Chronic respiratory diseases in Meru County, Kenya: how do public health systems respond and what are the opportunities for health system strengthening?

Thesis submitted in accordance with the requirements of the Liverpool School of Tropical Medicine for the Degree of Doctor of Philosophy by

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Declaration

I, Stephen Kikwe Mulupi, hereby declare that this PhD thesis is a presentation of original work.

Material contained herein has not been previously published, accepted, or presented for the award of any University degree. Every effort has been made to acknowledge the contribution of others.

Acknowledgements

Abstract

Introduction

Chronic respiratory diseases (CRD) are associated with premature mortality, poor health, impaired quality of life and adverse socioeconomic implications. Health systems need to be responsive to chronic respiratory diseases and other non-communicable diseases but many health systems in low- and middle-income countries are not designed or resourced to deliver chronic care effectively. This thesis is set in Kenya, a lower-middle income country in Eastern Africa. Kenya's health system was devolved in 2013 leading to 47 subnational governments (counties) managing most healthcare services, from primary healthcare to secondary referral hospitals. Over the last decade, Kenya has seen an increased focus on community health programmes and key health financing reforms such as the National Hospital Insurance Fund to achieve universal health coverage. The diagnosis and management of chronic diseases, however, remains neglected.

The burden of chronic respiratory diseases has been rising steeply over the last two decades, but Kenyan respiratory services continue to prioritise tuberculosis (TB) diagnosis and care. There is scarce evidence on the readiness of public healthcare systems to provide appropriate care for the wider group of people seeking care with symptoms of CRD who are *not* diagnosed with TB in Kenya. The main non-TB cause of CRD symptoms in Kenyan communities is asthma, which is associated with significant mortality and morbidity among both children and adults when untreated.

The aim of this study was to investigate the readiness of the devolved Kenyan public healthcare system to respond to people with symptoms of CRD and to explore the perceptions and impacts of living with CRD symptoms in Kenyan communities. The study used asthma diagnosis and care as a lens through which to identify opportunities to strengthen the response across the whole continuum of care for CRD.

Objectives

1. *Health system readiness*: To assess the readiness of the Meru County public healthcare system to respond to people with symptoms of CRD and identify opportunities for improvement of asthma diagnosis and care among adults and children in Meru County.
2. *Community experiences and perceptions*: To explore community perceptions and health-seeking behaviours related to symptoms of CRD and investigate the role of the community health system in supporting referral to healthcare services and the subsequent management of people with asthma.

3. ***Socioeconomic impact***: To estimate the socioeconomic impact, including catastrophic costs, of illness and care-seeking among adults with symptoms of CRD and assess the coverage and use of Kenya's social protection scheme the "National Hospital Insurance Fund" (NHIF) to pay for related healthcare facility visits.

Methods

The study was conducted in Meru County Kenya. Five public healthcare facilities representing primary healthcare (n=2), primary referral hospitals (n=2) and a secondary teaching and referral hospital (n=1); and community sites (n=8) were included. Different methods were used to address the three key objectives with cross cutting issues such as governance, financing and policy explored across multiple methods and levels.

Health system readiness: A readiness assessment at the five facilities examined availability of resources (infrastructure, equipment, drugs including inhalers, trained healthcare workers, policy guidelines), coordination of health care services delivery, and patients' responses to diagnosis, treatment, and management plans. Data were collected using a standardised questionnaire administered with healthcare workers and triangulated with findings from in-depth interviews with healthcare workers (n=44) and key informant interviews with decision-makers in the Meru County Department of Health (n=13).

Community experiences and perceptions: Community in-depth interviews and focus group discussions (FGDs) documented and explored the experiences of community health volunteers (n=81) in supporting referrals and linkage of community members to the formal health system; and community members' (n=32) experiences of healthcare delivery and access to primary healthcare facilities and secondary referral hospitals.

Socioeconomic impact: Exit interviews with adults seeking care for CRD symptoms (n=296) estimated lost income, and direct medical and non-medical costs of healthcare facility visits, membership of the NHIF and reasons for not enrolling; coping mechanisms for paying for healthcare services; and exposure to catastrophic healthcare expenditure of care-seeking, defined as total health-related costs >40% of monthly non-food/rent/leisure expenditure of the participants' households (also known as a household's "capacity to pay").

Findings

Health system readiness: key challenges identified included lack of healthcare workers' capacity, inadequate equipment, and poor coordination of systems for diagnosis and treatment of chronic respiratory diseases. These challenges indicate the health system is inadequately prepared to deal with chronic respiratory diseases. The quality and continuity of drug supply, including inhalers, was adequate.

However, the stigma related to the chronic respiratory diseases like asthma impacted on treatment plans and management, including prescription and demonstration of inhaler use. There were multiple challenges in health systems' governance, which if left uncorrected could significantly undermine chronic respiratory disease care and wider systemic reforms. These included: delays in payment of healthcare workers' salaries and lack of promotions, both of which led to frequent strikes; suboptimal financial accountability; and weak coordination of funds disbursement between the national and county governments.

