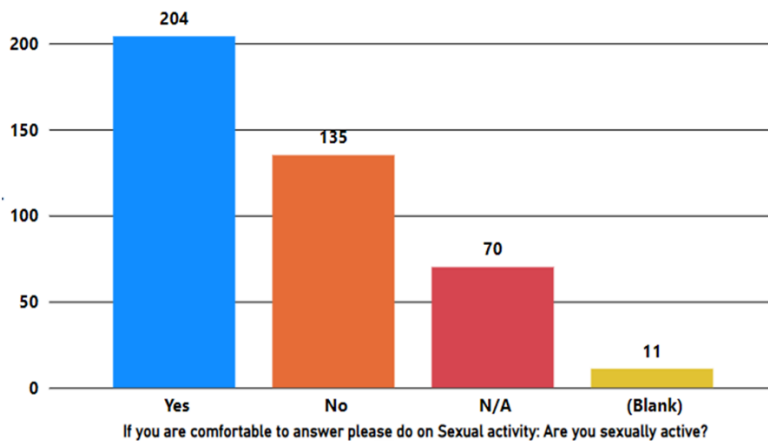


"Older PLWH face several social and psychological issues related to aging"²⁶. These issues are further complicated by physical health challenges that come with age, past experiences, biases in health services, societal stigma, isolation, financial struggles, and the absence of psychosocial support and social networks²⁷. All these factors can aggravate anxiety and depression for individuals living with HIV. A recent study found that a 42% rate of depression is significantly associated with higher levels of HIV-related stigma, poor cognitive functioning, and reduced energy levels²⁸. The study concluded that "Loneliness and HIV-related stigma explain depression among older HIV-positive adults"²⁹.

These above-mentioned findings are supported by literature review and correlate with the results of the longitudinal cohort study titled "The prevalence and correlates of depression before and after the COVID-19 pandemic" declaration among urban refugee adolescents and youth in informal settlements in Kampala, Uganda.

7.9. Sexuality and Sexual Activity

Sex and Sexuality



STEPSSA 50+ Project participants were asked if they were comfortable sharing information about their sex life and sexuality, some may have felt hesitant or uncomfortable. Nevertheless, 48% (n=204) bravely answered that they were still sexually active, while 32% (n=135) of respondents chose not to share. It is important to prioritize prevention for HIV-positive adults and risk reduction for certain cancers for this group and spread the message of Undetectable = Untransmissible with empathy and support.

We also must bear in mind the experiences of those who had lived longer and have experienced body changes and the impact that body changes have on intimacy.

Research indicates that individuals aged 50 and above living with HIV remain sexually active, representing diverse sexual orientations. Contrary to stereotypes, many of them are breadwinners and have dependents, challenging misconceptions about their roles and contributions within families and society.

"It is easy to talk generally about the virus but not easy to say "I am the victim" On the same breath you feel confident to counsel someone else because you were once or rather still in that journey. The other challenge is to be in an intimacy relationship, because of someone will walk away and you don't want to keep telling everyone/guy about your status and you opt for loneliness or not to be in a relationship. This is not by choice but because you don't want to start new relationship time and again and you end up suppress your feelings". _ Individual OPHIV, a professional in the education sector.

²⁶ March 2019: [Depression and aging with HIV: Associations with health-related quality of life and positive psychological factors - PMC \(nih.gov\)](#)

²⁷ Sept 2022: [The effects of social isolation stress and discrimination on mental health - PMC \(nih.gov\)](#)

²⁸ March 2023: [Depressive disorder \(depression\) \(who.int\)](#)

²⁹ [Loneliness and HIV-related stigma explain depression among older HIV-positive adults - PubMed \(nih.gov\)](#)

“The changes I see growing up with this disease is that things are not good between me and my husband because diabetes is affecting my sexual feelings, I end up having zero sexual desires to the point that when I see my husband naked I do not get sexual urge or interest. I can look at him naked and feel nothing, my body would not respond to what I’m seeing and it is caused by diabetes. Another issue is on my bones; I feel pain in my left leg from the hip to the bottom and it gets stiff. My veins pain a lot to the point I struggle to sleep at night” – Participant at the Ndzhelele Focus Group Discussion, Vhembe District

“There must be sessions for older men where they can be taught how to use condoms because they are going after young girls, that is why HIV is spreading all over and there is still that belief that HIV is cured by fresh blood/virgins. These young girls must be taught to use condoms as well. They must not be surprised when they see us demonstrating condoms at us events. They must be taught because they are very important. I am an ambassador and I have a big event coming this Friday so I always see them surprised when they see condoms. They must be taught that unprotected sex is not good or safe even older people must be taught “. Video: MVI-2577: Video 3.



A study 80 seniors (50 years and above) in 2016 who were HIV-positives found that, heterosexual men tend to continue living within their family circle (wife, children, and sometimes grandchildren), but in conflict and without sexual activity. Heterosexual women mostly live on their own, as they did at the time of infection, but they remain on good terms with their children³⁰.

Finally, bisexual men often live on their own, without any sexual activity and in conflict with their children and ex-partners. They turn out to be the most isolated and psychologically fragile sub-group of the study³¹.

8. Additional insights from the Listening Sessions

8.1. Challenges of Taking Lifelong ART

Table 2: Challenges of taking ART	
Qunu Listening Session	Gqeberha Listening Session
<ul style="list-style-type: none"> • Losing our body shape • Being an elephant and not even curious to know your wait because you are scared of • being overweight • Fat distribution in our bodies (fat sitting in wrong places) • The way we are serviced in clinics, separate queues for people living with HIV • Our partners or izesheli zethu get to know about our status before we tell them because of community members who are always on your case of being HIV positive. They disclose your status to the person before you can tell. • Nothing is better than by PLHIV in our communities. Once you disclose your status they will always be curious about your life (What you do and how you doing it because you HIV positive). Always waiting for your day to die <p>Being discriminated and stigmatised in our own communities, not being able to go and support or work in funerals or imigidi because people take you as a sick person.</p>	<ul style="list-style-type: none"> • Treatment fatigue • Discrimination because of age • Exclusion (being lonely or alone) phase. • Unemployment and not having food • Transportation problems because it needs money • Having skills but no place to show off them • Mental health issues • Depression and stress from our children and grand children • No families to support us

³⁰ [Navigating Life with HIV as an Older Adult in South African Communities: A Phenomenological Study - PMC \(nih.gov\)](#)

³¹ M Banens. Sexual relations between seniors living with HIV. Sexologies, 2016

From my inbox (inspired by a previous post, posted with Anon's permission)

About your recent post Tata. Been living with the virus for 11 years now and defaulted for 5 years. Haven't changed provinces. Ndifuna ubuyela coz ngoku ndiphuma izinto ezifunny emzimbeni. I need advice bhuti on everything. Please help me kudala ndicinga uvuka ndiyeclinic ndiyoyika and nurses pha ziyageza.

