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PULMONARY REHABILITATION IN AFRICA (COMMUNITY-DRIVEN CITIZEN SCIENCE APPROACH): (A FOCUS ON COPD IN LOW-RESOURCED COMMUNITIES IN SOUTH AFRICA)

PhD (Medicine) DISSERTATION

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Declaration/Preface

I Moses Isiagi, declare that this work is my original work (except where acknowledgements indicate otherwise).

Signed by candidate

Date: 14th February 2025

Dedication

This dissertation is dedicated to all who have made me who I am, above all to the LORD Almighty, my heart, my love, my all, my whole.

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Manuscripts from this thesis are currently being prepared for publication. The findings from Chapter 3 (Africa-wide survey) have been submitted to African Journal of Thoracic and Critical Care Medicine and have been accepted for publication. The Citizen science approach findings from Chapter 4 are being prepared for submission to the Journal of Community Health. A commentary titled “Global surgery in Africa: Access to surgery, an opportunity to adopt a participatory community-based approach” was accepted and published in South African Journal of Public Health.

The systematic review manuscript is also being prepared for submission to Annals of American Thoracic Society.

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Acronyms

COPD	**C**hronic **O**bstructive **P**ulmonary **D**isease
WHO	**T**he **W**orld **H**ealth **O**rganization
NCDs	**N**on-Communicable **D**iseases
LMICs	**L**ow-**M**iddle **I**ncome **C**ountries
TB	**T**uberculosis
PR	**Pulmonary rehabilitation**
USA	**U**nited States **O**f **A**merica
GOLD	**G**lobal **I**nitiative **F**or **C**hronic **O**bstructive **L**ung **D**isease
HRQoL	**H**ealth-**R**elated **Q**uality **O**f **L**ife
CRDs	**C**hronic **Re**spiratory **D**iseases
HBPR	**H**ome-**B**ased **Pulmonary rehabilitation Programmes**
RCTs	**R**andomized **C**ontrol **T**rails
CINAHL	**C**umulative **I**ndex **O**f **N**ursing **A**nd **A**llied **H**ealth)
MEDLINE	**M**edical **L**iterature **A**nalysis **A**nd **R**etrieval **S**ystem Online,
EMBASE	**E**xcerpta **M**edica Database
CABI	**C**entre **F**or Agriculture **A**nd **B**ioscience **I**nternational
AMED	**T**he **A**llied **A**nd **C**omplementary **M**edicine **D**atabase
PATS	**P**an **A**frican **T**horacic **S**ociety
SATS	**S**outh **A**frican **T**horacic **S**ociety
PRISMA	**P**referred **R**eporting **I**tems **F**or **S**ystematic **R**eviews **A**nd **M**eta-**A**nalyses
RoB	**R**isk **O**f **B**ias
6MWT	**S**ix **M**inute **W**alk **T**est
SGRQ	**S**t **G**eorge's **R**espiratory **Q**uestionnaire
mMRC	**M**odified **M**edical **R**esearch **C**ouncil
HIC	**H**igh **I**ncome **C**ountry
EMRO	**E**astern **M**editerranean **Region**
CAD	**C**oronary **A**rtery **D**isease

HCPs	**H**ealth **C**are **Pr**actitioners
HREC	**H**uman **R**esearch **E**thics **C**ommittee
HPCSA	**H**ealth **P**ractitioners **C**ouncil **o**f **S**outh **A**frica
FGD	**F**ocus **g**roup **d**iscussions
CSt	**C**itizen **s**cientist
CVD	**C**ardiovascular **di**sease
CMs	**C**ommunity **m**embers
RCT	**R**esearch **c**oordinating **t**eam
SES	**S**ocioeconomic **s**tatus
STI	**S**exually **T**ransmitted **I**nfection
PHC	**P**rimary **h**ealth **c**are
HBM	**H**ealth **B**elief **M**odel
TPB	**T**heory **o**f **P**lanned **B**ehaviour
ATS	**American Thoracic Society**
ERS	**European Respiratory Society**
PROSPERO	**Prospective Register of Systematic Reviews**
AJOL	**African Journals OnLine**

Keywords

COPD- Chronic obstructive pulmonary Disease

Low -resourced setting

Pulmonary rehabilitation

Citizen science

Community

Abstract

Introduction

Chronic Obstructive Pulmonary Disease (COPD) represents a significant global health challenge, particularly in low-and middle-income countries (LMICs), especially in Africa. Pulmonary rehabilitation (PR) is a well-established intervention to address COPD in High income countries (HICs) and has been incorporated into the healthcare systems in many settings. However, its implementation and population-level delivery in Africa are almost non-existent. This dissertation explored COPD management and PR services in low-resourced African settings, specifically focusing on a disadvantaged peri-urban community in South Africa. The study utilized a 3-pronged approach which we believe holds significant potential to investigate and perhaps, address these challenges.

The purpose of this study was to examine the current state of PR services in low-resourced settings in LMICs, evaluate healthcare providers' clinical awareness and support in Africa, and explore COPD risk perceptions and prevention preference in the study setting. In addition, the study utilizes the findings and lessons learnt to support the development of community-driven PR implementation strategies in the disadvantaged African setting using a participatory approach.

Methods

The methodology encompassed three distinct components**:**
First, a systematic review was conducted to gain understanding and map the landscape of home-based and community-based PR programmes in low-resourced African settings registered with PROSPERO (CRD42023480324). Second, a cross-sectional virtual electronic survey was administered between January and March 2020, targeting African clinicians with Pan-African Thoracic Society and South African Thoracic Society networks. Finally, a participatory community-based Citizen science project was implemented in the Klipfontein health district, incorporating focus group discussions, Citizen science interviews, and advocacy workshops.

Results

The study revealed a significant gap in research regarding PR programmes in African settings, with no published studies comparing home-based and community-based PR delivery models in the region. The closest relevant research was a Brazilian protocol for home-based cardiac rehabilitation. However, the survey of healthcare professionals from 23 countries demonstrated awareness and recognition of PR as an effective intervention for COPD. Despite significant implementation challenges, over 85% of the surveyed healthcare professionals expressed confidence in PR programmes' ability to improve symptoms and reduce patient exacerbation. Insights from Citizen science indicate limited community awareness of COPD, often confused with general respiratory conditions like asthma. Discussions and EpiCollect findings show that while communities recognize risk factors such as smoking and environmental exposure, there is a pressing need for targeted education about COPD before effectively implementing PR interventions. Furthermore, participants in the study were willing to participate in a community-driven PR intervention and listed important strategies that would make this intervention accessible, acceptable, and sustainable.

Conclusion

This study presents a novel approach to COPD risk perception and PR implementation in resource-limited settings. The need for pulmonary rehabilitation is well documented and understood at a scientific and specialist pulmonologist level. Local logistics, training, funding, and staffing challenges hindered the implementation. Community-based "out-of-hospital" PR programmes are well-described in high-income countries. However, they are almost non-existent in low-income settings. At the patient level, the lack of awareness of the diagnosis, understanding and access to treatment may inadvertently be the most important factor limiting the access of patients with COPD to an effective PR intervention.

While traditional 'medical science' methods have been instrumental in increasing access to PR in low-income settings, the potential of a more Citizen science approach with engagement at the community level with healthcare staff, patients, and community members is promising. This approach may facilitate the development and implementation of a better multilayered and acceptable programme to those who need it most (the vulnerable population in disadvantaged communities in Africa), offering hope for the future of COPD management in Africa.

Keywords: COPD, Pulmonary rehabilitation, Citizen science, Low-resourced settings, Africa

CHAPTER ONE

SCOPE OF THE THESIS

1.0 Background

Pulmonary diseases are increasingly significant and widespread causes of morbidity and mortality globally, with Chronic Obstructive Pulmonary Disease (COPD) as the most common chronic lung disease.(1,2) The World Health Organization (WHO) estimates a rise in COPD from the fourth to the third cause of death by 2030, heavily affecting low-middle-income countries.(1,2) COPD currently affects 65 million people, and 3 million people die annually.(3)

Previous studies have underscored several factors associated with increased risk of COPD, including tobacco smoking, second-hand smoke exposure, household air pollution (particularly exposure to biomass fuels and coal in low and middle-income countries), occupational exposure due to tobacco cultivation, history of asthma, and increasing age.(4–6) Smoking has caused more than 200 million deaths over the past 30 years and incurs annual costs exceeding US$1 trillion.(7,8) As the number of current smokers increased (1 billion as of 2019),(7) effective implementation and enforcement of tobacco control policies and interventions are urgently needed to mitigate health and economic consequences.(9–11)

Despite the challenge that preventing COPD presents to public health, it remains under-diagnosed and untreated particularly in low and middle-income countries (LMICs).(12) The focus in these regions has historically been communicable infectious diseases like pneumonia and tuberculosis (TB), with TB causing approximately 1.2 million deaths annually. However, the burden of non-communicable diseases (NCDs), particularly COPD and post-tuberculosis lung disease, has increased substantially.(13) COPD now affects an estimated 26.4 million people across the African continent (4.1% prevalence) and causes approximately 237,000 deaths annually. This represents a 102.1% increase in COPD-related mortality since 1990, significantly outpacing increases in TB mortality (17.9% increase over the same period).

Despite this substantial burden, COPD remains severely underdiagnosed, with studies suggesting that 70-80% of COPD cases in African settings remain undetected and untreated. The management efforts to contend with this increased burden in LMICs are mainly directed toward pharmacological treatment which do not specifically address the associated long-term conditions or resultant disabilities.(13) Although clinical guidelines for COPD management exist, major gaps exist in their implementation.(14)

Current State of Pulmonary Rehabilitation in Global Context

Pulmonary rehabilitation (PR) has evolved considerably over the past three decades, shifting from an experimental intervention to an evidence-based standard of care. Meta-analyses and systematic reviews consistently highlight its effectiveness in improving exercise capacity, reducing dyspnoea, enhancing quality of life, and decreasing healthcare utilization in patients with COPD.(15,16) The strength of evidence has led to PR's inclusion in all major COPD management guidelines, including those from the American Thoracic Society, European Respiratory Society, and Global Initiative for Chronic Obstructive Lung Disease (GOLD).(17–19)

Despite this robust evidence base, significant implementation gaps persist globally. Even in high-income countries (HICs), where resources and infrastructure are more abundant, PR remains severely underutilized. Recent data from the United Kingdom suggests that only 3-16% of eligible patients access PR services, while similar patterns of underutilization have been reported in the United States, Canada, and Australia.(20,21) This implementation gap represents what has been termed the "know-do gap" in healthcare which is the disconnect between what scientific evidence supports and what is actually delivered in practice .(22)

Several factors are attributed to this implementation gap in HICs, including limited or no referrals from primary care physicians, insufficient program capacity, inadequate funding models, geographical barriers, and patient-related factors such as transportation difficulties and competing commitments.(23,24) Additionally, many eligible patients decline PR referrals or drop out prematurely, often due to limited understanding of potential benefits, inconvenient program timing, travel barriers, and comorbidities.(24)

The implementation models in HICs have evolved from largely hospital-based programs to inclusion of various delivery options: outpatient hospital-based, community-based, home-based, and increasingly, telerehabilitation.(17)

Each model presents unique advantages and constraints regarding accessibility, resource requirements, and effectiveness. Meta-analyses comparing these delivery models suggest relatively equivalent outcomes across settings when core components are maintained , although more research is needed to identify which patients benefit most from particular delivery models.(25)

While implementation science research on PR has expanded in HICs, critical examination reveals that much of this research lacks theoretical underpinning and fails to adequately address contextual factors that influence implementation success. Furthermore, the applicability of HIC-derived implementation strategies to low- and middle-income country (LMIC) settings remains questionable given fundamental differences in healthcare system structure, resource availability, and sociocultural contexts.(26,27)

Pulmonary rehabilitation (PR) has emerged as a general standard of care for patients with COPD and a growing body of scientific evidence has shown effectiveness in reducing readmissions and improving outcomes through tailored exercise and education.(28,29) PR is defined as a "comprehensive intervention based on a thorough patient assessment followed by patient-tailored therapies that include but are not limited to, exercise training, education, and behaviour change.(17)

Successful PR programmes are multidisciplinary, individualized, and address both physical and social functioning, enhancing overall quality of life for patients with COPD. American Thoracic Society (ATS)/European Respiratory Society's (ERS) recent official statement summarises the advances in COPD guidelines.(17,30,31) Pulmonary rehabilitation has demonstrated physiological, symptom-reducing, psychosocial, and health-economic benefits for patients with chronic diseases.(25) Moreover, as such, it should be a standard of care alongside other well-established treatments such as non-pharmacological interventions,(32) smoking cessation,(33) reduction of other risk factors (e.g. exposure to open cooking fires), influenza vaccination.(34,35)

Most evidence supporting the benefits of PR has been derived from studies of patients with COPD.(36–39) However, the results obtained in patients with other respiratory diseases are similar to those observed in symptomatic patients with COPD.(40) Despite this, PR needs to be more utilised worldwide. A lack of resources, funding, and reimbursement coupled with a lack of health care professional/payer/and patient awareness and knowledge has contributed to the gap between the understanding of the science and benefits of PR versus the actual delivery of the PR services to the suitable patients.(25) The implementation and precise delivery of PR, especially regarding COPD care, are reported to be slow and moderate (41) and, in Africa, almost non-existent.

While this statement about PR implementation in Africa being "almost non-existent" is supported by clinical experience, it is important to note that this assertion has primarily been based on anecdotal evidence rather than systematic investigation. As will be explored in Chapter 2, there is a need to thoroughly document the precise nature and scope of this implementation gap, identify any emerging models of PR delivery that might exist in limited forms across the continent, and uncover transferable insights from other rehabilitation contexts that could inform future implementation efforts.

Unique Challenges of PR Implementation in Africa

The African continent presents distinct challenges for PR implementation that extend beyond those observed in HICs. These challenges can be categorized into healthcare system factors, healthcare provider factors, patient/community factors, and contextual factors that collectively create a complex implementation environment requiring unique approaches.

At the healthcare system level, African countries face severe resource constraints that limit basic healthcare delivery, let alone specialized services like PR. Many countries allocate less than 5% of GDP to healthcare, resulting in shortages of essential medications, diagnostic equipment, and rehabilitation facilities.(42) The workforce density for rehabilitation professionals is alarmingly low, with some countries having fewer than 0.5 physiotherapists per 100,000 population compared to 50-100 per 100,000 in many HICs.(43) This workforce shortage is compounded by uneven geographical distribution, with most specialists concentrated in urban centres.(44)

Healthcare financing models across Africa often fail to support rehabilitation services. Most countries lack universal health coverage, and out-of-pocket expenses remain high, creating financial barriers to accessing PR.(42) Where health insurance exists, rehabilitation services are frequently excluded from coverage or severely limited.(45) This financial context forces difficult resource allocation decisions, with communicable diseases often prioritized over chronic conditions like COPD.

At the healthcare provider level, awareness and knowledge gaps regarding PR are widespread. Studies from Nigeria, South Africa, and Uganda indicate that many healthcare providers have limited understanding of PR principles, benefits, and delivery methods.(46,47) Even when knowledge exists, attitudinal barriers may persist, including perceptions that PR is less important than pharmacological management or that implementation is unfeasible in resource-constrained settings.

Patient and community factors further complicate implementation. Health literacy regarding COPD and rehabilitation is generally low, with many patients unaware of their diagnosis or its implications .(48) Cultural beliefs about chronic disease, breathing difficulties, and appropriate treatments may vary with biomedical perspectives, potentially reducing acceptance of PR interventions.(49) Additionally, significant stigma surrounds respiratory symptoms in many communities, particularly in contexts where tuberculosis is prevalent, potentially deterring healthcare-seeking behaviour.(50)

Contextual factors create additional layers of complexity. Many African countries experience high ambient air pollution levels in urban areas and significant indoor air pollution from biomass fuels in rural settings, creating ongoing exposure to respiratory irritants that may reduce PR effectiveness.(51) Safety concerns in certain communities may limit outdoor exercise, a key component of many PR programs. Infrastructure challenges including unreliable electricity, limited internet connectivity, and inadequate transportation systems further complicate implementation of standard PR models.

The dearth of context-specific evidence regarding PR implementation in African settings represents a significant gap in the literature. While adaptation of HIC-derived PR models is common, such adaptations often occur without systematic evaluation of their appropriateness, feasibility, or effectiveness in African contexts. Recent reviews highlight the absence of high-quality studies examining PR implementation in sub-Saharan Africa, underscoring the urgent need for context-specific implementation research.(52,53)

A survey of primary care physicians, nurse practitioners and physicians in the United States of America (USA) highlights multiple barriers to COPD/pulmonary disease diagnosis, including a lack of easy access to spirometry and frequent failure to include spirometry in diagnostic confirmation.(54) From an African perspective, there is limited evidence on PR design and its effectiveness,(55) underscoring a critical need for more evidence-based and targeted research to formulate its guidelines, especially in low-resourced settings. These guidelines and recommendations should however be practical in a low-income, and should not depend heavily on extensive exercise equipment, while ensuring outcomes through comparable physical endpoints.

South Africa currently grapples with a concurrent epidemic of infectious and non-infectious chronic diseases(56) exacerbated by so-called "modifiable risk factors," including physical inactivity, unhealthy eating and overweight, smoking and excessive alcohol intake.(56) Promoting physical activity through PR is critical in addressing NCDs. There is also a growing recognition of the ecological, environmental and social determinants of NCDs, which are not under the control of the individual.(57) Economic and spatial inequalities in South Africa have contributed to the disproportionately high burden of NCDs among disadvantaged persons despite social grants and remittances targeting these groups post-1994 after democracy.(58)

A community-driven (Citizen science approach), could help in understanding disease risk perception (in this case, COPD) and would aid in developing prevention advocacy strategies. Citizen science enables community involvement in data collection, analysis, problem definition, integrating community perspectives into the research process.(59) Key questions include: Are PR services accessible? Are the required PR services available? Are PR services affordable? Are PR services acceptable to the population? What perceptions including awareness and knowledge, symptoms, experience, and stigma are in the community? What is the preferred and determined strategy for a participatory community-driven PR intervention?

Theoretical Frameworks for Community Engagement in Healthcare

The challenges of implementing PR in African settings require innovative approaches that stretch beyond traditional healthcare delivery models. Community engagement emerges as a particularly promising strategy, with substantial theoretical and empirical support from diverse healthcare contexts. Several theoretical frameworks inform this approach, providing the conceptual foundation for the Citizen science methodology employed in this thesis.

Community-Based Participatory Research (CBPR) represents a collaborative approach to research that equitably involves community members, organizational representatives, and researchers in all aspects of the research process.(60) CBPR highlights the unique strengths that each party contributes to the process and aims to integrate knowledge and action for mutual benefit.(61) The approach is grounded in principles of co-learning, capacity building, and balancing research with action. Within CBPR, community members transition from research "subjects" to active partners who contribute to problem definition, data collection, interpretation, and application of results.(61)

CBPR has demonstrated particular value in tackling health disparities in marginalized communities. A systematic review by De Las Nueces et al. (2012) revealed that CBPR approaches improved research participation among racial and ethnic minorities and enhanced the cultural appropriateness of interventions.(62) Similarly, Vaughn et al. (2017) showed improved health outcomes when CBPR principles guided intervention development, particularly for chronic disease management programs.(63)

While CBPR provides the broader theoretical foundation, Citizen science represents a specific methodological approach within this paradigm. Citizen science involves public participation in scientific research, with community members contributing to data collection, analysis, interpretation, and application.(59) The approach has evolved from primarily environmental applications to diverse health contexts, demonstrating utility in addressing complex health challenges. (59)

Haklay (2013) conceptualized a four-level framework for Citizen science engagement: (1) Crowdsourcing, where citizens act as basic sensors; (2) Distributed intelligence, where citizens interpret data; (3) Participatory science, where citizens contribute to problem definition and data collection; and (4) Extreme citizen science, where citizens collaborate on all aspects of the research process, including problem definition, methodology selection, and knowledge production. The approach used in this thesis aligns with levels 3 and 4, reflecting deep community engagement throughout the research process.(64)

The "Our Voice" model, developed at Stanford University, represents a specific application of Citizen science principles to community health promotion .(65) This model employs a systematic process whereby community members document environmental factors affecting their health, analyze these findings collectively, and advocate for relevant changes. The approach has demonstrated effectiveness across diverse health challenges and contexts.

Critical to these frameworks is the concept of knowledge co-production, which challenges traditional hierarchies of expertise by valuing both scientific and experiential knowledge.(59) This perspective recognizes that communities possess valuable insights about their contexts, needs, and potential solutions that complement professional expertise. In rehabilitation contexts, co-production approaches have shown promise in enhancing intervention relevance, acceptability, and sustainability.(66)

The application of these frameworks to PR implementation represents a novel approach with significant potential. Traditional PR implementation typically follows top-down models where interventions developed in specialized centres are adapted for different contexts with limited community input. By contrast, a Citizen science approach to PR implementation centers community perspectives, potentially enhancing contextual fit, acceptability, and sustainability.

While promising, community engagement approaches also present challenges. These include power imbalances between researchers and communities, differing timelines and priorities, and tensions between scientific rigor and community accessibility.(59) Additionally, scaling and sustaining community-engaged interventions requires careful consideration of institutional support, funding mechanisms, and policy contexts.(65)

By grounding this thesis in these theoretical frameworks, we establish a robust foundation for exploring community-driven approaches to PR implementation in African settings. This approach acknowledges both the unique implementation challenges in this context and the potential for community engagement to address these challenges in ways that traditional healthcare delivery models cannot.

The integration of these theoretical perspectives with practical implementation science provides a novel framework for addressing the significant gap between PR's established benefits and its limited implementation in African settings. This thesis aims to contribute to this emerging field by systematically exploring the potential of community engagement approaches to enhance PR implementation in resource-constrained contexts.

Through a Citizen science approach, stakeholders who utilise the health care services, not only engage as research respondents but also as partners in co-designing, analysing, and translating the data.(65) The *'Our Voice'* initiative , a community-based participatory model developed by Stanford University, USA, had been used to explore and address the barriers to equitable health care access, particularly in low resourced and rural settings where inequalities are pronounced.(67) This initiative emphasizes participation from beneficiaries, facilitating engagement and advocacy for health related changes.

A community can be defined as a people domiciled in and interacting in distinct areas.(68) It is further stratified into the provider community and the patient community.(68) The provider community includes various health professionals, while the often overlooked and marginalized patient community consists of patients, caregivers and advocacy groups.(68)

Engaging in community research enhances healthcare improvement opportunities including the perspectives and empirical knowledge about the community.(68). Citizen science involves the community in the research process, to improve healthcare in the community. This is an opportunity that can adopted for PR (Figure1) shows the effects of Citizen science. It is important to underscore that while Citizen science approaches have been used and utilized in various health contexts, their application to structured rehabilitation programs like PR remains exceptionally rare. This represents a significant innovation and novelty in the thesis, as it applies an established community engagement methodology to a novel health domain. The application of Citizen science to PR implementation tackles a critical gap between the

scientifically established benefits of PR and the practical challenges of implementation in resource-constrained settings with diverse cultural contexts.

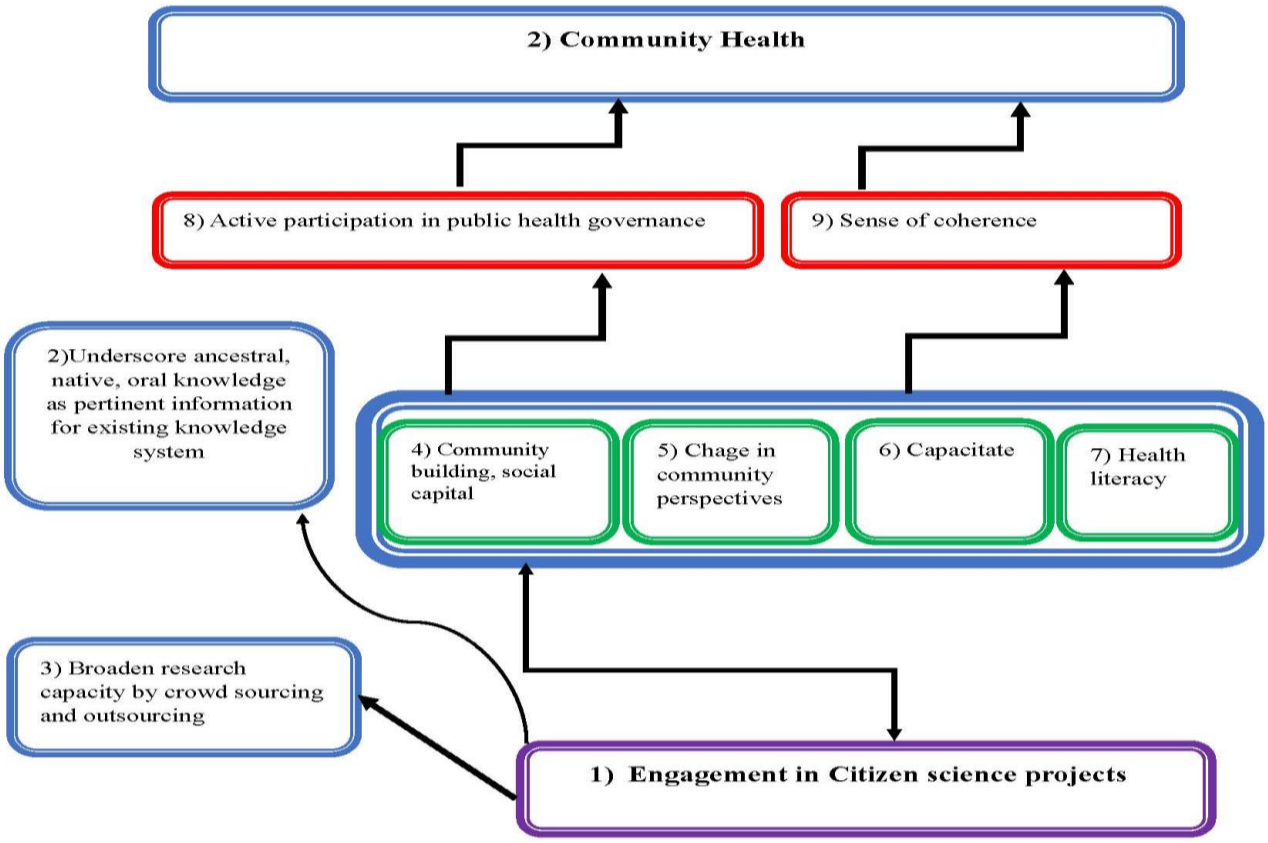

Figure 1.1: Effects of Citizen science in health, governance, and knowledge (Adapted from Den Broeder et al., 2018, page 518)

Little is known about community participation in patients with COPD, and there are no accepted and established tools to asses it.(26) A new tool or method would ideally measure participation frequency in formal and informal activities whilst being easy to administer. It would also measure the preferred and determined strategy for a participatory community-driven PR intervention.

Therefore, this PhD project sought to explore the understanding and availability of Pulmonary rehabilitation from clinician to patients and explore community-driven Pulmonary rehabilitation and advocacy strategies in a disadvantaged African setting using a Citizen science participatory approach.

1.1 Thesis Outline / Specific objectives of the study

1.1.1 Chapter two: A systematic review on home-based and community-based Pulmonary rehabilitation focused on low-income settings in Africa.

Aim

This systematic review aimed to explore and map the landscape of home-based and community-based PR programmes in low-resourced African settings, identify any existing implementation models, and gather insights that could inform contextually appropriate PR approaches.

1.1.2 Objectives of the systematic review included.

1) Explore the state of home-based and community-based PR programmes for COPD patients in low resourced settings in Africa.
2) Compare these two models of PR delivery.
3) Identify implementation barriers and facilitators to these two groups.

The scientific rationale to support Aim 1

It has been reported that Pulmonary rehabilitation is well-established, and evidence based. It can be applied within a community, including a non-specialised community health service, community service, or patient homes.(69) The GOLD (Global Initiative for Chronic Obstructive Lung Disease) Report 2023,(70) refers to the importance and utility of PR by highlighting a scarcity of data from LMICs regarding the epidemiological, clinical and approaches to prevention and control and clinical features of COPD. This coupled with diagnostic spirometry services, quality-assured pharmacological and non-pharmacological therapies not being readily available and highly inaccessible. In its original structure, exercise equipment, and physical therapist-based format, PR has decreased dyspnoea, increased exercise duration, improved quality of life and decreased hospitalisation.(71)

Comparing home-based and community-based PR delivery models is essential in the African context due to unique resource constraints, accessibility challenges, and cultural factors that may influence intervention effectiveness. Understanding which model may be more feasible and effective in low-resourced settings would guide the development of contextually appropriate PR programs, maximize limited resources, and potentially improve implementation and uptake. Previous reviews, such as Neves et al. (2016), have combined home-based and community-based interventions due to their overlapping nature.(72) However, in our systematic review, we attempted to distinguish between these approaches to provide clarity on their specific implementation in African contexts, although this proved challenging due to limited evidence.

In a systematic review of randomised studies on home-based PR in patients with COPD, Vieira et al. (2010)(73) sought out studies that reported exercise capacity to assess the PR intervention's benefits. They also assessed the risks of home-based PR and whether the findings were consistent across populations of COPD, supervision, and exercise training variation. They report that most of the studies showed improvement in health-related quality of life (HRQoL) (statistically and clinically significant) following home-based rehabilitation as compared with no standard care (no PR). The studies that compared home-based PR with hospital outpatient programmes could not show statistically and clinically significant differences in HRQoL and exercise capacity. Only one of these studies was done in an LMIC (India), and none was conducted in Africa. This chapter therefore explored the state of home based and Community based PR programmes for COPD patients in low resourced settings in Africa, identified and compared different models of PR delivery and finally identified implementation barriers and facilitators.

1.1.2 Chapter Three: Pulmonary rehabilitation across Africa: A continental evaluation of health care providers' awareness, availability, utilization, and barriers to accessing Pulmonary rehabilitation.

Aim

To evaluate the extent of clinical awareness, knowledge of and support for Pulmonary rehabilitation by health care providers and to identify barriers to Pulmonary rehabilitation in Africa.

The scientific rationale to support Aim 2:

Since Africa predominantly comprises LMICs, barriers to Pulmonary rehabilitation will differ in high-income settings. Furthermore, the continent has 54 countries, thus highlighting the need to evaluate the extent of clinical awareness, knowledge of and support for Pulmonary rehabilitation across the entire continent. A systematic review in Africa showed limited evidence of PR design and evaluation of its effectiveness in Sub-Saharan Africa. The only available data from the systematic review indicates and supports PR use in various respiratory conditions.(55) Additionally, important studies by Katagira et al. (2021), Bilungula et al. (2022), and Babaji et al. (2022) have begun to document the state of PR implementation in various African countries, providing valuable contextual background for this survey.(74–76)(77)

However, this systematic review underscores a need for more evidence-based research and for Africa to formulate its guidelines, especially in low-resourced settings, adapting those from the American and European societies. Data collected from across the continent will define gaps and enable adjustments and evidence-based recommendations to be implemented as part of a low-cost, community-based Pulmonary rehabilitation programme.

1.1.3 Chapter Four: Exploring COPD Risk Perception and Co-Designing Prevention and Advocacy Strategies for Pulmonary rehabilitation in South African Communities.

Aim:

This chapter aimed to explore COPD risk perceptions and support community-driven Pulmonary rehabilitation and advocacy strategies in a disadvantaged African setting using a participatory approach.

The three main objectives that this chapter aimed to accomplish were:

1) To explore the community COPD perceptions including, awareness and knowledge, symptoms, experience, and stigma.
2) To explore community support and resources including PR, awareness knowledge and utilization.
3) To determine the preferred strategy for participatory community-driven PR intervention using stakeholder engagement, result-sharing presentation, and community advocacy workshop.

The scientific rationale to support Aim 3:

Citizen science enables community involvement in data collection, analysis, problem definition, integrating community perspectives into the research process.(59) Through a Citizen science approach, stakeholders who utilise health care services, engage not only as research respondents but as partners in co-designing, analysing, and translating the data. (65)

The *'Our Voice'* initiative , a community-based participatory model developed by Stanford University, addresses barriers to health care access, particularly in low resourced and rural settings where iniquities are pronounced.(67) This initiative emphasizes participation from beneficiaries, facilitating engagement and advocacy for health related changes. A community can be defined as a people domiciled in and interacting in distinct areas.(68) It is further stratified into the provider community and the patient community.(68)

The provider community includes various health professionals, while the often overlooked and marginalized patient community consists of patients, caregivers and advocacy groups.(68) A community-driven (Citizen science approach), could help understand disease risk perception (in this case, COPD) and would aid in developing prevention advocacy strategies.

1.1.4 Chapter Five: Discussion

In this chapter, we summarise the findings of the previous chapters, review the strengths and limitations of the studies.

1.1.5 Chapter Six: Conclusions and Recommendations

In this chapter we provide recommendations for future implementation and what should be prioritized to leverage on existing networks and ensure sustainability. We propose a way forward for future research arising from the findings in this study, as well as any implications for public health.

1.1.6 Chapter Seven: Future Directions

In this chapter we highlight future directions including research priorities (short term and long term), practice development (phases and implementation of Citizen science and PR) and policy recommendations.

Note regarding timing of work and layout of thesis:

This PhD was significantly interrupted by the Global COVID-19 pandemic and funding/ community access disruptions. The African wide survey (Chapter 3) was undertaken initially, and further work interrupted by COVID-19. There were COVID-19 enforced delays to the systematic review (Chapter 2),due to limited access to university resources, disrupted regular supervisory meetings, and challenges with PROSPERO registration processes. Additionally, the collaborative screening and data extraction processes required for the systematic review methodology were challenged by remote working conditions and subsequent Citizen science engagement. The Chapter layout is presented in its current order leading with the systematic review for a more logical thought/scientific flow.

CHAPTER TWO

A SYSTEMATIC REVIEW ON HOME-BASED AND COMMUNITY-BASED PULMONARY REHABILITATION FOCUSED ON LOW-INCOME SETTINGS IN AFRICA.