Community experiences and perceptions of asthma care: the linkages between the community health system and healthcare facilities were weak. There was poor communication and working relations between community health volunteers and formal healthcare workers around chronic respiratory disease and asthma; inadequate material, financial and training support for community health volunteers; and poor coordination of service delivery. Conditions of poverty of participants' households made referral uptake difficult. Stigma related to asthma was widely reported as an important barrier to both health-seeking behaviour and chronic asthma management. These barriers were perceived to translate into missed opportunities and suboptimal involvement of community health volunteers in asthma management.

Socioeconomic impact associated with having symptoms of chronic respiratory disease: More than half of participants (142/296; 52%) experienced catastrophic healthcare expenditure related to seeking care for chronic respiratory disease symptoms. Factors independently associated with experiencing catastrophic healthcare expenditure included being female (adjusted odds ratio, aOR, 2.2, 95% CI 1.2-4.2, p=0.011); being the primary income earner of the household (aOR 2.0, 95% CI 1.0-3.9, p=0.044); belonging to the poorest tercile of participant households (aOR 2.4, 95% CI 1.2-4.8, p=0.017), and seeking care from a subcounty hospital (aOR 2.5, 95% CI 1.3-5.1, p= 0.008). The principal coping strategies were using savings (173/296; 58%) and borrowing money (91/296; 31%). Of the more than two thirds of participants (212/296; 72%) who were not covered by NHIF, the most common reported barriers to NHIF enrolment were unaffordability of insurance premiums (92/212; 43%), unawareness of eligibility (56/212; 26%) and inadequate information (44/212; 21%). Of those covered by NHIF, 73/84 (87%) did not use NHIF to pay for their chronic respiratory disease care due to not being asked about NHIF (30/73; 41%), not being up to date with NHIF premiums (22/73; 30%), or the healthcare facility not taking NHIF cards (16/73; 22%).

Discussion

This is the first reported evidence from Kenya showing inadequate health system responses to chronic respiratory diseases, high levels of asthma-related stigma and a high prevalence of catastrophic costs experienced by people seeking care for CRD symptoms, including asthma. These three areas (health system responses, community stigma and catastrophic costs) interact in a vicious cycle that spans from

community to health facilities. Being female, poorer, primary income earner, and seeking care at subcounty hospitals were independently associated with experiencing catastrophic costs. This indicates gender and socioeconomic inequalities in healthcare access for people seeking care with CRD symptoms and highlights the potential role for social protection including NHIF to reduce income loss and review of care-seeking, diagnostic, and referral pathways to reduce out-of-pocket costs, especially at subcounty hospital level. There are significant gaps in terms of equipment and training on chronic respiratory diseases in health facilities. Our findings indicate however that interventions such as social protection and health care worker training will not be effective unless communities and staff training are also addressing stigma.

Conclusions and recommendations

The Kenyan health system is inadequately prepared to provide adequate care for people with symptoms consistent with non-communicable CRD such as asthma. Priority, targeted interventions to achieve health system strengthening include empowering community stakeholders through stigma reduction programmes and enhanced social protection; enhancing diagnostic capacities through training healthcare workers to do peak flow diaries and spirometry testing and supply of peak expiratory flow meters; and through advocating for adequate remuneration of the community health volunteers, strengthening community health systems' linkage to healthcare facilities and county governance systems.

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Acronyms

CCP	Clinical care pathways
CDOH	County Department of Health
CEC	County Executive Committee
CHA	Community Health Assistant
CHC	Community Health Committee
CHE	Catastrophic health expenditure
CHEW	Community Health Extension Worker
CHMT	County Health Management Team
CHW	Community Health Worker
CHU	Community Health Unit
CHV	Community Health Volunteer
CFSP	County Fiscal Strategy Paper Continuing Medical Education
CME	Continuing Medical Education
COPD	Chronic Obstructive Pulmonary Disease
CIDP	County Integrated Development Plan
CRD	Chronic lung diseases
CRD	Chronic respiratory diseases
CRS	Chronic Respiratory Symptoms
DHS	Demographic Health Survey
DOTS	Directly Observed Therapy Short course
EML	Essential Medicines List
FCTC	Framework Convention on Tobacco Control
FGD	Focus Group Discussion
FIF	Facility Improvement Fund
GDP	Gross Domestic Product
GOK	Government of Kenya
HCW	Health care worker
HRH	Human Resources for Health
IDI	In-Depth Interview
ISAAC	International Study of Asthma and Allergies in Childhood
KEMSA	Kenya Medical Supplies Authority