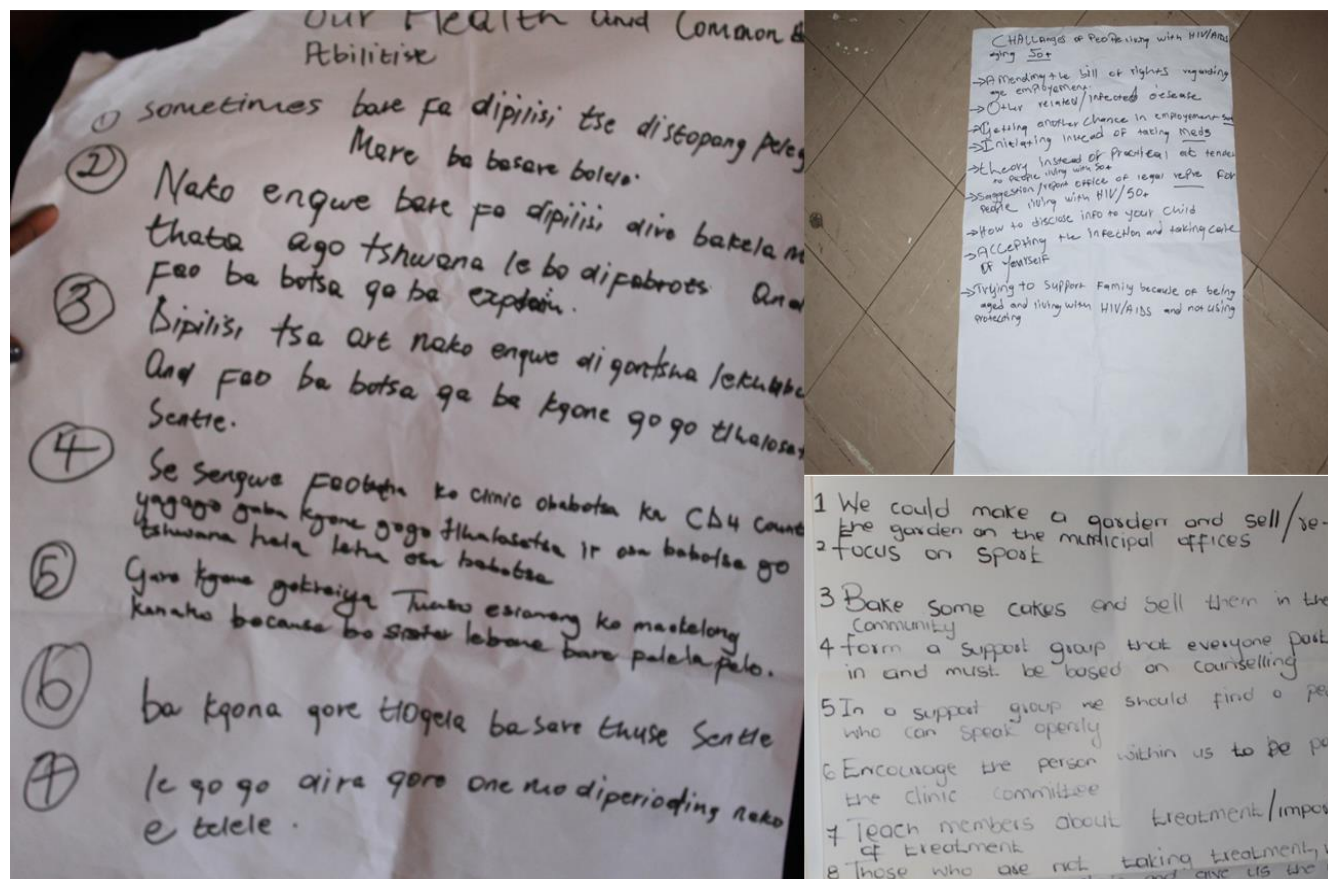
(I believe one of the major reasons being put forward as a hindrance is staff attitude. Anon has been referred to people who will assist her and ensure she gets her treatment as soon as possible)

9. What do Participant envisage as part of programming for OPLHIV?

During discussions, the STEPSSA 50+ Project participants articulated their aspirations. The participants discussed their pressing needs, highlighting the importance of comprehensive support to address specific aspects of their health and well-being. The needs expressed by the participants can be categorized into several key areas:

9.1. Comprehensive Health Support:	<p>The participants emphasized the necessity for holistic health services covering physical, mental, and social conditions.</p> <p>They longed for interventions that prioritize health promotion, education on positive living, treatment adherence, and disease management.</p>
9.2. Tailored Healthcare program and service:	<p>There was a shared desire for enhanced access to tailored healthcare services and ongoing counselling to address their specific needs.</p> <p>Participants stressed the importance of establishing support networks to facilitate mutual assistance and encouragement.</p>
9.3. Community Engagement and Stigma Reduction:	<p>The participants expressed eagerness for community engagement programs to reduce stigma, address negative attitudes within health services, and promote inclusivity.</p> <p>They envisioned interventions that fostered a supportive and accepting environment.</p>
9.4. Management of Comorbidities and Health Challenges:	<p>Managing comorbidities and other health challenges was a prominent concern.</p> <p>Participants highlighted the importance of nuanced services, access to good nutrition, nutrition education, proper care, and support to manage their health conditions effectively.</p>
9.5. Empowerment through Skill-Building and Advocacy:	<p>Empowerment through skill-building, employment opportunities, and advocacy were recognized as crucial for enhancing socio-economic status.</p> <p>Participants viewed the STEPSSA 50+ Project as a platform for facilitating personal growth and societal change.</p>

In a nutshell, the STEPSSA 50+ Project is seen as a vehicle for transforming the lives of OPLHIV by providing comprehensive support, fostering empowerment, and promoting superior health management. Participants aspire to create a society where OPLHIV thrive as active, healthy, and valued members of their communities. These aspirations underscore the importance of collaborative efforts and innovative programming in effectively meeting their aspirations and needs. Some of the needs are expressed below in the flipcharts from listening sessions group work sittings.