2.0 Introduction

Non-communicable diseases (NCDs), particularly chronic respiratory diseases (CRDs) pose a great threat to public health and represent a global health challenge. Chronic Obstructive Pulmonary Disease (COPD) has emerged as the most common CRD, with a global prevalence of 12.2%.(1,2) The impact is substantial, affecting 65 million people worldwide, and causing 3 million deaths annually.(78,79) The World Health Organization (WHO) estimated a rise in COPD mortality from the 4th leading cause of death in 2004 to 3rd by 2030, with over 90% of the morbidity and mortality related to COPD occurring in low-middle-income countries (LMICs).(1,2,80)

LMICs face distinct challenges in addressing the COPD burden. The disease remains undiagnosed and untreated in these regions,(3) partly due to low diagnostic capacity and inadequate therapeutic resources compared to high-income countries.(12) The situation is further complicated by historically prevalent infectious diseases like pneumonia and tuberculosis, causing respiratory morbidity.(18) This dual burden of communicable and non-communicable respiratory diseases has led to increased pressure on already very strained health care systems in Africa and other LMIC regions.(3,81–83) Pulmonary rehabilitation (PR) has emerged as a general standard of care for patients with chronic lung disease based on a growing body of scientific evidence.(14,28,29,84)

The American Thoracic Society (ATS) and the European Respiratory Society (ERS) define PR as a "comprehensive intervention tailored to individual patients, including exercise training, education, and behaviour change, designed to improve the physical and psychological condition of people with chronic respiratory disease."(17) PR has demonstrated significant benefits across physiological, psychosocial, and health-economic domains.(25)

As such, it is recommended as a standard of care alongside other well-established non-pharmacological interventions (32,85) such as smoking cessation,(33) reduction of other risk factors (e.g., exposure to open cooking fires),(32) and influenza vaccination.(34,35)
The delivery of PR typically involves a multi-disciplinary approach incorporating pulmonologists, physical medicine specialists, social workers, psychologists, nurses, respiratory therapists, occupational therapists, physiotherapists, general practitioners, pharmacists and dieticians.(86,87) However, despite its proven effectiveness, PR remains underutilized globally due to resource constraints, funding limitations, lack of awareness knowledge among health care professionals, players and patients.(25,41,86)

While traditional PR is typically accorded in hospital centres,(88) alternative delivery models have gained increased attention. These include community-based centre PR,(89) home-based PR, or telerehabilitation programmes.(90) The COVID-19 pandemic particularly accelerated the adoption of remote PR delivery for infection control purposes. The development of home-based Pulmonary rehabilitation programmes (HBPR) represents a promising strategy to address the limitations of traditional outpatient PR, particularly for patients with limited access to facilities. Thes alternative delivery models may help bridge the significant gap between the understanding and delivery of PR services to suitable patients, especially in resource constrained settings.

While evidence suggests that PR implementation in Africa is extremely limited, this assertion is primarily based on anecdotal evidence and clinical experience rather than systematic investigation. Our systematic review aimed not to merely confirm this gap but to thoroughly document its precise nature and scope. Furthermore, we sought to identify any emerging models of PR delivery that might exist in limited forms across the continent, as well as to uncover transferable insights from other rehabilitation contexts that could inform future implementation efforts. This comprehensive understanding of the current landscape was essential to contextualize the subsequent phases of this research and provide a solid foundation for developing contextually appropriate PR approaches.

2.1.1 Aim

This systematic review aimed to assess the effectiveness and implementation of home-based and community-based PR programmes in low-resourced African settings, with a specific focus on comparing these delivery models. Previous reviews, such as Neves et al. (2016) have combined home-based and community-based interventions due to their overlapping nature.(72) However, in our systematic review, we attempted to distinguish between these approaches to provide clarity on their specific implementation in African contexts, although this proved challenging due to limited evidence.

2.1.2 Objectives of the systematic review included.

1) Assess the effectiveness of home-based and community-based PR programmes for COPD patients in low resourced settings in Africa.
2) Compare these two models of PR delivery.
3) Evaluate implementation barriers and facilitators to these two groups.

2.2 Methods

The systematic review was registered with PROSPERO (registration number CRD42023480324) prior to conducting the searches, ensuring transparency and methodological rigor. (Appendix 2.1)

While a scoping review might have been more appropriate given the limited literature on PR in Africa, we opted for a systematic review to maintain methodological rigor in an attempt to specifically answer the question at hand. This approach allowed us to definitively document the absence of studies comparing home-based and community-based PR in low-resourced African settings, thereby establishing a clear knowledge gap and foundation for future research.

2.2.1 Systematic review methodology

This systematic review aimed to answer the specific question: What is the comparative effectiveness of home-based versus community-based pulmonary rehabilitation programs for COPD patients in low-resourced African settings? The review was not designed as a two-stage process, but rather as a focused comparison of these two specific delivery models within the African context.

2.2.2 Eligibility Criteria

Types of studies: We included Randomized Control Trails (RCTs) comparing home-based-Pulmonary rehabilitation to a comparator and community-based rehabilitation. All these studies that fulfilled this criterion were selected and included studies primarily written or translated into English, regardless of publication status. Studies were excluded if they: (1) were not conducted in African settings or other LMICs; (2) did not focus on COPD patients or chronic respiratory conditions; (3) described rehabilitation interventions that were not home-based or community-based; (4) were published in languages other than English; (5) were published before 2012; or (6) were not primary research studies.

Types of participants: Participants of interest comprised adults diagnosed with COPD (any definition and at least 40 years old and living in LMICs).

Types of Interventions: We included studies that compared either: (1) home-based PR versus standard care (no rehabilitation), (2) community-based PR versus standard care, or (3) home-based PR versus community-based PR. While our primary interest was direct comparison between home-based and community-based approaches, we included studies comparing either approach to standard care to allow for indirect comparisons where direct comparison studies were limited.

All studies involved at least one treatment arm, including a home-based rehabilitation program with lower limb endurance exercise training and a minimum duration of 4 weeks or 12 sessions.

The same criteria were considered for community-based rehabilitation programmes, which was the comparator. Any study that involved home-based/ community-based training to maintain the effects of inpatient or outpatient rehabilitation programmes or in which the training was not completed in either of the two settings and required regular visits to the hospital or rehabilitation centre was excluded.

Outcome measures: The following were considered as outcomes HRQoL, exercise capacity assessed by field tests (6MWT, shuttle walking test) or laboratory tests (incremental exercise test, endurance test, step test), symptom (dyspnoea), muscle strength and exacerbation rate and hospital admissions.

2.2.3 Search methods for identification of studies

The following databases were searched: Pub Med Central (2012-2024), EBSCOhost (MEDLINE, CINAHL EMBASE, CABI AMED, Health Source consumer edition, Health Source/ Advanced level edition and the Cochrane Central Register of Controlled Trials (CENTRAL) for adults living with COPD comparing home-based and community-based PR in low resourced settings in LMICs. The Cochrane database of systematic reviews was also searched to ascertain whether systematic reviews on this subject had been published and were duplicates. After the duplicate selection, data on exercise tolerance, health-related quality of life (HRQoL), breathlessness, included components, and mode of delivery were extracted. We utilised the Ryann to assess study quality and synthesise data narratively including Risk of Bias, the Ryan tool enabled us work seamlessly enhancing and conveniently.

Table 2.1 Shows the components that were utilised with a combination of relevant words of MESH terms and other vocabulary terms and include:
Chronic Obstructive Pulmonary Disease, Pulmonary rehabilitation, Home-based Pulmonary rehabilitation, community-based Pulmonary rehabilitation, and LMICs are all modified based on the databases were searched. We then studied the relevant reports from the reference list in the systematic review and scoped literature. We also manually studied abstracts presented at scientific conferences such as the European Thoracic Society, American Thoracic Society, and Pan Africa Thoracic Society. Finally, UpToDate was also utilised to find recent studies that fell within the inclusion and exclusion criteria to eliminate duplicates. We then reported the search results based on a Preferred Reporting ITEMS for Meta-Analyses statement (PRISMA).(91) (Appendix 2.2 and 2.3)

We chose to search multiple databases to ensure comprehensive coverage despite the limited literature. However, we acknowledge that excluding the African Journals Online (AJOL) database was a limitation. The review was restricted to studies from 2012-2024 to focus on contemporary evidence that would be most relevant to current healthcare systems and technologies, particularly given the rapid evolution of telehealth and remote rehabilitation approaches in the past decade.

Our search strategy incorporated MeSH terms (for PubMed) and equivalent controlled vocabulary for other databases, combined with appropriate Boolean operators (AND, OR). While we used broad geographical terms such as 'Africa' and 'low-resourced settings', we acknowledge that explicitly including all African country names would have enhanced the comprehensiveness of our search strategy.

Table 2.1 – Terms used for systematic search of relevant studies.

No	Keyword (MeSH or modified term for other databases)
#1	((Pulmonary) AND (Rehabilitation)
#2	(Home-based) OR (Community-based)
#3	COPD
#4	LIC
#5	Low resourced setting
#6	(Exercise capacity) OR (Health-Related Quality of Life)
#7	(((Pulmonary) AND (Rehabilitation))) AND (((Home-based) OR (Community-based)
#8	(((((Pulmonary) AND (Rehabilitation))) AND ((Home-based) OR (Community-based))
#9	(LMIC) OR (low-resource setting)
#10	(((((Pulmonary) AND (Rehabilitation))) AND ((Home-based) OR (Community-based))) AND ((LMIC) OR (low-resource setting))

2.2.4 Data Management

Three researchers (MI, AYZ, and JG) independently screened titles and abstracts against the inclusion and exclusion criteria. Full texts of potentially eligible studies were retrieved and independently assessed by two reviewers (MI and AYZ), with disagreements resolved through discussion or consultation with a third reviewer (JG). The selection process was documented using a PRISMA flow diagram.

We utilized Rayyan QCRI to record the search results from the electronic databases, removed duplicate studies from the various sources, and excluded studies based on title and abstract.

We then acquired data from the reviewed studies using a predesigned standardized data extraction form (Table 2). We then utilised a modified data extraction form from the Cochrane data collection form for RCTS (https://dplp.cochrane.org/data-extraction-forms) to assess the studies' eligibility and the study characteristics. Excluded studies did not require further filling of the study details.

(Table 2.2) was incorporated into a Microsoft Office spreadsheet to track the studies chosen for the review. A summary was included of the eligible studies in the systematic review. Overall, the process included data extraction using standardized forms, organization int structured tables, narrative synthesis of the key findings, thematic analysis of implementation features and a visualization of the results.

Table 2.2: Data Collection form

General Information		
Name of person extracting data Author Publication Status ☐ Published ☐ Unpublished Source ☐ Database (Specify) ☐ Hand-search ☐ Grey literature. Year of Study Year of publication (if present): Country of Study	Study ID:	
Study Eligibility: **Study Characteristics met? (Y/N/Unclear**	**Eligibility Criteria**	**Eligibility Criteria**
Type of Study: RCT ☐ Quasi-RCT ☐ Non-RCT ☐ Type of comparison: Type of outcome measures Inclusion status Include ☐ Exclude ☐ Reason for inclusion		
Study Characteristics-Methods		
Aim: RCT Design: Duration of Study: Ethical approval obtained (Y/N/Unclear:		
Study Characteristics- Participants		
Population Description: Setting: Inclusion criteria: Exclusion criteria: Informed consent (Y/N/Unclear): Age:		
Intervention Description		
Exercise: Type: Duration: Frequency Intensity: Supervision Supervised ☐ Unsupervised ☐ Guidelines: Control Description		
Outcome measures, unit, and tool		
CRF:		

Results		
Number of participants (n	Total:	Home-based, Community-based
Mean Age (SD):		
Exercise Capacity		
6MWT		
HRQoL		
Adherence n (%)		
Non-adherence n (%)		
Lost to follow-up n (%)		

2.2.5 Data Analysis

Risk of bias (RoB) assessment was utilised to avoid selection bias, performance, attrition, detection, and other biases. Studies which took steps to avoid bias were considered. Due to the nature of the interventions, studies that explicitly stated outcome assessment were blinded to allocation. Also, studies that had published protocols were assessed. We focused on exclusively English language (Anglophone) studies published from year 2012-2024. This data range ensured that the review incorporated current, pertinent literature, minimized language bias and enhanced acceptability and applicability to contemporary health care systems. Overall, three authors Moses Isiagi, Andre Yvan Zolo-Ossou and Jacob Gizamba reviewed and screened the titles and abstracts for inclusion and exclusion. (Appendix 2.2 and Appendix 2.3)

The 6 MWT, St George's Respiratory Questionnaire (SGRQ), and modified Medical Research Council (mMRC) was evaluated in the papers to assess functional capacity and breathlessness, respectively, between the group and within-group comparisons were compared. Furthermore, contrasts in terms of mode of intervention, duration, setting, comparator, and baseline measurements were assessed to ascertain if a decision to undertake a meta-analysis would suffice. Studies were assessed based on whether outcomes were positive (that is, interventions were significantly beneficial), negative (interventions were significantly harmful) or had no effect. Changes in functional capacity were measured.

2.2.6 Components of the Intervention

All the interventions entailed exercise and non-exercise components, including.

Exercise Components:

- Endurance training (including interval training), resistance/ strength training, upper limb exercise, flexibility training, breathing exercises.

Other components:

- Pursed-lip breathing, diaphragmatic breathing, knowledge (disease/medication), skill acquisition (airway clearance, inhaler technique, use of oxygen), psychological interventions (CBT, relaxation, coping strategies (pacing, energy conservation), Nutrition, Physical Activity (unsupervised exercise), smoking cessation, self-management, social support (including walking aids), pharmacological optimisation.

2.2.6 Models of Care

The studies included two major PR models according to the settings in which they are delivered.

- Primarily home-based rehabilitation
- Community-based rehabilitation.

The program setting, duration and intervention type, frequency and session duration, supervision was reported, coupled with adherence to the PR.

2.3 Results

2.3.1 Studies selection

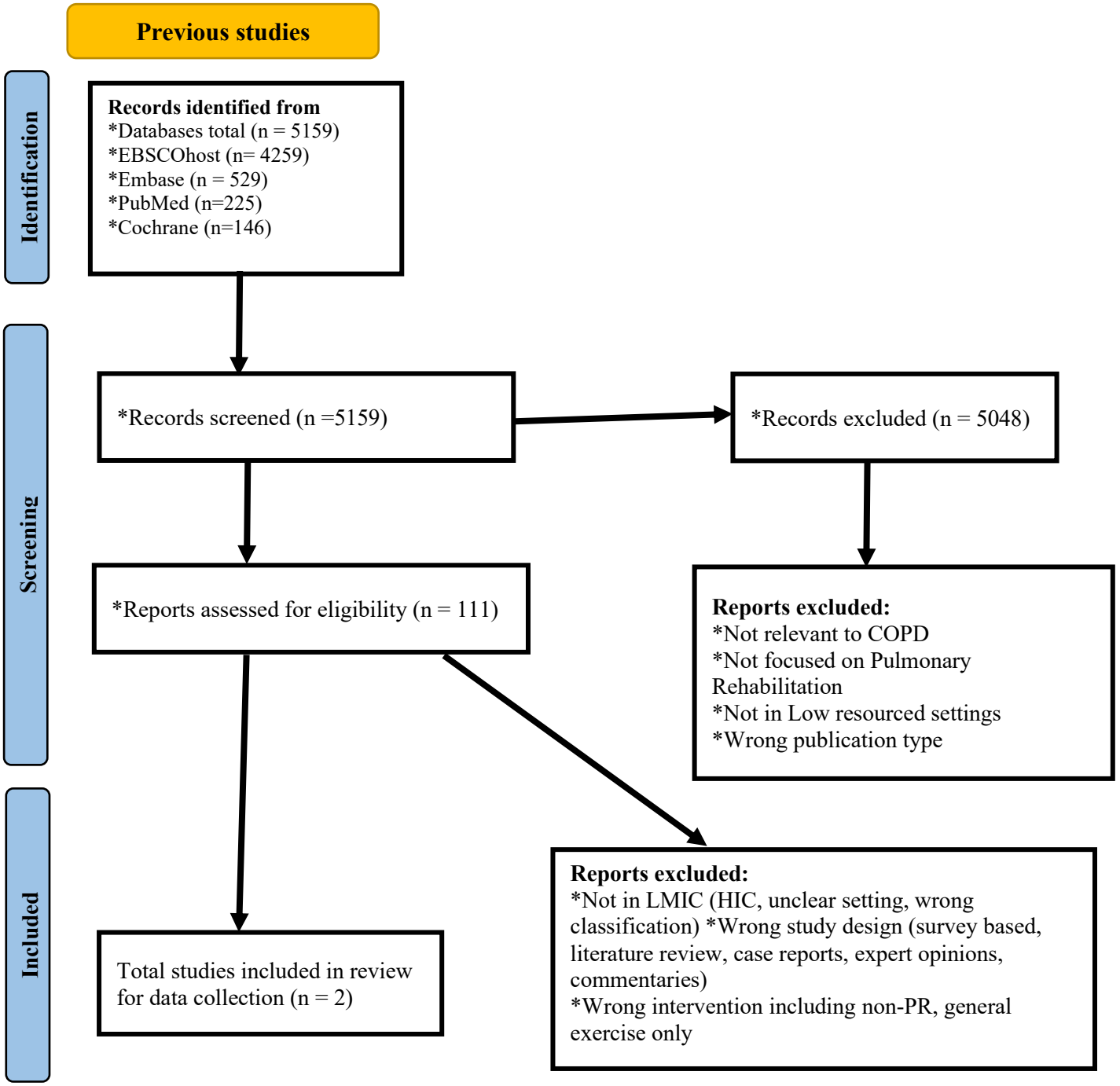

Figure 2.1 Flow chart of study selection : Source: Page MJ, et al. BMJ 2021;372: n71. doi: 10.1136/bmj. n71.

The data base search yielded 5159 in total. For a PubMed search history (Appendix 2.4), There were 225 studies related to the search terms between 2012-2024. Upon including developing/ LMICs, we got 0 studies. The Cochrane database (Appendix 2.5) had 146 studies related to our search terms of interest between 2012-2024, upon including developing/ LMICs, we again got 0 studies. The Embase search (appendix 2.6) had 529 studies related to your search terms of interest between 2012-2024. Like the previous searches, once we included developing/ LMICs, we got 0 results. Finally with EBSCOhost search history (Appendix 2.7), we got 4259 studies related to our search terms of interest between 2012-2024. When we restricted the studies to LMICs, 111 were deemed eligible and we included them.

Characteristics of the included studies and results of the synthesis

Two studies were included in the final synthesis. The two included studies, while not directly evaluating PR for COPD, were included as they provided relevant contextual insights.

The first study was a systematic review which investigated the impact of humanitarian disasters on NCDs in LMICs.(92) This study was included because it provided valuable information on managing chronic diseases in humanitarian settings in LMICs, offering transferable lessons for PR implementation. It evaluated the epidemiology, interventions, and treatment options concerning NCDs in disaster affected settings, with the aim of guiding future research endeavours. Of the 85 publications included in the review, the majority were observational studies, with half (48.9%) originating from the Eastern Mediterranean Region (EMRO). The study showed a notable lack of research from African regions. The findings reveal that NCDs represent a significant burden of populations impacted by humanitarian crises, despite limited availability of data from specific regions and disease categories. While most of the studies offered important epidemiological insights regarding the burden of disease, a few addressed the clinical management or the implementation of effective interventions.

The second study included was a home-based cardiac rehabilitation in Brazil's Public Health Care: Protocol for a Randomized Controlled Trial (an LMIC country).(93) The second study was included despite its cardiac focus because it represented one of the few rehabilitation intervention protocols specifically designed for a LMIC context with similar resource constraints to our target setting.

The cardiac rehabilitation model offered valuable transferable insights for PR implementation, given the similarities in exercise components, multidisciplinary approaches, and resource requirements between cardiac and pulmonary rehabilitation. It presented a present a two-arm, single-blinded, and randomized controlled design protocol, which would compare the traditional cardiac rehabilitation (centre-rehab) with the home-based cardiac rehabilitation (home-based) in 72 patients affected by coronary artery disease (CAD). A summary of this study is explained in Table 2.3.

Table 2.3: Summary of Home-based Cardiac Rehabilitation in Brazil's Public Health Care: Protocol for a Randomized Control Trial.

Category	**Details**
Study Title	Home-based Cardiac Rehabilitation in Brazil's Public Health Care: Protocol for a Randomized Control Trail.
Setting and Region	*Brazil (Belo Horizonte metropolitan region). *Public hospital setting. *Low/ middle income country context.
Study Design	*Two-arm, single-blinded randomized controlled trial. *Duration:12 weeks intervention +3 months follow up.
Sample size	72 participants (36 group).
Objectives	*Verify patient compliance with home-based cardiac rehabilitation. *Compare effectiveness between the home-based and traditional centre-based rehabilitation. *Evaluate the feasibility of accessible, low-cost technology.
Intervention Groups	**Home-based group**: 2 supervised + 58 home sessions, *Weekly phone monitoring. *Heart rate monitor and pedometer use. *6 educational sessions. **((Control Group) (Traditional cardiac rehabilitation**): *24 supervised + 36 home sessions, *Face-to face-centre supervision, *6 educational sessions.
Primary Outcomes	*Compliance with cardiac rehabilitation sessions (≥75% completion.
Secondary Outcomes	*Functional capacity (6-minute shuttle test), *Cost analysis *Morbidity, *Cardiovascular risk factors, *Quality of Life, *Depression levels, *Physical activity level, *Disease knowledge, *Equipment usability (home group)
Limitations	*Only includes low/moderate risk patients. *Limited to one metropolitan region. * May not be generalizable to high-risk patients or other settings.
Strengths	*First Brazilian study on remote cardiac rehabilitation using accessible technology. *Addresses accessibility barriers in low-resourced African settings. *Practical solution for increasing rehabilitation participation.

Table 2.4: Summary of The Impact of Humanitarian Disasters on NCDs in LMICs: A Systematic Review.

Category	Details
Study Title	The Impact of Humanitarian Disasters on NCDs in Low- and Middle-Income Countries: A Systematic Review
Setting and Region	Multiple LMICs with focus on disaster-affected regions * 48.9% from Eastern Mediterranean Region (EMRO) * Limited studies from African regions
Study Design	Systematic review * 85 publications included * Majority were observational studies
Sample Population	Populations affected by humanitarian disasters * Focus on NCD burden and management
Objectives	Evaluate epidemiology of NCDs in disaster settings * Assess interventions and treatment options * Identify research gaps * Guide future research priorities
Key Findings	NCDs represent significant burden in humanitarian crisis contexts * Limited data from specific regions (particularly Africa) * Most studies focus on epidemiology rather than interventions * Few studies addressed clinical management or implementation
PR-Relevant Insights	Highlights challenges of chronic disease management in resource-constrained settings * Emphasizes need for contextually appropriate interventions * Demonstrates transferable lessons for PR implementation in complex environments
Limitations	Limited intervention studies * Regional imbalance in research coverage * Focus on general NCDs rather than respiratory conditions specifically
Relevance to this Review	Provides contextual understanding of healthcare delivery challenges in LMICs * Offers implementation insights for chronic disease management in resource-limited settings * Highlights importance of adapting interventions to local contexts

2.4 Discussion

Two insightful studies underpin our final synthesis, but there are no published studies that directly compared home-based and community-based PR programmes in low-resourced African settings. This underscores the significant knowledge gap regarding PR implementation models specifically tailored for African contexts.

It is important to acknowledge the apparent inconsistency between the studies cited in Chapter 3 (32,73) and their exclusion from this systematic review.

These studies were excluded from the present review because they did not meet our specific inclusion criteria of comparing home-based versus community-based PR or evaluating either approach in isolation. The Bickton et al. (2020) review synthesized evidence on PR generally in sub-Saharan Africa but did not focus specifically on home-based or community-based delivery models.(32) Similarly, the Bilungula et al. (2022) study assessed the general state of PR in Africa but did not evaluate specific delivery models.(73) This highlights a limitation of our narrow inclusion criteria and suggests that a broader approach incorporating various types of evidence might have yielded more comprehensive insights.

There are no studies that assesses the effectiveness of home-based and community-based PR programmes for COPD patients in low resourced settings in Africa. In addition, there are no published studies that compares these two models of PR delivery. The closest study to PR is a protocol for a randomized controlled trial titled "Home-Based Cardiac Rehabilitation in Brazil's Public Health Care," focused on comparing traditional cardiac rehabilitation with home-based approaches among 72 patients with coronary artery disease (CAD).
Previous reviews have combined home-based and community-based interventions due to their overlapping nature.(72) However, in our systematic review, we attempted to distinguish between these approaches to provide clarity on their specific implementation in African contexts, although this proved challenging due to limited evidence.
The lack of published studies underscores the need for Pulmonary rehabilitation programmes to be adapted to the African continent and should be in the local context while maintain the clinical effectiveness.

2.4.1 Lessons from the Brazilian Protocol

The lessons from the Brazilian protocol for PR Implementation in Africa and LMICs include.

- ***Accessibility and reach***: It is possible to implement rehabilitation that focuses on overcoming barriers in low resourced settings with limited technology requirements.
- ***Technology Integration***: It is possible to implement home-based rehabilitation with basic technology that includes phone-based monitoring and limited digital requirements.
- ***Cost Implications:*** It is possible to focus on low-cost solutions like Citizen science that has minimal equipment requirements and would require less staff and expertise to implement.

- ***Monitoring and safety:*** It is possible to implement PR with limited direct supervision that focuses on low/moderate risk patients.
- ***Program structure:*** It is possible to have a mix of supervised and home sessions for a 12-week program that has an educational component in it.
- ***Community system/ Citizen science integration:*** It is possible to collaborate with the community and integrate them through a Citizen science approach whilst working with limited resources.

2.4.2 Comparative Analysis of PR Models in LMICs

Although our systematic review did not identify studies directly comparing home-based and community-based PR models in African settings, the Bickton et al. (2020) review provides valuable insights into the general state of PR implementation in sub-Saharan Africa.(46)

Their review identified eight studies (six from South Africa, one from Uganda, and one from Kyrgyzstan) that evaluated various PR approaches in these regions.

Key findings from the Bickton review relevant to our analysis include:

1) ***PR Effectiveness in African Contexts:*** The review demonstrated that PR is feasible and effective in improving exercise capacity and quality of life for patients with chronic respiratory diseases in sub-Saharan African settings, albeit with some adaptations to local contexts.
2) ***Implementation Models:*** While not directly comparing delivery models, the review documented various implementation approaches: hospital-based outpatient programs (predominant in South Africa), mixed models combining facility-based and home-based components (Uganda), community health worker-supported interventions (Kyrgyzstan).
3) ***Resource Adaptations:*** The studies highlighted creative adaptations to resource constraints: Use of local materials for exercise equipment, integration with existing healthcare infrastructure, simplified exercise protocols requiring minimal equipment, group-based approaches to maximize supervision with limited personnel
4) ***Implementation Barriers:*** Common barriers to PR implementation identified across studies included: Limited trained personnel, resource constraints (equipment, facilities).transportation challenges for patients, low awareness among healthcare providers, financial sustainability challenges.

5) ***Cultural Considerations:*** The review emphasized the importance of cultural adaptations to PR programs: Incorporating locally relevant activities, addressing language barriers in educational materials, considering family and community dynamics in program design

While our focused search strategy did not yield studies meeting our specific comparative criteria, we acknowledge that there is emerging evidence on PR implementation in LMICs more broadly, as documented in the Bickton et al. (2020) review.(32) This existing literature, while not specifically comparing delivery models, provides valuable context for developing contextually appropriate PR programmes in Africa.

2.5 Limitations

One outstanding limitation of this review is the decision to limit the studies to only those published in English due to our pre-set goal. This approach might restrict the inclusion of non-English based research, thereby excluding potentially significant data related to COPD and PR in non-English speaking and LMICs. Such reliance on English based studies may introduce a potential publication bias, resulting in the omission of unpublished or less accessible studies which could skew the overall data and findings. Furthermore, the variability of the designs of the included studies presents challenges in the synthesis and interpretation of the collected data.

Our search strategy may have been overly restrictive in focusing exclusively on the comparison between Home-based and community-based PR for COPD in Africa. Broadening the scope to include similar respiratory rehabilitation interventions or adaptable models from other chronic conditions might have yielded more transferable insights.

While a scoping review might have been more appropriate given the limited literature on PR in Africa, we opted for a systematic review to maintain methodological rigor. This approach allowed us to definitively document the absence of studies comparing home-based and community-based PR in low-resourced African settings, thereby establishing a clear knowledge gap and foundation for future research.

2.5.1 Critical Reflection on Methodological Choices

The decision to focus exclusively on RCTs and assess 'effectiveness' reflects an uncritical application of Western research hierarchies that may not be appropriate for understanding PR implementation in African contexts. A more inclusive approach incorporating grey literature, implementation reports, and local knowledge sources would have provided a more comprehensive understanding of PR services in these settings.

In retrospect, this methodological choice represents a tension between adhering to conventional systematic review standards and adapting research approaches to the realities of healthcare research in low-resourced settings. The evidence hierarchy that prioritizes RCTs may be well-suited to established healthcare interventions in high-income countries but fails to capture the nuanced implementation experience in contexts where formal research infrastructure is limited.

Furthermore, our emphasis on effectiveness outcomes rather than implementation processes potentially missed valuable insights about contextual adaptations and feasibility considerations that would be particularly relevant to developing PR programs in African settings. The decision to exclude non-English language publications, while pragmatic, likely excluded relevant research from Francophone and Lusophone African countries.

These limitations highlight the need for research methodologies that balance scientific rigor with contextual relevance when studying healthcare interventions in low-resourced settings. Future reviews might consider employing realist review methodologies, mixed-methods approaches, or implementation science frameworks that are better equipped to address the complex interplay of contextual factors affecting intervention success in these settings.

2.6 Recommendations for Pulmonary rehabilitation in Africa and LMICs

The recommendations for PR in Africa based on the Brazilian protocol should include the following:

Programme structure and delivery.

It should have a home-based focus with a minimal 2-3 supervised sessions for assessment and education coupled with 12 week programmes with structured progress.(94) It should also entail resource optimization that includes training Citizen scientists/health workers to support PR delivery while utilizing the existing structures in their communities.(55,59)

Monitoring and use of Technology.

Usage of simple pulse oximeter and implementation of phone-based follow up that includes usage of what's app groups that support monitoring.(95) Documentation that includes simple based exercise diaries that also have pictorial exercise guides could come in handy coupled with basic symptom tracking tools.(96)

Cultural Adaptation.

Incorporating locally relevant activities and co-developing and co-creating activities, (Citizen science)(97) with available household items for resistance training is key and these exercises should be suitable for the local environments including walking and functional strength exercises which should adapt the intensity based on monitoring tools.(95)

Education and Self-Management.

It should cover community perceptions and awareness of COPD including basic disease understanding, stigma, symptom management medication use, diagnosis, Pulmonary rehabilitation and this can be done by using community participatory research and Citizen science,(59,97) and this encourages the community to produce culturally appropriate educational materials that utilise the local language and involve loved ones.

Implementation strategy.

Starting with pilot programmes would be key and should be started in urban centres then expanded to rural areas and these should be integrated with existing health programmes or involve co-creating aspect with the community members.(55,59)

Monitoring and evaluation.

It would need to monitor outcome measures with simple functional tests and monitor symptoms(98,99) with validated scales(98,99) which would be able to track adherence. This should be followed up by a regular program review(52) that encompasses the community and has participant feedback.(59,97)

2.7 Conclusion.

This systematic review demonstrated a significant gap in literature directly comparing home-based and community-based PR programmes in low-resourced African settings. While our focused search strategy did not yield studies meeting our specific comparative criteria, we acknowledge that there is emerging evidence on PR implementation in LMICs more broadly, as documented in the Bickton et al. (2020) review.(46) This existing literature, while not specifically comparing delivery models, provides valuable context for developing contextually appropriate PR programmes in Africa.

There is a need to develop contextually appropriate PR programmes in Africa and draw lessons from the successful homebased models in high-income countries and whilst be conscious of local resources and constraints. There is an opportunity to develop culturally appropriate education material through the Citizen science model which utilises co-creation and co-designing.

CHAPTER 3

PULMONARY REHABILITATION ACROSS AFRICA: A CONTINENTAL EVALUATION OF HEALTH CARE PROVIDERS' AWARENESS, AVAILABILITY, UTILIZATION AND BARRIERS TO ACCESSING PULMONARY REHABILITATION.

Preamble: A manuscript was successfully developed from the data obtained from this aspect of the thesis. This manuscript has been accepted (after thorough editorial reviews) for publication in a peer-reviewed Journal (African Journal of Thoracic and Critical Care Medicine).

3.0 Background

It is important to recognise the rising concern of pulmonary diseases, which are widespread causes of morbidity and mortality globally. Chronic respiratory diseases, including both obstructive and restrictive diseases such as asthma, post-TB lung disease, bronchiectasis, and pulmonary fibrosis, are on the rise and have a significant impact on public health. Chronic obstructive pulmonary disease (COPD) is the most common chronic respiratory disease, with an exponentially increasing global prevalence of 12.2%.(2) COPD currently affect 65 million people, resulting in about 3 million deaths annually.(79) The burden of COPD is high, and the World Health Organization (WHO) estimated a rise in COPD mortality from the 4th leading cause of death in 2004 to 3rd leading cause by 2030, with over 90% of the morbidity and mortality related to COPD occurring in low-middle-income countries (LMICs)(1)(2) Unfortunately, in the LMIC settings, there are significant gaps in COPD prevention and management, including understanding its diagnosis, treatment, and prevention.(1,3)

Despite this challenge, COPD remains underdiagnosed and untreated in most countries, particularly LMICs, partly due to low diagnostic capacity and inadequate therapy compared to high-income countries.(3) In addition to historically prevalent infectious diseases like pneumonia and tuberculosis, causing respiratory morbidity.(13)

While communicable diseases like tuberculosis (with 1.2 million deaths annually in LMICs) have historically dominated respiratory health priorities in Africa, COPD now affects an estimated 26.4 million people across the continent (4.1% prevalence) and causes approximately 237,000 deaths annually in Africa. This represents a 102.1% increase in COPD-related mortality since 1990, significantly outpacing increases in TB mortality (17.9% increase over

the same period). Despite this substantial burden, COPD remains severely underdiagnosed, with studies suggesting that 70-80% of COPD cases in African settings remain undetected and untreated.(13)(49)

Management efforts to contend with this increased burden on LMICs are mainly directed toward pharmacological treatment.(13) but some patients may require hospitalisation for several reasons, including the severity of symptoms, failure to respond to initial treatment, poor or low-resourced home-based care, and the presence of comorbidities, which are long-term conditions associated with disabilities. (13)(100)

This highlights the need to address the rising burden of pulmonary diseases in LMICs, including improved access to diagnostic tools and effective therapy.