KEPH	Kenya Essential Package for Health
KES	Kenya shillings
KHSSP	Kenya Health Sector Strategic Plan
KII	Key Informant Interview
LMIC	Low- and Middle-Income Country
LSTM	Liverpool School of Tropical Medicine
MCA	Member of County Assembly
MOH	Ministry of Health
MTRH	Meru Teaching and Referral Hospital
NCD	Non-Communicable Disease
NGO	Non-Governmental Organisation
NHIF	National Hospital Insurance Fund
NTLD	National Leprosy, TB and Lung Disease Program
ODK	Open Data Kit
OECD	Organisation for Economic Co-operation and Development
OOP	Out-Of-Pocket
PAL	Practical Approach to Lung health
PEN	Package of Essential Non-communicable disease interventions
PHC	Primary Health Care
QI	Quality Improvement
SARA	Service Availability and Readiness Assessment
SDGs	Sustainable Development Goals
SSA	sub-Saharan Africa
TB	Tuberculosis
UHC	Universal Health Coverage
USD	United States Dollars
WHO	World Health Organization

Chapter 1: Introduction

The introductory chapter of this thesis describes the global and Kenyan context of chronic respiratory diseases (CRD) and situates the health systems responses in the devolved Kenyan Health system. It explains the use of asthma as a lens to investigate health systems responses to CRD. The aim and objectives of the study follow and link to the exposed evidence gaps. The chapter then provides an overview of the thesis structure, which responds to the objectives and evidence gaps. As the thesis is framed around three papers being prepared for publication, a more detailed description of the study context is then given in this introductory chapter. The chapter concludes by summarising my own role in the study.

Three key definitions need framing upfront as they are used repeatedly in the text (Box 1). A more complete glossary can be found in Appendix 1.

Box 1: Key definitions

Chronic respiratory diseases (CRD): refers to chronic non-communicable diseases affecting the airways and other structures of the lungs. It is a collective term for a group of respiratory diagnoses including asthma, chronic obstructive pulmonary disease (COPD), post-TB lung disease and bronchiectasis. The term excludes active tuberculosis (TB), even if the symptoms of active TB have been going on for several weeks or months.

Chronic respiratory symptoms (CRS): refer to coughs lasting more than two weeks' duration, coughs that persist after any treatment at a healthcare facility, coughs that persist after negative diagnostic tests of TB, wheezing, noisy breathing, chest pain, and repetitive blood in sputum.

Devolution: A form of decentralisation involving transfer of administrative, political, and fiscal responsibilities of public services from a national government to an elected subnational government.

1.1. Chronic respiratory diseases: the global and Kenyan context

1.1.1. Non communicable diseases are a significant burden on health systems.

Every year, non-communicable diseases (NCDs) kill 41 million people worldwide, accounting for 71% of the global deaths [1]. The majority of NCDs are chronic and, currently, at least 77% of all NCD deaths occur in low- and middle-income countries [1]. In Kenya, for example, NCDs accounted for 50% of all hospital admissions and 55% of all hospital deaths in 2012 [2]. The NCD burden is predicted to increase due to

urbanisation, epidemiologic shifts associated with an ageing population and globalisation processes that drive the marketing of harmful products like tobacco [3, 4]. LMICs are already burdened with a high prevalence of infectious diseases, maternal mortality, and accidental injuries [5]. The rising burden of NCDs will compound health system shortages and impede socioeconomic development [6]. In 2010, for example, NCDs alone accounted for 1.34 out of 2.49 billion (54%) disability-adjusted life years worldwide [6].

1.1.2. The burden of chronic respiratory diseases is rising in LMICs and in Kenya

Chronic respiratory diseases (CRD) are among the four main non-communicable diseases (others are cardiovascular diseases, diabetes and cancers), accounting for 85 percent of premature deaths globally [1]. Asthma and chronic obstructive pulmonary diseases (COPD) are the leading CRD with prevalence highest among children and older people respectively. In 2015, asthma prevalence globally was 358 million, and accounted for 0.4 million deaths [7]. It is estimated that by 2030, COPD will be the third leading cause of all deaths globally [8, 9]. Available evidence suggests the burden of CRD is highest in high-income countries [7]. However, the limited evidence base from low- and middle-income countries (LMICs) shows a rapidly rising burden, particularly in Asian and sub-Saharan African countries [10, 11] where most asthma-related deaths occur [1]. The scarcity of evidence on the true burden of CRD in Sub-Saharan Africa (SSA) has been highlighted as an important barrier to CRD management efforts.

The few studies that have been done in Sub-Saharan Africa found disparities in the prevalence of COPD, which ranged from 4.1% to 22.2% [12]. Efforts to compare trends across countries are hampered by a lack of clear case definitions [13, 14]. A review conducted by van Germet and colleagues about management of COPD in Kenya, Uganda and Ethiopia concluded that, in Kenya, 'current prevalence of COPD is unknown' but the few hospital-based studies available estimated COPD prevalence to be 200 per 100,000 of the population [9]. The main risk factors for COPD include exposure to tobacco smoke, indoor household air pollution from biomass fuels, occupational exposures, and acute, recurrent, and chronic lower respiratory tract infections, all of which are on the rise with the poorest people having the greatest exposure risk [8, 15]. An expanding market for tobacco products in Africa portends the increased incidence of COPD in particular [16].