Picture 8: Various Flip Charts from Listening Sessions and Focus Group Discussion by participants, capturing their discussions and conclusions.

10. Programme activities completed to date.

10.1. Demonstration Project: IACT /Sensitization and Skills Training

The ISO IACT/Sensitization for OPLHIV SG Facilitators Content Training was implemented as the first demonstration project for the 12th to the 15th of March 2024 at a Methodist church in Soweto.

Skills Training was conducted on the 16th April 2024 and it focused on Group Development, Group Dynamics and Challenging Behaviours. Presentation, Counselling and facilitation skills were also part of the content for skills training. Seventeen OPLHIV support group facilitators attended. The STEPSSA 50+ Project's demonstration pilot training aimed to train older persons living with HIV (OPLHIV) who participated in the assessment or scoping sessions. The goal was to enable them to assume roles as support group facilitators, prevention advocates, and treatment ambassadors. This training was considered crucial to comprehensive HIV care and advocacy activities.



Picture 9: Demonstration IACT Sensitization and Skills Training Session for OPLHIV Facilitators held in Soweto, Gauteng RSA



Picture 10: Demonstration IACT Sensitization and Skills Training Session for OPLHIV Facilitators held in Soweto, Gauteng RSA

- **Participants' expectations included:** To gain more information on how to live longer and happily with HIV, being patient & following the right way of taking treatment and learning more new information on HIV and treatment because it constantly changes.
- Trained OPLHIV support group facilitators from Isizinda and EPOC have committed to going back to their communities to create safe spaces to support other OPLHIV. They all felt that much support is needed to enhance their skill and they coined the slogan "OPLHIV are still trainable".



Picture 11: Recently Trained OPLHIV Facilitators in an on-the-job training during Health Jamboree in Dlamini, Soweto, CoJ - Gauteng Province RSA

- **Pre and Post-Test) Scores (Table 2 below):** This demonstrated that OPLHIV are trainable, as evidenced by participant 16, who improved their score from 36% in the pre-test on understanding basics in HIV, treatment, and sensitization, to 76% in the post – test evaluation."

10.2. Pre and Post Training Test Scores

Table 2: Demonstration of knowledge improvement analysis of recently trained OPLHIV Facilitators

Student #	Gender	Pre-Test		Post-Test		Prevs PostTest	
		Total	%	Total	%	Gain/Loss	%
1	M	11	44%	14	56%	3	50
2	M	15	60%	19	76%	4	68
3	M	15	60%	20	80%	5	70
4	TRANS	13	52%	17	68%	4	60
5	M	8	32%	0	0%	-8	16
6	F	6	24%	6	24%	0	24
7	F	11	44%	15	60%	4	52
8	M	10	40%	18	72%	8	56
9	M	11	44%	19	76%	8	60
10	M	15	60%	18	72%	3	66
11	F	9	36%	17	68%	8	52
12	F	13	52%	17	68%	4	60
13	F	14	56%	19	76%	5	66
14	F	16	64%	19	76%	3	70
15	F	16	64%	17	68%	1	66
16	F	9	36%	19	76%	10	56
17	F	4	16%	11	44%	7	30
18	F	0	0%	15	60%	15	30



Picture 12: Recently Trained OPLHIV Facilitators with their Trainer from SA Partners

10.3. Demonstration Project: Outreach/Jamboree

This activity was implemented to provide a platform for trained Support Group Facilitators to share information with community aged 50+ increasing awareness and providing screening for Non-Communicable Diseases. Anova Men's Health, Quadcare Clinic and Isizinda Sempilo were on side for clinical and psychosocial support service to 83 attendees on the 17th of April. The project aimed to empower OPLHIV to actively engage in outreach and health services, strengthen community systems, and encourage dialogue and education around development and health issues.



Picture 13: Community Health Services Jamboree attendees and Nursing Sister who provided some of the Health Services, and Partner tents who were providing Screening and Testing Services for Free.

The objectives of the project were as follows:

- To test the ability of OPLHIV to provide health talks and essential services to older persons with HIV - To facilitate community engagement and strengthen community systems.
- To increase awareness of health issues among community members.

To achieve these objectives, the following activities were carried out:

- The Community Dialogue provided OPLHIV and general participants a platform to engage on specific health issues, discuss access to health services, and HIV/TB/STI in the context of the aging population.
- Outreach Services capacitated the trained OPLHIV Support Group Facilitators to actively engage in providing outreach services, including health screenings and support services, to older persons with HIV within the community.

The demonstration project activity yielded the following results:

- **Empowered OPLHIV:** The project successfully capacitated OPLHIV Support Group Facilitators, enabling them to provide essential services to older persons with HIV confidently.
- **Strengthened Community Systems:** Through community engagement activities, the project contributed to the importance of strengthening community systems to foster ongoing dialogue, participation, and collaboration among community members.
- **Increased Awareness:** Attendee community members were made aware of Tuberculosis (TB) and Chronic Illnesses and how to take care of oneself through access to health services, leading to enhanced knowledge and understanding of key topics.
- **Health Services** were provided onsite, community engagement session was also conducted, and Primary Health Care Nurses were in attendance.

10.4. Health Services Accessed and Numbers Reached

Table 3: Services provided at the Health Jamboree, including numbers of people who were in attendance

Number of - HIV assessment	45	
Number of - STI assessment	45	
Number of - TB assessment	45	
Referred for HIV testing	19	
Done glucose testing	45	
Number of ppl on HIV Medication	7	
Number of ppl on BP Medication	27	
Number of ppl on Diabetes Medication	6	
TOTAL NUMBER OF PEOPLE ACCESSED THE HEALTH SERVICES IS 45		
TOTAL NUMBER OF PEOPLE EDUCATED ON HEALTH TOPICS IS 83		

Community engagement and community system strengthening through the dialogues encouraged community participation and increase awareness around development and health issues.