The complexity of the respiratory disease burden in Africa is summarised as follows:

- The dual burden of infectious diseases (tuberculosis, pneumonia) and rising non-communicable respiratory conditions.
- Limited health care resources and diagnostic capabilities.
- Barriers to accessing specialized care.
- Growing urbanization and environmental risk factors.

The World Health Organization's Rehabilitation 2030 initiative specifically highlights workforce capacity as a distinct challenge from access to specialized care. While access refers to the availability of services, workforce capacity encompasses the presence of appropriately trained personnel to deliver those services.(74) In the African context, training community health workers to deliver aspects of PR under supervision has been proposed as a potential solution to workforce limitations, potentially extending the reach of rehabilitation services beyond specialized centres.

It is imperative that healthcare professionals explore the optimal combination of pharmacological and non-pharmacological treatment strategies, including lifestyle changes, to manage COPD) effectively. While clinical guidelines for managing COPD provide evidence-based recommendations, significant gaps still exist in their implementation.(101) For instance, Pulmonary rehabilitation (PR) has emerged as a general standard of care for patients with chronic lung disease based on a growing body of scientific evidence.(29)

However, there are some known barriers to implementing PR in low-resourced African settings such as limited resources, lack of awareness, and patient-related costs.(46,102)

PR, as defined by the American Thoracic Society (ATS) and the European Respiratory Society (ERS), encompasses a "comprehensive intervention tailored to the individual patient, including exercise training, education, and behaviour change, designed to improve the physical and psychological condition of people with chronic respiratory disease and to promote the long-term adherence of health-enhancing behaviours."(17) PR has demonstrated physiological, symptom-reducing, psychosocial, and health-economic benefits for patients with chronic respiratory diseases.(25) As such, it is recommended as a standard of care alongside other well-established non-pharmacological interventions,(32) such as smoking cessation, (33) reduction of other risk factors (e.g., exposure to open cooking fires),(32) and influenza vaccination.(35) PR is considered a critical and integral component of integrated patient management and usually involves a range of healthcare professionals to ensure optimal outcomes.(86,87)

The multi-disciplinary team commonly involves pulmonologists, physical medicine specialists, social workers, psychologists, nurses, respiratory therapists, occupational therapists, physiotherapists, general practitioners, pharmacists and dieticians.(86)
The essential components of PR are summarized as follows.

Comprehensive patient assessment

- Respiratory symptoms and exacerbation history.
- Exercise capacity and muscle function evaluation.
- Physical activity level measurement.
- Quality of life assessment.
- Anxiety and depression screening.
- Activities of daily living evaluation.

Tailored Interventions

- Structured exercise training.
- Patient education programmes.
- Self-management strategies.
- Psychological support.
- Nutritional counselling when indicated.

Even with this level of evidence, PR needs to be more utilized worldwide.(86) A lack of resources, funding, and reimbursement coupled with a lack of health care professional/payer/ and patient awareness and knowledge has contributed to the gap between understanding and delivery to suitable patients.(25) (41) (86)

In Africa, there is very limited empirical evidence of the utility and availability of PR. A systematic review that synthesized the evidence and efficacy of PR in sub-Saharan Africa between 1997 and 2019 only got data from three countries in the region.(55,77) Additional recent studies have further highlighted the limited implementation of PR programs across the continent, with particular challenges noted in workforce capacity and resource availability. (76,77,103) This underscores the need for more evidence-based research and an understanding of Africa's barriers to PR implementation. This chapter aimed to explore the clinical awareness, knowledge, utilisation, and barriers to PR implementation in (Health care practitioners) HCPs actively involved in respiratory care across Africa.

3.1 Methods

We conducted a cross sectional virtual electronic survey between January and March 2020 targeting African clinicians within the networks of the Pan-African Thoracic Society and South African Thoracic Society. The survey was adapted from a previous survey (54) and the content was validated to an African context through an expert panel review of two professors pulmonologists, a professor of exercise science, a physiologist, a physiotherapist senior lecturer, two biokineticists. It was then piloted to 8 health care providers and refined based on the pilot feedback and the final revision was based on the expert input. Two reminder emails at 2 weeks intervals were sent to the PATS and SATS members. We had real time data validation, weekly completeness checks and monthly quality assurance reviews. The inclusion criteria were active membership in PATS and SATS, with current involvement in respiratory care and working in an African healthcare setting.

The questionnaire was distributed to doctors, nurses, and allied health workers across Africa. An email invitation was sent through the distribution channels of the Pan African Society, the South African Thoracic Society, and allied networks. This email included the background and aims of the study, the hypothesis, research questions and implications. (Appendix 3.1) If the HCPs decided to take part, their participation would be anonymous, with only ages and country of practice being discernible personal identifiers. The University of Cape Town's Faculty of Health Sciences Human Research Ethics Committee (HREC863/2019) approved the study. (Appendix 3. 2 and its subsequent renewal Appendix 3.4)

The questionnaire included demographic information: speciality, age, gender, and additional practice-related information, including practice site (rural/urban/suburban) and practice location (what country). Specific questions about PR included if the HCPs had access to PR and if they had access to PR guidelines. It further queried if they utilised spirometry in their respective practices and whether lack of PR knowledge was a barrier. (Appendix 3.4)

The second set of questions interrogated their knowledge of COPD treatments, including whether treatments were effective for symptom improvement, decreased exacerbations, and improved longevity in diseased pulmonary patients. The third set of questions interrogated the tests and factors they deemed essential in making COPD diagnosis, and these included having access to chest x-ray, a trial of corticosteroids coupled with whether patients had ready access to a trial of bronchodilators and if they had the means to screen for Alpha-1 Antitrypsin Deficiency. The fourth and last set of questions interrogated their perceived barriers, attitudes and beliefs, barriers related to pulmonary diseases and its treatment, including differentiation in symptoms, the effectiveness of treatment and how it impacted making a diagnosis. In addition, we also interrogated the ease of spirometry to ascertain if it this hampers the ability to diagnose and rehabilitate the patients.

3.1.2 Data Analysis

Simple descriptive statistics were used to illustrate the demographic characteristics of the responders and the distribution of their responses to the knowledge and attitude questions. Additionally, a comparison of knowledge and attitude responses across different areas of practise, genders and locations using a Chi-square test to assess statistical significance at $p<0.05$ level. All data were analysed using Statistica version 14.0. 1 - July 2022. Stat Soft ® 2022Windows developed by IBM Corp in New York).

Given the categorical nature of most variables and the exploratory purpose of the survey, we primarily utilized chi-square tests for comparisons between groups. The analysis focused on describing patterns rather than testing specific hypotheses about differences between professional groups or regions. Non-parametric tests were considered but not utilized due to the descriptive nature of the study and small subgroup sample sizes.

Chi-square tests were employed to compare responses between urban and suburban/rural practitioners to identify potential geographic disparities in PR knowledge, resources, and implementation barriers. These comparisons are valuable for understanding whether contextual factors influence healthcare providers' experiences and perspectives regarding PR, which could inform targeted implementation strategies for different settings. However, I acknowledge the limited inferential value of these comparisons given the exploratory nature of the survey and the relatively small sample sizes in some subgroups. The primary purpose of these analyses was to generate hypotheses for future research rather than to draw definitive conclusions about differences between settings.

3.2 Results

A total of 110 responses were received from the combined 196 practitioners of PATS and SATS, indicating a response rate of 56% for this study (Table 1). This represents a robust response rate significantly exceeding typical survey response rates in healthcare research, which often fall below 30%. The strong response rate suggests considerable interest in PR among respiratory healthcare practitioners in Africa and enhances the generalizability of our findings within this specific professional network.

Two of the questionnaires completed had insufficient data to be included in the data analysis, and we omitted in the analysis. Among the 108 complete responses, 73 (67.6%) were male and the median (IQR) age was 41.0 years (37.0, 48.5) with no significant differences between the urban and suburban/rural locations. More than two-thirds of the HCPs (78%) reported having access to PR practice guidelines, although less than half (47%) overall reported having access to PR, including equipment and practice.

3.2.1 Healthcare Practitioners' Knowledge and Attitudes toward PR

The 108 HCPs were distributed across 23 different African countries and constituted more than 30 professions. The details are summarised in Figure 3.1 and Table 3.2 below. Additionally, Table 3.3 provides the further details on the PATS and SATS registrations with the Health Practitioners Council of South Africa (HPCSA) and their respective practice fields.

Table 3.11: Demographic information of respondents

	Urban (N=94)	**Suburban/ Rural (N=14)**	**Combined (N=108)**	**P-value**
Age, median (Q.I., Q3)	41.0 (37.0, 48.8)	45.0 (36.0, 48.0)	41.0 (37.0, 48.5)	0.706
Men	61 (64.9%)	12 (85.7%)	73 (67.6%)	0.120
Do you have access to Pulmonary practice guidelines?	72 (76.6%)	13 (92.9%)	85 (78.7%)	0.166
Do you have access to Pulmonary rehabilitation?	43 (45.7%)	8 (57.1%)	51 (47.2%)	0.425
Do you utilise spirometry in your practise?	72 (76.6%)	11 (78.6%)	83 (76.9%)	0.870
Is lack of Pulmonary rehabilitation knowledge a barrier to your practice?	55 (58.5%)	8 (57.1%)	63 (58.3%)	0.923

Demographic information of respondents

Data presented as median (interquartile range) for age and count (percentage) for all categorical variables. For rows 3-6, values represent number and percentage of respondents answering 'Yes' to each question. % (refers to specific number/total number x 100). $p < 0.05$ is statistically significant

For the purpose of this analysis, we categorized healthcare practitioners into five groups: pulmonologists (n=18, 17%), medical doctors not specialized in pulmonology (n=25, 24%), physiotherapists (n=11, 10%), nurses (n=5, 5%), and other allied health professionals (n=48, 44%). While physiotherapists and nurses can be considered allied health professionals in some classification systems, we categorized them separately due to their distinct roles in PR delivery. The 'other allied health professionals' category included occupational therapists, pharmacists, respiratory therapists, clinical technologists, and various other specialties.

Descriptive statistics were calculated using Statistica version 14.0.1, with categorical variables presented as counts and percentages, and continuous variables presented as median and interquartile range due to non-normal distribution. Comparisons between groups were performed using chi-square tests for categorical variables and Mann-Whitney U tests for continuous variables.

The professional distribution detailed in Table 3.2 is summarised as follows:

- Pulmonologists:18 (17%)
- Medical doctors: 25 (24%)
- Physiotherapists :11 (10%)
- Nurses: 5 (5%)
- Other allied health professionals: 48 (44%)

3.2.2 Diagnostic Practices and Resources

Table 3.2: Professions of the HCPs distributed across the Africa region.

Profession	Number	Profession	Number
Allergist	1	Paediatric pulmonologist	2
Allied health worker	1	Paediatric pulmonologist and critical care	1
Cardiothoracic surgeon	3	Pharmacist	1
Chest physician	1	Physician	7
Clinical exercise physiologist	1	Physiatrist (physical medicine and rehab)	1
Clinician	1	Physician: physiology and functional explorations	1
Clinician and public health practitioner	1	Physiotherapist	10
Consultant physician	1	Pneumologist	1
Consultant pulmonologist	1	Private respiratory nurse practitioner	1
Medical doctor	24	Public health	1

General practitioner	1	Public health clinical specialist	1
Health expert and advocate	1	Public health epidemiologist	1
Internal medicine doctor	1	Public health physician	1
Internist, pulmonary and critical care subspecialist	1	Public health specialist	2
Medical doctor (paediatrician)	1	Pulmonary and critical care physician	2
Medical educator (paediatrician and lecturer)	1	Pulmonologist	17
Medical practitioner	1	Research assistant	1
Medical public health physician	1	Research and clinician	1
Nurse	4	Researcher	1
Nurse specialist in anaesthesia and critical care	1	Respiratory physiotherapist	1
Occupational medicine specialist	2	Respiratory therapist Respiratory physiotherapist	1
Paediatrician	1	University professor	1
Person-centred care management	1	Paediatric pulmonologist	1
		Total	**108**

Values represent the number of respondents in each self-reported professional category.

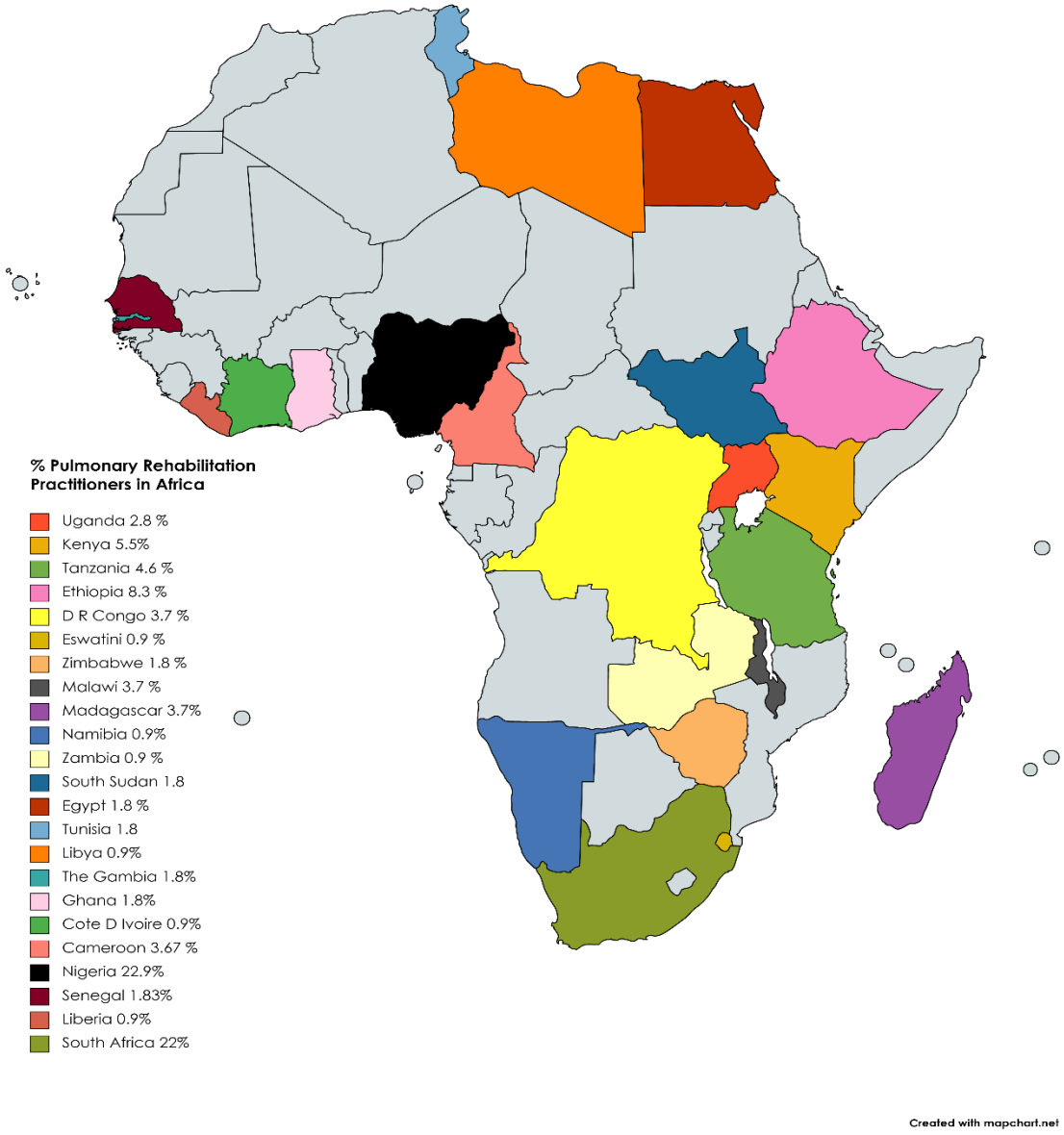

Figure 3.1: Respondents' countries and frequencies of their responses

The geographic distribution is summarised as follows: Southern Africa: 45%; East Africa: 25%; West Africa: 20%; North Africa: 10%. . It is important to note that while all respondents were involved in respiratory care through their PATS or SATS membership, not all were PR practitioners specifically. The survey included questions about respondents' involvement in PR delivery, which allowed us to identify that only 32% of respondents had direct experience delivering PR services, highlighting the limited availability of specialized PR practitioners across the continent

Table 3.3: Demographics of the PATS and SATS members registered with the Health Professionals Council of South Africa and their field of Profession. HPCSA-registered PATS and SATS members

	PATS			SATS			PATS and SATS
Registered Professions	Female	Male	Total	Female	Male	Total	Total
Clinical technologist	1		1	5	4	9	10
Medical practitioner	4	5	9	12	10	22	31
Occupational medicine specialist					1	1	1
Physiotherapist				1		1	1
Pulmonologist	1	1	2	1	7	8	10
Specialist	5	5	10	9	30	39	49
Sub specialist	9	12	21	13	38	51	72
Supernumerary registrar					1	1	1
(Blank)	2	1	3	11	7	18	21
Total	22	24	46	52	98	150	196

PATS and SATS Field of Practise	**PATS**			**SATS**			**PATS and SATS**
Fields of practise	**Female**	**Male**	**Total**	**Female**	**Male**	**Total**	**Grand total**
Adult pulmonology	9	17	26	21	56	77	103
Anaesthesiology					2	2	2
Cardiopulmonary physiotherapy, Pulmonary rehabilitation	0	0	0	1	0	1	1
Clinician / Researcher	0	0	0	1	0	1	1
Clinical research/general practitioner	0	0	0	1	0	1	1
Clinical technology	1		1	5	4	9	10
Clinical trials	0	0	0	1	0	1	1
Histopathologist	0	0	0	1	0	1	1
Internal medicine	0	2	2	0	7	7	9
Occupational medicine	0	0	0	1	0	1	1
Paediatric pulmonology	9	3	12	9	12	21	33

Research	0	0	0	0	1	1	1
Thoracic surgery		1	1	1	2	3	4
(Blank)	3	1	4	10	14	24	28
Total	22	24	46	52	98	150	196

A substantial (87%) of the HCPs expressed strong agreement on the effectiveness of COPD treatments in alleviating symptoms related to pulmonary diseases, while a majority (98%) acknowledged their role in reducing exacerbations (Table 3.4). Furthermore, most HCPs emphasized the necessity for Pulmonary rehabilitation for patients with pulmonary diseases (97%), with 87% sharing the belief that these treatments contributed to reduced patient mortality.

Table 3.4: Value of the HCPs placed on COPD treatment.

	Urban (N=94)	**Suburban/ Rural (N=14)**	**Overall (N=108)**	**p-value**
Are treatments effective for symptom improvement in pulmonary diseases?	68 (86.1%)	11 (91.7%)	79 (86.8%)	0.594
Do treatments decrease exacerbations in pulmonary disease patients?	78 (98.7%)	12 (100.0%)	90 (98.9%)	0.695
Do treatments improve longevity in pulmonary disease patients?	69 (87.3%)	10 (83.3%)	79 (86.8%)	0.702
Is Pulmonary rehabilitation necessary for pulmonary disease patients?	77 (97.5%)	12 (100.0%)	89 (97.8%)	0.577
Do you believe pulmonary diseases primarily affect men?	27 (34.6%)	3 (25.0%)	30 (33.3%)	0.511
Do you believe that Pulmonary conditions are usually symptomatic after 60?	33 (41.8%)	5 (41.7%)	38 (41.8%)	0.994

% (refers to specific number/total number x 100). Values represent proportion of respondents answering 'Yes' to each item. $p < 0.05$ is statistically significant.

Chest X-ray was identified as the most employed diagnostic tool, for COPD with 94.4%) of HCPs reporting access and utilization of this modality, and these results were not different by location (Table 5). Furthermore, 80% of the HCPs indicated availability of a trial of bronchodilators. Notably, the utilization of a trial of bronchodilators for COPD diagnosis was more prevalent among suburban and rural clinicians, with the utilization rates of 100% and 77.6% respectively, in contrast to urban clinicians.

Table 3.5: Tests and factors HCPs consider important in making COPD diagnosis.

	Urban (N=94)	**Suburban/ Rural** (N=14)	**Overall** (N=108)	**p-value**
Do you have ready access to chest X-rays?	80 (94.1%)	14 (100.0%)	94 (94.9%)	0.352
Do you have ready access to a trial of corticosteroids?	63 (75.0%)	13 (92.9%)	76 (77.6%)	0.138
Do patients have ready access to a trial of Bronchodilators?	66 (77.6%)	14 (100.0%)	80 (80.8%)	0.049
Are you easily able to screen for Alpha-1 Antitrypsin Deficiency?	22 (25.9%)	5 (35.7%)	27 (27.3%)	0.444

% (refers to specific number/total number x 100). Values represent proportion of respondents answering 'Yes' to each item. $p < 0.05$ is statistically significant.

The significant barriers perceived by HCPs in administering and implementing PR include patients under-reported symptoms (74%), patients having multiple chronic conditions (71%) and a lack of effective treatment, which impacts the urgency to make a diagnosis (67%) (Table 6). Additionally, more than half (52%) reported that lack of access to spirometry hampered the diagnostic process and follow-up, especially concerning PR.

3.2.3 Barriers to PR Implementation and Referral

Table 3.6: HCPs barriers to administering/implementing PR.

	Urban (N=94)	Suburban/ Rural (N=14)	Overall (N=108)	p-value
Do lack of specific symptoms in Pulmonary rehabilitation affect your management strategy?	46 (53.5%)	4 (28.6%)	50 (50.0%)	0.084
Do you feel that patients underreport symptoms?	62 (73.8%)	10 (71.4%)	72 (73.5%)	0.852
Do patients having multiple chronic conditions impact on your ability to make a diagnosis?	64 (74.4%)	7 (50.0%)	71 (71.0%)	0.062
Does lack of effective treatment impact on agency especially in making a diagnosis?	59 (70.2%)	7 (50.0%)	66 (67.3%)	0.135
Does lack of easy access to spirometry hamper your ability to diagnose and rehabilitate patients?	46 (53.5%)	6 (42.9%)	52 (52.0%)	0.460

% (refers to specific number/total number x 100). Values represent proportion of respondents answering 'Yes' to each item. $p < 0.05$ is statistically significant

3.3 Discussion

The survey results reveal a substantial awareness and recognition of pulmonary rehabilitation to be an effective intervention for COPD among the HCPs from 23 African. This is a positive outcome and indicates the likelihood of HCPs in Africa to implement COPD prevention using PR, particularly, if they are provided with capacity development on PR. Importantly, the majority (over 85%) of the surveyed HCPs had expressed confidence in the ability of PR programmes to improve symptoms and reduce patient exacerbation emphasizing the value they place on COPD treatments despite the challenges they face. However, there were observed significant barriers towards implementing COPD intervention that is more appropriate to the local settings in Africa.

A significant limitation of this survey is its representativeness. While we achieved a high response rate (56%) among PATS and SATS members, these societies primarily include specialists and those with particular interest in respiratory medicine. This creates an inherent selection bias that likely overestimates awareness and knowledge of PR compared to the broader healthcare workforce in Africa. Furthermore, the survey reached practitioners from only 23 of Africa's 54 countries, with stronger representation from Southern and East African regions. The perspectives of healthcare providers in Central and West Africa, as well as those working in primary care settings without specialty society affiliations, are underrepresented.

The survey methodology, which relied on PATS and SATS networks, may have limited representation from certain essential PR team members such as dieticians, occupational therapists, and psychologists, who are typically integral to comprehensive PR delivery but may not be well-represented in these respiratory-focused societies. A snowball sampling approach could have enhanced recruitment of diverse PR professionals beyond the respiratory societies' networks, potentially capturing more comprehensive perspectives from the multidisciplinary teams involved in PR delivery across Africa.

3.3.1 Comparison with Recent Surveys in LMICs

A comparison with survey data from other regions such as the United States of America and the Middle East, provides valuable insights into perceptions and attitudes of HCPs towards PR and COPD treatments. (104) This underscores the need for and evidence-based research to understand the knowledge, beliefs, awareness, availability, utilization, and barriers in accessing Pulmonary rehabilitation across the continent as surveys in the global north and high-income countries generally have a differing focus.

Recent surveys from other LMICs provide important comparative context for our findings. Katagira et al. (2021) surveyed healthcare providers in Uganda, finding similar barriers to PR implementation but with notably lower awareness of PR benefits (62% compared to our 87%). (103) Babaji et al. (2022) documented PR awareness among Nigerian physicians, highlighting the critical gap between knowledge and implementation capacity, with only 8% of knowledgeable providers having access to PR facilities.(76)

These comparisons highlight that while awareness may vary across African regions, implementation barriers related to resources, training, and infrastructure remain consistent challenges throughout the continent.

One international survey of 200 United states physicians highlights the effectiveness of treatments for improving symptoms and longevity in pulmonary disease patients, (104) the physicians reported high confidence in current COPD therapies, with 68% of physicians agreeing that "better treatments led to improved COPD outcomes", and 10% reported that PR was helpful. This is comparable to 86% of our survey clinicians who reported treatments effective for symptom improvement and treatments improving longevity in pulmonary disease patients and, in our context, COPD. The survey also highlighted similar disparities in the use and access to spirometry with the higher use and access to spirometry to our study: 86% in the United States compared to 77% across Africa (table 3.1).

A study in the Middle East assessed healthcare providers' attitudes, beliefs and barriers to Pulmonary rehabilitation for patients with chronic obstructive pulmonary disease in Saudi Arabia and showed a high level of agreement with our survey regarding the positive impact of Pulmonary rehabilitation on reducing symptoms and improving quality of life for patients with chronic obstructive pulmonary disease.(105) The HCPs in this study report high agreement (collective Likert scale ratings of 4 "agree" and 5 "strongly agree") that PR would reduce symptoms of dyspnoea and fatigue (85.9%), improve anxiety and depression (81.6%) and improve quality of life (87.2%).

There is an absence of recent studies in Africa have reported on HCPs' knowledge, attitudes and beliefs, or PR-related care activities. The published evidence is of the utility and availability of PR, (55,77,106) but this evidence shows that utility and availability are low. This underscores and emphasizes the need for more evidence-based research to comprehend the healthcare providers' level of awareness, availability, utilization, and barriers to accessing Pulmonary rehabilitation and implementation in Africa. Furthermore, a systematic review has underscored the need for more evidence-based research and for Africa to formulate its guidelines, especially in low-resourced settings, adapting those from the American and European societies and creating African-centric guidelines.(55) HCPs would readily accept PR, but defining the factual implementation gaps to enable adjustments and implementing evidence-based recommendations will require resources and support from local HCPs.

Limitations and Strengths of the Study

This survey has some limitations, as do online-based all surveys. For instance, it was primarily sent to the HCPS within the SATS and PATS network and could have excluded potential target participants. This limitation is particularly notable regarding the representation of certain essential PR team members such as dieticians, occupational therapists, and psychologists, who may not be well-represented in these respiratory-focused societies.

The survey content was also focused mainly on medical aspects of diagnosis and treatment. Important barriers to utilization and accessibility were not queried, such as lack of knowledge /access to evaluation tools that allow for a comprehensive patient assessment. The survey also did not query information about practices regarding taking exacerbation history, evaluating disease-specific symptom burden, evaluating symptoms of anxiety and depression, evaluating components of physical fitness (muscle function, exercise capacity), and capturing (impairments in) participation in daily physical activity.

Despite these limitations, the study highlighted strengths: It had a comprehensive coverage as it sought a multi-country perspective, had diverse health care settings and various professional groups. The study also had methodological rigour as the survey/questionnaire was validated, with a high response rate of 56% and a detailed assessment of PR components.

Overall, the positive enthusiasm for PR among the surveyed HCPs in this group is encouraging. With some support and investment, PR could become a reality in many settings the study highlights clinical relevance including practice-oriented findings, actionable insights and policy implications It is also noteworthy to acknowledge the diversity and nuances across the African continent with 54 countries and to interpret the data cautiously without generalizing or relying solely on the “mean data”.

3.4 Conclusion

The substantial awareness and recognition of Pulmonary rehabilitation to be an effective intervention for COPD and other chronic lung diseases across Africa is remarkable. The wide and diverse range of respondents (30 professions from 23 African countries) could indicate the feasibility of implementing a multi-disciplinary approach to deliver PR for equitable access to COPD management in Africa. Despite the existing barriers, equipping all healthcare workers with the requisite skills to implement an effective, locally acceptable PR programme will significantly impact patients with COPD and mitigate the high burden of COPD in Africa.

CHAPTER FOUR

EXPLORING COPD RISK PERCEPTION AND CO-DESIGNING PREVENTION AND ADVOCACY STRATEGIES FOR PULMONARY REHABILITATION IN SOUTH AFRICAN COMMUNITIES

Preamble: A perspective piece was successfully developed from the data obtained from this aspect of the thesis. This manuscript has been accepted and published (after thorough editorial reviews) in a peer-reviewed Journal (South African Journal of Public Health)

4.1 Introduction

This chapter aimed to explore COPD risk perceptions and support community-driven pulmonary rehabilitation and advocacy strategies in a disadvantaged African setting using a participatory approach. Pulmonary rehabilitation (PR), as defined by the American Thoracic Society (ATS) and the European Respiratory Society (ERS), encompasses a "comprehensive intervention tailored to the individual patient, including exercise training, education, and behaviour change, designed to improve the physical and psychological condition of people with chronic respiratory disease and to promote the long-term adherence of health-enhancing behaviours."(17)

PR is well-established, evidence-based, and has been successfully implemented in the Global North within community settings, including non-specialised community health services and health centres.(69) However, Habib et al., (107) in their systematic review highlighted the under-provision, delivery and poor uptake of PR services in low and middle-income countries (LMICs), especially in low-resourced African settings. The potential for the positive outcomes of PR in LMICs is significant, offering an opportunity for improved health and well-being. Having realised the benefits of PR, especially in COPD, many wealthy countries have incorporated it as a structural component of health care delivery.

The World Health Organisation (WHO) and other organisations have recognised and acknowledged an unmet need and underscored a need for rehabilitation in the LMICs. WHO, therefore recommended an upscaling and investment in the workforce and infrastructure.(108) This strategy would benefit from an participatory community-driven intervention to address PR needs, particularly in socio-economically disadvantaged settings.

The World Health Organization's Rehabilitation 2030 initiative specifically highlights the need to scale up rehabilitation services globally, with particular emphasis on LMICs.(74) The WHO has supported the development of a 'Package of Interventions for Cardio-Pulmonary Rehabilitation' aimed at facilitating global adoption and adaptation of rehabilitation services. This initiative aligns with our community-driven approach by emphasizing the importance of contextual adaptation and integration with existing health systems.(74)

In settings with limited exercise equipment and resources, a community-driven (Citizen science approach) is seen as an effective method for exploring the disease risk perception, and this has proved successful within past cardiovascular disease strategies in LMIC communities. (59,109) Citizen science studies employ the community-based participatory approach (using *"Our Voice" model)* has been utilised to effectively explore barriers to seeking healthcare services and support community participation in service delivery, especially in underserved communities, including rural environments with pronounced inequities.(59,65,67)

The "*Our Voice*" Citizen science model is validated and embraced globally to facilitate community-based Citizen science for advancing health equity.(65,97,110,111) Citizen science emphasises the involvement of beneficiaries in the research process, aims to probe health-related concerns within their community and fosters participation and advocacy for change. In the domain of Citizen science, the community assumes the central and cardinal role and can be delineated into the provider community and the patient community.(68)

The provider community comprises a multifaceted system encompassing specialist and non-specialist surgical and anaesthetic clinicians, nurses, mid-level providers, community health workers, and essential cadres involved in delivering healthcare and often represent the collective voices of healthcare providers.(68)

Intervention or care beneficiaries have often been neglected during the research process, including patients and their families, caregivers, community health workers, community health forum leaders/liaison officers, and advocacy groups.(68) Working with these actors would engender acceptability, ownership and sustainability of interventions.

The forefront of Citizen science and other participatory approaches like participatory action research (PAR) accentuates the pivotal role of community engagement.
Citizen science can be stratified in three significant ways: contributory, collaborative and co-created.(112,113)

- Contributory Citizen science entails data collection by the scientists and patient community.
- Collaborative Citizen science extends to involvement by the patient community in the data analysis.
- Co-created Citizen science furthers the involvement of the patient community by inviting them to define the problem in their terms, heeding their perspectives, and translating the research findings into public health interventions.(113)

Through a Citizen science approach, evidence is generated from the stakeholders who utilise the services, not only as research respondents but also as partners in co-designing, analysing, and translating the data.(113)

Citizen science methodology enhances on the principles of conventional participatory approaches. For example, Citizen science explicitly positions community members as researchers rather than merely participants. This distinction is particularly important in contexts where power dynamics between healthcare professionals and communities may influence intervention acceptability. We have critically compared our approach with other participatory methodologies, noting that each has strengths and limitations.

The Citizen science approach was selected for its emphasis on community ownership and capacity building, which we hypothesized would enhance sustainability in resource-limited settings. However, we acknowledge that this approach may be more time-intensive than techniques like nominal group process and requires significant investment in relationship building.

The three main objectives of this chapter were:

1) Examining community COPD perceptions including awareness and knowledge, symptoms, experience, and stigma using focus groups and engagement.
2) Exploring community support and resources, including PR, awareness knowledge and utilisation using Citizen science interviews
3) Determined the preferred strategy for participatory community-driven PR intervention using stakeholder engagement, result-sharing presentation, and community advocacy workshop.

4.2 Methodology

4.2.1 Research Setting

The Klipfontein Health district in the peri-urban Cape province of South Africa was chosen for its social and economic status (SES) disparities and high prevalence of NCDs including COPD.(33) Encompassing approximately 4,275 hectares, the district includes areas of Manenberg and Heideveld.(114) In 2011, the district recorded a population of 384,189, with 97,125 households, an increase of 22% since 2001. Key demographic indicators included a Coloured (49%) and Black African (45%) population and pertinent socioeconomic and health statistics. The study received Ethical approval from the University of Cape Town Faculty of Health Sciences Human Research Committee (HREC 157/2023). It adhered to the Declaration of Helsinki (2020) principles of human subject research.