The prevalence of **asthma** in Africa is estimated to be between 6-20% [12]. Longitudinally, the prevalence has increased steadily over the past two decades with an estimated annual increase of 0.35% per year particularly among children [17]. A cross-sectional survey in Malawi estimated prevalence of chronic respiratory symptoms, spirometric obstruction, and restriction, at 13.6 % [18]. Vialle-Valentin *et al*, analysed data from household surveys investigating prevalence of chronic diseases in low- and middle-income

countries (LMICs) including Ghana, Kenya and Uganda [19]. The study estimated prevalence of asthma to be 10% (Ghana), 20% (Kenya) and 13% (Uganda). Rates of 'ever having asthma' were reported to be 15.5% and 18.2% respectively by Sudanese respondents of International Study of Asthma and Allergies in Childhood (ISAAC) Phase III and Global Asthma Network (GAN) Phase I [20]. In Kenya, there appears to be a high and rising burden of asthma in both urban and rural communities. Cross sectional surveys using the ISAAC methodology among 3,258 school children aged 13-14 years in a rural environment in Eldoret established a significant increase of asthma prevalence from 6.6% to 12.6% over a six-year period (Esamai and Anabwani 1996, Esamai, Ayaya et al. 2002). However, these decades old estimates are not appropriate in describing the current CRD burden in Kenya due to the epidemiologic and demographic transitions in population morbidity and mortality that have since occurred [21]. Furthermore, while acknowledging that there were no population-based studies that investigated the prevalence of asthma and COPD among all age groups, the National Strategic Plan for TB, Leprosy and Lung Health, 2015-2018, estimated a 10% prevalence of asthma in Kenya, based on ISAAC studies [22]. A systematic review of 18 studies conducted more recently in Kenya established wide variation in asthma prevalence from 3 to 28% [23]. The studies highlighted in the review enrolled different population subgroups and used varying case definitions, making it difficult to compare findings across studies. Consequently, the true burden of asthma at population level is difficult to estimate. A more recent study in 2022 found asthma to be the most common clinically diagnosed CRD in outpatient clinics in Kenya although with spirometry testing some of these cases turned out to be COPD [24]. Nationally representative studies representing population subgroups are needed to provide reliable estimates of asthma and other CRD in Kenya.

1.1.3. The impact of CRD on individuals, communities, and health systems in LMICs

CRD is associated with significant morbidity and mortality among both children and adults. While asthma death is largely regarded as preventable in high income countries, this is not the case in LMIC. A two years' cohort study in Uganda, [25] for example, estimated a 27 fold risk of asthma mortality in Uganda, compared to Italy [26]. Apart from causing premature deaths, CRD diminish quality of life and opportunities of livelihoods for affected households. Consequently, millions of households may experience increased financial vulnerability, and a vicious cycle of poor health and poverty [27]. Asthma also impairs school attendance, putting in jeopardy educational attainment and future opportunity prospects for children [8, 28]. This is despite existing simple and cost-effective technologies for managing asthma including inhaled steroids for prevention and inhaled beta-2 agonists for relief of symptoms [7].

The rising burden of CRD puts pressure on chronically under-resourced health systems in LMIC, including Kenya. Translation of global policy resolutions to stem the rise of NCDs face serious obstacles. CRD receive dismal attention from governments, families and health providers [29]. Comparatively, the agenda for NCD control has focused more on political commitments than the mobilisation of resources at the international and domestic levels [4]. Consequently, health systems in sub-Saharan Africa (SSA) are inadequately prepared to manage CRD [29]. This is exemplified by low diagnostic capacity, inadequate human resources and drug supplies and financing for CRD. Treatment of CRD is mainly 'episodic' relating to acute deterioration in symptoms rather than prevention or chronic symptom control [5, 29]. Recent readiness assessments in Tanzania and Sudan demonstrated widespread gaps in public health facilities on the training, staffing, equipment and drugs for treating CRD [30]. This is endorsed findings from elsewhere that show the health systems' responses in many LMICs are orientated at dealing with the exclusion of active TB disease and the treatment of acute exacerbations of asthma [31-33]. Few facilities have capacity for supporting long term asthma control. According to the WHO, "there are no global management recommendations for patients aged 5 years and over with respiratory symptoms at any level of the health infrastructure, with the exception of TB" [34]. This situation raises critical questions about the fate of 80-90% patients that test negative for TB but have ongoing symptoms of CRD [15]