Picture 14: Dialogue, Outreach and Health Services Jamboree Demonstration Pilot Project attendees

11. Dissemination Workshop

Our **Dissemination** Workshop was held on the 24th and 25th of April 2024 and included stakeholders like the National Social Development, EPOC, ISO, and Wits RHI, including two OPLHIV representatives, one coordinator from all covered areas of South Africa. We had a comprehensive representation of stakeholders, including government agencies, academic institutions, and representatives from affected communities. A Social Contract was developed and adopted by all attendees of OPLHIV at the Dissemination Workshop, with the key recommendations being:

- Adoption of the NSP 2023-2028 for HIV, TB, and STIs and the NSP on GBVF 2020 to 20230 as the guiding policy framework and roadmap for guiding the response of 50+ Project
- Designing and implementing a comprehensive response package that integrates prevention, treatment, care, and support to ensure that no one is left behind, inclusive of the LGBTQI+ and other key and vulnerable Populations



Picture 15: Various attendees/participants at the Dissemination Workshop. These included partners and STEPSSA 50+ Project participants representatives from all 9 Provinces of RSA

11.1. The Social Contract

As part of their commitment statement, a Social Contract, participants from all nine provinces of South Africa and various areas covered by the STEPSSA 50+ Project have collectively agreed to the following:

- That the intervention will be named **50+ Project** going forward.
- Create community support networks program aimed at assisting in fostering a supportive ecosystem that empowers OPLHIV in general and specifically improves health outcomes.
- Implement targeted awareness campaigns to promote the cause of OPLHIV and elevate mental health, NCDs, and socio-economic challenges within a framework for exploring the nuanced challenges and potential solutions at the intersection of aging and HIV, TB, STI, and NCDs in South Africa.
- Work towards developing a locally owned and community-led comprehensive nutrition program tailored specifically to the needs of 50+ to address the nutritional deficiencies that are common in the aging population in its diversity and to people living with HIV.
- Continuously Advocate for preventive care measures, management of comorbidities, treatment adherence, and other HIV nuanced conditions
- Adopt the NSP 2023-2028 for HIV, TB, and STIs and the NSP on GBVF 2020 to 20230 as the guiding policy framework and roadmap for guiding the response of 50+ Project.
- Design and implement a comprehensive response package that integrates prevention, treatment, care, and support to ensure that no one is left behind, inclusive of the LGBTQI+ and other key and vulnerable Populations
- Ensure all program support structures are inclusive, gender-sensitive, culturally competent, human rights centered, and accessible.

UNANIMOUSLY: All agreed to toil for an empowered OPLHIV movement that will achieve improved health outcomes, mobilize service demand, reach people with services, support health system strengthening, mobilize political and traditional leadership, change social attitudes and norms, and create an enabling environment that promotes equal access.

12. Limitations

The STEPSSA 50+ Project faced limitations during its implementation phase, such as time constraints that left little room for extensive consultations with local key stakeholders, including health facilities and development partners. This limitation impeded the depth of engagement at semi-structured interviews level for comprehensive health systems status quo understanding. Despite these limitations, the project team adopted a stringent approach to participant outreach, adhering closely to predetermined targets set in collaboration with Gilead. The project exceeded expectations by reaching over 200% of the targeted Older People Living with HIV (OPLHIV) despite its limited resources.

The availability of assistance services proved to be a recurring obstacle, particularly due to the nature of sessions, which often triggered traumatic experiences and reopened old wounds among participants. Although the project provided an essential platform for healing and support, concerns persisted about the sustainability of these efforts. The project team remained aware of the delicate balance between offering essential services and ensuring long-term viability. Ensuring the sustainability of the STEPSSA 50+ Project beyond the scoping phase was the most pressing limitation faced by the project.

This endeavour demanded continued support and unwavering commitment from stakeholders at various levels. Securing ongoing resources and maintaining momentum posed a formidable task, requiring sustained advocacy efforts and strategic planning. Emphasizing the project's role as a scoping initiative to inform future frameworks, advocacy briefs, and proposals became imperative in securing buy-in from stakeholders invested in long-term health outcomes.

Finally, the sustainability of the project beyond the scoping phase requires continued support from stakeholders at various levels. The project's role as a scoping initiative to inform future frameworks, advocacy briefs, and proposals is vital in securing buy-in from stakeholders invested in long-term health outcomes.

13. Conclusions and Recommendations

- **ALIGNMENT:** The RSA NSP 2023 -2028 Goal 3 aims to enhance healthcare and community systems to address the needs of people living with HIV (PLHIV). For the 50+ Project, this can be achieved by working within existing healthcare facilities to provide comprehensive care, introducing geriatric HIV care and mental health support, and managing age-related comorbidities.
- **ADVOCACY** for policy change and resource mobilization is crucial to addressing the needs of OPLHIVs aged 50+ within NSP, partner programs, and healthcare systems.
- **SENSITIZATION**/training programs should be conducted to ensure that healthcare providers are equipped to meet the tailored needs of older PLHIV. These programs should focus on prevention, treatment, and psychosocial support and include effective communication strategies to address stigma and discrimination.
- **CAPACITY-BUILDING** initiatives aimed at empowering communities of OPLHIV to participate actively in local institutions, healthcare services, and decision-making processes can help achieve this goal. This can be achieved through ongoing training and workshops on treatment adherence, self-management strategies for age-related conditions, and advocacy skills training to engage in policy discussions affecting rights and access to care.
- **CREATING COMMUNITY SUPPORT NETWORKS** tailored to OPLHIV aged 50+ needs can provide social and emotional support, information sharing, and opportunities for socialization, which can reduce feelings of isolation and promote overall well-being. Peer support and community engagement can also be critical in improving the quality of life for older PLHIV.



Picture 16: Trained OPLHIV Facilitators

Despite hurdles, the project achieved commendable success in surpassing targeted objectives and reaching vulnerable populations. Moving forward, addressing limitations will be crucial in strengthening the project's impact and ensuring its continued relevance in promoting health and well-being among older individuals living with HIV.

C. ACKNOWLEDGEMENTS

The realization of the STEPSSA 50+ Project stands as a testament to the unwavering dedication, invaluable contributions, and profound generosity of numerous individuals and groups who have lent their support and expertise to this endeavour. We extend our sincerest thanks to all those who have played a key role in making this project a reality. Appreciation goes to the older people living with HIV (OPLHIV), along with their networks, communities, and partners. Your courage in sharing your experiences and insights has enriched our understanding of the status quo and propelled our collective efforts toward positive change.