4.2.2 Study Design and Rationale

This study used a participatory community-based Citizen science. The design and rationale of the study are depicted by the flow chart (Figure 4.1). This phase of the study was implemented in the following ways.

- A qualitative research phase that comprised of community engagement and stakeholder consultation.
- Focus group discussions (FGD) and qualitative Citizen science interviews were used to gather, analyse, and interpret data regarding participants' COPD-related awareness and knowledge, stigma, symptoms, and experience, and
- Advocacy workshop with selected relevant stakeholders to discuss findings and discuss possible strategies and solutions for COPD prevention.

We also explored the community support and resources for a community-driven PR in our advocacy workshop.(115–117) The advocacy workshop was conducted with the participants, Citizen scientists and relevant stakeholders that included:

- Manenberg Health Forum (a non-governmental organisation that helps create awareness and educate about the disease, holds monthly health calendars in the community as needed, and participates in Western Cape parliamentary meetings to engage in policy decisions).
- Manenberg Health Committee (a legislative structure of the city of Cape Town that addresses community complaints to parliament and facilitates clinical awareness).
- Lerato Foundation (an arts and creative non-profit organisation that tutors teenagers and children and has youth empowerment drives).
- Manenberg Clinic (one of Cape Town's clinics) provides healthcare services, including men's health, general TB, sexually transmitted Infection (STI) care, and substance abuse support. The clinic meets the needs of the surrounding communities' primary health care (PHC) and offers the community complete and basic computer literacy.

- Manenberg People's Centre (first established as a political organisation, later transitioned to an organisation that would raise funds to meet the community's needs. It holds a record as the very first centre in South Africa to offer community participatory research and officially opened in March 1991 after the community participatory research findings. It offers training skills development, access to employment, social upliftment care and support, food security and income generation initiatives. The projects cater to older persons, Families, youth, and the disadvantaged.

This workshop was utilised to discuss the findings of the FGDs and Citizen science interviews and co-create acceptable community-driven strategies for implementing PR in the community setting based on participants' priorities. We utilised the “Our Voice” Citizen science model to support this co-creation and advocacy workshop. Prior research has similarly utilised FGDs to explore (Cardiovascular Disease) CVD risk perception, presentation, and communication in African communities, and the Citizen science approach has been used to enhance the co-creation of strategies and advocacy with stakeholders.(118,119)

4.2.3 Sampling Strategy and Representativeness

This study employed purposive sampling to select participants who could provide rich and diverse perspectives on COPD and community health. The purposive approach was chosen over probability sampling as our aim was not statistical generalization but rather to capture the depth and breadth of community experiences with respiratory health. We developed a sampling framework with the following dimensions: (1) age (ensuring representation across age groups 35-50, 51-65, and >65 years); (2) gender (aiming for balanced male and female representation); (3) socioeconomic status (including participants from different housing types and employment situations); and (4) health status (including both individuals with self-reported respiratory conditions and those without).

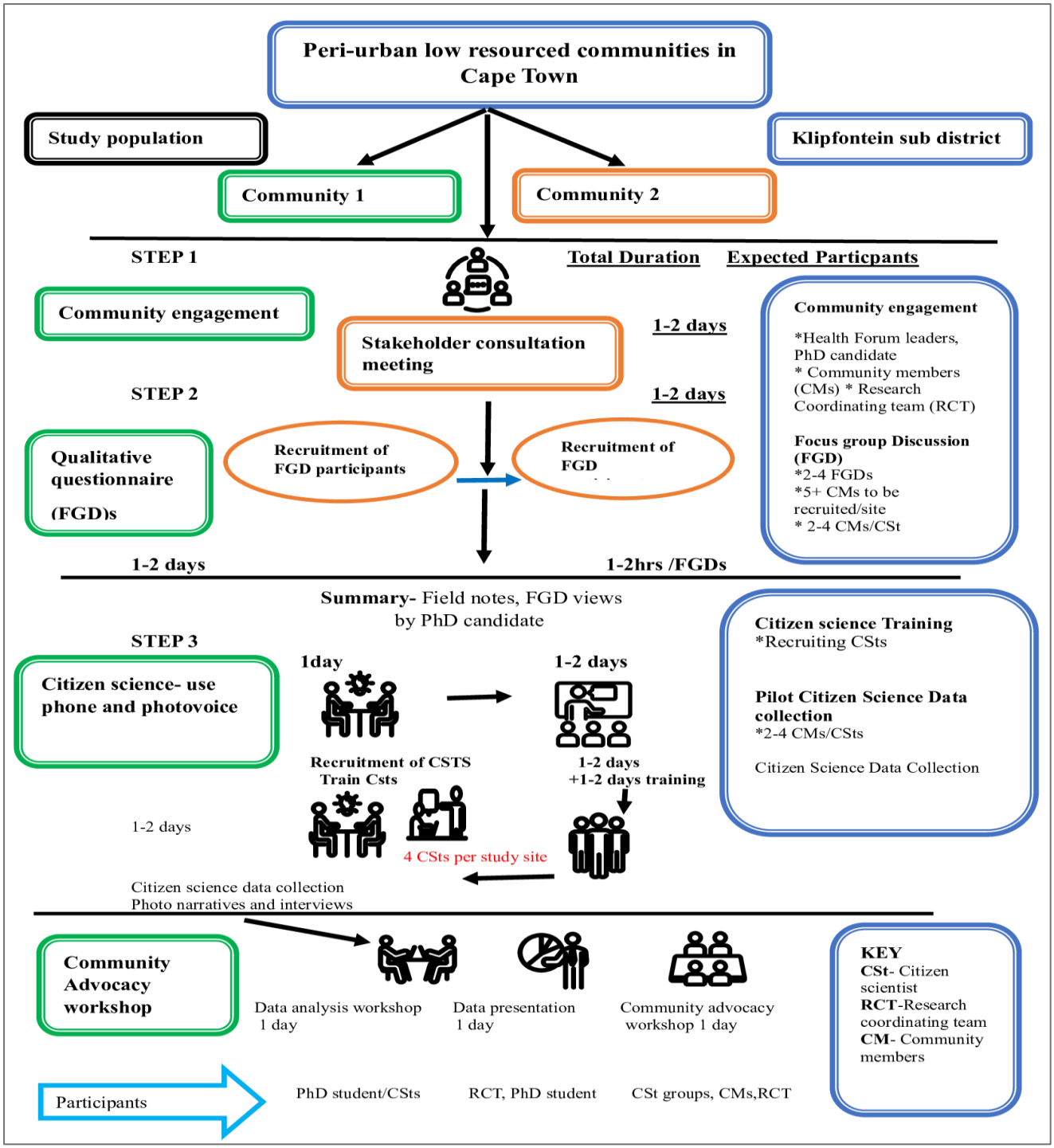

Figure 4.1: Research Design/Flowchart

This approach allowed us to examine how perspectives might vary across these dimensions while ensuring representation of key community subgroups. We recognize the limitations of this approach in terms of statistical representativeness, but it aligns with the qualitative and participatory paradigm of Citizen science, which prioritizes depth of understanding over statistical generalizability.

The technique was used to sample the study participants for focus group discussions (FGDs) and those earmarked for Citizen science interviews. We then collected FGD data from 2 separate groups of men and women aged 35 and above. Each group comprised 12-15 participants (26 persons). We trained three citizen scientists (CSts) to collect EpiCollect-based photo-voice data from the 26 persons in the two communities participating in the FGDs.

4.2.4 Recruitment and Enrolment

To recruit participant for FGDs in each community, we sent a letter to the Health Forum leaders who through the community liaison officer who then identified the potential subjects and briefed them about upcoming research regarding lung health, what they knew about lung health, if it affected them, and what they did to treat and prevent it. The liaison office kept in touch with the PhD candidate who supervises and coordinate the study implementation.

After the logistics were sorted the liaison potential subjects received an information letter detailing the background and purpose of the study, and written consent was obtained for participation. Subsequently three community members were recruited to serve as Citizen scientists (CSts) in each community to facilitate interviews and advocacy workshops. The CSts were recruited after community engagement and stakeholder consultation meetings. The categories of participants in the engagement meetings with the community included:

- Health Forum leaders (community liaison officers), who are experts in local community health, helped identify potential Citizen scientists.
- Each CSt was tasked with recruiting and interviewing 8-10 members aged 35 and above in their community who had completed at least a primary school education, using purposive sampling to ensure a proper comparison of the study.

4.2.4.1 Citizen science constructs that were considered in the recruitment of CSts.

Multiple-level constructs can influence Citizen science, including individual, interpersonal, environmental, and policy levels,(120) and these were adopted in the recruitment of citizen scientists (CSt). For this chapter, the selection of the Citizen scientist primarily focused on personal and interpersonal constructs, including demographics (age, gender, and SES), having an amicable social community bond, civic engagement, confident self-efficacious behaviour, resilience, trailblazers, activists, and those whom the community leans towards in times of crisis.

4.2.4.2 Implementation plan and data collection procedures

Implementing community engagement and Citizen science processes involved recruiting Citizen scientists (CSts) to facilitate data collection, analysis, and interpretation; the engagement included consultations with community stakeholders, including health forum leaders, clergy, and ward councillors. Exploring community COPD perceptions, including awareness and knowledge, symptoms and experience, and stigma, formed the bulk of the engagement. Furthermore, community support and resources were explored, including PR, awareness knowledge and utilisation.

4.2.4.3 Focus Group Discussions (FGDs)

The PhD candidate and an assistant, a colleague and the community liaison officer facilitated two focus groups consisting of a total of 26 participants. Each FGD lasted 60 minutes and was audio-recorded. The PhD candidate with the colleague and community liaison officer each summarised the findings for each community using field notes and an audio recorder to capture risk perceptions and prevalent themes. The audios were then transcribed using a transcription software turbo scribe (https://turboscribe.ai/). These summaries and transcribed audio were crucial for planning and implementing the Citizen science interviews and advocacy in the communities.

The Focus Group Discussion guide (Appendix 4.4) was developed through a collaborative process involving the research team and community representatives. The guide was structured around five key domains: (1) awareness and knowledge of lung health, (2) community experiences with breathing problems, (3) risk perception and understanding, (4) impact and consequences of respiratory conditions, and (5) community-based solutions and preferences for intervention. The guide was piloted with a small group of community members not participating in the main study and refined based on their feedback.

4.2.4.4 Citizen science Process

To support implementation, we utilised and adapted the community-driven participatory Citizen science protocol.(121) The Citizen science process included recruiting Citizen scientists and training them on Citizen science methods including interviews, data collection (photo-voice) and advocacy.

The training focused on:

- Citizen science approaches of conducting semi-structured walk-along interviews with photovoice shown in Appendix 4.5.
- Epi Collect 5, a mobile app, was used to collect the data shown in Appendix 4.5.
- Essential tips on summating and utilisation of data are shown in Appendix 4.6 and 4.7.
- The conducting of community-level advocacy meetings.

4.2.4.5 Citizen science Questions (EpiCollect Data Collection)

Data was collected using the EpiCollect questionnaire to explore community perceptions of COPD, further causes and risks, and how they would love information to be presented to them. The questionnaire is attached in Appendix 4.5.

The tips on the training are provided in the Appendix 4.6 and 4.7 and 4.8.

Photovoice, implemented through the EpiCollect 5 mobile application, was selected as a participatory visual research method to capture community perspectives on both COPD risk factors and potential rehabilitation environments.

This approach was justified by its demonstrated effectiveness in health research with marginalized communities, allowing participants to document their lived experiences and environments without relying solely on verbal communication. Participants received structured guidance on taking photographs that represented: (1) perceived causes of respiratory problems, (2) environmental factors affecting lung health, and (3) community spaces that could potentially support rehabilitation activities. While the resulting photographs predominantly focused on COPD risk factors rather than rehabilitation spaces, this outcome itself provided valuable insights into community priorities and understanding.

EpiCollect 5, a mobile data collection platform developed by Imperial College London, was utilized to systematically collect photovoice data. Citizen scientists were trained to use this application on their smartphones to capture photographs, record accompanying narratives, and answer structured questions about each image. The EpiCollect platform facilitated real-time data upload, geolocation tagging, and centralized data management, enhancing the rigor and systematicity of the qualitative data collection process.

4.2.4.6 Citizen Science Interview

Citizen scientists (CSts) were given a brief training on community data collection during community-walk-along mobile phone interviews using EpiCollect.(122) For each community, the CSts were asked to gather data from 8-10 community members. The photo-voices data collected included photographs, observations and narratives regarding perceptions, interpretations, insights, and presentation of risk. The entire process after data collection entailed that the narratives obtained be translated and transcribed into English and apportioned accordingly in relation to the photos and narratives. This was critical for further analysis based on simple formats the PhD candidate would facilitate.

4.2.4.7 Community Advocacy and workshop with stakeholders

The culmination of each study community involved sharing the Citizen science findings with key community stakeholders in an advocacy workshop. This result-sharing presentation was crucial to determining the preferred strategy for participatory community-driven PR intervention using stakeholder engagement; an invitation letter to 7 community leaders was sent by the PhD candidate and through the Citizen scientists, and 5 five of the community leaders honoured the invite. The community leaders and the organizations they represented were as follows:

- Manenberg Health Forum (a non-governmental organisation that helps create awareness and educate about the disease, holds monthly health calendars in the community as needed, and participates in Western Cape parliamentary meetings to engage in policy decisions).
- Manenberg Health Committee (a legislative structure of the city of Cape Town that addresses community complaints to parliament and facilitates clinical awareness).
- Lerato Foundation (an arts and creative non-profit organisation that tutors teenagers and children and has youth empowerment drives).
- Manenberg Clinic (one of Cape Town's clinics) provides healthcare services, including men's health, general TB, sexually transmitted Infection (STI) care, and substance abuse support. The clinic meets the needs of the surrounding communities' primary health care (PHC) and offers the community complete and basic computer literacy.
- Manenberg People's Centre (first established as a political organisation, later transitioned to an organisation that would raise funds to meet the community's needs. It holds a record as the very first centre in South Africa to offer community participatory research and officially opened in March 1991 after the community participatory research findings. It offers training skills development, access to employment, social upliftment care and support, food security and income generation initiatives. The projects cater to older persons, Families, youth, and the disadvantaged.

The advocacy meeting was a crucial step that followed the data extraction, exploration, and analysis phases. It was carried out in three stages indicated below:

1) The PhD candidate presented the findings from the FGDs and Citizen science interviews.
2) The community and stakeholders explored the causes of lung disease, barriers to PR, and what PR intervention they perceived best (Appendix 4.11).
3) They were divided into four groups to co-design an intervention for the community based on these three scenarios. (Appendix 4.12). These scenarios required them to list barriers to receiving care/treatment of the personas, list enablers to receiving care, and finally design a preferred intervention for the persona based on barriers, enablers, and mention who the key stakeholders would be.

4) They were required to (choose between home-based and community-based, what education components would be needed, what resources one would need, safety considerations, and a cultural intervention).
5) Finally, the leaders were queried on their acceptability of a PR intervention, and this was recorded and transcribed.

This community advocacy and engagement with stakeholders facilitated data sharing and dissemination for valuable insights to drive informed evidence-based context-specific solution co-creation. The themes and ideas from the advocacy meeting were collated for future engagements with policymakers and the Western Cape government to research further or explore future ideas. In total, 33 people were involved (24 participants, 3 Citizen scientists, five community leaders, A senior lecturer and pharmacist from the Department of Surgery 9 University of Cape Town) and the PhD candidate, a Biokineticist).

4.2.4.8 Data Analysis

The research methodology was both adaptable and responsive and entailed translating and transcribing narratives, thematic analysis of FGD data, collaborative analysis with CSts and the community, integrating photovoice data and findings, and stakeholder identification of prevention and advocacy strategies during advocacy workshops. The FGD findings were collated, and the themes were drawn collectively in conjunction with the PhD candidate, his colleague (a senior lecture and qualitative researcher experienced in participatory work), the Citizen scientists and the community liaison officer, ensuring cultural appropriateness throughout the process.

During the analysis process, 'cultural appropriateness' referred to our analytical lens for identifying and prioritizing themes that reflected local values, beliefs, and practices. This included analyzing how community members discussed rehabilitation in relation to existing community structures (e.g., churches, community centres), cultural attitudes toward physical activity and smoking, and local health beliefs. The focus group discussion guide explicitly included questions about culturally acceptable intervention approaches, and these responses were thematically analysed with particular attention to cultural nuances that might influence PR implementation.

Qualitative data facilitation and analysis occurred during a workshop at the university. The PhD candidate provided the step-by-step process of analysis and reporting of qualitative research data, as well as refining the perceptions of COPD. This methodology was similar to the evidence based participatory science methods, particularly the "photo voice", from which the overall approach was adapted. The PhD candidate guided team in question interpretation and clarity based on the transcribed materials, audio recordings and notes taken by the group, summarizing priority issues with the help of flipcharts and handwritten notes.

The summarised findings where then shared to agree on the common themes and get consensus. A similar procedure was applied to the EpiCollet data, which was downloaded, and the associated pictures and narratives validated and agreed upon. Through this meeting, key stakeholders were identified for the advocacy meeting, and the findings of the FGDs and Epicollect were presented. The culmination of these efforts was the co-created an intervention tailored for the community. The entire process of activities is summarised on Table 4.1

Table 4.1: Timelines for activities

	2024				***2025***	
Develop research-related activities	***Nov***	***Nov***	***Dec***	***Jan***	***Feb***	
Community engagement / Recruitment and Citizen scientists						
Community engagement and recruitment of the community members and FGD			M2			
Focus group feedback session			M2			
Implementation of Citizen science						
Recruiting Citizen scientists (CSts)			M3			
Training CSts on Citizen science processes and interviews			M3			
Conducting Citizen science interviews			M3			
Community Advocacy workshop with stakeholders				M4		

M1: Ethical proposal approval; **M2:** Community engagement and FGD conducted; **M3:** Citizen science interviews done; **M4:** Community advocacy workshop conducted.

4.3 Results

4.3.1 Focus Group Discussion Narrative

The FGDs explored the perceptions of COPD in these two communities and assessed their understanding of lung health. The FGD discussions revealed key insights and provided a platform for co-designing prevention and advocacy strategies. The transcriptions of the FGDs for the two communities and key results are presented below.

4.3.1.1 Focus Group Participant Demographics

A total of 26 participants (12 in the first FGD and 14 in the second) participated in the focus group discussions. The participants included 11 males (42.3%) and 15 females (57.7%), with an age range of 35-72 years (mean age 51.7 years). Education levels varied: 15.4% had some primary education, 3.8% had completed primary school, 61.5% had some high school education, and 19.2% had completed matric (high school graduation). Most participants (73.1%) reported having a family member with respiratory issues, and 26.9% reported personal experience with diagnosed lung disease.

Key Findings from the FGDs

Key findings are culled from the thematic analyses (Table 4.2) The two communities demonstrated a limited awareness of COPD as a distinct condition; they often conflated/ mixed it up with general respiratory problems like Asthma.

Furthermore, smoking emerged as a generally accepted community practice, with some participants describing it as a necessity for daily activities and routines:

"And when you are done eating lunch, breakfast, supper, and when you sit on the pot, you must smoke. It's like dessert."

"It is better than breakfast in the pot. So, we are saying that smoking is dessert. It is like breakfast.". "After your meal, you must smoke. It is breakfast, lunch, supper. You must have a cigarette even when you go to the restaurant."

The FGDs highlighted the community's understanding of the risk factors of COPD, including smoking (identified as a primary risk factor), industrial pollution, workplace hazards, vehicle emissions, and dust exposure. It also highlighted their experiences with COPD, both at personal and communal impact, and their coping strategies, including informal medication networks that facilitated unauthorised medication trading, self-medication practises, non-prescribed medication access, and community-based medication sharing. The FGDs also underscored significant barriers to health care access, including distance to facilities, provision of appropriate care, delays in receiving care and a lack of specialised care. It also highlighted the community-based solutions, including their preferred interventions. A comprehensive thematic analysis is presented in (Table 4.2)

Table 4. 2: Thematic analysis from the FGDs

Question	Themes	Notable community quotes
Awareness and knowledge	• Basic understanding of lung function • Participants showed basic knowledge of lung health. • Had a limited understanding of the complexity of respiratory health. • Some understanding and awareness of lifestyle factors and environmental factors affecting lung health.	*"Keeps you alive, keeps you breathing."* *"When I used to smoke, later, I was diagnosed with hypertension."*
	Recognition of risk factors • Smoking was recognised as a primary risk factor. Other risk factors were: • Industrial pollution. • Workplace hazards. • Vehicle emissions. • Dust exposure.	*"There is dumping, dumping takes place, oh, yes, and then guys come and burn copper."*
Community experiences with breathing problems	• Personal and communal impact • Widespread difficulty with breathing problems. • Most indicated personal and family struggles and common symptoms described include shortness of breath, tiredness, night-time breathing difficulties, and chest tightness.	*"But sometimes when I smoke, it feels like this is blocked."* *"Sometimes, I do not even smoke at night because that is how my body tells me you have had enough cigarettes for today."* *"I get tired very quickly."*
	Coping strategies • Open windows • Sleep naked • Use brown paper to breathe in (traditional). ***Inherent societal issues around drug use*** • Informal medication networks, including unauthorised medication trading, self-medication practises, non-prescribed	*"And you continue smoking even though you have Asthma? Yes, because I cannot have any sleep now."* *"They get the medicine and sell it to the vendors outside. Moreover, they buy it, and they sell it again."* *"You cannot go to sleep without a cigarette, and you cannot wake up without a cigarette."* *"And when you sit on the pot, you must smoke. It is like dessert."*

	medication access, community-based medication sharing. • Social and ritualistic aspects of smoking, drug abuse and addiction.	
	Medical Interventions The participants use prescribed medications, nebuliser use, have emergency hospital visits, and use inhalers.	*"Whenever we go, my insulin pump is in, my asthma medication is in, my hospital card is in."*
Healthcare access and challenges	***Structural barriers*** • Long distance to healthcare facilities. • Limited diagnostic services. • Limited access to specialised care. • Long waiting times for appointments.	*"Because sometimes there are not doctors, so then you get a clinical nursing professional person as a CFP, you get them, and CFPs are not always very. I think, up for them, not very professional in how they handle people."*
	Issues about perceived quality of Care • Brief consultations with minimal examination. • No continuity of care. • Inadequate follow-up systems.	*"Maybe if it is not that far, there is,* *So, there is no specialist for the lungs?* *"Then they go for the lungs. They send him back to the hospital."*
Social and economic impact	***Activities of daily living limitations*** • Reduced mobility. • Difficulty with routine tasks. • Sleep disturbances.	*"Personal experience, I get tired very quickly."* *"They are tired. They are walking. People cannot walk. They are tired. She said we must slow down. The chest was tight."* *(Even then, it was weird) Why am I so sweaty? I did exercise, but it is not working for me. Okay, why? I am getting tired too quickly."*
	Economic Burden • Medication expensive. • Cost to health care centres high. • There is an informal medication trade.	*"They get their charge of medicine and the tablets, and they go sell it at Manuel Johnson, they sell it here, and those people go repurchase it."* *"They get the medicine and sell it to the vendors outside. To the vendors. Moreover, they buy it, and they sell it again."*
Community-based solutions	***Desired Interventions*** • Regular exercise programmes. • Support groups. • Awareness campaigns. • Cigarette bans. • Structured rehabilitation.	*"I once quit for six months, and then I started again on that question, is there help? There is not a lot, but posters are up there. All of us, you know, we never notice it. It is a helpline to quit smoking."* *Are there any community support groups for people who want to stop smoking? No. Would you like one? (Yes.)*
	Implementation preferences • Community-based rather than individual intervention. • Regularly scheduled sessions. • Professional guidance and support. • Accessible facilities. • Support with transport. ***Stakeholder Involvement*** • Community leaders needed. • Health professionals needed. • Need for local Government support. ***Resource requirements*** • Dedicated facilities. • Exercise equipment. • Trained personnel.	*"When we are in workshops, and it is gang fighting and stuff, then whoever organises the workshops most of the time, there is transport."* *"That is for our leaders. What do they do? They organise the workshops and stuff, then the food, the food, whatever. They set up the hall, wherever it is."* *"So, which one do you prefer? The individual one, the community one?* *The individual one does not work."* *"The manager of the clinic must be there. So, there is a lot, so it cannot be one day."* *"In the case of a programme, they should look at having like a WhatsApp group. Most people are on WhatsApp. (WhatsApp group must also be part of awareness, education, (and encouragement that's going on."*

		"So, there are facilities available here. However, no one wants to take control, or that is like trainers that come and do something." *"So, there is no person that will tell you what exercises to do" "Completely no one. If there are, they want to be paid. So, in these places, there are even no physiotherapists, right? No, nothing"*

4:3.2 EpiCollect Survey (Photovoice Key Findings)

The EpiCollect (mobile questionnaire) survey was used to collected additional data from 26 participants (29% male and 71% female). We a 100% response rate. The mobile-based survey explored community perceptions regarding lung disease risk, causes, and the history of lung disease within and among family relatives. This was facilitated the researcher's understanding of the study particiants preferred methods for receiving information about lung diseases.

Among the 26 complete responses, none of the individual education levels showed statistically significant differences between male and female cohorts (all p values <0.05). However, the "completed high school" category showed the most balanced distribution between the two groups. Notably, 65% of the participants reported having a family relative with lung disease, and all participants (100%) of the community perceived the possibility of a relative acquiring lung disease. The participant demographics and community perceptions based on the Epi-Collect Citizen science Interviews are shown in (Table 4.3).

Table 4.3: The participant demographics and community perceptions (Epi-collect / Interview)

	Whole cohort	Male	Female	p-value
Demographics				
Age (years)*(median)(IQR)*	51 (41,58), 59)	57(53,60)	46(39,55)	<0.05
Education level *N (%)*				
No formal schooling	0/26 (0%)	0/8 (0%)	0/18 (0%)	(No variation
Some primary school	4/26 (15%)	2/8 (25%)	2/18 (11%)	0.287
Completed primary school	1/26 (4%)	0/8 (0%)	1/18 (6%)	0.692
Completed high school	16/26 (62%)	6/8 (75%)	10/18 (56%)	0.231
Completed matric	0/26 (19%)	0/8 (0%)	5/18 (28%)	0.130
COPD perceptions lived experience				
History of lung disease	7/26 (27%)	2/8(25%)	5/18 (27%)	0.365
Knowledge of family relatives with lung disease	17/26 (65%)	3/8(38%)	14/18 (77%)	0.055
Possibility of relative acquiring lung disease	26/26 (100%)	8/8(100%)	18/18 (100%)	(No variation between groups)
Health education is the preferred method to understand/ learn about lung disease	25/26 (65%)	7/8(9%)	18/18 (100%)	0.308

The transcribed audio and images from the EpiCollect (Figure 4.2) highlight concerns within the community regarding lung health. They reveal that the community was aware of multiple risk factors for lung disease. They mainly focused on smoking and environmental exposures. This awareness stems from the formal warnings on the various cigarette packages and the lived experience of their environment (exposure to deteriorating and dilapidated building materials).

4.3.2.1 Community perceptions of what caused lung disease.

The community acknowledged that these environmental hazards posed a serious risk to their respiratory health. Their perceptions are categorised into the following themes:

- **Environmental health awareness:** The community understood behavioural (smoking habits) and environmental (asbestos) risk factors.
- **Public health education**: The community recognised the warning labels and health messaging from the various cigarette types, including dangers to pregnant mothers, the environment, unborn babies, and heart health.
- **Housing conditions**: The community revealed a connection between the building materials used and the health risks they posed.
- **Community knowledge:** There was a consensus on understanding lung disease causes.

The main themes from the pictures included substance use and tobacco use, as the pictures showed the various kinds and types of cigarettes the community consumed and how they also did not dispose of cigarette butts. Old/ unventilated homes with asbestos roofs were also a central theme.

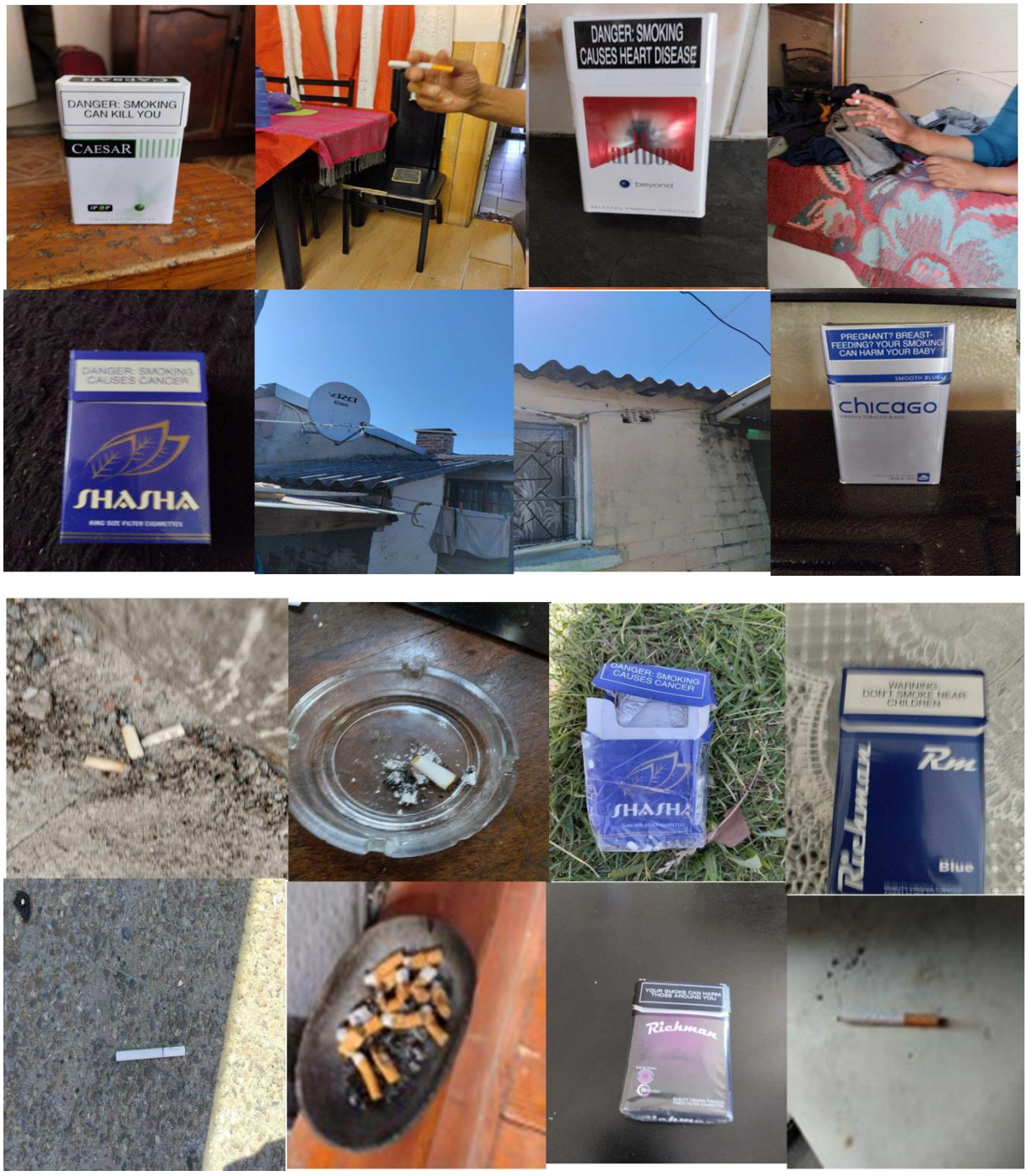

Figure 4.2: EpiCollect images of community perceptions of what caused lung disease.

4.3.2.2 What the community considered 'good' for lung health

While the community recognised the risk factors for lung disease, some demonstrated an understanding that some household items and activities they routinely did contribute positively to good health (Figure 4.3).

The key themes that could be identified from this positive outlook can be summarised as follows:

- **Safety in natural elements:** Plants and flowers could be considered safe environmental features that did not lead to or contribute to disease.
- **Household safety**: Common household items and appliances (refrigerators, cups, vases) were considered safe for lung health.
- **Routine daily activities:** The community recognised that daily activities and even board games like 30 Seconds could be part of healthy living without causing lung disease.