At the community level, gaps in the identification of CRD risk factors, cases, and referrals to healthcare facilities, undermine CRD management. This is partly due to stigma towards people with CRD within communities [35]. Addressing facility readiness is an important step. Hospitals in Gezira district in Sudan have introduced training; equipment such as peak flow meters; and preventive drugs (including inhaled corticosteroids and long-acting beta agonists), and have seen a reduction in hospital admissions and emergency-room attendances [36]. Yet even this increase in uptake is suboptimal when compared with the far higher prevalence of undiagnosed asthma in surrounding communities. A complex and interacting range of barriers to uptake cause many people with chronic respiratory symptoms to not access available services. The same is likely to be the case in Kenya. When Novartis™ recently supplied inhalers free at the point of use as part of a randomised control trial on access to drugs in Kenya there was no increase in their uptake in the intervention arm, indicating drug availability and cost were not the only barriers [37]. Understanding community perspectives and barriers to services uptake are therefore a crucial component of any response in Kenya.

1.1.4. The national policy response to chronic respiratory symptoms in Kenya

The Kenyan constitution is rights-based and guarantees every person the right "to the highest attainable standard of health, which includes the right to health care services" (Cap 43) [38]. The Kenyan government

acknowledges the rising burden of chronic respiratory symptoms. In the devolved Kenyan health system (see section 1.1.5) the national level is responsible for guidelines and policy development. Kenya has developed specific policy strategies and treatment guidelines to address the problem of CRD. The official Ministry of Health policy and strategic plans highlight policy prioritisation of CRD control, at least on paper. Kenya has also adopted the Global Action Plan for Prevention and Control of Non-Communicable Diseases [39]. The Ministry of Health has developed treatment guidelines for chronic respiratory diseases drawing from the WHO Essential Medicines Lists (EML) [40]. The prioritisation of universal health coverage in the current regime's 'Big Four' agenda, suggests consideration for different population needs, including chronic respiratory diseases [41]. The Kenya Medical Supplies Authority (KEMSA) is the main public purchaser and supplier of drugs to the subnational county governments.

Prior to this PhD research, I led an exploratory study on policy and health services provision for people with CRD (see Appendix 2). This showed Kenya and four other Sub-Saharan Africa countries were equally ill prepared to provide adequate healthcare services for people with CRD. The study identified a vicious cycle of neglect of CRD identification, care, and management at both the strategic policy level and health facility services delivery level. Inadequate data on CRD burden of chronic respiratory diseases influenced budget allocation decisions for healthcare services, which in turn was associated with low prioritisation of CRD in service delivery plans. This situation in turn influenced data collected (or not collected) at the health facility levels and subsequently policy level decisions [42]. These relationships are depicted in Figure 1.1 below.

Figure 1.1 Intersecting vicious cycles of neglect for chronic respiratory diseases in sub–Saharan Africa

Source: Mulupi and Ayakaka et al. [43]

A separate study focusing on the policy landscape combined a desk review with key informant interviews (KIIs) in five countries, including Kenya. The study established that Kenya had made significant strides in putting in place policies to address CRD [44]. For example, in 2018, Kenya was in the process of ratifying Article 15 of the Framework Convention on Tobacco Control (FCTC) to eliminate illicit trade in tobacco products [45]. The final ratification was done in May 2020 [46]. Conversely, the study established significant gaps in the service provision level, for example, lack of adequate diagnostic equipment for CRD in spite of having published Kenyan guidelines for the management of asthma [44].

1.1.5. The county level response to CRD in a devolved Kenyan health system

The Kenyan healthcare system was devolved in 2013, following a constitutional change in 2010 [38](Republic of Kenya 2010). Fiscal and administrative decision-making powers for health service provision became vested on the 47 subnational county governments. The devolved public health care delivery system is structured across six levels: Level 1 - community; Levels 2 and 3 - primary care, comprising dispensaries and health centres, respectively providing basic outpatient services and some inpatient services for expectant women; Level 4 - sub county hospitals, which are the primary referral hospitals in the devolved system; Level 5 - county referral hospitals, and Level 6 - national referral hospitals, providing specialised services, laboratory support, and blood transfusion services [47, 48].The subnational county governments are mandated to provide healthcare services from community level to county referral hospitals level (5 out of the 6 levels of healthcare delivery). They also budget for and oversee Level 1 to 3 services, often making stark choices about what conditions and geographic areas are prioritised for services [49]. Healthcare services at the county level are organised through the County Department of Health (CDOH). County and subcounty health management teams oversee all the planning and decision-making and provision of support to health facilities at the county and subcounty levels [50]. The national government is mandated to design policies and regulations, manage the national referral hospitals and specialised facilities, develop the capacity of health care workers and provide technical assistance to counties [48].