We extend our heartfelt gratitude to our Consultants, whose wisdom has guided us through the complexities of this project, ensuring its relevance and effectiveness. Thank you for shaping our strategies and approaches and enhancing our activities' impact. To the dedicated members of the SA Partners Admin Team, Provincial Coordinators, and District Leads, we owe a debt of gratitude for your tireless efforts in orchestrating the project's logistical and operational aspects. To the Monitoring and Evaluation (M&E) Team members, Literature Review Consultants, and Participants, we appreciate your invaluable contributions to this project's qualitative evidence gathering. The data collection, analysis, and feedback have been essential in estimating prevention, treatment, and psychosocial needs services for OPLHIV and informing future directions.

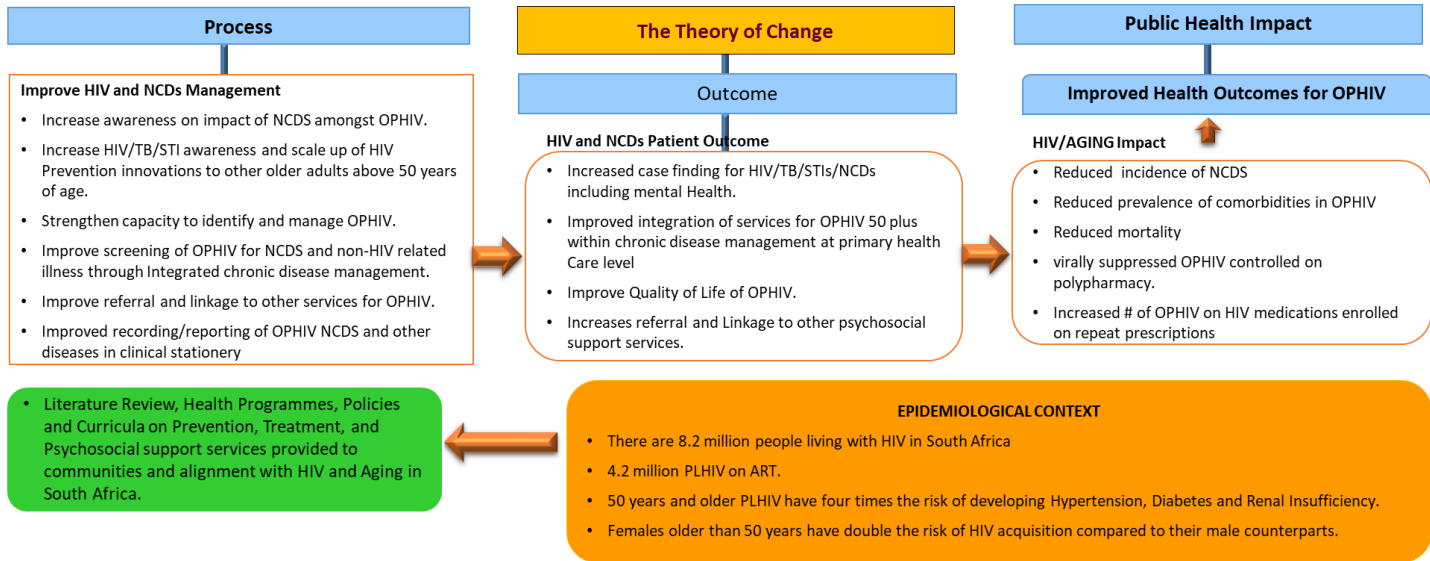
We are grateful to South Africa Partners for their stewardship and commitment to advancing the plights of older people living with HIV. You have strengthened the fabric of networking and collaboration and reinforced our shared vision of a more inclusive and equitable society. The efforts, long hours, and unwavering dedication have culminated in the content of this report, which serves as a testament to the noble work undertaken through the STEPSSA 50+ Project.

The success of the STEPSSA 50+ Project stands as a collective triumph, made possible by Gilead Africa's resourcing and the collaboration through their contribution. We offer our deepest gratitude and appreciation to each person and organization that participated in this journey. Your unwavering support, dedication, and commitment to the cause of Older Persons with HIV have not gone unnoticed and will continue to resonate far beyond the pages of this report. Thank you for being champions of change.

4. Organisations	5. Individual Contributors	6. Institutions
<ul style="list-style-type: none"> • South Africa Partners • Marang Information and Carer Centre • Isizinda Sempilo Organization (ISO) • Centre for Positive Care (CPC) • Oziel Mdletshe Foundation (OMF) • Greater Taung People Living with HIV/AIDS Organisation (GTPLHIV) • Ekurhuleni LGBTQIA+ (EPOC) • Songe Social Change • ESSA Christian AIDS Programme • ATA-Boy Men and Boys Organisation • NAPWA • TAC • TAG • PWN • Sanarela 	<ul style="list-style-type: none"> • Dr Mbali Mhlongo • Lindi Dlamini • Tshepo Ngoato • Thembi Ngubane-Zungu • Paddy Nhlapo • Menzi Hadebe • Dr Tony Diesel • QuadCare CEO • Provincial Director for HIV and AIDS Programmes • SA HIV Clinicians Society • Nutrition and Comorbidities Senior Lecturer • HIV and AIDS Chief Director 	<ul style="list-style-type: none"> • Waterberg District Municipality • Gqeberha District Health Office • PWLHIV Sector

D. ANNEXURES

I. Theory of Change



II. Advocacy Brief

Definition of OPHIV

- Older persons living with HIV, often referred to as "older adults" or "older individuals" maturing with HIV, are herein referred to as OPHIV in the context of this Advocacy Brief, we will mean coverage of individuals aged 50 years and above who have been diagnosed with the human immunodeficiency virus (HIV). This demographic cluster represents a growing sector of the HIV-positive population due to advancements in HIV treatment and the increasing lifespan of people living with the virus.
- Through the STEPSSA 50+Project four group discussions and accompanying questionnaires, we discovered that out of 420 participants, 313 reported living with HIV as a lifelong challenge. The Conversation AFRICA research report, released on February 28, 2024, attests to this claim. Evidence shows that an increasing number of adults aged 50 years and over are living with HIV (United Nations, HIV and Aging: A Social Supplement to the UNAIDS Report on the Global AIDS Epidemic 2013, Geneva: UNAIDS (2013).