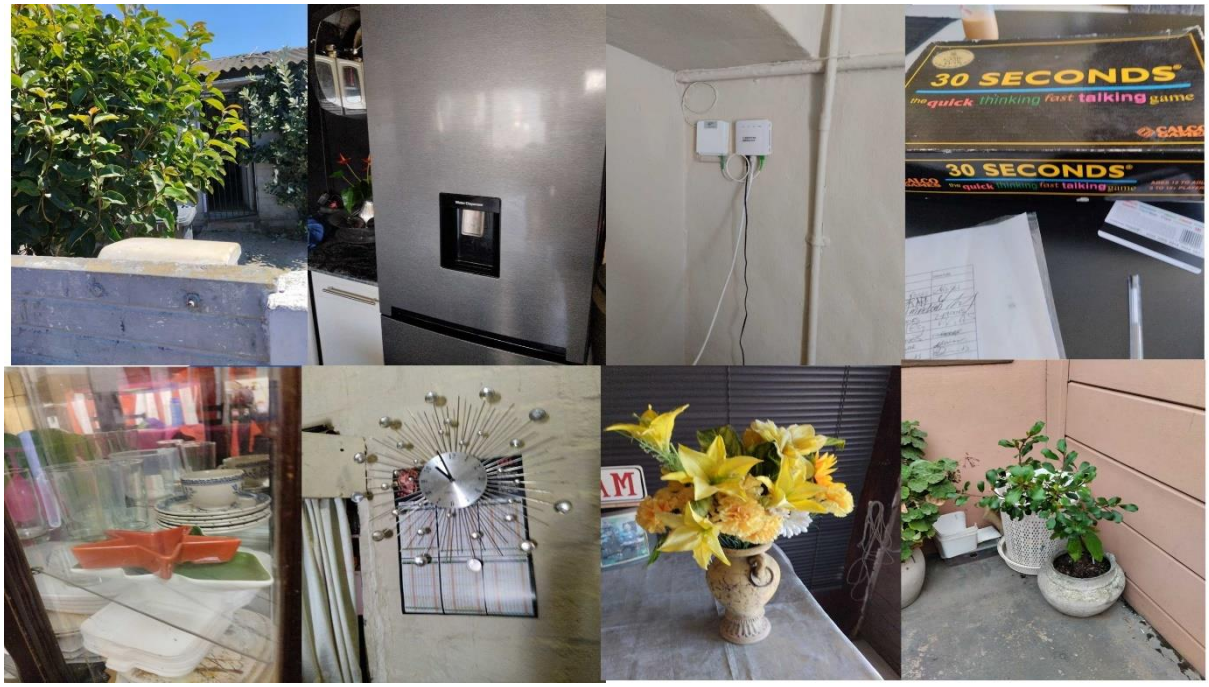

Figure 4.3: Pictorial of what community considered good for lung health

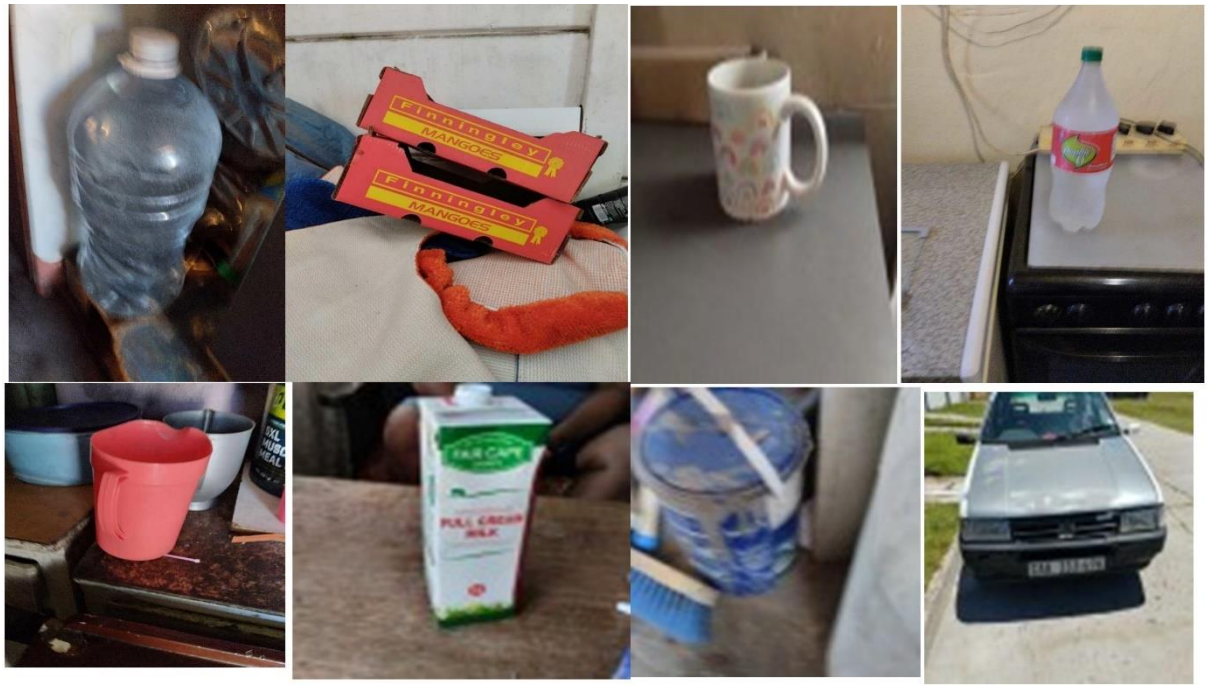

Figure 4.3: Pictorial of what community considered good for lung health

While they took pictures of what they thought was positive for their health, the limitation in the audio transcription was that the community only gave a few standard answers: " We believe that this flower, car, boxes, fridge" does not cause lung disease. Only one responded that the water was good because it “washed their lungs.” The transcription and images underscore how communities had little practical understanding of safe environmental elements. Therefore, the PhD candidate took the first 20 minutes explaining what the images meant, asked for clarity from the community, and intentionally asked the community leaders about their perception and acceptance of PR.

4.3.3 Thematic analysis from the community advocacy meeting

The community advocacy had a co-creation and co-development aspect (Appendix 4.10 and 4.11) based on FGD findings.

The first minutes of the session recapped what the community had indicated in the focus group discussions and the Epicollect community co-created solutions. The emerging themes were as follows:

The findings during the advocacy meeting regarding causes of lung disease, barriers to PR and what PR intervention the community and health leaders perceived to be best (Appendix 4.10-4.12) were as follows:

- Smoking was ranked as the most compelling cause of lung disease, with 86% (22/29) ranking it as first. It was followed by work at 55% (16/29) (work in a mine or dusty place) and finally, air pollution at 41% (12/29).
- Lack of awareness about COPD and lack of awareness about PR was ranked as the most important barrier to PR with 41% (12/29), followed by cost 31% (9/29) (medication is expensive and treatment is expensive) and crime 31% (9/29).
- Both the community leaders and the community members considered group and community-based forms of the best form of rehabilitation.

4.3.3.1 Perception and awareness of risk of lung health

These findings reveal that both the community and the community leaders were aware of the effect of substance abuse on lung health. The preferred strategy for participatory community-driven PR intervention was both group-based and community-based. Based on these three scenarios, the co-designing of an intervention and preferred strategy for the community revealed the following themes (Table 4.4).

Table 4:4 Thematic Analysis of the Community Advocacy Meeting

Theme	Subtheme	Details
Barriers	Access	• Clinics far from residences. • Fear to walk alone due to crime. • Limited mobility. • No access to rehabilitation facilities.
	Financial	• No support from family. • High transport costs. • Cannot afford to miss work. • No medical aid and no personal medical equipment. • No regular income (no transportation to work). • Shared phone with husband.
	Knowledge and Behavioural	• Limited understanding of COPD • Use smoking as a stress-coping strategy.

		• Never sought formal COPD diagnosis. • Inappropriate use of neighbours' Asthma pump. • No knowledge of illness.
	Health behaviours	• Long smoking habits. • Overuse of cough medication. • Persistent cough without medication. • Breathing problems affecting work.
Enablers	Social support	• Part of the savings group. • Strong family support systems. • Community connections (workers union).
	Personal resources	• Essential mobile phone for communication. • Completed grade 10/ 11 education. • Employment provides income. • Access to mobile phones through shared.
	Community assets	• Traditional healing knowledge. • Church group support system.
Preferred intervention	Home-based components	• Preferred based on work schedule. • Family support system integration.
	Community-based components	• Community centre establishment. • More healthcare workers are needed. • Community awareness and training on COPD and PR essential. • Safe group activities. • Integration with clinic resources.
	Educational components	• COPD awareness and understanding. • Smoking cessation support. • Health literacy development. • Traditional medicine integration. • Proper training on medical usage. • Caution on sharing medication.
	Resource requirements	• **Physical**: Mobile health monitoring tools, Education materials, medication management systems, community centre space, transportation solutions. • **Human**: Additional doctors, community health workers, health

		educators, support group facilitators, and trained community members (Citizen scientists).
	Safety considerations	• Group based. • Safe spaces. • Daytime programmes. • Community safety protocols. •
	Stakeholder Involvement	• Workers union representatives. • Family members. • Occupational health workers.
	Cultural Integration and Implementation Strategy	• Traditional healing practices. • Church group involvement. • Culturally sensitive health education. • Leverage on savings networks. • Integrate with existing community centres. • Create safe spaces for health activities. • Mobile health activities.

4.3.3.2 Community determined and preferred PR intervention.

The thematic analysis results indicate that the community prefers a home-based intervention approach blended with community centre activities. This would entail training the community members about COPD, establishing a local support system, and creating safe spaces for PR and health care delivery. The intervention would be sensitive to the cultural context while gradually introducing formal medical care. The church group and family members would accord emotional support, enhancing communication and ensuring adherence to the intervention. The community analysis of the three scenarios reveals critical insights into future community health work, especially in managing COPD and chronic conditions. These three scenarios demonstrate that effective community interventions are multifaceted.

4.3.3.3 Community acceptability of a PR intervention

The final aspect of the Advocacy meeting entailed the community leaders being queried on their acceptability of a PR intervention, and this was recorded and transcribed. (Appendix 4.12) The summary of the community leaders' intervention strategies and proposed action or acceptable intervention for community-driven PR are highlighted in Table 4.5.

Table 4:5: Summary of COPD intervention strategies and community acceptability of PR

Proposed Intervention Strategies		
Strategy type	**Key Actions Points/interventions**	**Supporting statements**
Support groups	• Community-based support systems. • Group exercises in safe places/venues.	"For us as a health forum, the best intervention should be a support group. We should also have an exercise group where people can come to a safe space. Services should be brought closer to the community with education around that."
Education	• Health education and awareness sessions. • Community worker training.	"As the chairperson of the health committee. I think we need more interventions and workshops surrounding COPD, where we can involve our community members to gain more knowledge about COPD."
Alternative Behaviours	• Stress management techniques. • Counselling support. • Better and healthier eating.	"As the coordinating director of the Lerato Family Foundation. I think we should look at small interventions for to curb smoking habits like advising people to try eating sweets when the craving comes".
Health care access	• Services delivered closer to the community. • Door-to-door community care.	"For us as a health forum, we should have e a support and exercise group in a safe space. But we should look also look at how services can be brought closer to the community."
Assessment of Acceptable Community-driven PR		
Aspect	**Findings**	**Supporting Evidence**
Preferred Approach	• Community-based interventions are preferred over individual-based.	A community-based intervention is better than an individual because when you are with other people, you feel better coming out of your comfort zone and you realize you are not the only one with the illness."
Challenges identified	• Consistent smoking habits. • Smoking impact on non-smokers. • Post-meal smoking habits.	As a non-smoker, I am inhaling secondary smoke, and it gets worse with infections. I cough worse than the person who smokes and I am sicker than the smoker."
Behavioural insights	• Smoking is recognised as a need more than a want.	"I am also a smoker. This is a conflict of interest to me, but I think this is just a bad habit gone wrong, because now you started, and do not know how to stop."

Implementation considerations	• It must be long-term. • It needs comprehensive support. • A focus should be on broader community reach.	"It's going to be a process, not overnight. It's a long-term process for people have smoked it would be a process for people, you know, to get out of the habit.

The transcript reveals strong community support for collective intervention approaches, with emphasis on education and support systems. The recognition of smoking as a habit rather than a need suggests an openness to change. The presence of smokers among health leaders indicates the complexity of the challenge. The health leaders actively went out for smoke breaks after the session breaks smoked a couple of cigarettes and apologised upon return. This complexity indicates a need to explore the Health Belief Model (HBM)(123) and Theory of Planned Behaviour, (124) which health educators have used to design interventions that can improve individual and public health. The HBM model underscores an individual's perceptions of the threat posed by a health problem (susceptibility, severity), the benefits of avoiding the threat, and factors influencing the decision to act (barriers, cues to action, and self-efficacy).(124)

4.3.4 Integration of Data Sources

Comparing data across the two community FGDs revealed notable consistencies in themes related to smoking behaviours, environmental hazards, and barriers to healthcare access. However, differences emerged in proposed solutions, with Community 1 emphasizing formal healthcare system improvements while Community 2 focused more on community-based support structures. The photovoice data complemented the FGD findings by providing visual documentation of environmental risk factors discussed verbally in the groups. The advocacy meeting data added an additional layer by incorporating the perspectives of community leaders and healthcare providers, who emphasized implementation considerations not fully articulated by community members.

4.4 Discussion

This study introduces a collaborative community-based Citizen science methodology/approach to exploring community COPD perceptions, including awareness and knowledge, symptoms, experience and stigma, and community support and resources, including PR, awareness knowledge and utilisation in a low-resourced setting.

Recommendations from the FGDs and community advocacy meetings highlight their desired interventions, such as regular exercise programmes, support groups, awareness campaigns, and cigarette and smoking bans. The participants strongly desired community-based initiatives, highlighting the importance of stakeholder support, dedicated available and accessible resources, and trained personnel. These solutions and recommendations reinforce the value of community participation in health research, especially in low-resourced African settings. It builds onto "Our voice Citizen science model, "emphasising community participation in health research. (15–20)

The study yielded five key findings that are crucial for understanding community perceptions of COPD.

1) ***Community awareness, knowledge, and experiences with breathing problems.*** The focus group discussion (FDG) brought to light the community's comprehensive understanding of the risk factors of COPD, including smoking (identified as a primary risk factor), industrial pollution, workplace hazards, vehicle emissions, and dust exposure. This in-depth understanding, coupled with their experiences with COPD, both at personal and communal impact, and their coping strategies, including informal medication networks, demonstrates the community's resilience and resourcefulness in dealing with this health issue.

2) ***Disparities in health care access***. The FDGs also underscored and highlighted the study's findings, which highlight disparities in healthcare access in these communities, including structural barriers (long distances to healthcare facilities, limited diagnostic services, limited access to specialised care, long waiting times for appointments) and quality of care barriers (brief consultations with minimal examinations, no continuity of care, inadequate follow-up).

3) ***Community awareness of risk factors for COPD***. The main themes from the pictures from the Epi collect included tobacco and substance use as the pictures showed the various kinds and types of cigarettes the community consumed and how they also did not dispose of cigarette butts. Old/ unventilated homes with asbestos roofs were also a central theme. They

reveal that the community was aware of multiple risk factors for lung disease. They mainly focused on smoking and environmental exposures. This awareness stems from the formal warnings on the various cigarette packages and the lived experience of their environment (exposure to deteriorating and dilapidated building materials).

4) ***Community preferred PR intervention.*** The advocacy engagement meeting revealed a promising acceptance of the proposed intervention by the community. The suggested hybrid approach, combining home-based support with community centre activities, was met enthusiastically. This positive response suggests a potential for change and improvement in the community's health outcomes, instilling a sense of hope and optimism in the audience.
5) ***Complexity of the intervention*.** Recognising smoking as a habit rather than a need suggests a potential for change within the community. However, the presence of smokers among health leaders underscores the complexity of the challenge. This complexity necessitates a deeper exploration of the Health Belief Model (HBM) and the Theory of Planned Behaviour, which health educators have used to design interventions that can improve individual and public health.

The focus group discussions (FGDs) and the Citizen science (EpiCollect) findings highlighted that the communities were aware of risk factors for lung disease, mainly focusing on smoking and environmental exposures. The findings further highlight the general and often lack of awareness and understanding regarding COPD at a local community level, not uncommonly seen across Africa and LMICs, leading to associated stigma and isolation coupled with fear.(125) The reason for limited awareness in our study, like many African/LMIC regions, could be due to the glaring gaps in COPD prevention and management, including understanding its diagnosis, treatment, and prevention coupled with low diagnostic capacity and inadequate therapy.(3,39)

Community perceptions are cardinal and crucial in influencing healthcare experiences and health-seeking behaviour.(126) Despite the participants recognising the risks associated with smoking in our study, some participants described it as a necessity for daily activities and routines: "And when you are done eating lunch, breakfast, supper, And when you sit on the pot, you must smoke.

It is like dessert." "It is better than breakfast in the pot. So, we are saying smoking is dessert. It is like breakfast" "After your meal, you must smoke. It is breakfast, lunch, supper. You must have a cigarette even when you go to the restaurant."

Economic and social-cultural factors in LMICs significantly influence health behaviours. For example, a study in Ghana on perceptions of community members on contextual factors driving cardiovascular disease behavioural risk identified economic (poverty and unemployment), psychosocial (worries, hardship), medical (pain suppression), sexual (performance boost) and social-cultural (curse, invocation) as drivers of alcohol consumption and smoking.(127) Our study did not query what factors influenced their smoking behaviour.

The EpiCollect mobile-based survey and FGDs also revealed a growing concern among the communities about the causes of lung disease. The pictures of cigarette packs with stark warnings "Danger; smoking causes cancer, Danger, smoking can kill you, danger smoking causes heart disease, Pregnant? Breast feeding? Smoking can harm your baby' "left strong impressions on the community. The community perceptions of awareness, knowledge, and utilisation of PR health underscored health care access and challenges, including long distance to health care facilities, limited diagnostic services, limited access to specialised care, long waiting times for appointments, brief consultations with minimal examination, no continuity of care, inadequate follow up systems. These challenges to healthcare provision align with the three levels of the delay model: The decision to seek care, accessing a healthcare facility and receiving adequate care,(128) which emphasises systemic issues impacting healthcare accessibility.(128,129) The results from our study highlight the disparities in healthcare access in South Africa.

While the South African constitution guarantees health care provision,(130) significant inequities are still evident in South Africa, stemming from a history of discrimination and income inequalities.(131) Although most public health resources are concentrated in urban areas, many in peri-urban and rural areas remain underserved.(132) In other LMICs, the most significant proportion of their populations also rely on public healthcare facilities due to affordability and access issues,(132) and an underfunded and overburdened reality often characterises their health systems; for example, in India, Nigeria, South Africa.(132–134)

The results from the advocacy engagement meeting suggest that the community accepts an intervention and suggests a hybrid approach that combines home-based support with community centre activities and would involve an education component, establishing a local support network. This intervention would be culturally sensitive, and the community, including the church, would be crucial in providing emotional support. Recognising smoking as a habit rather than a need suggests an openness to change in the community. However, the presence of smokers among health leaders indicates the complexity of the challenge.

This complexity indicates a need to explore the Health Belief Model (HBM)(123) and Theory of Planned Behaviour, which health educators have used to design interventions that can improve individual and public health. The HBM model underscores an individual's perceptions of the threat posed by a health problem (susceptibility, severity), the benefits of avoiding the threat, and factors influencing the decision to act (barriers, cues to action, and self-efficacy). Utilising these two models in Manenberg will facilitate the development and understanding of population-based COPD screening with improved outcomes – like reach, acceptability, and efficient implementation processes. It is worth noting that clinical people tend to prescribe outcomes and not strategies, and sometimes, the guidelines provided reduce motivation and erode autonomy (25).

4.5 Limitations and strengths of the study

The study has limitations. The study also employed a convenience sample of two peri-urban communities in South Africa, where high crime rates create distrust and reluctance from the communities to share authentic experiences. The inability to verify information about health-seeking behaviour, as the community may withhold information because of fear of being stigmatised. These findings are, therefore, not generalisable to all South African communities or ethnic groups.

However, the study provided insight into community-level COPD risk perceptions and care barriers whilst establishing a feasible way forward for future referral and PR services. The study also fostered a community-driven advocacy network and enhanced community engagement in COPD understanding, prevention, and management.

A notable limitation was the absence of exercise training practitioners among the healthcare provider stakeholders. This gap is significant given that PR is predominantly exercise-based. Despite efforts to include such professionals, their limited availability in the community setting reflects the broader challenge of accessing specialized rehabilitation services in low-resourced areas a finding that itself reinforces the need for building local capacity in exercise training.

While the thesis focuses on pulmonary rehabilitation, the predominance of data on COPD risk factors rather than rehabilitation preferences reflects an important finding in itself. This pattern suggests that in communities with limited awareness of COPD as a distinct condition and minimal exposure to rehabilitation concepts, establishing a foundation of basic respiratory health knowledge must precede detailed discussions of rehabilitation preferences. The emphasis on risk factors in participants' responses highlights the need for a staged approach to PR implementation in such settings, beginning with education and awareness-building before introducing formal rehabilitation programs.

4.5.1 Researcher Reflexivity and Positionality

As the primary researcher, I acknowledge that my position as a healthcare professional (Biokineticist) and non-community member may have influenced data collection and interpretation. My medical training potentially oriented me toward biomedical rather than cultural understandings of respiratory health. However, my African background and familiarity with similar communities helped mitigate cultural disconnects. Throughout the research process, I maintained a reflexive journal documenting how my assumptions might influence the study and regularly discussed emerging interpretations with community members to ensure they resonated with their lived experiences.

4.6 Conclusion and Recommendations

The study represents a novel approach to understanding COPD risk perception and PR implementation in resource-limited settings through a community-driven Citizen science methodology. It successfully identified the community-level COPD perceptions and bridged the gap between clinical knowledge and community understanding while initiating the potential co-creation of a sustainable, culturally appropriate intervention. The findings highlight the community's awareness of health challenges and their ardent desire for structured interventions, particularly those with community involvement and support, but faced with enormous barriers stemming from diagnosis through to treatment, with limited general health education and disease understanding.

One key recommendation is that supporting robust community engagement in implementation of culturally relevant and context-driven PR is critical to addressing the COPD in socio-economically disadvantaged African setting. This approach needs to equipping clinicians and community-based health care workers to provide PR, co-creating programmes that are locally sustainable based on robust data. This approach can broadly increase awareness and knowledge base of the community about COPD risks, treatments, that can support respiratory wellbeing. Fostering partnerships between health care providers, institutions of learning, community leaders, and organisations is required, given the huge gap identified between Pulmonary rehabilitation science and local community understanding and buy-in.

CHAPTER FIVE

DISCUSSION

As previously highlighted in this thesis, pulmonary diseases pose a significant global health threat, with Chronic Obstructive Pulmonary Disease (COPD) emerging as the most prevalent condition. This underscores the urgency and importance of our discussion.(1,2)

Pulmonary rehabilitation (PR) has become the basis/foundation of care for hospitalised COPD patients, and substantial evidence shows its effectiveness in reducing readmissions and enhancing outcomes through personalised exercises and education.(17,29,135) While much of this evidence comes from COPD studies, similar benefits have been observed in patients with other respiratory diseases.(36–40) Despite these positive findings, PR implementation for COPD has been disappointingly slow, particularly on the African continent, where limited resources, inadequate funding, and a lack of awareness among healthcare professionals, providers and patients create a mismatch between the benefits of PR and its actual delivery. (25,41,52)

5.1 The Role of Citizen Science in Pulmonary Rehabilitation

The Citizen science model (59) emerges as a promising solution to bridge the gap in South Africa, combating infectious and non-communicable chronic diseases exacerbated by modifiable risk factors like inactivity and poor diets. A community-driven (Citizen science approach) approach could help patients, and the community understand disease risk perception (in this case, COPD) and engage with and even drive the demand for Pulmonary rehabilitation. It would aid in developing prevention advocacy strategies with health care providers. Citizen science enables community involvement in data collection, analysis, problem definition, and integrating community perspectives into the research process.(110,136,137) Little is known about community participation in patients with COPD, and there are no accepted and established tools to assess it.(26)

5.1.1 Innovation in Applying Citizen Science to Pulmonary Rehabilitation

The application of Citizen science methodology to PR implementation represents a significant innovation not only in COPD management but in rehabilitation interventions more broadly. While participatory approaches have been employed in some health contexts, their application to structured rehabilitation programs like PR remains exceptionally rare. The approach demonstrated in this thesis offers a template that could be adapted for other rehabilitation contexts, such as cardiac rehabilitation, stroke rehabilitation, or diabetes management programs. The transferability of this approach is particularly valuable in resource-constrained settings where conventional implementation models often fail due to contextual misalignment. By positioning community members as co-researchers rather than merely recipients of care, this approach directly addresses the power imbalances that frequently undermine the sustainability of externally designed interventions.

There is a clear need for a new tool or method to measure community participation in COPD management. Ideally, this tool should be easy to administer and should capture the frequency of participation in both formal and informal activities. The community-driven (Citizen science) approach has laid a solid foundation for understanding disease risk perception and developing prevention advocacy strategies. It enables community involvement in data collection, analysis, problem definition, and integrating community perspectives into the research process. This coupled with traditional scientific methods of clinical evaluation of potential programmes, synthesis of global data and understanding of the knowledge attitudes and practice of potential providers, should provide a solid foundation for a sustainable, acceptable, and efficacious community level PR intervention.

5.2 Synthesis of Findings Across Chapters

Chapter two aimed to comprehensively explore the state of PR services in LMICs and their uptake, especially in low-resourced African settings in Africa, with a systematic review. The primary objective was to evaluate how effectively home-based and community-based PR programmes served COPD patients in these resource-limited environments and compare their delivery models, outcomes, and implementation approaches.

We also aimed to identify and examine the factors that hindered or supported their implementation, providing insights for future program development and implementation in South Africa.

PR in HICs is a well-established, but despite its proven benefits, access to these services remains limited. Currently we know that only 3% of people with Chronic diseases have access to PR globally.(27)

This systematic review in chapter two, demonstrated the almost non-existent literature exploring the state of PR services in LMICs and their uptake, especially in low-resourced African settings in Africa. It underscored the urgent need to formulate and adapt Pulmonary rehabilitation programmes to the local African context while maintaining clinical effectiveness. The need for culturally appropriate PR programmes to be developed and implemented in Africa is pressing. Although we can draw lessons from the successful home-based models in high-income countries, we should remain conscious of local resources and constraints. There is thus an opportunity to develop through co-creation and co-designing. culturally appropriate education material utilising a Citizen science model integrated with traditional scientific evidence.

In Chapter three, we aimed to evaluate the extent of clinical awareness, knowledge of and support for Pulmonary rehabilitation by healthcare providers and to identify barriers to Pulmonary rehabilitation in Africa. As stated earlier , less than 3 % of people with chronic lung disease have access to PR globally and literature from HIC indicates that several barriers contribute to poor access of PR in HICS.(27)

These include lack of knowledge among health care professionals regarding the benefits and construct of PR. We also know that uptake and completion rates of PR programmes in HICS are suboptimal (only 35%of eligible patients are referred to PR), uptake rates range from 69% to 80% of referred patients.(27) Therefore in chapter three, we aimed to evaluate the extent of clinical awareness, knowledge of and support for Pulmonary rehabilitation by healthcare providers and to identify barriers to Pulmonary rehabilitation in Africa.

The positive results revealed a substantial awareness and recognition of Pulmonary rehabilitation as an effective intervention for COPD and other chronic lung diseases across Africa. The wide and diverse range of respondents (30 professionals from 23 African countries) suggests the potential feasibility of implementing a multi-disciplinary approach to deliver PR for equitable access to COPD management in Africa. Despite the existing barriers, equipping all healthcare workers with the requisite skills to implement an effective, locally acceptable PR programme will significantly impact patients with COPD and ultimately mitigate the high burden of COPD in Africa. The survey however is not truly representative of all healthcare workers in the respiratory space as it engaged with active networks with in SATS and PATS, outside of which greater barriers may exist.

A significant limitation of this survey is its representativeness. While we achieved a high response rate (56%) among PATS and SATS members, these societies primarily include specialists and those with particular interest in respiratory medicine. This creates an inherent selection bias that likely overestimates awareness and knowledge of PR compared to the broader healthcare workforce in Africa. Furthermore, the survey reached practitioners from only 23 of Africa's 54 countries, with stronger representation from Southern and East African regions. The perspectives of healthcare providers in Central and West Africa, as well as those working in primary care settings without specialty society affiliations, are underrepresented. This limitation should be considered when interpreting the findings and highlights the need for future research encompassing a broader range of healthcare practitioners across diverse African contexts.

In this clinician focussed survey, the medical aspects of diagnosis and treatment and knowledge were the scientific motivation, patient level barriers to utilisation and accessibility were not explored. Despite these shortcomings, the study including a multi-country perspective, diverse healthcare settings encouragingly reflected a positive enthusiasm for PR among HCPS suggesting that its implementation is feasible with adequate and appropriate support plus investment. The findings providing actionable insights and policy implications, whilst being cautious in recognising the rich diversity across the 54 countries on the African continent and avoiding overgeneralisation based on the "mean" data.

In chapter four, understanding the need, barriers and system challenges highlighted through the findings of chapters two and three, we sought to explore the understanding and availability of Pulmonary rehabilitation at a patient level. From High income countries we also know that barriers to access for PR include patient-related barriers including lack of perceived benefits, stigma and reduced help-seeking.(27) We also know that that PR programmes are scarce in High income countries especially in the rural areas with 73% lacking an outpatient program.(27) We know that innovative solutions such as educational programmes, focus group discussions have shown promise in establishing culturally contextual PR services in rural and low resourced areas .(27) We know that involving the patients (participatory Citizen science) focuses on the for-the-people and by-the-people models to achieve engagement for sustainable research and intervention adoption and use. We know that robust engagement with the community helps create models especially for Africa as a continent

Evidence has shown that in recent years, participatory Citizen science leveraging on 'Our Voice' Citizen science has been utilised to innovatively co-design and implement over 100 population-based research and interventions in poor and disadvantaged settings, with good results.(65) Therefore, using a Citizen science participatory approach, we explored COPD risk factors and supported community-driven Pulmonary rehabilitation and advocacy strategies in a disadvantaged African setting and determined the preferred strategy for participatory community-driven PR intervention using stakeholder engagement, result-sharing presentation, and community advocacy workshop. The findings reveal a limited awareness of COPD among the community, as many conflated it with general respiratory conditions such as asthma.

The EpiCollect and focus group discussions highlighted that the communities were aware of risk factors for lung disease, mainly focusing on smoking and environmental exposures. The findings further underscore the general and often lack of awareness and understanding regarding COPD across Africa and LMICs, leading to associated stigma and isolation coupled with fear.(125) The reason for limited awareness in our study, like many African/LMIC regions, could be due to the glaring gaps in COPD prevention and management, including understanding its diagnosis, treatment, and prevention coupled with low diagnostic capacity and inadequate therapy.(1,3)

The community perceptions of awareness, knowledge, and utilisation of PR health underscored health care access and challenges, including long distance to health care facilities, limited diagnostic services, limited access to specialised care, long waiting times for appointments, brief consultations with minimal examination, no continuity of care, inadequate follow up systems. These challenges to healthcare provision align with the three levels of the delay model: The decision to seek care, accessing a healthcare facility and receiving adequate care,(128) which emphasises the gravity of systemic issues impacting healthcare accessibility.(128,138)

Focus group discussions and community advocacy meeting recommendations highlight their desired interventions, such as regular exercise programmes, support groups, awareness campaigns, and cigarette and smoking bans. The participants strongly desired community-based initiatives, highlighting the importance of stakeholder support, dedicated available and accessible resources, and trained personnel. These solutions and recommendations reinforce the value of community participation in health research, especially in low-resourced African settings. It builds onto "Our voice Citizen science model, " emphasising community participation in health research.(59,65,137,139–141)

The study has limitations as with other studies that deal with community perceptions, such as the inability to verify information about health-seeking behaviour, as the community may withhold information because of fear of being stigmatised. The study also employed a convenience sample of two peri-urban communities in South Africa, where high crime rates create distrust and reluctance from the communities to share authentic experiences. These findings are, therefore, not generalisable to all South African communities or Ethnic groups. However, the study provided insight into community-level COPD risk perceptions and care barriers whilst establishing a feasible way forward for future referral and PR services. The study also fostered a community-driven advocacy network and enhanced community engagement in COPD understanding, prevention, and management.

While the thesis focuses on pulmonary rehabilitation, the predominance of data on COPD risk factors rather than rehabilitation preferences reflects an important finding in itself. This pattern suggests that in communities with limited awareness of COPD as a distinct condition and minimal exposure to rehabilitation concepts, establishing a foundation of basic respiratory health knowledge must precede detailed discussions of rehabilitation preferences. The emphasis on risk factors in participants' responses highlights the need for a staged approach to PR implementation in such settings, beginning with education and awareness-building before introducing formal rehabilitation programs.

This chapter and the overall study represent a novel approach to understanding COPD risk perception and PR implementation in resource-limited settings by employing a community-driven Citizen science methodology. It successfully identified the community-level COPD perceptions and bridged the gap between clinical knowledge and community understanding while co-creating a sustainable, culturally appropriate intervention. The findings highlight the community's awareness of health challenges and ardent desire for structured interventions, particularly those that involve and support the community.

The 'by the people, for the people' nature of engagement in the research, the participation and the findings underscore a significant strength of the Citizen science approach. Unlike top-down implementation guidelines often developed by external experts and stakeholders with limited contextual understanding, these requirements emerged directly from community experiences and priorities. This origin enhances their legitimacy, relevance, and potential sustainability. For example, the emphasis on security considerations for group activities directly reflects the lived reality of community members, a factor that might be overlooked in externally developed guidelines but could be critical to program success in this context.

5.3 Critical Analysis of the Citizen Science Process in PR Implementation

The Citizen science approach utilized in this thesis demands critical examination beyond merely reporting outcomes. This section examines the theoretical foundations, methodological choices, implementation challenges, and ethical considerations of using Citizen science for PR development.

5.3.1 Theoretical Positioning of the Citizen Science Approach

Citizen science exists on a spectrum from contributory models (where citizens primarily collect data defined by scientists) to collaborative models (where citizens help analyse data and refine methods) to co-created models (where citizens participate in all research stages including problem definition). The approach used in this thesis aimed toward the co-created end of this spectrum but operated within practical constraints.

While this research aimed for community-driven problem definition, we acknowledge that the initial framing around COPD and PR was researcher-determined. This creates an inherent tension with the ideals of co-created Citizen science, where problems should emerge from community priorities. The community participants did not independently identify PR as a priority need, but rather responded to our framing of respiratory health as the research focus. This limitation reflects broader challenges in balancing scientific agendas with community priorities.

5.3.2 Critical Evaluation of the 'Our Voice' Methodology

The 'Our Voice' framework provided the methodological backbone and foundation for our implementation. Its strengths included its accessible technology platform, established protocols for community engagement, and emphasis on moving from data to action. However, several challenges emerged during implementation:

1) ***Digital literacy barriers:*** Some community members struggled with the EpiCollect application despite simplifications, highlighting technology access disparities.
2) ***Representation challenges:*** Despite efforts to ensure diverse participation, certain community sub-groups (particularly working-age men) were underrepresented due to their limited availability during scheduled activities.
3) ***Translation complexities:*** Moving between different languages (isiXhosa, Afrikaans, and English) during data collection and analysis introduced potential interpretation challenges.
4) ***Power dynamics*****:** Despite intentions for equal partnership, hierarchical relationships between researchers and community members persisted in subtle ways that likely influenced participation and data interpretation.

5.3.3 Knowledge Co-Production: Challenges and Realities

True knowledge co-production requires challenging traditional expertise hierarchies. While our approach positioned community members as experts on their lived experience, the interpretation of findings and development of implementation recommendations ultimately remained heavily influenced by the research team's medical and clinical framing.

The research team retained significant control over which community insights were prioritized for implementation. For example, the predominant community focus on smoking as a central concern was academically acknowledged but somewhat redirected toward the predetermined PR implementation focus. This highlights the challenge of honouring community priorities while maintaining scientific objectives.