At the conceptualisation phase of this PhD research, it was not clear how Level 2-3 facilities fitted into CRD care in the devolved Kenyan health system. Although absent in the national community health strategy [51, 52], the role of community health volunteers (CHVs) in referral and support of people with TB in terms of case finding, contact tracing, notification and adhering to treatment has been widely documented in Kenya and other LMIC contexts [53-56]. However, the roles of CHVs in supporting referrals and subsequent management of CRD and the readiness of public healthcare facilities at the devolved county level to diagnose,

treat and provide subsequent CRD management – including, for example, infrastructure, healthcare workers, diagnostic equipment, essential drugs' supply, and coordination of services – were undocumented.

The Constitution requires an equitable share of at least 15% of national revenues be distributed to all the counties. Counties then allocate these funds to priority services. The national government can also provide grants to counties to implement specific programmes [38, 57]. Devolution is expected to enhance local priority setting mechanisms, encourage faster decision-making and increase public accountability [49, 58]. However, research on the early experiences of the Kenyan health system post-devolution showed the system was fraught with challenges [50]. These included inadequate and unpredictable financing of the health system, insufficient capacity of key county decision-makers to manage the system, a restless healthcare workforce characterised by frequent incidences of nation-wide strikes by various healthcare workers' cadres due to poor working environments and inadequate remuneration. The devolved health system is also plagued by unreliable drugs and supplies management, political interference in healthcare decision-making and governance [49, 50, 58] and diminished autonomy of hospital managers owing to new governance structures [59]. The autonomy of counties poses a big risk of fragmenting the healthcare system because individual counties' priorities may differ. It is likely that CRD management may not be a top priority for all counties, irrespective of shared geographical boundaries, risk factors and disease prevalence.

1.1.6. Kenyan communities and chronic respiratory diseases

While there is much evidence on TB in Kenyan communities, including on the role of community health volunteers [53, 54] as explained in section 1.1.5. above, there is negligible literature on the impact of CRD at community level in Kenya. For example, there are no published papers on community understandings of cough that is not TB and little on the patient experience of living with a CRD in Kenya [60].

As well as poor understanding of the community perceptions of CRD symptoms, little is known about the financial and socioeconomic impact on people living with CRD symptoms. The Kenyan government is reforming the social health insurance scheme – the National Hospital Insurance Fund (NHIF) – in its pursuit for universal health coverage [61]. During the timespan covered by this thesis (2000-2022), the Kenyan government undertook significant reforms in the NHIF. These included enhanced revenues collection by the NHIF through change of monthly premiums by formal workers from 320 Kenyan Shillings (US$2.8[1]) to 1700 shillings (US$ 14.6) and expansion of benefits cover to include care for chronic diseases, and inclusion of outpatient care in the benefits package [62]. The Fig 1.2. below shows a summary of the structure of the NHIF

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[1] (**1 US$= Kenya shillings 116.4, based on Oanda currency converter-** https://www.oanda.com/currency-converter/en/?from=USD&to=KES&amount=1)

and mechanisms of the NHIF in relation to the members and health facilities contracted to provide services[63, 64]

The NHIF

Leadership: Board of Management

Schemes:

- National health scheme (Supacover)- open to all Kenyan residents.
- Enhanced scheme- comprehensive care. Covers civil servants, police, parastatals, professional groups.
- Linda Mama- Antenatal care, delivery, postnatal care to 6 months
- Edu Afya- secondary students

Service delivery: 95 branches + Service points in 'Huduma centres'

Benefits

Out-patient, in-patient, maternity, renal dialysis, kidney transplant, radiology, oncology, chronic (diabetes & hypertension), lab tests, surgery

Information on eligibility, access to care, payment rates & modes of payment

Monthly contributions, Information on preferred facilities, feedback on services

NHIF Membership (beneficiaries)

- 18 years and above, Kenyan residents
- 6.3 million principal members (2016); estimated 25 million beneficiaries
- Formal (mandatory contributors) and informal (voluntary contributors).
- Dependents: children <18 years/ students/ disabled

Monthly contributions:

- 500 Kenyan shillings (US$ 4.3) (voluntary)
- Graduated scale 170-1700 Kenyan shillings (US$ 1.5-15) based on salary bands, for minimum income 6000 Kenyan shillings (US$ 51.5)

Contract and pay, monitor service delivery

Provide care

Select health facility, provide NHIF identification when accessing services.

Information for contracting; medical claims

Public and private healthcare facilities:

- 7000 + health facilities empaneled
- Primary care facilities & hospitals,
- Specialist stand-alone e.g. radiography, laboratory, dialysis/ oncology

Only 1 healthcare facility chosen per member/ dependent for outpatient care

Figure 1. 2 The structure and mechanisms of NHIF

The arrows and descriptions in text boxes in Fig 1.2 show the ideal relationships and interactions between the NHIF, healthcare facilities and patients (stakeholders), the flow of information or financial resources, and specific actions or obligations by each of these three key stakeholders. It is not known how people in Kenya perceive or use the NHIF cover to access healthcare services, especially for symptoms of CRD or management of CRD such as asthma.