Policy environment on HIV+ who are 50 Plus

- The guiding principle of the country's National Strategic Plan for HIV, TB, and STIs 2023-2028 is that of Universal health coverage (UHC) and comprehensive responses that integrate prevention, treatment, care, and support to ensure that no one is left behind. However, the same strategic plan does not seem to make a concerted effort to address the complex interrelationship between aging, HIV, and multi-morbidities.

Rationale for prioritization

- A study on HIV and Aging in South Africa, conducted in 2011 by Jan AC Hontela and Mark N Lurie, discovered that the number of patients aged 50 and over who are affected by HIV is anticipated to almost double within the next 30 years. Moreover, the proportion of HIV-positive patients aged over 50 is estimated to triple within the same time frame.
- The prioritization of individuals aged 50 and above in for HIV, TB, STIs, and NCD management programming through ensuring that "a substantial proportion of measurable community-led, and community-based interventions driven by empowered communities, including key and other priority populations" (NSP 2023-2028) is of utmost importance, given their unique healthcare requirements. The OPHIV demographic's healthcare intermediations require customization to cater to their specific needs, leading to an enhanced quality of life. Furthermore, allocating resources towards this age group will optimize the utilization of healthcare resources, resulting in a more sustainable and efficient healthcare system. Therefore, we must work collaboratively to ensure that our seniors receive the care they require and deserve.
- Focusing on the unique healthcare needs of older people with HIV is not just a social responsibility but also an excellent health and development investment. Addressing this demographic's needs can significantly improve health outcomes, drive innovation, and create societal value. It's time to recognize this demographic's untapped potential and take action to leverage this prospect.

STEPSSA 50+Project Recommendations

ADVOCACY IMPERATIVE: Develop and implement a powerful six-pronged strategic program at the local level for the OPHIV movement! Let this program be a robust platform to establish and renew community support networks that enhance prevention, treatment, psychosocial support, and health service provision. The multi-pronged program must engage in continuous advocacy efforts and activities to garner support, mobilize resources, and promote policy changes that prioritize the well-being of PLHIV to ensure comprehensive care and community engagement. Remember: SA Partners and its core collaborators will provide technical support, including qualitative and quantitative data management through community monitoring, tracking, and evaluation methods.

ADVOCACY: Let's get to work and make a real difference!

COMPONENTS

STEPSSA 50+Project Recommendations

Business Case for Focusing on Older People with HIV

Brand Reputation: SANAC, Civil Society, Development Partners, Government, and Businesses need to be drawn into prioritization of older adults with HIV and devise strategies to enhance their campaigns, interventions, and brand reputation through extending goals and objectives to overtly envelope OPHIV. By demonstrating a commitment to the social inclusion of OPHIV, these structures and brands can attract loyalty from their past, current, and future audiences and enhance their care standing within the community. Greater Involvement of People Living with HIV (GIPA)


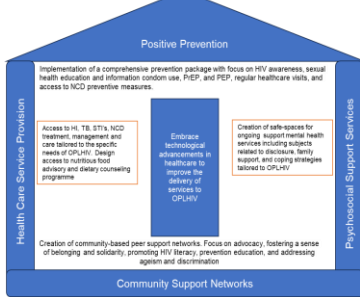
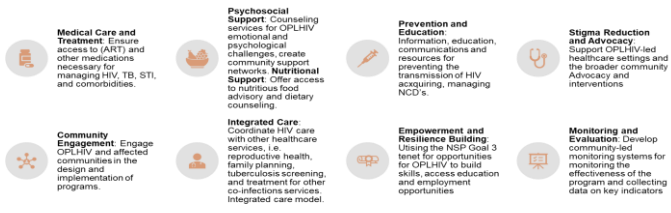
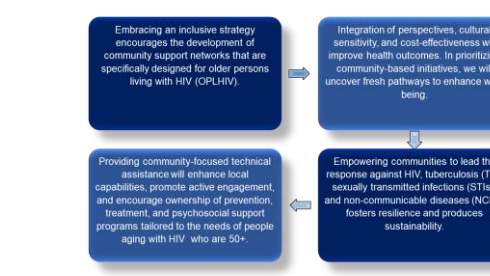
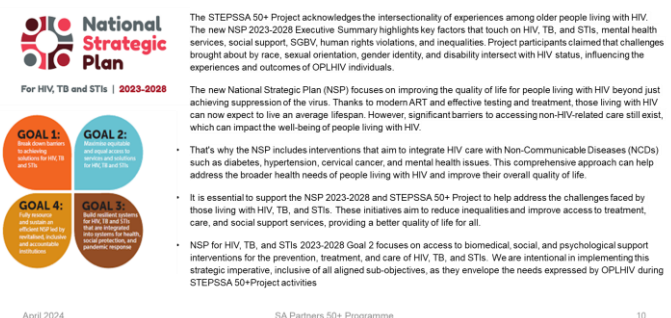
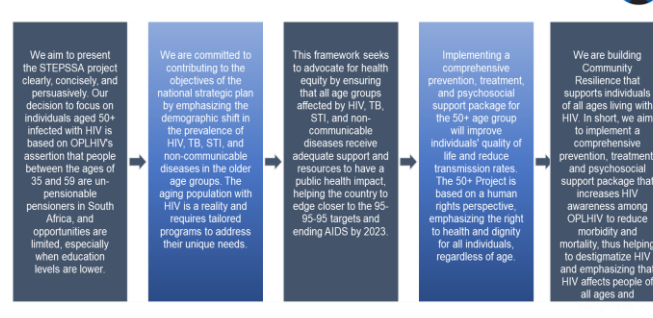
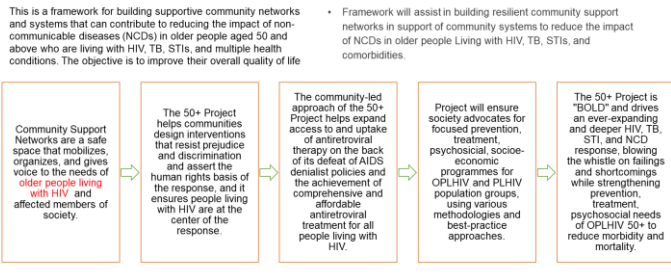

Innovation and Differentiation: Focusing on older people with HIV, who are 50+ (equitably) may help drive innovation, enhance a people- and communities-centred approach to prevention, treatment and care programmes for HIV, TB and STIs and other healthcare products and services. Enterprises that develop innovative solutions tailored to specific and nuanced demographics may differentiate themselves in the market and gain a competitive edge.