5.3.4 Ethical Considerations in Community Engagement

Several ethical tensions arose during implementation:

1) ***Expectations management:*** The research process inevitably raised community expectations for sustained intervention, which may not be immediately fulfilled without continued funding.
2) ***Compensation considerations*****:** The decision to provide modest compensation to citizen scientists raised questions about motivations for participation and sustainability beyond the funded research period.
3) ***Data ownership****:* While community members collected data, the university retained ultimate control over data storage, analysis, and publication, creating inherent power asymmetries and dynamics.
4) ***Representation legitimacy*****:** Citizen scientists were positioned as community representatives, but the extent to which they genuinely represented diverse community perspectives remains a valid question which should be explored in future engagements.

5.3.5 Scalability and Healthcare System Integration

For the Citizen science approach to meaningfully impact PR access in Africa, considerations for scaling and health system integration are necessitated . Several challenges and opportunities emerged from our process:

1) ***Healthcare system readiness*:** While the approach successfully engaged communities, parallel health system capacity building is needed for proper sustainability. Community demand for services should be matched with provider capacity.
2) ***Resource requirements:*** The intensive nature of the Citizen science process requires substantial human and financial resources that may limit large-scale implementation without adaptation.
3) ***Knowledge transfer mechanisms*:** Processes for transferring insights between communities are underdeveloped, potentially requiring each implementation to begin from first principles.
4) ***Diverse health applications:*** Beyond COPD, this approach shows promise for other rehabilitation contexts including cardiac rehabilitation, mental health, and diabetes management, though adaptation would be necessary for each condition.

5.3.6 Evaluation Framework for Citizen Science in PR

Evaluating the impact of this approach requires assessment across multiple dimensions:

1) ***Scientific outcomes:*** Traditional measures of knowledge generation and publication impact
2) ***Participant outcomes:*** Enhanced knowledge, skills, and empowerment among citizen scientists
3) ***Community outcomes***: Broader awareness, capacity building, and social capital development
4) ***Health system outcomes:*** Changes in healthcare provider practices, referral patterns, and service provision
5) ***Sustainability outcomes***: Continued community ownership and adaptation beyond the funded research period

Moving forward, systematic measurement across these dimensions would provide a more comprehensive understanding of the approach's true impact and value.

This critical analysis demonstrates both the significant potential and important limitations of the Citizen science approach for PR implementation. While not a panacea, when implemented with awareness of its constraints and careful attention to power dynamics, it offers a promising pathway toward more contextually appropriate and sustainable PR services in low-resourced African settings.

Overall, the findings in the three chapters feed into the Citizen science Framework and model (Figure 5.1). The framework incorporates three levels of Citizen science: ***contributory***, which is data collection by scientists and the patient community; ***collaborative*****, which is** community involvement in data analysis*;* ***co-created*** community definition of problems; and translation of findings to interventions.

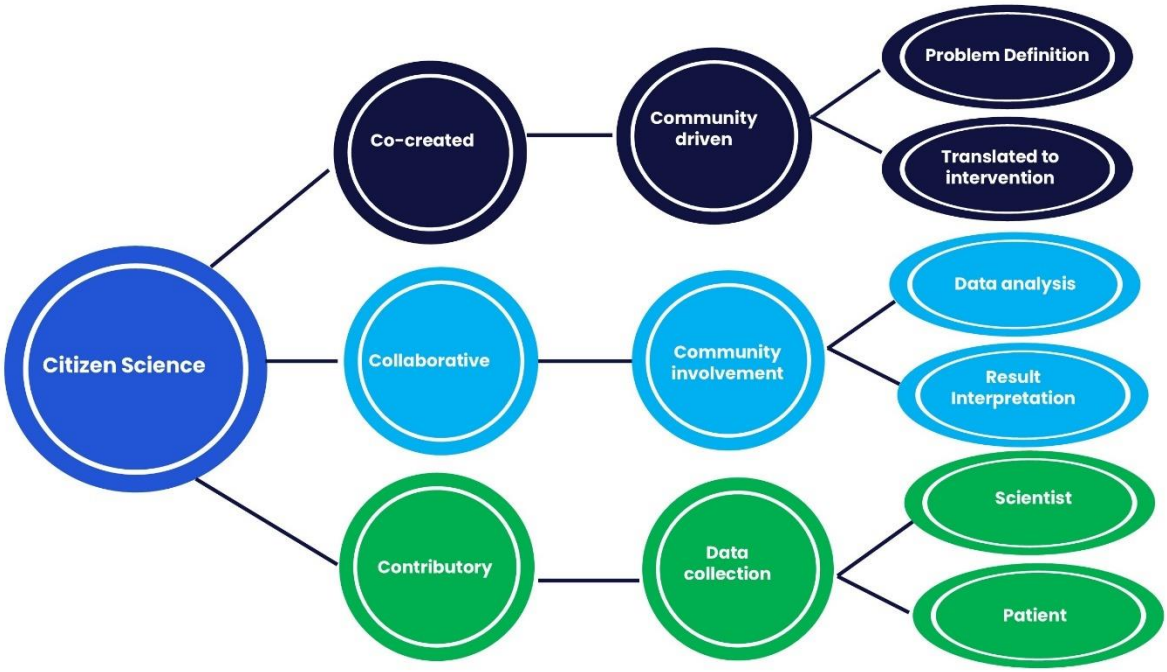

Figure 5.1: Citizen science Framework and model

In summary, the need for Pulmonary rehabilitation is well documented and understood at a scientific and specialist pulmonologist level. The implementation of PR faced with many global but also local logistic, training, funding, and staffing challenges. The evidence for community based/ "out of hospital" PR programmes well described in high income countries but almost non-existent in low-income settings, and ultimately at the patient level lack of awareness of the diagnosis, understanding and access to treatment may inadvertently be the most important factor limiting the access of patient with COPD to an effective PR intervention.

Whilst utilizing traditional 'medical-science methods' to increase access to PR in low-income settings, a more Citizen science strategy with engagement at community level with both health care staff, patients and community members may provide a better multilayered and acceptable programme to those that need it most.

5.4 Contextualizing Citizen Science within Global PR Implementation Efforts

When positioned within the broader landscape of global PR implementation research, the Citizen science approach employed in this thesis offers both complementary insights and distinct advantages compared to conventional implementation methodologies. This section critically evaluates this approach in relation to other PR implementation strategies from both high-income and low- and middle-income countries.

5.4.1 Comparison with Conventional Implementation Approaches

Traditional PR implementation research has primarily focused on provider-centered strategies such as healthcare professional training, clinical pathway development, and referral system optimization. These approaches, while valuable for addressing capacity limitations, often fail to adequately engage with contextual factors that influence program acceptance and sustainability, particularly in diverse cultural settings.

The provider-centred implementation approach dominant in high-income countries assumes that building healthcare capacity will naturally translate to service utilization. However, experience from other health interventions suggests that this supply-side focus is insufficient without corresponding attention to demand-side factors the community's understanding, acceptance, and active participation in program development.

By contrast, the Citizen science approach explicitly addresses these demand-side factors by positioning community members as active stakeholders rather than passive recipients. This represents a fundamental shift in implementation philosophy that may be particularly valuable in settings where healthcare provider-patient relationships are characterized by significant power imbalances or cultural distances.

5.4.2 Critical Assessment of Strengths and Limitations

The Citizen science approach demonstrated several comparative strengths:

1) ***Contextual sensitivity:*** Unlike standardized implementation protocols, the approach allowed for deep understanding and knowledge of local factors that would influence PR acceptance and utilization.
2) ***Community ownership:*** By involving community members as researchers rather than subjects, the approach fostered a sense of program ownership and togetherness that may enhance sustainability.
3) ***Cultural appropriateness:*** The methodology enabled identification of cultural factors that would not be apparent to external implementers, such as the centrality of church-based community structures.
4) ***Bidirectional learning:*** Healthcare providers gained insights from community perspectives that challenged professional assumptions.

However, several limitations must also be acknowledged:

1) ***Resource intensity****:* The approach required substantial time and human resources that may not be feasible in all implementation contexts.
2) ***Balancing rigor and accessibility:*** Methodological adaptations to ensure community participation sometimes compromised research standardization.
3) ***Expertise integration challenges:*** Reconciling community knowledge with clinical expertise occasionally created tensions in intervention design.
4) ***Scale-up complexity:*** The deeply contextual nature of findings raises questions about transferability to other settings.

5.4.3 Adaptation for Different LMIC Contexts

The application of this approach across diverse LMIC settings would require careful adaptation. Several contextual factors would influence implementation:

1) ***Urban vs. rural settings****:* The approach would require significant modification for rural settings where communities are more dispersed and technology access more limited.
2) ***Health system structure:*** Integration would differ significantly between centralized health systems versus more decentralized models.
3) ***Cultural factors:*** The balance between individual and collective decision-making varies significantly across cultures, affecting how community engagement should be structured.
4) ***Existing community structures****:* The approach leverages existing community organizations, which vary tremendously across contexts.

5.4.4 Toward an Integrated Implementation Science Framework

Rather than positioning Citizen science as an alternative to conventional implementation approaches, this analysis suggests the need for an integrated framework that combines:

1) ***Supply-side interventions*****:** Healthcare workforce development, resource allocation, and clinical pathway optimization
2) ***Demand-side engagement:*** Community participation, education, and co-design processes
3) ***System-level coordination****:* Mechanisms for sustainable integration between community initiatives and healthcare structures

Such an integrated approach acknowledges that neither top-down nor bottom-up strategies alone can address the complex challenge of PR implementation in resource-constrained settings. This critical contextualizing of the Citizen science approach within broader implementation science highlights both its unique contributions and the need for complementary strategies to achieve meaningful improvements in PR access and outcomes across diverse African settings.

CHAPTER SIX

RECOMMENDATIONS

Our study employed a novel community-driven Citizen science methodology to understand COPD risk perception and develop contextually appropriate PR implementation strategies in a resource-limited setting in South Africa.

This chapter outlines evidence-based recommendations derived directly from our empirical findings. Each recommendation is explicitly linked to specific results from our research, ensuring that these suggestions are not merely general principles but are grounded in the community's expressed needs, barriers, and preferences.

6.1 Evidence Base for Recommendations.

The recommendations in this chapter are derived from three primary sources of evidence gathered in this thesis:

1) The systematic review (Chapter 2), which identified significant gaps in comparative research on home-based versus community-based PR in African settings
2) The continent-wide survey of healthcare practitioners (Chapter 3), which revealed knowledge, resource, and implementation barriers
3) The Citizen science process (Chapter 4), which provided rich community perspectives on respiratory health and rehabilitation preferences

This triangulation of evidence ensures that recommendations address both healthcare system realities and community priorities. Where recommendations draw primarily from one source, this is explicitly noted to maintain transparency about the evidence base.

6.2 Community-Identified Implementation Priorities

The following priorities emerged directly from the Citizen science process described in Chapter 4, representing authentic community voice:

Community involvement is a critical element to successfully implement ‘community level’ PR programmes. Despite all the global evidence end advocacy for PR, at our community level the vast disconnect between practitioner and patient needs to be managed.

Improving the basic understanding of COPD, education about respiratory diseases alongside improved access to diagnosis and treatment is of paramount importance before any 'rehabilitation' is offered. This prioritization of education before formal rehabilitation was explicitly articulated during community focus groups, with one participant stating: "We cannot rehabilitate what we do not understand" (Chapter 4, FGD1). The community photovoice process revealed that 78% of images related to risk factors rather than rehabilitation environments, further reinforcing that community understanding begins with risk perception rather than treatment modalities

We need to encourage the patient community to actively participate in the design and execution around NCDs and lung disease research, advocacy, implementation, and education initiatives(136). By raising awareness about COPD and PR(59), we empower the community to take charge of their health and resources. Citizen scientists play a pivotal role in addressing and voicing the specific needs of communities through their impactful services, including health promotion, disease prevention, and post-discharge follow-up care. They then are able to implement a culturally adapted community-based PR using minimal equipment.(142)

Our citizen scientists identified specific contextual factors that must be addressed in PR implementation, including:

1) ***Safety concerns****:* 31% of community participants highlighted crime and safety as barriers to outdoor activities, noting "We cannot exercise outside after dark." This necessitates daytime scheduling and secure venues for PR activities.
2) ***Transportation challenges*****:** 43% of participants mentioned difficulties accessing healthcare facilities, necessitating programs within walking distance of community residences.
3) ***Integration with existing community structures*****:** Participants expressed strong preference for utilizing familiar community spaces such as churches (mentioned by 58% of participants) and community centres (mentioned by 64%), rather than creating new, unfamiliar venues.
4) ***Group-based approach:*** 78% of participants expressed preference for group activities that align with community collectivist values, with one participant noting: "When we do things together, we heal together" (Chapter 4, FGD2).

6.3 Citizen Science-Derived Implementation Principles

Capacity building is needed to sustain and expand on implementation. Training and capacity-building programmes should be implemented to empower the patient community with skills that would drive health education, health promotion, and further research using community-based PR as the vehicle. Capacity building and ongoing research in one established programme will provide knowledge and skills to expand the programme into other areas/ communities, using the skills and knowledge acquired in one community to assist other communities to grow their own citizen scientists and community relevant interventions.

Our Citizen science process in Chapter 4 demonstrated that community members can be effectively trained to collect and analyse health data. As one community member reflected: "I never knew I could be a scientist, but now I see how my knowledge of the community is valuable" (Citizen scientist reflection, Chapter 4). This experience provides a template for capacity building that can be replicated in other communities.

Funding and sustainability must be co-developed to prevent "white elephant" projects fuelling scientific-community mistrust. Funding to create and sustain community-led support groups, provide education on COPD management and PR, and empower community-led advocacy must be sought. (59)(111) Post implementation, evaluation metrics are key, not only to satisfy academic/research or philanthropy funding but also to persuade community supports to continue funding. Social, personal and community outcomes are needed alongside physiological and health outcomes to support the Citizen science projects and may further open doors to diverse funding, especially if the project aligns with new funders mission. Some may choose to invest as part of corporate and social responsibility commitment based on demonstrable outcomes. (59)·(111)

Community members expressed concern about abandoned projects, with one community leader stating: "We have seen many projects come and go when the funding ends" (Chapter 4, Advocacy Meeting). This distrust of externally driven initiatives underscores the need for community co-ownership of funding models.Citizen science can be considered a valuable and necessary approach in exploring the understanding and availability of Pulmonary rehabilitation from clinicians to the patients and community level. The following recommendations emerge directly from our empirical work and are organized by implementation domain as illustrated in Figure 6.1.

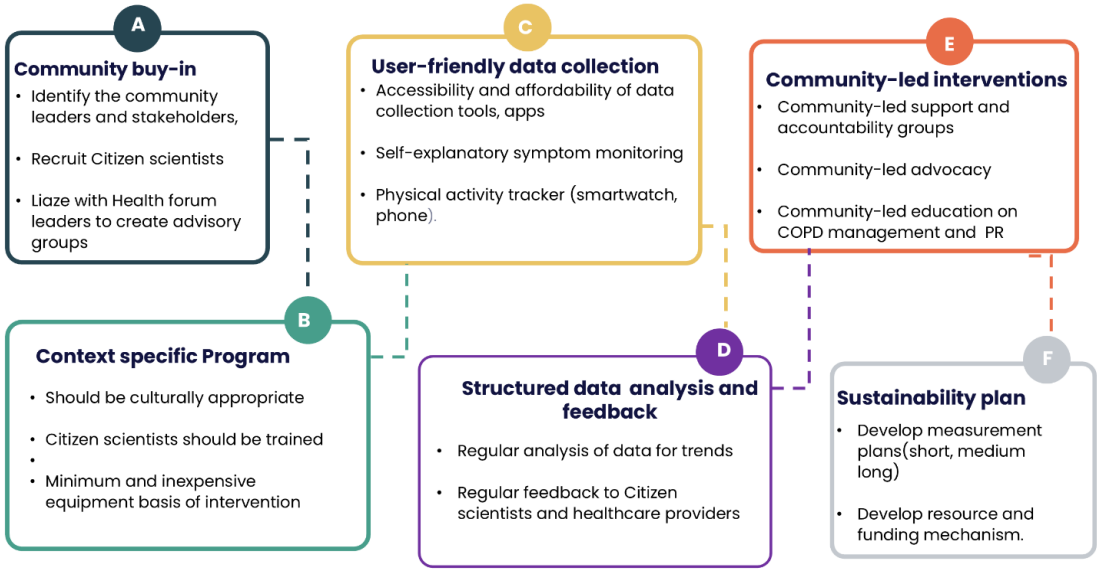

Figure 6.1: Evidence-Based Recommendations for PR Implementation in Low-Resourced African Settings

The following recommendations integrate findings from all three empirical chapters, with particular emphasis on incorporating community perspectives gathered through the Citizen science approach:

6.4 Program structure and delivery.

Based on both survey findings (Chapter 3) and community preferences (Chapter 4), PR programs should combine supervised elements with home-based components. Initial assessment and supervision should be conducted by trained healthcare professionals, ideally pulmonologists or physiotherapists where available, or specially trained primary care providers with appropriate skills in respiratory assessment. The capacity-building component should include training these professionals in standardized assessment protocols adapted for low-resource settings.

Our healthcare practitioner survey revealed that 73% of respondents believe lack of trained personnel is a major barrier to PR implementation (Chapter 3). Simultaneously, community members expressed hesitation about purely home-based approaches, with one participant noting: "We need someone to show us the correct way to do exercises" (Chapter 4, FGD2).

This supports a hybrid approach with initial supervised sessions followed by home practice, with periodic group reinforcement.

Programs should follow a 6–12-week structure with clearly defined progression, based on both established PR guidelines and community preferences for defined timeframes expressed during focus groups. Community venues identified through the photovoice process in Chapter 4 (including community centres, churches, and schools) should be prioritized as implementation sites to enhance accessibility and cultural acceptability.

6.5 Monitoring and use of Technology.

Monitoring approaches should be tailored to available resources while ensuring basic safety and effectiveness measures. Our survey of healthcare practitioners (Chapter 3) found that 82% had access to mobile phones for patient communication, suggesting technology-enabled monitoring is feasible. Community participants identified WhatsApp as their preferred communication platform (mentioned by 87% of participants in Chapter 4), making it an appropriate choice for group support and monitoring.

Documentation should include culturally appropriate, visual exercise guides with minimal text, as suggested by community members during the Citizen science process who noted: "Pictures are better than words for showing how to exercise" (Chapter 4, FGD1). Simple symptom diaries using visual analogue scales can overcome literacy barriers identified in our community assessment.

Monitoring and evaluation should combine clinical measures with community-defined outcomes. While standard clinical measures (exercise capacity, symptom scales) provide important data on program effectiveness, the Citizen science process identified additional outcomes valued by the community, including:

1) Ability to perform daily activities independently.
2) Reduced burden on family caregivers.
3) Social participation and community engagement 4. Reduced stigma associated with respiratory symptoms

Evaluation should be participatory, with regular community feedback sessions to assess program acceptability and identify areas for improvement. As one community member stated: "We want to see if it's working for us, not just what the doctors say" (Chapter 4, FGD2).

6.6 Cultural Adaptation.

Developing PR protocols that address specific cultural concerns identified by community members, including:

- Incorporating group-based activities aligned with community collectivist values.
- Addressing safety concerns through daytime scheduling and secure venues.
- Integrating smoking cessation support that acknowledges the social role of smoking in community rituals.
- Utilizing local community centers and churches as implementation sites to enhance accessibility and cultural acceptability.

These specific elements directly address barriers identified during community focus groups, including concerns about crime (mentioned by 31% of participants), the social embeddedness of smoking behaviours, and transportation challenges to healthcare facilities. Exercise should incorporate functional movements relevant to daily activities valued by community members, such as carrying water, gardening, and household tasks identified during the photovoice process in Chapter 4.

6.7 Education and Self-Management.

Education materials must and need to be developed to address the specific knowledge gaps identified in our Citizen science process. The most critical gaps identified in Chapter 4 include:

1) Basic understanding of COPD as a disease (only 23% of community participants could describe COPD) .
2) The relationship between smoking and COPD (widely misunderstood as evidenced in focus groups).
3) Recognition of symptoms that require medical attention 4. Use of medication and understanding of inhaler techniques

Materials should be developed in collaboration with community members to ensure cultural relevance and appropriate literacy levels. Our focus groups revealed strong preferences for visual learning, with one participant stating: "We learn best through stories and pictures" (Chapter 4, FGD2).

Self-management strategies should build on existing community coping mechanisms identified through the Citizen science process, including family support structures and community networks. The preferred delivery method identified by participants was group-based education sessions led by trained community members, supported by healthcare professionals.

6.8 Comprehensive Care Components

Beyond exercise training, PR programs should integrate psychological support, smoking cessation programs, occupational therapy, and nutritional counselling. These components should be adapted to local contexts and delivered by appropriately trained community health workers under professional supervision where specialized practitioners are unavailable. The Citizen science process in Chapter 4 identified significant comorbidities in the community, with participants highlighting the need for holistic approaches that address multiple health concerns simultaneously.

6.9 Policy and System Recommendations

Recommendations stemming from Chapter two and three relating to policy/ guidelines/ research for PR within Africa specifically:

1: Short term Actions

- There is a need to develop basic PR protocols that are culturally relevant to Africa and South Africa, informed by the community preferences identified in Chapter 4
- Optimize existing limited resources (staff, medication, diagnostic tools) based on the specific constraints identified in our healthcare practitioner survey, where 68% reported inadequate diagnostic equipment (Chapter 3)
- Establish standardized assessment protocols adapted for low-resource settings, incorporating the functional outcomes valued by communities as identified in Chapter
- Create training programs for community health workers to extend the reach of PR services, addressing the severe shortage of respiratory specialists identified in our survey (Chapter 3, only 17% of respondents were pulmonologists)

2: Long Term Strategies

- Build sustainable PR infrastructure across Africa, with particular attention to the regional disparities identified in our survey (Chapter 3, showing significant differences in resource availability between regions).
- Develop culturally specific guidelines that account for regional blocs in Africa (ECOWAS, COMESA, EAC, SADC, AMU, IGAD, CEN-SAD) before focusing on local community level, acknowledging the diverse contexts found across the continent as evidenced by our 23-country survey (Chapter 3).

- Create monitoring systems that consider African regional differences in resources and infrastructure, based on the specific constraints identified in our healthcare practitioner survey • Engage with established teaching platforms such as COSECSA and PATS MECOR to improve clinician awareness and skills, addressing the knowledge gaps identified in our survey where 47% of respondents reported inadequate training in PR (Chapter 3).
- Partner with global stakeholders such as GOLD to adapt implementation recommendations to African contexts, informed by the community perspectives gathered through our Citizen science approach.

6.10 Implementation Process Recommendations

The Citizen science process in Chapter 4 revealed important insights about how PR implementation should proceed in community settings. Key process recommendations include:

1) Begin with community education and awareness before introducing formal rehabilitation components.
2) Engage community leaders early and maintain their involvement throughout implementation.
3) Train community members as program facilitators to enhance sustainability and cultural relevance.
4) Establish clear referral pathways between community-based programs and healthcare facilities.
5) Create mechanisms for ongoing community feedback and program adaptation.

This process-oriented approach directly addresses the implementation barriers identified in both the healthcare practitioner survey (Chapter 3) and community engagement (Chapter 4).

In conclusion, for Africa to truly implement culturally relevant and contextual PR, it needs to adopt a multifaceted approach equipping clinicians to provide PR, co-creating programmes that are locally sustainable based on robust data, whilst also broadly increasing awareness and knowledge about disease risks, treatments, and respiratory wellbeing. Fostering partnerships between health care providers, institutions of learning, community leaders, and organisations is required given the huge gap identified between Pulmonary rehabilitation science, and local community understanding and buy-in.

CHAPTER SEVEN

FUTURE DIRECTIONS

7.1 The Current State

The World Health Organization (WHO) estimates a rise in COPD from the fourth to the third cause of death by 2030, heavily affecting low-middle-income countries.(1,2) COPD currently affecting an estimated 65 million people, with 3 million dying annually.(3) This global burden requires a global strategy and necessitates culturally relevant and context-specific solutions. Prior Citizen science initiatives in Africa relating to other diseases, such as obesity and cardiovascular disease, have offered a promising approach that has offered community awareness, education and research.(121,136) This first-of-its-kind Citizen science approach to COPD and PR has highlighted the glaring chasm between science and community in this space. Much more work is now required to bridge this gap from a known effective intervention (PR) to communities where such an intervention is needed. However, supporting awareness and understanding of disease and buy-in are not established.

The World Health Organization's Rehabilitation 2030 initiative specifically highlights workforce capacity as a distinct challenge from access to specialized care. This global initiative supports the development of a 'Package of Interventions for Cardio-Pulmonary Rehabilitation' aimed at facilitating global adoption and adaptation of rehabilitation services. Our research aligns with this initiative by providing specific contextually insights into the addressing the implementation challenges in African settings.

Research in the COPD and Pulmonary rehabilitation (PR) space, using a Citizen science approach to co-create learning needs, disease management strategies and acceptable PR intervention, is needed to close this gap between clinical expertise and community awareness. While low-middle-income countries and Africa are diverse and not homogenous, the potential impact of community engagement is significant. Strategies and approaches may be best planned at a regional level, but local community engagement has been highlighted in this thesis as a critical aspect of any future research. The power of community involvement in designing, implementing, and evaluating PR programmes is critically important in supporting cost-efficient and acceptable community-driven solutions for sustainable PR.

Broadly, future directions and actionable items for Citizen science implementation of Pulmonary rehabilitation in a low-resourced African community based on the systematic review, exploring health practitioners' awareness and the Citizen science process can be grouped as follows in a low-resourced group.

This thesis represents the first application of Citizen science methodology to PR implementation in African settings. While successful in generating valuable insights, this novel approach requires further development and evaluation. Future work should refine the methodology, expanding both its theoretical foundation and practical application across diverse African contexts.

7.2 Actionable plans/Action plans

The recommendations in Chapter 6 provide a foundation for immediate action. This section builds upon these recommendations by articulating a longer-term vision and strategic framework for sustainable implementation. The following actionable plans are directly informed by the findings from our systematic review (Chapter 2), continent-wide survey (Chapter 3), and Citizen science process (Chapter 4):

1) ***Research Priorities/ Research Evaluation***

   There is an urgent need to employ participatory research methods; community involvement is critical in designing, implementing, and evaluating PR programmes because this highlights the priorities needed for each phase. Additionally, context-specific outcome measures should be developed and validated. Each community has a specific need and priority. For example, in our study, assessing the effectiveness of PR programmes should only start after the community buy-in and community awareness have been ascertained. Longitudinal studies and prospective studies to assess the impact and sustainability of Citizen science-based PR programmes. As seen in this community, the community recognised smoking as a habit rather than a need, suggesting an openness to change in the community as part of the PR process. However, the presence of smokers among health leaders indicates the challenge's complexity, which would require a longer process.

Our research identified significant gaps in knowledge regarding both the implementation and evaluation of PR in African settings. Future research should:

- Develop and validate culturally appropriate outcome measures that capture both clinical improvements and community-defined success metrics
- Conduct mixed-methods implementation science studies that examine the process of establishing PR programs using the Citizen science approach
- Pursue longitudinal studies to assess the sustainability of community-driven PR initiatives over time
- Compare different implementation models (e.g., purely home-based, purely community-based, hybrid approaches) in terms of effectiveness, adherence, and sustainability
- Investigate cost-effectiveness of Citizen science-based PR compared to conventional delivery models in low-resource settings

2) ***Capacity building and Community engagement.***

There is a need to train and educate stakeholders in the community, including community members, leaders, and citizen scientists, on PR principles, research methods and data collection, right from subjective diagnosis of COPD in the community to find a referral pathway that leads to an objective diagnosis in the hospitals. More community outreach and awareness is needed; community outreach leads to established partnerships with local community organisations, healthcare facilities and traditional leaders to raise awareness about COPD, Citizen science and PR. The use of simple, inclusive, and accessible language should be a priority so the community can understand. Our community needed a constant reminder of what COPD was and what the pathophysiology was from the moment one smoked till they were diagnosed.

Our Citizen science process demonstrated that community members can be effectively trained as co-researchers, but more comprehensive capacity building is needed. Future directions should include:

- Development of standardized training materials for citizen scientists focused on respiratory health
- Creation of tiered training programs that allow community members to progressively develop skills from basic health promotion to more complex aspects of PR delivery

- Establishment of mentor relationships between healthcare professionals and community leaders to strengthen knowledge transfer and sustainability
- Cross-community knowledge exchange to allow successful implementations to serve as models for new communities
- Integration of Citizen science training into formal health worker curricula to institutionalize the approach

3) Policy and advocacy recommendation.

Advocacy and awareness, coupled with support for PR and Citizen science initiatives, are crucial among policymakers, health leaders, and community members. Our study has highlighted the key items that could emerge from an advocacy meeting, emphasising the need for systemic change. Developing and disseminating policy briefs and recommendations that integrate Citizen science-based PR into both district and national healthcare policies and plans is essential. These policies need to be in collaboration with national authorities to align health priorities and strategies, ensuring a systemic approach to addressing the COPD burden.

Our research found that policy environments often fail to prioritize respiratory rehabilitation. Future advocacy efforts should:

- Develop evidence briefs that showcase the economic and social benefits of PR using data from African implementations
- Engage with national health insurance schemes to explore reimbursement models for community-based PR
- Advocate for the integration of PR into existing primary health care structures
- Partner with patient advocacy groups to amplify community voices in policy discussions
- Work with WHO regional offices to incorporate Citizen science approaches into regional implementation of the Rehabilitation 2030 initiative

7.3 Contribution to Knowledge and Practice

This thesis makes several distinct contributions to the field of PR implementation research in LMICs:

- It definitively documents the absence of comparative studies on home-based versus community-based PR in African settings, establishing a clear knowledge gap
- It provides the first continent-wide assessment of healthcare practitioner perspectives on PR in Africa, revealing both encouraging awareness and significant implementation barriers
- It pioneers the application of Citizen science methodology to PR implementation, demonstrating both the value and limitations of this approach
- It establishes the critical importance of addressing basic awareness and understanding of respiratory conditions before attempting to implement formal PR programs in communities with limited prior exposure to these concepts
- It develops a framework for culturally appropriate PR implementation that integrates both healthcare system constraints and community preferences

7. 4 Desired state/future directions

A comprehensive framework to address the burden of COPD in Africa, specifically for South Africa is essential to support the recommended participatory community-driven solutions. By fully engaging in research, community engagement policy initiatives and prioritising these initiatives that lead to culturally relevant and context-specific solutions that will improve health outcomes for our population affected by COPD. Engaging with other communities across the continent to identify commonalities/ differences in community-level understanding /acceptance of PR using a similar Citizen science approach and other researchers within Africa to formulate a standard community-based PR protocol. Figure 7.1 summarises the vision for potential future directions.

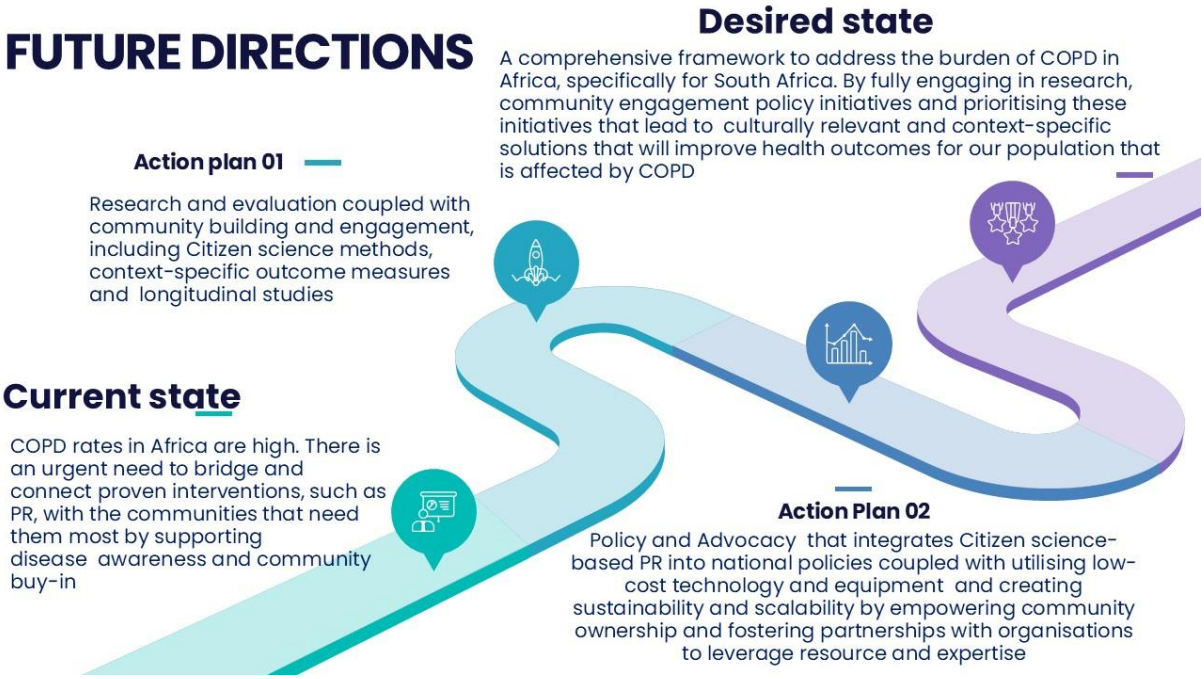

Figure 7.1 Future directions for Citizen science-based COPD and PR in low resourced African settings

In conclusion, the future directions outlined above offer a comprehensive and compelling framework for addressing the burden of COPD in Africa, specifically in South Africa. By strategically and fully engaging in research, practice, and policy initiatives and prioritising these initiatives, Africa can develop culturally relevant and context-specific solutions in the diverse 54 countries and seven regional blocs that will improve health outcomes for our population affected by COPD. Ultimately, these efforts will not only help alleviate the burden of this disease but will also expand on the understanding and application of pulmonary rehabilitation across the continent. From a post-doctoral point of view, there is a potential to build upon this body of work, and to explore it further at a bigger and more diverse scale and larger community level to ascertain its feasibility and effectiveness of the proposed model. Critical will be the research into effective integration with current services to enhance overall patient care complimented by community-engaged non-clinic care.