1.2. The lens of asthma to examine health systems responses in Kenya.

This PhD research investigated CRD through the lens of symptoms rather than a specific CRD. Although there are no population-level data on the burden of CRD symptoms, symptoms of wheeze, breathlessness and cough are easily understood by patients and communities and are presenting features when people with asthma seek care. This approach was used to facilitate research into community perceptions and individual level understandings of CRD in Kenyan communities. The deliberate focus on people presenting with CRD symptoms, rather than with a formally diagnosed CRD acknowledges the challenges experienced in the correct diagnosis of CRD, mainly due to comorbidities and case definitions. By focusing on CRD symptoms, the PhD research can investigate experiences of patients who have been diagnosed with a specific CRD, as well as those whose conditions may not be diagnosed. Finally, the focus on CRD symptoms is an important opportunity to highlight public health systems responses in Kenya to both infectious and non-infectious respiratory conditions. It sets the findings apart from studies focusing on infectious diseases, including TB, which have historically received significant external funding and resources in Kenya. This provides insights into how the health system may respond to disease areas lacking external partner funding. As noted in box 1 ('Key definitions') I have assumed the exclusion of active TB as an explanation for cough and am interested in what happens to people (and how the system responds) when TB has effectively been ruled out, but CRD symptoms persist.

At times in the thesis, a single disease focus was required (e.g., for assessing the quality of diagnosis or the availability of specific treatments) and I selected the lens of asthma. 'Asthma' is a disease label commonly used by lay people in Kenya in relation to symptoms of wheeze and chronic cough. It was therefore expected that by referring to asthma, certain discussions could be held consistently and meaningfully across the health consumer and service provider divide. I also selected asthma because asthma affects both children and adults allowing us to examine experiences and responses for both. Asthma has a clear and agreed treatment pathway with evidence-based global recommendations for its chronic management [65]. The impacts of early diagnosis and good ongoing care for asthma are enormous (unlike in some other CRD such as end stage COPD) and improvements in asthma care are a low-hanging fruit in terms of improved school attendance, growth, quality

of life and decreased need for hospital attendance. A struggling, under-resourced health system would reap great benefit for improved asthma care and the Lancet Poverty Commission lists asthma as a key health sector priority intervention for LMICs [66]. Acute, fatal asthma exacerbations are largely preventable in strong health systems able to identify and manage patients with long-term inhaled corticosteroids [65].

1.3.   Aim, objectives, and methods overview.

The aim of this PhD research was to investigate the readiness of the devolved Kenyan public healthcare system to respond to people with CRD or CRD symptoms and to explore the perceptions and impacts of living with CRD in Kenyan communities. The research used asthma diagnosis, treatment, and care as a lens through which to identify opportunities to strengthen the response across the whole continuum of care. The specific objectives of the research were:

1. *Health system readiness:* To assess the readiness of the Meru County public healthcare system to respond to people with symptoms of chronic respiratory diseases and identify opportunities for improvement of asthma diagnosis and care among adults in Meru County.
2. *Community experiences and perceptions*: To explore community perceptions and health-seeking behaviours related to chronic respiratory diseases and investigate the role of the community health system in supporting referral to healthcare services and the subsequent management of people with asthma.
3. *Socioeconomic impact:* To estimate the socioeconomic impact, including catastrophic health expenditure (CHE), of illness and care-seeking among adults with CRD symptoms and assess the coverage and use of Kenya's NIHF to pay for related healthcare services in public healthcare facilities.

The objectives were met through a mixed methods observational study, the justification for which is described in each results chapter respectively. Johnson et al have described the various definitions of mixed methods research, from the perspective of various experts. [67] This study adopts the definition by John Creswell: "Mixed methods research is a research design (or methodology) in which the researcher collects, analyzes, and mixes (integrates or connects) both quantitative and qualitative data in a single study or a multiphase program of inquiry" [67]. That is the case in this thesis, whereby the application of these different methods enhanced the understanding of the issues under investigation and informed the design of subsequent methods and tools. For example, the Facility Readiness Surveys (section 3.2.3), identified important issues in drugs' supplies, human resources availability and availability of essential equipment. Subsequent qualitative interviews incorporated and explored these issues further. Additionally, the issues identified in exit interviews for example relating to NHIF membership and use of NHIF cards at the health facilities, informed development of

the qualitative tools. In data analysis, quantitative findings were triangulated with qualitative perspectives to enhance contextual clarity and provide insights for some trends. Table 1.1 gives a brief overview of how the methods link to the objectives.