Regulatory Incentives: We recommend that the country coordinating mechanism, civil society, governments, and regulatory bodies be lobbied to offer incentives or grants for organizations or enterprises that address the healthcare needs of OPHIV to edge closer to achieving results linked to Goal 3 of the NSP 2023-2028 and all linked objectives. These incentives are proposed in order to enhance the building of "robust and resilient systems for HIV, TB, and STIs integrated into systems for health, social and pandemic response

Stigma and Discrimination: We are informed by the communities of OPHIV in STEPSSA 50+ activities that they want to strengthen community-led responses to HIV, TB, and STIs. Redressing stigma, discrimination, and stereotypes against OPHIV must be localized and multifaceted and include education, advocacy, policy reform, and efforts to promote inclusivity and acceptance within communities and healthcare systems. Addressing these issues is crucial for ensuring equitable access to care and support.

Market Opportunity: The OPHIV represents a growing market for healthcare services, medications, and support programs for parents, grandparents, or caregivers—only if tailored needs are addressed. Meeting these needs can create new revenue streams for healthcare providers, pharmaceutical companies, and healthcare sector programs, acknowledging their needs and challenges while recognizing opportunities for service provision and support.

III. Framework for OPLHIV Programming

<h4>THE FRAMEWORK RATIONALE</h4>  <p>The STEPSSA 50+ Project scoped healthcare needs and challenges faced by older people living with HIV and concluded that they constitute a critical area of concern, particularly in the context of South Africa's unique socio-political and health landscape.</p> <p>The intersection of aging with HIV presents a distinct set of health challenges, necessitating a nuanced understanding and approach to care, a setting this proposal and framework seeks to respond to. The discussions highlighted the significance of social support in addressing the challenges of stigma, isolation, and discrimination.</p> <p>Components and pillars of this framework are informed first by the scoped lived experiences on the ground and aligned to existing literature, policies and programs. The scoping process assisted the STEPSSA 50+ Project in constructing the development of a comprehensive prevention, treatment, and psychosocial support program focus for PLHIV Aged 50+ on long-term ART to reduce morbidity and mortality in the era of Test and Treat</p> <p>April 2024 SA Partners 50+ Programme 3</p>	<h4>FOCUS AREAS</h4>  <p>We aim to present the STEPSSA 50+ project concisely and persuasively. Our decision to focus on individuals aged 50+ infected with HIV is based on OPLHIV's contention that people between the ages of 35 and 59 are un-pensionable pensioners in South Africa, and opportunities are limited, especially where education levels are subordinate.</p> <p>We are committed to contributing to the objectives of the national strategic plan by emphasizing the demographic shift in the prevalence of HIV, TB, STI, and non-communicable diseases in the older age groups.</p> <p>We are building Community Resilience that supports individuals of all ages living with HIV. In short, we aim to implement a comprehensive prevention, treatment, and psychosocial support package that increases HIV awareness among OPLHIV to reduce morbidity and mortality, thus helping to destigmatize HIV and emphasizing that HIV affects people of all ages and backgrounds.</p> <p>April 2024 SA Partners 50+ Programme 6</p>
<h4>SUPPORT NETWORKS PROGRAMS</h4>  <p>Medical Care and Treatment: Ensure access to (ART) and other medications necessary for managing HIV, TB, STI, and comorbidities.</p> <p>Psychosocial Support: Counselling services for OPLHIV emotional and psychological challenges, create community support networks. Nutritional Support: Offer access to nutritious food and dietary counseling.</p> <p>Prevention and Education: Information, education, and resources for preventing the transmission of HIV, acquiring, managing NCDs.</p> <p>Stigma Reduction and Advocacy: Advocate and interventions.</p> <p>Community Engagement: Engage OPLHIV and affected communities in the design and implementation of programs.</p> <p>Integrated Care: Coordinate HIV care with other healthcare services, i.e. reproductive health, family planning, tuberculosis screening, and treatment for other co-infections services. Integrated care model.</p> <p>Empowerment and Resilience Building: Using the NSP Goal 3 lever for opportunities for OPLHIV to build skills, access education and employment opportunities.</p> <p>Monitoring and Evaluation: Develop community-led monitoring systems for monitoring the effectiveness of the program and collecting data on key indicators.</p> <p>April 2024 SA Partners 50+ Programme 7</p>	<h4>KEY MESSAGE FRAMEWORK</h4>  <p>Embracing an inclusive strategy encourages the development of community support networks that are specifically designed for older persons living with HIV (OPLHIV).</p> <p>Integration of perspectives, cultural sensitivity, and cost-effectiveness will improve health outcomes. In prioritizing community-based initiatives, we will uncover fresh pathways to enhance well-being.</p> <p>Providing community-focused technical assistance will enhance local capabilities, promote active engagement, and encourage ownership of prevention, treatment, and psychosocial support programs tailored to the needs of people aging with HIV, who are 50+.</p> <p>Empowering communities to lead the response against HIV, tuberculosis (TB), sexually transmitted infections (STIs), and non-communicable diseases (NCDs) fosters resilience and produces sustainability.</p> <p>April 2024 SA Partners 50+ Programme 8</p>
<h4>ALIGNMENT: NSP 2023 TO 2028</h4>  <p>National Strategic Plan For HIV, TB and STIs 2023-2028</p> <p>GOAL 1: To achieve epidemic control for HIV, TB and STIs</p> <p>GOAL 2: To ensure that all people living with HIV, TB and STIs have access to quality care and support</p> <p>GOAL 3: To ensure that all people living with HIV, TB and STIs have access to quality care and support</p> <p>GOAL 4: To ensure that all people living with HIV, TB and STIs have access to quality care and support</p> <p>The STEPSSA 50+ Project acknowledges the intersectionality of experiences among older people living with HIV. The new NSP 2023-2028 Executive Summary highlights key factors that touch on HIV, TB, and STIs, mental health services, social support, SGBV, human rights violations, and inequalities. Project participants claimed that challenges brought about by race, sexual orientation, gender identity, and disability intersect with HIV status, influencing the experiences and outcomes of OPLHIV individuals.</p> <p>The new National Strategic Plan (NSP) focuses on improving the quality of life for people living with HIV beyond just achieving suppression of the virus. Thanks to modern ART and effective testing and treatment, those living with HIV can now expect to live an average lifespan. However, significant barriers to accessing non-HIV-related care still exist, which can impact the well-being of people living with HIV.</p> <ul style="list-style-type: none"> That's why the NSP includes interventions that aim to integrate HIV care with Non-Communicable Diseases (NCDs) such as diabetes, hypertension, cervical cancer, and mental health issues. This comprehensive approach can help address the broader health needs of people living with HIV and improve their overall quality of life. It is essential to support the NSP 2023-2028 and STEPSSA 50+ Project to help address the challenges faced by those living with HIV, TB, and STIs. These initiatives aim to reduce inequalities and improve access to treatment, care, and social support services, providing a better quality of life for all. NSP for HIV, TB, and STIs 2023-2028 Goal 2 focuses on access to biomedical, social, and psychological support interventions for the prevention, treatment, and care of HIV, TB, and STIs. We are intentional in implementing this strategic imperative, inclusive of all aligned sub-objectives, as they envelope the needs expressed by OPLHIV during STEPSSA 50+ Project activities <p>April 2024 SA Partners 50+ Programme 10</p>	<h4>FRAMEWORK APPROACH LOGIC</h4>  <p>We aim to present the STEPSSA 50+ project clearly, concisely, and persuasively. Our decision to focus on individuals aged 50+ infected with HIV is based on OPLHIV's contention that people between the ages of 35 and 59 are un-pensionable pensioners in South Africa, and opportunities are limited, especially when education levels are lower.</p> <p>We are committed to contributing to the objectives of the national strategic plan by emphasizing the demographic shift in the prevalence of HIV, TB, STI, and non-communicable diseases in the older age groups. The aging population with HIV is a reality and requires tailored programs to address their unique needs.</p> <p>This framework seeks to advocate for health equity by ensuring that all age groups affected by HIV, TB, STI, and non-communicable diseases receive adequate support and resources to have a public health impact, helping the country to edge closer to the 95-95-95 targets and ending AIDS by 2023.</p> <p>Implementing a comprehensive prevention, treatment, and psychosocial support package for the 50+ age group will improve individuals' quality of life and reduce transmission rates. The 50+ Project is based on a human rights perspective, emphasizing the right to health and dignity for all individuals, regardless of age.</p> <p>We are building Community Resilience that supports individuals of all ages living with HIV. In short, we aim to implement a comprehensive prevention, treatment, and psychosocial support package that increases HIV awareness among OPLHIV to reduce morbidity and mortality, thus helping to destigmatize HIV and emphasizing that HIV affects people of all ages and backgrounds.</p> <p>April 2024 SA Partners 50+ Programme 13</p>
<h4>POSITIONING</h4>  <ul style="list-style-type: none"> This is a framework for building supportive community networks and systems that can contribute to reducing the impact of non-communicable diseases (NCDs) in older people aged 50 and above who are living with HIV, TB, STIs, and multiple health conditions. The objective is to improve their overall quality of life Framework will assist in building resilient community support networks in support of community systems to reduce the impact of NCDs in older people Living with HIV, TB, STIs, and comorbidities. <p>The community-led approach of the 50+ Project helps expand access to and uptake of antiretroviral therapy on the back of its defeat of AIDS denialist policies and the achievement of comprehensive and affordable antiretroviral treatment for all people living with HIV.</p> <p>The 50+ Project is "BOLD" and drives an ever-expanding and deeper HIV, TB, STI, and NCD response, blowing the whistle on failings and shortcomings while strengthening prevention, treatment, psychosocial needs of OPLHIV 50+ to reduce morbidity and mortality.</p> <p>April 2024 SA Partners 50+ Programme 14</p>	<h4>TECHNICAL SUPPORT FOCUS</h4>  <p>Strategic</p> <p>Programmatic</p> <p>Technical</p> <ul style="list-style-type: none"> • Skills Development • Training • Organizational Development • Data Management • Community Monitoring • Activity Reporting • Production of creative information • Financial Management • Accountability • Our integrity • Reporting <p>April 2024 SA Partners 50+ Programme 15</p>