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Appendices

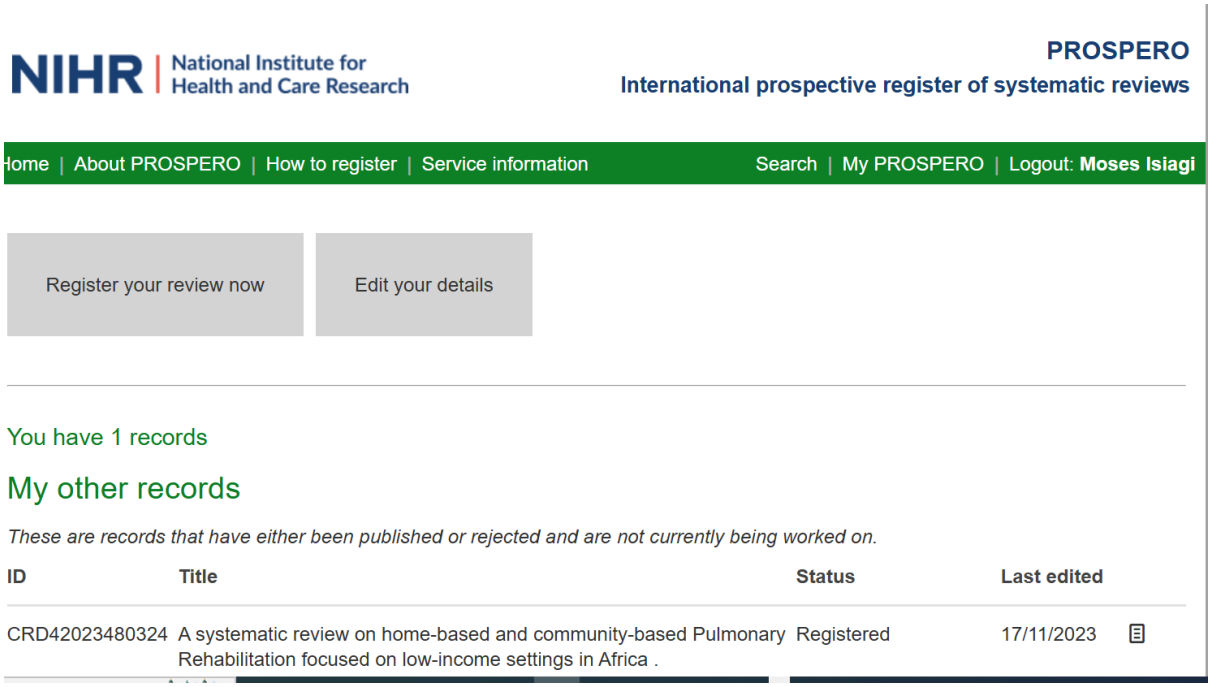
Appendix 2.1: Prospero Registration

This systematic review was registered with PROSPERO prior to conducting searches to ensure methodological transparency and rigor.

Registration Date: 15 January 2023

Primary Reviewer: Moses Isiagi

Review Team: Moses Isiagi, Richard van Zyl-Smit, Kufre Joseph Okop



Appendix 2.2: Prisma 2020 Checklist

Section and Topic	Item #	Checklist item	Location where item is reported
TITLE			
Title	1	Identify the report as a systematic review.	Cover page
ABSTRACT			
Abstract	2	See the PRISMA 2020 for Abstracts checklist.	23
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of existing knowledge.	3
Objectives	4	Provide an explicit statement of the objective(s) or question(s) the review addresses.	3
METHODS			
Eligibility criteria	5	Specify the inclusion and exclusion criteria for the review and how studies were grouped for the syntheses.	3
Information sources	6	Specify all databases, registers, websites, organisations, reference lists and other sources searched or consulted to identify studies. Specify the date when each source was last searched or consulted.	4
Search strategy	7	Present the full search strategies for all databases, registers, and websites, including any filters and limits used.	4
Selection process	8	Specify the methods used to decide whether a study met the inclusion criteria of the review, including how many reviewers screened each record and each report retrieved, whether they worked independently, and if applicable, details of automation tools used in the process.	5
Data collection process	9	Specify the methods used to collect data from reports, including how many reviewers collected data from each report, whether they worked independently, any processes for obtaining or confirming data from study investigators, and if applicable, details of automation tools used in the process.	7
Data items	10a	List and define all outcomes for which data were sought. Specify whether all results that were compatible with each	8

Section and Topic	Item #	Checklist item	Location where item is reported
		outcome domain in each study were sought (e.g. for all measures, time points, analyses), and if not, the methods used to decide which results to collect.	
	10b	List and define all other variables for which data were sought (e.g. participant and intervention characteristics, funding sources). Describe any assumptions made about any missing or unclear information.	11
Study risk of bias assessment	11	Specify the methods used to assess risk of bias in the included studies, including details of the tool(s) used, how many reviewers assessed each study and whether they worked independently, and if applicable, details of automation tools used in the process.	7
Effect measures	12	Specify for each outcome the effect measure(s) (e.g. risk ratio, mean difference) used in the synthesis or presentation of results.	7
Synthesis methods	13a	Describe the processes used to decide which studies were eligible for each synthesis (e.g. tabulating the study intervention characteristics and comparing against the planned groups for each synthesis (item #5)).	7
	13b	Describe any methods required to prepare the data for presentation or synthesis, such as handling of missing summary statistics, or data conversions.	7
	13c	Describe any methods used to tabulate or visually display results of individual studies and syntheses.	8
	13d	Describe any methods used to synthesize results and provide a rationale for the choice(s). If meta-analysis was performed, describe the model(s), method(s) to identify the presence and extent of statistical heterogeneity, and software package(s) used.	8
	13e	Describe any methods used to explore possible causes of heterogeneity among study results (e.g. subgroup analysis, meta-regression).	8
	13f	Describe any sensitivity analyses conducted to assess robustness of the synthesized results.	8
Reporting bias assessment	14	Describe any methods used to assess risk of bias due to missing results in a synthesis (arising from reporting biases).	8
Certainty assessment	15	Describe any methods used to assess certainty (or confidence) in the body of evidence for an outcome.	8

Section and Topic	Item #	Checklist item	Location where item is reported
RESULTS			
Study selection	16a	Describe the results of the search and selection process, from the number of records identified in the search to the number of studies included in the review, ideally using a flow diagram.	9
	16b	Cite studies that might appear to meet the inclusion criteria, but which were excluded, and explain why they were excluded.	10
Study characteristics	17	Cite each included study and present its characteristics.	11
Risk of bias in studies	18	Present assessments of risk of bias for each included study.	11
Results of individual studies	19	For all outcomes, present, for each study: (a) summary statistics for each group (where appropriate) and (b) an effect estimate and its precision (e.g. confidence/credible interval), ideally using structured tables or plots.	11
Results of syntheses	20a	For each synthesis, briefly summarise the characteristics and risk of bias among contributing studies.	
	20b	Present results of all statistical syntheses conducted. If meta-analysis was done, present for each the summary estimate and its precision (e.g. confidence/credible interval) and measures of statistical heterogeneity. If comparing groups, describe the direction of the effect.	11
	20c	Present results of all investigations of possible causes of heterogeneity among study results.	11
	20d	Present results of all sensitivity analyses conducted to assess the robustness of the synthesized results.	11
Reporting biases	21	Present assessments of risk of bias due to missing results (arising from reporting biases) for each synthesis assessed.	
Certainty of evidence	22	Present assessments of certainty (or confidence) in the body of evidence for each outcome assessed.	11
DISCUSSION			

Section and Topic	Item #	Checklist item	Location where item is reported
Discussion	23a	Provide a general interpretation of the results in the context of other evidence.	12
	23b	Discuss any limitations of the evidence included in the review.	13
	23c	Discuss any limitations of the review processes used.	13
	23d	Discuss implications of the results for practice, policy, and future research.	13
OTHER INFORMATION			
Registration and protocol	24a	Provide registration information for the review, including register name and registration number, or state that the review was not registered.	19
	24b	Indicate where the review protocol can be accessed, or state that a protocol was not prepared.	19
	24c	Describe and explain any amendments to information provided at registration or in the protocol.	19
Support	25	Describe sources of financial or non-financial support for the review, and the role of the funders or sponsors in the review.	
Competing interests	26	Declare any competing interests of review authors.	
Availability of data, code, and other materials	27	Report which of the following are publicly available and where they can be found template data collection forms; data extracted from included studies; data used for all analyses; analytic code; any other materials used in the review.	19

Appendix 2:3 Abstracts Checklist

Section and Topic	Item #	Checklist item	Reported (Yes/No)
TITLE			
Title	1	Identify the report as a systematic review.	Y
BACKGROUND			
Objectives	2	Provide an explicit statement of the main objective(s) or question(s) the review addresses.	Y
METHODS			
Eligibility criteria	3	Specify the inclusion and exclusion criteria for the review.	Y
Information sources	4	Specify the information sources (e.g. databases, registers) used to identify studies and the date when each was last searched.	Y
Risk of bias	5	Specify the methods used to assess risk of bias in the included studies.	Y
Synthesis of results	6	Specify the methods used to present and synthesise results.	Y
RESULTS			
Included studies	7	Give the total number of included studies and participants and summarise relevant characteristics of studies.	Y
Synthesis of results	8	Present results for main outcomes, preferably indicating the number of included studies and participants for each. If meta-analysis was done, report the summary estimate and confidence/credible interval. If comparing groups, indicate the direction of the effect (i.e. which group is favoured).	Y
DISCUSSION			
Limitations of evidence	9	Provide a summary of the limitations of the evidence included in the review (e.g. study risk of bias, inconsistency, and imprecision).	Y
Interpretation	10	Provide a general interpretation of the results and important implications.	Y
OTHER			
Funding	11	Specify the primary source of funding for the review.	
Registration	12	Provide the register name and registration number.	Y

From: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ 2021;372:n71. doi: 10.1136/bmj.n71

Appendix 2:4 : Pub Med Search

Search number	Query	Sort By	Filters	Search Details	Results	Time
22	((((pulmonary) AND (rehabilitation)) AND ((home-based) OR (community-based))) AND (((Exercise capacity) OR (Health-Related Quality of Life)) AND (Chronic Obstructive Pulmonary Disease,[MeSH Terms])) AND (2012:2024[pdat])) AND ("Developing Countries"[Mesh])			("lung"[MeSH Terms] OR "lung"[All Fields] OR "pulmonary"[All Fields]) AND ("rehabilitant"[All Fields] OR "rehabilitants"[All Fields] OR "rehabilitate"[All Fields] OR "rehabilitated"[All Fields] OR "rehabilitates"[All Fields] OR "rehabilitating"[All Fields] OR "rehabilitation"[MeSH Terms] OR "rehabilitation"[All Fields] OR "rehabilitations"[All Fields] OR "rehabilitative"[All Fields] OR "rehabilitation"[MeSH Subheading] OR "rehabilitation s"[All Fields] OR "rehabilitational"[All Fields] OR "rehabilitator"[All Fields] OR "rehabilitators"[All Fields]) AND ("home-based"[All Fields] OR "community-based"[All Fields]) AND ((((("exercise"[MeSH Terms] OR "exercise"[All Fields] OR "exercises"[All Fields] OR "exercise therapy"[MeSH Terms] OR ("exercise"[All Fields] AND "therapy"[All Fields]) OR "exercise therapy"[All Fields] OR "exercising"[All Fields] OR "exercise s"[All Fields] OR "exercised"[All Fields] OR "exerciser"[All Fields] OR "exercisers"[All Fields]) AND ("capacities"[All Fields] OR "capacity"[All Fields])) OR ("quality of life"[MeSH Terms] OR ("quality"[All Fields] AND "life"[All Fields]) OR "quality of life"[All Fields] OR ("health"[All Fields] AND "related"[All Fields] AND "quality"[All Fields] AND "life"[All Fields]) OR "health related quality of life"[All Fields])) AND "pulmonary disease, chronic obstructive"[MeSH Terms]) AND 2012/01/01:2024/12/31[Date - Publication] AND "Developing Countries"[MeSH Terms]	0	16:48:54
17	(((pulmonary) AND (rehabilitation)) AND ((home-based) OR (community-based))) AND (((Exercise capacity) OR (Health-Related Quality of Life)) AND (Chronic Obstructive Pulmonary Disease,[MeSH Terms]))		from 2012 - 2024	(("lung"[MeSH Terms] OR "lung"[All Fields] OR "pulmonary"[All Fields]) AND ("rehabilitant"[All Fields] OR "rehabilitants"[All Fields] OR "rehabilitate"[All Fields] OR "rehabilitated"[All Fields] OR "rehabilitates"[All Fields] OR "rehabilitating"[All Fields] OR "rehabilitation"[MeSH Terms] OR "rehabilitation"[All Fields] OR "rehabilitations"[All Fields] OR "rehabilitative"[All Fields] OR "rehabilitation"[MeSH Subheading] OR "rehabilitation s"[All Fields] OR "rehabilitational"[All Fields] OR "rehabilitator"[All Fields] OR "rehabilitators"[All Fields]) AND ("home-based"[All Fields] OR "community-based"[All Fields]) AND ((((("exercise"[MeSH Terms] OR "exercise"[All Fields] OR "exercises"[All Fields] OR "exercise	225	16:41:54

			therapy"[MeSH Terms] OR ("exercise"[All Fields] AND "therapy"[All Fields]) OR "exercise therapy"[All Fields] OR "exercising"[All Fields] OR "exercise s"[All Fields] OR "exercised"[All Fields] OR "exerciser"[All Fields] OR "exercisers"[All Fields]) AND ("capacities"[All Fields] OR "capacity"[All Fields])) OR ("quality of life"[MeSH Terms] OR ("quality"[All Fields] AND "life"[All Fields]) OR "quality of life"[All Fields] OR ("health"[All Fields] AND "related"[All Fields] AND "quality"[All Fields] AND "life"[All Fields]) OR "health related quality of life"[All Fields])) AND "pulmonary disease, chronic obstructive"[MeSH Terms])) AND (2012:2024[pdat])		
9	(((pulmonary) AND (rehabilitation)) AND ((home-based) OR (community-based))) AND (((Exercise capacity) OR (Health-Related Quality of Life)) AND (Chronic Obstructive Pulmonary Disease,[MeSH Terms]))		("lung"[MeSH Terms] OR "lung"[All Fields] OR "pulmonary"[All Fields]) AND ("rehabilitant"[All Fields] OR "rehabilitants"[All Fields] OR "rehabilitate"[All Fields] OR "rehabilitated"[All Fields] OR "rehabilitates"[All Fields] OR "rehabilitating"[All Fields] OR "rehabilitation"[MeSH Terms] OR "rehabilitation"[All Fields] OR "rehabilitations"[All Fields] OR "rehabilitative"[All Fields] OR "rehabilitation"[MeSH Subheading] OR "rehabilitation s"[All Fields] OR "rehabilitational"[All Fields] OR "rehabilitator"[All Fields] OR "rehabilitators"[All Fields]) AND ("home-based"[All Fields] OR "community-based"[All Fields]) AND ((((("exercise"[MeSH Terms] OR "exercise"[All Fields] OR "exercises"[All Fields] OR "exercise therapy"[MeSH Terms] OR ("exercise"[All Fields] AND "therapy"[All Fields]) OR "exercise therapy"[All Fields] OR "exercising"[All Fields] OR "exercise s"[All Fields] OR "exercised"[All Fields] OR "exerciser"[All Fields] OR "exercisers"[All Fields]) AND ("capacities"[All Fields] OR "capacity"[All Fields])) OR ("quality of life"[MeSH Terms] OR ("quality"[All Fields] AND "life"[All Fields]) OR "quality of life"[All Fields] OR ("health"[All Fields] AND "related"[All Fields] AND "quality"[All Fields] AND "life"[All Fields]) OR "health related quality of life"[All Fields])) AND "pulmonary disease, chronic obstructive"[MeSH Terms])	270	16:41:41
14	"Developing Countries"[Mesh]	Most Recent	"Developing Countries"[MeSH Terms]	83,115	16:39:57
8	((Exercise capacity) OR (Health-Related Quality of Life)) AND (Chronic Obstructive Pulmonary Disease,[MeSH Terms])		((("exercise"[MeSH Terms] OR "exercise"[All Fields] OR "exercises"[All Fields] OR "exercise therapy"[MeSH Terms] OR ("exercise"[All Fields] AND "therapy"[All Fields]) OR "exercise therapy"[All Fields] OR "exercising"[All Fields] OR "exercise s"[All Fields] OR "exercised"[All Fields] OR "exerciser"[All	9,597	16:30:58

				Fields] OR "exercisers"[All Fields]) AND ("capacities"[All Fields] OR "capacity"[All Fields])) OR ("quality of life"[MeSH Terms] OR ("quality"[All Fields] AND "life"[All Fields]) OR "quality of life"[All Fields] OR ("health"[All Fields] AND "related"[All Fields] AND "quality"[All Fields] AND "life"[All Fields]) OR "health related quality of life"[All Fields])) AND "pulmonary disease, chronic obstructive"[MeSH Terms]		
7	(Exercise capacity) OR (Health-Related Quality of Life)			(("exercise"[MeSH Terms] OR "exercise"[All Fields] OR "exercises"[All Fields] OR "exercise therapy"[MeSH Terms] OR ("exercise"[All Fields] AND "therapy"[All Fields]) OR "exercise therapy"[All Fields] OR "exercising"[All Fields] OR "exercise s"[All Fields] OR "exercised"[All Fields] OR "exerciser"[All Fields] OR "exercisers"[All Fields]) AND ("capacities"[All Fields] OR "capacity"[All Fields])) OR ("quality of life"[MeSH Terms] OR ("quality"[All Fields] AND "life"[All Fields]) OR "quality of life"[All Fields] OR ("health"[All Fields] AND "related"[All Fields] AND "quality"[All Fields] AND "life"[All Fields]) OR "health related quality of life"[All Fields])	658,353	16:30:42
5	(((pulmonary) AND (rehabilitation)) AND ((home-based) OR (community-based))) AND (Chronic Obstructive Pulmonary Disease,[MeSH Terms])			("lung"[MeSH Terms] OR "lung"[All Fields] OR "pulmonary"[All Fields]) AND ("rehabilitant"[All Fields] OR "rehabilitants"[All Fields] OR "rehabilitate"[All Fields] OR "rehabilitated"[All Fields] OR "rehabilitates"[All Fields] OR "rehabilitating"[All Fields] OR "rehabilitation"[MeSH Terms] OR "rehabilitation"[All Fields] OR "rehabilitations"[All Fields] OR "rehabilitative"[All Fields] OR "rehabilitation"[MeSH Subheading] OR "rehabilitation s"[All Fields] OR "rehabilitational"[All Fields] OR "rehabilitator"[All Fields] OR "rehabilitators"[All Fields]) AND ("home-based"[All Fields] OR "community-based"[All Fields]) AND "pulmonary disease, chronic obstructive"[MeSH Terms]	387	16:24:58
4	Chronic Obstructive Pulmonary Disease,[MeSH Terms]			"pulmonary disease, chronic obstructive"[MeSH Terms]	70,826	16:22:51
3	((pulmonary) AND (rehabilitation)) AND ((home-based) OR (community-based))			("lung"[MeSH Terms] OR "lung"[All Fields] OR "pulmonary"[All Fields]) AND ("rehabilitant"[All Fields] OR "rehabilitants"[All Fields] OR "rehabilitate"[All Fields] OR "rehabilitated"[All Fields] OR "rehabilitates"[All Fields] OR "rehabilitating"[All Fields] OR "rehabilitation"[MeSH Terms] OR "rehabilitation"[All Fields] OR "rehabilitations"[All Fields] OR	883	16:20:38

				"rehabilitative"[All Fields] OR "rehabilitation"[MeSH Subheading] OR "rehabilitation s"[All Fields] OR "rehabilitational"[All Fields] OR "rehabilitator"[All Fields] OR "rehabilitators"[All Fields]) AND ("home-based"[All Fields] OR "community-based"[All Fields])		
2	(home-based) OR (community-based)			"home-based"[All Fields] OR "community-based"[All Fields]	107,845	16:19:33
1	(pulmonary) AND (rehabilitation)			("lung"[MeSH Terms] OR "lung"[All Fields] OR "pulmonary"[All Fields]) AND ("rehabilitant"[All Fields] OR "rehabilitants"[All Fields] OR "rehabilitate"[All Fields] OR "rehabilitated"[All Fields] OR "rehabilitates"[All Fields] OR "rehabilitating"[All Fields] OR "rehabilitation"[MeSH Terms] OR "rehabilitation"[All Fields] OR "rehabilitations"[All Fields] OR "rehabilitative"[All Fields] OR "rehabilitation"[MeSH Subheading] OR "rehabilitation s"[All Fields] OR "rehabilitational"[All Fields] OR "rehabilitator"[All Fields] OR "rehabilitators"[All Fields])	34,694	16:18:09

Appendix 2.5: Cochrane Data Base

Search Name: Date Run: 18/11/2024 06:15:06 Comment: ID Search Hits	
#1 (((pulmonary) AND (rehabilitation)) AND ((home-based) OR (community-based))) (Word variations have been searched)	617
#2 MeSH descriptor: [Pulmonary Disease, Chronic Obstructive] explode all trees	8385
#3 ((Exercise capacity) OR (Health-Related Quality of Life))(Word variations have been searched)	48799
#4 #1 AND #2	200
#5 with Publication Year from 2012 to 2024, in Trials	146
#6 (low middle income countries) (Word variations have been searched)	4707
#7 #5 AND #6	0

Appendix 2.6:EMBASE Data Base Search

dat			
	Search/Query	Results	Date
#6.	#4 AND #5		17 Nov 2024
#5.	'Low middle income country'	1,191	17 Nov 2024
#4.	#3 AND (2012:py OR 2013:py OR 2014:py OR 2015:py OR 2016:py OR 2017:py OR 2018:py OR 2019:py OR 2020:py OR 2021:py OR 2022:py OR 2023:py OR 2024:py)	529	17 Nov 2024
#3.	#1 AND #2	623	17 Nov 2024
#2.	'Chronic obstructive lung disease'	195,477	17 Nov 2024
#1.	pulmonary AND ('rehabilitation'/exp OR rehabilitation) AND ('home based' OR 'community based'	1,155	17 Nov 2024

Appendix 2:7 EBSCOhost search

	Print Search History: EBSCOhost		**Sun, November 17,2024 2:45:38 PM**	
#	**Query**	**Limiters/Expanders**	**Last Run Via**	**Results**
S7	TX Pulmonary rehabilitation AND TX (home-based) OR (community-based)) AND TX (chronic obstructive pulmonary disease or copd) AND TX low-middle income countries AND TX ((Exercise capacity) OR (Health-Related Quality of Life))	Limiters - Publication Date: 20120101-20241231 Expanders - Apply equivalent subjects Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE Complete	97
S6	TX pulmonary rehabilitation AND TX ({home-based) OR (community-based)) AND TX (chronic obstructive pulmonary disease or copd) AND TX low-middle income countries	Limiters - Publication Date: 20120101-20241231 Expanders - Apply equivalent subjects Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE Complete	111

S5	TX pulmonary rehabilitation AND TX ((home-based) OR (community-based)) AND TX (chronic obstructive pulmonary disease or copd)	Limiters - Publication Date: 20120101-20241231 Expanders - Apply equivalent subjects Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE Complete	4,259
S4	TX pulmonary rehabilitation AND TX ((home-based) OR (community-based)) AND TX (chronic obstructive pulmonary disease or copd)	Expanders - Apply equivalent subjects Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE Complete	5,183
S3	TX pulmonary rehabilitation AND ((home-based) OR (community-based))	Expanders - Apply equivalent subjects Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE Complete	1,327
S2	TX pulmonary rehabilitation	Expanders - Apply equivalent subjects Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE Complete	65,953

S1	Pulmonary rehabilitation	Expanders - Apply equivalent subjects Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE Complete	19,914

Appendix 3.1 : Letter to the SATS and PATS members

UNIVERSITY OF CAPE TOWN
IDYUNIVESITHI YASEKAPA • UNIVERSITEIT VAN KAAPSTAD

Faculty of Health Sciences
Lung Clinical Research Unit
Division of Pulmonology and Department of Medicine Science University of Cape Town Lung Institute (Pty) Ltd

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PULMONARY REHABILITATION ACROSS AFRICA: A CONTINENTAL EVALUATION OF HEALTH CARE PROVIDERS' AWARENESS, AVAILABILITY, UTILIZATION AND BARRIERS TO ACCESSING PULMONARY REHABILITATION.

(Africa wide survey)

Dear Practitioner

We are field researchers, representing the Division of Pulmonology and Department of Medicine, University of Cape Town & Groote Schuur Hospital in the Faculty of Health Sciences, at the University of Cape Town. You are receiving this invitation, as part of a community of doctors, nurses, allied health professionals in an African setting.

You have been invited to participate in a project in which we hope to explore the attitudes, beliefs, knowledge and perspectives of doctors and other allied health professionals as regards Pulmonary rehabilitation in its entirety, its diagnosis and barriers to its diagnosis and finally value of treatment regimen for Pulmonary diseases Africa wide.

We have chosen you as a doctor, nurse and /or other allied health professionals in South Africa and across Africa.

All participants who will receive the questionnaire online and their willingness to answer the question and will be treated as consent. We shall give you two weeks to be able to fill in all the questions and submit the questionnaire to us. This research study already has Ethical approval from the University of Cape Town Health Sciences Research Ethics committee. Should you have any concerns.

Background to the study

Pulmonary diseases are increasingly becoming causes of morbidity and mortality in the modern world. Chronic Obstructive Pulmonary Diseases (COPD) are the most common chronic lung diseases, and a significant cause of lung-related death and disability. Based on projections, COPD (one of the pulmonary conditions) will be the third leading cause of death worldwide by 2020 (Lõpez-Campos et al, 2016).

Clinical guidelines for the management of patients with COPD include recommendations based on high levels of evidence, but gaps exist in their implementation (Kylien et al., 2011). Although there are high levels of evidence for COPD we are not sure If the same applies to Africa

Research questions

Are Doctors, nurses and allied health professions in Africa UpToDate as regards Pulmonary rehabilitation including diagnosis, treatment regiments and guidelines. Do they follow the same set of guidelines in their respective countries?.

Hypothesis

Doctors, nurses, allied health professionals in an African setting have gaps and barriers to Pulmonary rehabilitation including diagnosis and value of treatment regimen

Study Aim

To explore the attitudes, beliefs, knowledge and perspectives of Doctors and other allied health professionals as regards Pulmonary rehabilitation in its entirety, its diagnosis, and barriers to its diagnosis and finally value of treatment regimen for Pulmonary diseases Africa wide.

Ethics

The ethical considerations for this research involving human subjects complies with the Declaration of Helsinki (2013). The study involves a questionnaire which is non-invasive self-report. All participants will receive the questionnaire and their willingness ness to answer the question will be treated as consent. This research study will seek approval from the University of Cape Town Health Sciences Research Ethics committee. Should the participants have any concerns the following persons can be contacted:

Professor Richard van Zyl-Smit : email: richard.vanzylsmit@uct.ac.za

(Project leader, Supervisor)

Moses Isiagi: email: isiagimoses@gmail.com

(Student investigator)

Associate Professor Mark Blockman: Chair of the Health Science Faculty Research Ethics Committee, Old Main Building of Groote Schuur Hospital, Floor E52, Room 23, Observatory, 7925. Phone: 021-406 6496

Appendix 3.2: Original Ethics Approval

UNIVERSITY OF CAPE TOWN
Faculty of Health Sciences
Human Research Ethics Committee

Room G50-46 Old Main Building
Groote Schuur Hospital
Observatory 7925
Telephone [021] 406 6492
Email: hrec-enquiries@uct.ac.za
Website: www.health.uct.ac.za/fhs/research/humanethics/forms

21 January 2020

HREC REF:863/2019

A/Prof R van Zyl-Smit
Lung Clinical Research Unit
UCT lung Institute
Mowbray

Dear A/Prof van Zyl-Smit

PROJECT TITLE: DOCTORS, NURSES, ALLIED HEALTH CLINICIAN'S KNOWLEDGE, ATTITUDES AND BELIEFS REGARDING PULMONARY REHABILITATION

Thank you for your response letter dated 10 January 2020, addressing the issues raised by the Faculty of Health Sciences Human Research Ethics Committee (HREC).

It is a pleasure to inform you that the HREC has **formally approved** the above-mentioned study including the following documentation: -

1. PI generated synopsis
2. Protocol version 1 dated 20 November 2019
3. Participant Information Sheet V 1 dated 20 November 2019 (English)
4. Pulmonary Rehabilitation Questionnaire v1 dated 20 November 2019
5. CV, ICH, GCP Certificate, Licence and insurance Certificate for PI- A/Prof R van Zyl-Smit, co-investigator- Mr Moses Isiagi

Approval is granted for one year until the 30 January 2021.

Please submit a progress form, using the standardised Annual Report Form if the study continues beyond the approval period. Please submit a Standard Closure form if the study is completed within the approval period.
(Forms can be found on our website: www.health.uct.ac.za/fhs/research/humanethics/forms)

Please quote the HREC REF in all your correspondence.

Please note that the ongoing ethical conduct of the study remains the responsibility of the principal investigator.

Please note that for all studies approved by the HREC, the principal investigator **must** obtain appropriate institutional approval, where necessary, before the research may occur.

HREC 863/2019sa

Yours sincerely

PROFESSOR M BLOCKMAN
CHAIRPERSON, FHS HUMAN RESEARCH ETHICS COMMITTEE

Federal Wide Assurance Number: FWA00001637.
Institutional Review Board (IRB) number: IRB00001938
NHREC-registration number: REC-210208-007

This serves to confirm that the University of Cape Town Human Research Ethics Committee complies to the Ethics Standards for Clinical Research with a new drug in patients, based on the Medical Research Council (MRC-SA), Food and Drug Administration (FDA-USA), International Council for Harmonisation of Technical Requirements for Pharmaceuticals for Human Use: Good Clinical Practice (ICH GCP), South African Good Clinical Practice Guidelines (DoH 2006), based on the Association of the British Pharmaceutical Industry Guidelines (ABPI), and Declaration of Helsinki (2013) guidelines. The Human Research Ethics Committee granting this approval is in compliance with the ICH Harmonised Tripartite Guidelines E6: Note for Guidance on Good Clinical Practice (CPMP/ICH/135/95) and FDA Code Federal Regulation Part 50, 56 and 312.

HREC 863/2019sa

Appendix 3:3 Renewal Of Ethics

UNIVERSITY OF CAPE TOWN

FACULTY OF HEALTH SCIENCES
Human Research Ethics Committee

FHS016: Annual Progress Report / Renewal

HREC office use only (FWA00001637; IRB00001938) This serves as notification of annual approval, including any documentation described below.			
☑ Approved	Annual progress report	Approved until/next renewal date	30.8.2025
☐ Not approved	See attached comments		
Signature Chairperson of the HREC/ Designee	pp CBurgess	Date Signed	26/08/2024

Note: Please email this form and supporting documents (if applicable) in a combined pdf-file to hrec-enquiries@uct.ac.za.
Please clarify your plan for research-related activities during COVID-19 lockdown.
Please use the latest form found on our website: http://www.health.uct.ac.za/fhs/research/humanethics/forms

Comments to PI from the HREC

Principal Investigator to complete the following:

1. Protocol information

Date (when submitting this form)	21 August 2023		
HREC REF Number	863/2019	Current Ethics Approval was granted until	30 Aug 2024
Protocol title	Doctors, Nurses, Allied Health clinician's knowledge, attitudes and beliefs regarding Pulmonary Rehabilitation.		
Protocol number (if applicable)	NA		
Are there any sub-studies linked to this study?	☐ Yes	✓ No	
If yes, could you please provide the HREC Reference number for all sub-studies? **Note:** A separate FHS016 must be submitted for each sub-study.			
Principal Investigator	Professor Richard Nellis Van Zyl-Smit		
Department / Office Internal Mail Address	UCT Lung Institute, George Street, Mowbray, 7700, Cape Town		

(Note: Please complete the Closure form (FHS010) if the study is completed within the approval period)

HUMAN RESEARCH ETHICS COMMITTEE
21 AUG 2024
HEALTH SCIENCES FACULTY
UNIVERSITY OF CAPE TOWN

Email Address	
2. **Internal Journal Billing:**	
Fund Number:	
Cost Centre Number:	
Account Holder Name:	
Division of Account Holder:	

2. List of documentation for approval

NA

3. Protocol status (tick ✓)

☐	Open Enrolment
✓	Closed to enrolment (tick ✓)
☐	Research-related activities are ongoing
☐	Research-related activities are complete, long-term follow-up only
✓	Research-related activities are complete, data analysis only
☐	Main study is complete but sub-study research-related activities are ongoing
☐	Study is closed → Please submit a Study Closure Form (FHS010)

4. Enrolment

Number of participants enrolled to date	110
Number of participants enrolled, since last HREC Progress report (continuing review)	0
Additional number of participants still required	0

5. Refusals

Total number of refusals (participants invited to join the study, but refused to take part)	0

6. Cumulative summary of participants

Total number of participants who provided consent	110
Number of participants determined to be ineligible (i.e. after screening)	0
Number of participants currently active on the study	0
Number of participants completed study (without events leading to withdrawal)	110
Number of participants withdrawn at participants' request (i.e. changed their mind)	

(Note: Please complete the Closure form (FHS010) if the study is completed within the approval period)

Number of participants withdrawn by PI due to toxicity or adverse events	0
Number of participants withdrawn by PI for other reasons (e.g. pregnancy, poor compliance)	0
Number of participants lost to follow-up. Please comment below on reasons for loss of follow-up.	0
Number of participants no longer taking part for reasons not listed above. Please provide reasons below:	0

7. Progress of study

Please provide a brief summary of the research to date including the overall progress and the progress since the last annual report as well as any relevant comments/issues you would like to report to the HREC:
Data analysis is ongoing. No recruitment.

8. Protocol violations and exceptions (tick ✓ all that apply)

✓	No prior violations or exceptions have occurred since the original approval
☐	Prior violations or exceptions have been reported since the last review and have already been acknowledged or approved
☐	Unreported minor violations that have occurred since the last review, as well as significant deviations not yet reported, are attached for review

9. Amendments (tick ✓ all that apply)

✓	No Prior amendments have been made since the original approval
☐	Prior amendments have been reported since the last review and have already been approved
☐	New protocol changes/ amendments are requested as part of this continuing review (See note below)

Note: If new protocol changes are being requested in this review, please complete an amendment form (FHS006).
Specific changes in the amended protocol and consent/assent forms must be **bolded**, *italicised* or tracked and all changes must include a rationale.