IV. Social Contract

We resolved to



- Endorse that the intervention be named 50+ Project, and mean individuals aged 50 years and above who have been diagnosed with HIV and are living with comorbidities. This cluster definition will not be to the exclusion of other HIV-positive populations but guarantee tailoring to the 50+.
- Build relationships through positive stakeholder engagement, collaborations, and proactive initiative-building to address the critical healthcare needs and challenges faced by older individuals living with HIV, with a specific focus on the unique socio-economic, socio-political, and health service environment
- Create community support networks program aimed at assisting in fostering a supportive ecosystem that empowers OPLHIV in general and specifically improves health outcomes.
- Implement targeted awareness campaigns to promote the cause of OPLHIV and elevate mental health, NCDs, and socio-economic challenges within a framework for exploring the nuanced challenges and potential solutions at the intersection of aging and HIV, TB, STI, and NCDs in South Africa.
- Work towards developing a locally owned and community-led comprehensive nutrition program tailored specifically to the needs of 50+ to address the nutritional deficiencies that are common in the aging population in its diversity and to people living with HIV.
- Continuously Advocate for preventive care measures, management of comorbidities, treatment adherence, and other HIV nuanced conditions
- Adopt the NSP 2023-2028 for HIV, TB, and STIs and the NSP on GBV 2020 to 20230 as the guiding policy framework and roadmap for guiding the response of 50+ Project
- Design and implement a comprehensive response package that integrates prevention, treatment, care, and support to ensure that no one is left behind, inclusive of the LGBTQI+ and other key and vulnerable Populations
- Ensure all program support structures are inclusive, gender-sensitive, culturally competent, human rights centered, and accessible.

In conclusion, the social contract means...



The empowered OPLHIV movement will achieve improved health outcomes, mobilize service demand, reach people with services, support health system strengthening, mobilize political and traditional leadership, change social attitudes and norms, and create an enabling environment that promotes equal access.

The intention of **_STEPSSA 50+ Project was** to understand current efforts geared towards reducing morbidity and mortality in the Era of HIV Test and Treat All in South Africa. The project was implemented as a bottom-up approach where communities of OPHIV thrashed out the issues impacting them, arrived at solutions they believe suitable.

Ensure all program support structures are inclusive, gender-responsive, non-binary, culturally proficient, human rights centered, and accessible. **The 50+ Project!**