10. Adverse events

10.1 Please provide below or attach a narrative summary of serious adverse events and/ or unanticipated problems since the last progress report. Please indicate changes made to the protocol and informed consent document(s) as a result (if not already reported to the HREC). Please comment on whether causality to any study procedure or intervention could be established.
NA

10.2 Have participants received appropriate treatment/ follow-up/ referral when indicated (e.g. in the case of abnormal or incidental clinical findings, distress or anxiety)?		
☐ Yes	☐ No	✓ Not applicable
If yes, please describe:		

11. Summary of Monitoring and Audit Activities (tick ✓)

11.1 Was this study monitored or audited by an external agency (e.g. SAHPRA, FDA)?		
☐ Yes	☐ No	✓ Not applicable

11.2 Did a Data and Safety Monitoring Board publish a report?		
☐ Yes	☐ No	✓ Not applicable

11.3 If yes, please identify the agency and attach a summary of the findings.					
Agency Name		Report attached	☐ Yes	☐ No	✓ Not applicable
		DSMB report attached	☐ Yes	☐ No	✓ Not applicable

11.4 Has there been any agency, institutional or other inquiry into non-compliance in this study, or any finding of non-compliance concerning a member of the research team?	
☐ Yes	✓ No
If yes, please explain:	

12. Level of risk (tick ✓)

12.1 In light of your experience of this research, please indicate whether the level of risk to participants has:	
☐	Increased
☐	Decreased
✓	Shown no change

(Note: Please complete the Closure form (FHS010) if the study is completed within the approval period)

If there has been a change, please explain:

12.2 Please provide a narrative summary of recent relevant literature that may have a bearing on the level of risk.
NA

13. Insurance

Please confirm that valid no fault insurance is still in place? **(tick ✓)**			
☐ Yes	☐ No	✓ Not Applicable – N/A	
If yes, please complete the following:			
Insurer's name:			
Policy no.		*Coverage Period:	
For UCT sponsored studies please liaise the Insurance office via fhs.sponsorship@uct.ac.za regarding the required documentation and information required obtain a renewed UCT No-fault Insurance Certificate.			

14. Statement of conflict of interest

Has there been any change in the conflict of interest status of this protocol since the original approval? (tick ✓)	
☐ Yes	✓ No
If yes, please explain and if necessary, attach a revised conflict of interest statement (Section #7 in the New Protocol Application Form FHS013):	

15. Signature

My signature certifies that the above is complete and correct.				
Signature of PI	Professor Richard van Zyl-Smit	Digitally signed by Professor Richard van Zyl-Smit Date: 2024.08.21 12:02:11 +02'00'	Date	21 August 2023

Appendix 3.4: Questionnaire: Doctors, Nurses, Allied Health Clinician's Knowledge, Attitudes, And Beliefs Regarding Pulmonary Rehabilitation

Doctors, Nurses, Allied Health clinician's knowledge, attitudes, and beliefs regarding Pulmonary rehabilitation

(AFRICA WIDE STUDY)

Pulmonary rehabilitation study (Questionnaire)

Section 1	**Demographics**	
How old are you?		
What is your gender?	Male ☐	☐ Female
What is your profession?		
How many years have you been in practise?		
Which country do you practice in?		
Do you practise in a rural or an urban setting? (Tick one) √	Rural ☐	☐ Urban
Do you have access to Pulmonary practice guidelines? (Tick one) √	Yes ☐	No ☐
Do you use GOLD, ATS,ERS COPD guidelines (Tick one) √	Yes ☐	No ☐
Do you utilise spirometry in your practise? (Tick one) √	Yes ☐	No ☐
Do you have access to Pulmonary rehabilitation?	Yes ☐	No ☐
Is lack of Pulmonary rehabilitation knowledge a barrier to your practise?	Yes ☐	No ☐

Section 2 Perceived barriers to diagnosing Pulmonary diseases. This section deals with the common barriers clinicians face in Diagnosing various pulmonary diseases (It requires you to agree or strongly agree)		
Do lack of specific symptoms in Pulmonary rehabilitation affect your management strategy?	Strongly agree ☐	Agree ☐
Do you feel that patients underreport symptoms?	Strongly agree ☐	Agree ☐
Do patients having multiple chronic conditions impact on your ability to make a diagnosis?	Strongly agree ☐	Agree ☐
Does lack of effective treatment impact on agency especially in making a diagnosis?	Strongly agree ☐	Agree ☐
Does lack of easy access to spirometry hamper your ability to diagnose and rehabilitate patients?	Strongly agree ☐	Agree ☐

Section **3** **Tests and Factors important in making a COPD /pulmonary diagnosis.** This section deals with which factors one considers in important in making a diagnosis for any pulmonary condition (We aim to find out which is the most employed or reported tool)		
Do you have ready access to chest X-rays?	Strongly agree ☐	Agree ☐
Do you have ready access to a trial of corticosteroids?	Strongly agree ☐	Agree ☐
Do patients have ready access to a trial of Bronchodilators?	Strongly agree ☐	Agree ☐
Trial of Bronchodilators	Strongly agree ☐	Agree ☐
Are you easily able to screen for Alpha-1 Antitrypsin Deficiency?	Strongly agree ☐	Agree ☐
Section 4 Value of pulmonary treatments		

Are treatments effective for symptom improvement in pulmonary diseases? (Tick one) √	Yes ☐	No ☐
Do treatments decrease exacerbations in pulmonary disease patients? (Tick one) √	Yes ☐	No ☐
Do treatments improve longevity in pulmonary disease patients? (Tick one) √	Yes ☐	No ☐
Is Pulmonary rehabilitation necessary for pulmonary disease patients? (Tick one) √	Yes ☐	No ☐
Do you believe pulmonary diseases primarily affect men? (Tick one) √	Yes ☐	No ☐
Do you believe that Pulmonary conditions are usually symptomatic after 60? ? (Tick one) √	Yes ☐	No ☐

Appendix 4.1: The Study Information Sheet

UNIVERSITY OF CAPE TOWN
IDYUNIVESITHI YASEKAPA • UNIVERSITEIT VAN KAAPSTAD

COMMUNITY-DRIVEN CITIZEN SCIENCE: EXPLORING COPD DISEASE RISK PERCEPTIONS AND CO-DESIGNING PRIORITY PREVENTION STRATEGIES IN LOW-RESOURCED SOUTH AFRICAN COMMUNITIES

Who are we, and what is this project about?

We are field researchers representing the Division of Medicine and Department of Pulmonology in the Faculty of Health Sciences at the University of Cape Town.

Associate Professor Mark Blockman, Chair of the Health Science Faculty Research Ethics Committee, Old Main Building of Groote Schuur Hospital, Floor E52, Room 23, Observatory, 7925. Phone: 021-406 6496

You are receiving this invitation as part of a community in one of the peri-urban areas in Cape Town. You have been invited to participate in a project in which we hope to understand better the perspectives of COPD, a lung disease we get when we fail to breathe out normally. We want to know what you know about the disease, how one detects it, what they use in the hospital to detect it, if you are on any treatment or medication for it, and if any programmes involve treating COPD in your community. We have chosen groups in different parts of Klipfontein district firstly so that it does not involve additional travel for you and adds good variety to our results to understand better.

If I choose to participate, what is expected of me?

When we visit, we will ask questions concerning what you know or think about lung diseases (COPD) in your community. What do you think causes COPD (failing to breathe out normally), and what intervention/treatment do you believe would be best?

Should you decide to volunteer, we will also ask you to sign a consent form and fill in the questions.

Are there any benefits or risks in taking part in this project?

There are no direct benefits to you personally in participating in this project. We will be sharing the overall results with participants. However, participating in the project also has no risks to your health or well-being. Completing the questionnaires will take about 30 minutes of your time to save travel time and inconvenience. Upon completing the questionnaire, you will be presented with a shopping voucher or cell phone voucher for R 100 as a token of appreciation for your participation.

Will my information be protected and remain confidential? To whom will the results of this project be shared?

The information you provide in the questionnaires will remain confidential. Once you have signed your consent form and agreed to participate in the study, you will be given a study number, and your results will be stored separately in your name. The overall results of this study will be used to prepare a report and manuscript to share with other researchers and policymakers so that they may be informed about how lung disease. You will never be identified by name or your community or church group in any report or document.

Am I obliged to participate or remain in the study?

You may choose to take part in this study, or you may choose not to take part. If you choose to participate in the project, you can withdraw at any stage.

What if I have any questions or concerns?

If you have any queries or questions regarding the research study or your rights as a participant, please contact any of the following people to share your concerns or answer your questions.

Professor Richard VanZyl Smit……..… (Principal Investigator Supervisor)

Dr Kufre Okop Joseph……..… (Principal Investigator Supervisor

Moses Isiagi..... (Co-Principal Investigator)

✂ ----------

PARTICIPANT WRITTEN CONSENT

INFORMED CONSENT

The study has been described to me in a language I understand, and I freely and voluntarily.

I agree to participate. My questions about the study have been answered. I understand that my identity will not be disclosed and that I may withdraw from the study without giving a reason at any time, and this will not negatively affect me in any way.

Participant's name…….

Participant's - Yes ……

- No …….

Signature ……...

Date: ……

Appendix 4.2: Data Collection Tool

UNIVERSITY OF CAPE TOWN
IDYUNIVESITHI YASEKAPA • UNIVERSITEIT VAN KAAPSTAD

COMMUNITY-DRIVEN CITIZEN SCIENCE: EXPLORING COPD DISEASE RISK PERCEPTIONS AND CO-DESIGNING PRIORITY PREVENTION STRATEGIES IN LOW-RESOURCED SOUTH AFRICAN COMMUNITIES

DATA COLLECTION TOOL
DATE OF COLLECTION:

DETAILS OF CITIZEN SCIENTIST/DATA CAPTURER:

Name		Surname	

PARTICIPANT INFORMATION:

Name		Surname			
Address	*Number* *Street* *Town*	How long have you lived here?	*12 months*	*> 12 months*	
	PLEASE CIRCLE YOUR SITE SELECTION				
	Tambo Village/Square	Heideveldt	Silvertown	Sherwood Park	Manenberg
	Barcelona	Europe	Gugulethu	KTC	Nyanga
Nationality					

Date of Birth	*Date*	*Month*	*Year*	Sex	*Male*	*Female*	*Other*
Age			*Years*				

EMPLOYMENT

Do you have a monthly income?	*Yes*	*No*	What is your monthly income?						
If yes	*Permanent*	*Temporary*	*Self Employed*	*Grant*	*> R2 000*	*R 2,000-R5,000*	*R5,000 - R10,000*	*R10 ,000 -R20,000*	*> R20,000*

EDUCATION LEVEL ATTAINED **(What is your highest level of education completed.)**

No formal schooling	*Some Primary School (Grade R to 6)*	*Completed Primary School (Grade 7)*	*Completed some High School (Grade 8 to 11)*	*Completed High School (Matric)*	*Tertiary*

Appendix 4.3: Attendance Form:

S/N	Name:	Age	Gender	Location (address)	Education	

Appendix 4.4: Focus Group Discussion Guide

UNIVERSITY OF CAPE TOWN
IDYUNIVESITHI YASEKAPA • UNIVERSITEIT VAN KAAPSTAD

COMMUNITY-DRIVEN CITIZEN SCIENCE: EXPLORING COPD DISEASE RISK PERCEPTIONS AND CO-DESIGNING PRIORITY PREVENTION STRATEGIES IN LOW-RESOURCED SOUTH AFRICAN COMMUNITIES

FOCUS GROUP DISCUSSION (FGD) GUIDE

Introduction:

First, introduce yourself and the team. Then, give a brief overview of the study (see below).

Brief overview of COPD

Chronic Obstructive Pulmonary Disease (COPD) is the most common chronic lung disease. The normal process is breathing in and breathing out, but most people with COPD fail to breathe out normally. COPD is a disease that blocks the airways in the lungs, making it very hard for people to breathe normally. World Health Organization (WHO) predicts that COPD will become the third leading cause of death by 2030, with over 90% of the deaths occurring in Sub-Saharan Africa. COPD currently affects 65 million people, and 3 million people die from COPD every year.

Many people worldwide do not understand how to recognize COPD, how it is treated, or how to prevent it. This lack of knowledge is common in African communities, where people often mistake COPD for a persistent cough. When healthcare workers inform them about their COPD risk, many don't understand the seriousness of the condition and fail to seek further screening, leading to additional lung damage.

Purpose of the study:

Today, we want to discuss what you know or think about lung disease (COPD) in your community. We want to understand your views on living with lung conditions and what interventions or treatments you believe would be most helpful

Ground rules:

The atmosphere is open and safe, and everyone's opinion is welcome and valued
We have prepared questions to guide our discussion, but please feel free to add anything you think is important
There are no right or wrong answers ,we are interested in your experiences and perspectives

QUESTIONS TO GUIDE THE DISCUSSION

Awareness and Knowledge

1. Can you please tell us what you think are the functions (or benefits) of our lungs?	*Participant to mention 1-2 functions of the lungs*

2.What kinds of things do you think can affect our lungs and breathing?	*[Probe for: Environmental factors like pollution, lifestyle factors like smoking, occupational hazards] like dust*
Community Experience with Breathing Problems	
Could you tell me about your experiences with breathing problems in your community?	*[Probe: Personal experiences or those of family/friends]* *[Explore: Types of breathing problems how they affect daily life]*
What do people in your community typically do when they have breathing problems?	*[Probe: Healthcare-seeking behaviour, like going to hospital, traditional remedies like visiting a traditional healer, self-management]*
Risk Perception and Understanding	
How do you think smoking affects breathing and lung health?	*[Explore: Community attitudes towards smoking and lung health]* *[Probe: Both direct smoking and second-hand smoke exposure]*
Impact and Consequences	
How do breathing problems affect people's daily lives in your community?	*[Probe: Work, family life, social activities]* *[Explore: Both physical and emotional impacts]*
What challenges do people with breathing problems face in your community?	*[Probe: Access to healthcare, social support, stigma]*
Awareness knowledge and utilisation of PR	
What kinds of things do people do to help with their breathing problems?	*[Probe: Both medical and non-medical approaches]* *[Explore: Traditional remedies, exercise, lifestyle changes.*
What do you know about breathing exercises and physical activity for lung health?	*[Probe: Awareness of Pulmonary rehabilitation]* *[Explore: Experience with or knowledge of structured programmes]*
Community-Based Solutions	
What do you think could be done in your community to prevent breathing problems?	*[Probe: Both individual and community-level interventions]*

How could we better support people who already have breathing problems?	*[Explore: Ideas for community-based programmes]*
Co-designing Solutions	
If we were to create a community program for lung health, what would make it successful?	*[Probe: Format, location, timing, leadership]* *[Explore: Barriers and facilitators to participation*
What role could community members play in such a program?	*[Probe: Interest in peer support or leadership roles]* *[Explore: Resources and support needed]*

Appendix 4.5: Citizen science Questions (Epicollect Data Collection Form)

COMMUNITY-DRIVEN CITIZEN SCIENCE: EXPLORING COPD DISEASE RISK PERCEPTIONS AND CO-DESIGNING PRIORITY PREVENTION STRATEGIES IN LOW-RESOURCED SOUTH AFRICAN COMMUNITIES					
DATE OF COLLECTION:					
DETAILS OF CITIZEN SCIENTIST/DATA CAPTURER:					
EDUCATION LEVEL ATTAINED (What is your highest level of education completed.)					
Name	*Gender*	*Age*	*Education*	*Income*	
COPD status					
Qn 1. Have you had any lung-related disease or breath-related problem?				*Yes*	*No*
Epi Collect					
Q 1b. Take a picture of anything around you that you think can affect (in a good or bad way) the health of your lungs or that of others.					
Qn 2. Do you know anyone (relatives, friends, others) that has any lung-related disease - such as COPD or TB? If you say 'No', move to 3a.				*Yes*	*No*
Qn 2b. Take a picture of something that could cause this disease. Tell us more about this picture.					
Is it good or bad?				*Good*	*Bad*
Qn 3. Please take a picture of something that you believe could make you or anyone feel strongly that you may develop a lung-related disease such as COPD, lung cancer, or TB.					
Could you please explain more about your picture					
Qn 4 How would you want to receive information about the potential risk of developing a life-threatening illness like (COPD)? (SMS, Whats app, News, Tiktok, Instagram 5. Would you be willing to learn more about lung-related disease (such as COPD), and its prevention? If Yes, would you prefer: if) health education (one-on-one or structured learning about lung health, disease processes, and prevention strategies ii) community health promotion(broader public health initiatives and awareness campaigns; iii) group-based learning(Peer support and shared learning experiences; iv) social media, e.g. WhatsApp; v)exercise-based Programmes(: supervised exercise training, breathing technique workshops, home-based rehabilitation programmes, Telehealth rehabilitation sessions, smoking cessation support groups, vi) Other					

Appendix 4.6: Manual For Citizen Scientist Data Collection/Analysis

: Manual for Citizen Scientist Data Collection/Analysis
1) Pictures and narratives are to be printed. 2) Divide the CSts into 4 discussion groups. 3) Each group is to select a leader and a scriber. 4) Groups to discuss narratives and pictures with study aims and objectives as focal points (theme) 5) Similar pictures and narratives in individual groups were selected and divided into two themes (enablers and barriers and summated) 6) Groups to re-convene and each to elaborate on their collective findings (the PhD candidate facilitates this. The proposed resources include whiteboards, Epi collect and outs of narratives. 7) In groups of 3-4. Each CSt will take five photos, which will later be discussed and summated in the combined CSt groups.

APPENDIX 4.7: Citizen science Guidance Document

Citizen science Guidance Document
1) Recruit study participants- Use guidance on those selected for the interviews. Each Citizen Scientist is to recruit between 5-10 participants from their community, ensuring diverse representation of age, gender, and health status 2) Relay information on data collection based on EpiCollect processes and follow and attend to every question religiously. 3) Seek verbal consent from the recruited participant. An interpreter or team researcher will administer this process of consent. 4) CSt to elaborate on EpiCollect and clarify how it is used on the EpiCollect mobile App (Refer to Epi Collect guidance tool) 5) CSt will aid in data collection by providing the participant's demographics, including unique ID, location, and gender. 6) As the process unfolds, allow the participants to take pictures and give narratives—when the need arises, provide guidance. 7) Epi Collect questions should be relayed to those unfamiliar with English in the local language, and the CSt should facilitate this. 8) Following the data collection phase. Proceed to how the EpiCollect should be utilised.
Guidance for EpiCollect Data collection
1) Install the EpiCollect 5 App from the App Store (maximum 1 minute) 2) Click for EpiCollect App and search for Citizen science COPD_PR_SA 3) Click on COPD risk South Africa PR 4) Enter the data. 5) You will be prompted to take a picture, give a narrative (asking why you took it and if it is an enabler (a good thing) or a barrier (a bad thing) 6) Click on Add Entry on the top right-hand side of the screen each time you finish an entry. 7) The first question is: What is your study ID number? Type the Unique ID for the participant, e.g. 001 K (For Manenberg); 001 G (for Gugulethu)—Second Question: Name of your community. Insert the name and click on 'next'. 8) Respond to the following questions and take pictures and narratives at each stage. 9) Remember to Click "next" after each question is appropriately answered.

10) At the end of the session, please remember to synchronise the information collected and download it.

Appendix 4.8: Data Extraction Guide

Citizen science Guidance Document

1) Print narratives and pictures.
2) Apportion the discussion into groups of 3 to 5 members.
3) The groups will congregate and choose a lead.
4) The discussions in the groups shall focus on pictures and narratives based on based on what causes COPD.
5) Collate similar pictures and narratives in each group and summarise these into two categories the enhancers and barriers)
6) Allow the groups to converge and discuss the similarities in their findings. The PhD candidate should be accorded the freedom to engage meaningfully without interruption. The resources needed are whiteboard papers, EpiCollect, and printouts of narratives.
7) Depending on the number of CSts, the photos and narratives will be shared in the bigger groups.

Appendix 4.9:Ethical Approval

UNIVERSITY OF CAPE TOWN
Faculty of Health Sciences
Human Research Ethics Committee

Room 45 E-52-E-Floor- Old Main Building
Groote Schuur Hospital
Observatory 7925
Telephone [021] 406 6492
Email: hrec-submissions@uct.ac.za
Website: www.health.uct.ac.za/home/human-research-ethics

06 December 2023

HREC REF: 157/2023

Prof R van Zyl-Smit
UCT Lung Institute
Mowbray
Email: Richard.vanzyl-smit@uct.ac.za
Student: Moses.isiagi@uct.ac.za

Dear Prof van Zyl-Smit

PROJECT TITLE: PULMONARY REHABILITATION IN AFRICA: (A FOCUS ON COPD INLOW-RESOURCED COMMUNITIES IN SOUTH AFRICA)-
(PHD CANDIDATE-MR MOSES ISIAGI)

Thank you for your response letter received 06 November 2023, addressing the issues raised by the Faculty of Health Sciences Human Research Ethics Committee (HREC).

It is a pleasure to inform you that the HREC has **formally approved** the above-mentioned study.

Approval is granted for one year until the 30 December 2024.

Please submit a progress form, using the standardised Annual Report Form (FHS016) or FHS017 if the study continues beyond the approval period. Please submit a Standard Closure form if the study is completed within the approval period.
(Forms can be found on our website: www.health.uct.ac.za/fhs/research/humanethics/forms)

The HREC acknowledge that the student: Mr Moses Isiagi will also be involved in this study.

Please quote HREC REF 157/2023 in all your correspondence.

Please note that the ongoing ethical conduct of the study remains the responsibility of the principal investigator.

Please note that for all studies approved by the HREC, the principal investigator **must** obtain appropriate institutional approval, where necessary, before the research may occur.

Yours sincerely

PROFESSOR M BLOCKMAN
CHAIRPERSON, FACULTY OF HEALTH SCIENCES HUMAN RESEARCH ETHICS COMMITTEE

Federal Wide Assurance Number: FWA00001637. Institutional Review Board (IRB) number: IRB00001938 NHREC-registration number: REC-210208-007
This serves to confirm that the University of Cape Town Human Research Ethics Committee complies to the Ethics Standards for Clinical Research with a new drug in patients, based on the Medical Research Council (MRC-SA), Food and Drug Administration (FDA-USA), International Council for Harmonisation of

Technical Requirements for Pharmaceuticals for Human Use: Good Clinical Practice (ICH GCP), South African Good Clinical Practice Guidelines (DoH 2020), based on the Association of the British Pharmaceutical Industry Guidelines (ABPI), and Declaration of Helsinki (2013) guidelines. The Human Research Ethics Committee granting this approval is in compliance with the ICH Harmonised Tripartite Guidelines E6: Note for Guidance on Good Clinical Practice (CPMP/ICH/135/95) and FDA Code Federal Regulation Part 50, 56 and 312.

HREC/ref 157.2023

Appendix 4.10: Co-Creation And Co-Development Workshop Guide 1

UNIVERSITY OF CAPE TOWN
IDYUNIVESITHI YASEKAPA • UNIVERSITEIT VAN KAAPSTAD

Box 1:

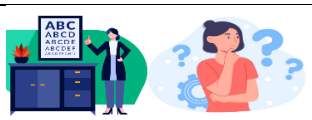
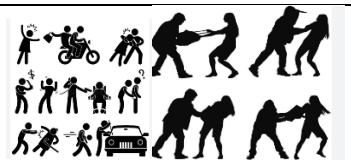
DEMOGRAPHY **(What causes lung disease**	**Tick here (at least 3 you consider most important cause** ✔
Smoking	
Air pollution	
Work (work in a mine, dusty place	
Genetics (inherited from parent	
Age (as we grow old, we most likely will get lung disease)	
COVID-19	

DEMOGRAPHY **(What causes lung disease**	**Tick here (at least 1 you consider the most important thing** ✔ and rank t 1-3
Smoking	
Air pollution	
Work (work in a mine, dusty place	
Genetics (inherited from parent	
Age (as we grow old, we most likely will get lung disease)	
COVID-19	

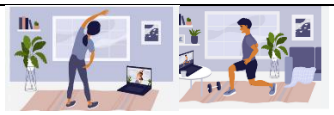
Box 1.

DEMOGRAPHY **(What causes lung disease**	**Tick here (at least 1 you consider the most important thing** ✔
Smoking	
Air pollution	
Work (work in a mine, dusty place	
Genetics (inherited from parent	
Age (as we grow old, we most likely will get lung disease)	
COVID-19	

Box 2: Barriers to Pulmonary rehabilitation

Barriers to Pulmonary Rehab/Treatment	Graphics	Tick here (at least 3 you consider the most important thing ✔ and rank them 1-3
Cost (Medication is expensive, and treatment is expensive)		
Lack of health care practitioners /doctors		
Lack of treatment facilities/ treatment facilities are far (Hospitals are far)		
Lack of awareness about COPD and lack of awareness about Pulmonary rehabilitation		
I am old and may not be able to use it.		
Crime in the neighbourhood		
Others:		

BEST FORM OF REHABILITATION
Box 3:

Group-based or NOT	**Graphics**	**Tick here (at least 1 you consider the most important thing ☑**
Individual-based		
Group-based and community		

Appendix 4.11 :Co-Creation and Co-development Workshop Guide 1

Dear Community stakeholders, Based on the findings from the Focus group discussions, we shall co-design an intervention for the community based on these three scenarios.

Scenario1: The Community Elder

Josephine Brookes is a 65-year-old former domestic worker now living at home, she is respected in the community, has a basic mobile phone for calls, completed grade 10 and has been a smoker for 40 years (still smoking), she has a persistent cough and has never formally gone to check if she has COPD, Josephine uses traditional remedies to help with her condition and is also part of a church group that could offer support. For Josephine, there is no nearby clinic, she has a limited understanding of COPD, and the cost of transportation to the hospital is very high, although she has adult children who could assist with transport; she says she has so much stress and Smoking helps her cope, she fears to walk for Exercise because of crime in the community.

1) List her barriers to receiving care/treatment.
2) List her enablers to receiving care.
3) What preferred intervention would you design for her, and who would be the key stakeholders? (choose between home-based and community-based, what education components would be needed, what resources one would need, safety considerations, and cultural intervention.

Scenario 2: Working Father

Johann Devilries' is a 55-year-old working father. John is a construction worker who completed grade 11; he has smoked since age 15 years, has frequent chest infections, and struggles with work due to breathing problems; he overuses the use of cough medicine and sometimes buys informally from Nyanga junction. Johann cannot afford to miss work whenever he has a hospital appointment. He also has limited financial resources and lives in a high-crime area with limited access to transportation. Johann has no medical aid. Johann has a basic mobile phone to help me, is motivated to continue working, has a strong family support system, and is connected to the workers' union.

1) List his barriers to receiving care/treatment.
2) List his enablers to receiving care.
3) What preferred intervention would you design for him, and who would be the key stakeholders? (choose between home-based and community-based, what education components would be needed, what resources one would need, safety considerations, and cultural intervention.

Scenario 3: The Community Member

Name: Melody Swart is a 45-year-old street vendor who completed matric. Because of peer pressure, she started smoking and has since developed breathing problems. Sometimes, she uses her neighbour's Asthma pump but has never visited a hospital to check for breathing problems. Melody has basic literacy skills; she is part of a women's savings group and shares a phone with her husband. Melody has limited knowledge of COPD and no regular income because of the nature of her Job. She lives in a neighbourhood with no access to rehabilitation facilities, and her neighbourhood is unsafe for outdoor activities.

1) List her barriers to receiving care/treatment.
2) List her enablers to receiving care.
3) What preferred intervention would you design for her, and who would be the key stakeholders? (Choose between home-based and community-based; what education components would be needed, what resources would one need, safety considerations, cultural intervention.

Appendix 4.12 : Transcription From The Community Leaders On Acceptability And Preferred Strategy For Participatory Community-Driven COPD And PR

Note on Focus of Discussion

While smoking emerged as a dominant theme in these discussions, reflecting its significance in the community's understanding of respiratory health, we recognize that the conversation could have been more effectively steered toward broader pulmonary rehabilitation implementation aspects. This tendency for discussions to focus heavily on smoking behavior rather than rehabilitation strategies represents a valuable insight into community perspectives that influenced our approach to program design.

[Speaker 1] (0:00 - 1:41):I want to transcribe the next session and just find out from us. First, thank you so very much for today's session. I want to ask a few questions to us.

So, one for the leaders, so the health forum leaders and the rest, what intervention do you think would be the best? Because I saw when we had a break many of us were to smoke, so I'm wondering. Yeah, so I noticed, right? It's almost like when you go to the hospital, and they tell you please do not smoke one minute later. Yeah, so I want to ask first the leaders, what intervention do you think would be the best for us from a COPD point of view? And for those that do not fully understand COPD.

So, the C stands for chronic, which is chronic means lifelong, long more than one year. The O stands for obstruction of the lungs, like I explained. The P stands for pulmonary, which is the lungs. Then the D is a group of diseases. So, it's not one disease because you have, it's a lot of diseases. So, you have emphysema, you have bronchitis. Yeah, so asthma sits on the other side. So, asthma is a restriction. Yeah, so if you fail to breathe in, you have asthma. That's why you need an asthma pump. When you fail to breathe out, you have COPD, so your lungs need to be open. So that's the difference. So, do you understand? Yeah, so I wanted to ask.

[Speaker 4] (1:41 - 1:56):Okay, so for now we're speaking to the health committee, the health forum, the clinic, the ratification, and now, we're not speaking to the participants, we're speaking to the stakeholders now.

[Speaker 1] (1:56 - 1:57):Stakeholders, then we'll...

[Speaker 4] (1:57 - 2:03):So, he's asking what interventions do you think would be the best for our community?

[Speaker 1] (2:03 - 2:29):Because they know that we have a smoking problem. We have learned that we, what smoking does to you long-term. We know that we need intervention. So, what do you think would be the best thing for us to do? All of us, so... Okay, this is for the health committee.

[Speaker 2] (2:29 - 3:08):For us as a health forum, the best intervention should be a support group. We should also have an exercise group where people can come to a safe space to do exercise. But also, having that too, we should also look how can services be brought closer to the community, and education around that. Because it doesn't make sense for you to have a whole exercise thing, and you don't know why you're exercising. So, for us, that is important.

[Speaker 1] (3:09 - 3:12):Thank you so much. Any other...

[Speaker 2] (3:12 - 3:12):First one?

[Speaker 5] (3:18 - 3:57):I'm Catherine, I'm the chairperson of the health committee. For me, I think we need more interventions, more workshops surrounding the COPD, and where we can involve our community members to gain more knowledge surrounding the COPD. And like Halima also said, must bring services to the community to gain more knowledge. Thank you so much. Any other?

[Speaker 3] (3:57 - 5:20): My name is Betsy Daniels, coordinating director of the Lerato Family Foundation. I think on a community level, where we engage and interact with the community, what would also help is to look at small interventions in terms of what other alternatives to curb that smoking habit could be. You know, in terms of looking at, you know, to tell people and advice, maybe, you know, rather try to eat sweets, you know, when that urge or that craving comes.

Because like most people say, it's like, I stress and then I start to smoke again. You know, and I think, you know, that we encourage those kinds of things and maybe get the person, if the person comes and the person is stressful, try to, you know, take that person for that moment. And, you know, just try to sit with that person.

Because I think sometimes people also just need somebody to listen to them. Because now they have nobody to listen to them. They are in the moment, in the situation. And then, you know, that is where they just jump to. And I think these small things, also in terms of healthy eating, you know, they try to eat some fruit, you know, instead of wanting to smoke, you know, and it's a process. It's not going to, you know, you didn't start to smoke now.. So, it's going to be a process, like it's not overnight. It's a long-term process that people have smoked if you heard about the three scenarios that we just did now. And so, it would be a process for people, you know, to get out of the habit.

[Speaker 1] (5:22 - 5:24):Thank you so much. And from the clinic?

[Speaker 4] (5:30 - 5:56):I think what's important from the medical health forum side is that also that we need to train our community, our care workers, that are very closely involved with communities and patients, because they do door-to-door and all those things. And I think training is going to be very, education around, so that they are able to share with the wider community on the process. Yeah.

[Speaker 1] (5:56 - 5:57)And the clinic?

[Speaker 5] (6:01 - 6:05);To give health education, more health education.

[Speaker 1] (6:06 - 6:21):Thank you so much. And from, so what intervention would be the best? Individual-based at your home, community-based, support group? What do you think is the best one? Community-based. Community-based. Does everyone agree that the community-based should be?

[Speaker 2] (6:21 - 7:01) :A community-based intervention is better than an individual, because sometimes you don't feel like doing it alone at home. So, when you're with other people, you

might also feel better, because you come out of your comfort zone into another area. And you might, your illness, you think that you are the only one suffering with that illness, but when you meet other people with similar illnesses, you understand more what you're going through. So, community-based interventions would be the best.

[Speaker 4] (7:02 - 7:08)Can you reach a wider audience of people if you do community-based work?

[Speaker 1] (7:08 - 7:21)Okay, cool. Any other person with a closing remark for the participants? I wanted to ask, after learning about smoking, why did you smoke? Anyone? Smoking break?

[Speaker 2] (7:24 - 8:10)

There's just one thing that is a concern for me. As a non-smoker, I'm inhaling secondary smoke. And that, I think that should also be addressed. What can that cause to you as a non-smoker? So, it's important that we also understand that part. Because for me, sometimes I get chest infections. I'm not smoking, but I cough worse than the person that smokes. And I'm sicker than the person that smokes. So, for me, it's important to understand, I mean there's other people in this room that doesn't smoke, what it does to us as non-smokers.

[Speaker 1] (8:12 - 8:26):So, for us, who went to smoke, I'm on you. I will not let you rest. Anyone? After learning about smoking, why did you go and smoke? Did you feel like you needed to smoke? Or what happened?

[Speaker 4] (8:27 - 8:34);When you eat, you need to smoke after that, really. Because the food needs to digest.

[Speaker 1] (8:34 - 8:41) :Oh sorry, the food needs to digest. Any other person? Okay, when you're supposed to need to smoke.

[Speaker 4] (8:41 - 8:48) Okay, cool. Is it a need or is it a want?

[Speaker 1] (8:48 - 8:50) It's a want.

[Speaker 4] (8:50 - 8:51)It's a want.

[Speaker 5] (8:55 - 9:17)

I am also a smoker. This is actually a conflict of interest to me, but in a way. I think this is just a bad habit. It’s a very bad habit gone wrong, because now you started, and now you don't know how to stop. Well, thank you so much.