Table 1.1 Study objectives, methods, and study participants

Objective	Domains explored	Study participants and methods of data collection				
		Policy makers	Healthcare workers	Community health volunteers	Community members	Patients
1	• Infrastructure • Human resources- availability and training • Equipment • Guidelines • Drugs supply • Financing	KIIs	IDIs Facility readiness surveys	FGDs IDIs	FGDs	IDIs at health facilities
2	• Community awareness • Stigma • Strengths and weaknesses in the community strategy • Referral and linkage to formal healthcare system • Trust		IDI	FGDs, IDI	FGDs	
3	• Direct medical and non-medical expenditures for facility visit • Indirect costs of facility visit • Awareness, ownership and use of health insurance coverage • Coping mechanism for health care expenditures					Exit interview surveys

IDI (In-depth interview); KII = Key informant interview; FGD = focus group discussion

1.4. Thesis outline

This thesis is presented in six chapters (see Figure 1.3).

Chapter 1 outlines the introduction and description of the burden of chronic respiratory diseases in Kenya, a description of Kenya's devolved healthcare system, objectives of the study, and description of my role in the study.

Chapter 2 introduces the concepts of health system readiness for CRD. It reviews conceptual frameworks relevant to the WHO health system building blocks, the community health system and person-centred health care, and then relates these to chronic care models. It examines what is already known about the current state of readiness for diagnosis, treatment, and management of CRD (especially asthma) in Kenya. The chapter concludes by presenting a revised conceptual framework that shapes the holistic approach taken in this thesis to chronic conditions like CRD.

Chapters 3, 4, and 5, the main body of the thesis, are presented in the format of three papers each drafted with the ultimate intention of submission for peer reviewed publication. The descriptions of the different methods are integrated in the respective paper chapters, therefore there will be no '*Methods'* chapter. Each of these chapters includes an introduction tailored to the paper, a description of the methods, a summary of key findings and a discussion examining the implications of the findings for the diagnosis, treatment, and management of CRD (and/or asthma) in Meru County. A fourth paper that captures time-motion data and models patient flow through the facilities is under development. Although this is not presented in the thesis, the experience of collecting and analysing these data have affected my interpretation of the findings presented in Chapters 3, 4, and 5 and helped shape the discussion in Chapter 6. Despite duplication, a description of study site and facility sampling is outlined again in each chapter, allowing these chapters to stand alone as future papers. Each paper describes relevant aspects of the study sites depending on its aim (Meru facility site descriptions, community site descriptions and socio-economic situation respectively). In these three papers I shift from using the first person singular that I use elsewhere in the thesis to using 'we' as the papers will be submitted as collaborative publications reflecting the work of a research team.

Chapter 3 describes the sub study conducted to explore issues outlined in objective 1 on health system readiness. This used the Service Availability and Readiness Assessment (SARA) checklist adapted from the WHO [68] to assess the availability of infrastructure, equipment and services in relation to the key WHO health systems building blocks.

Chapter 4 describes the sub study conducted to explore objective 2 on community perceptions. This used qualitative methods with health care workers, community health volunteers and community members to explore perceptions and health seeking.

Chapter 5 describes the sub study conducted to explore objective 3 on quantitative socioeconomic impact of CRD illness and care seeking including catastrophic health expenditure and financial coping strategies. This used cost data captured at facility exit interviews with patients who had CRD symptoms.

Chapter 6, the discussion section, summarises the thesis, weaving key findings from the previous chapters and underlining my convictions about what must be done to move towards a Kenyan public healthcare system that is responsive to CRD symptoms. Figure 1.3 outlines the thesis chapters.

Chapter 1: Introduction, burden of chronic respiratory diseases- global and Kenyan context

Description of Kenya's devolved healthcare system.

Aim and objective of the study and description of my role in the study

Chapter 2: Literature review

Concepts of health system readiness for CRD and description of conceptual frameworks

Chapter 3: Health facility and health system readiness to respond to chronic respiratory diseases, viewed through lens of asthma

Chapter 4: Community perceptions of asthma, health seeking behaviours and role of the community health system in supporting access to health services

Chapter 5: Assessing the socio-economic impacts and healthcare seeking for CRD, including catastrophic costs and coping mechanisms

Chapter 6: Discussion

Figure 1.3 Outline of thesis chapters

1.5. Meru County

This study was conducted in Meru County. As the study setting is cross cutting across thesis chapters a more complete picture of the county and how its geography and health system structure influence identification and management of CRD is presented as an introduction. Meru is in the Central region of Kenya, straddled by Mount Kenya, and traversed by the Equator (Figure 1.4). In 2019, the population of Meru County was estimated at 1,545,673 people with women accounting for 50.3% of the population (see table 1.2) [69].The main economic activities are agriculture, including horticulture, tea, coffee, tobacco, sugar cane and khat farming. Other economic activities include mining of rocks for building materials. Industrial fertilizers, some agricultural processes (e.g., for sugar cane processing) and mining that are also common in Meru County have been linked to CRD in similar rural contexts [70, 71].
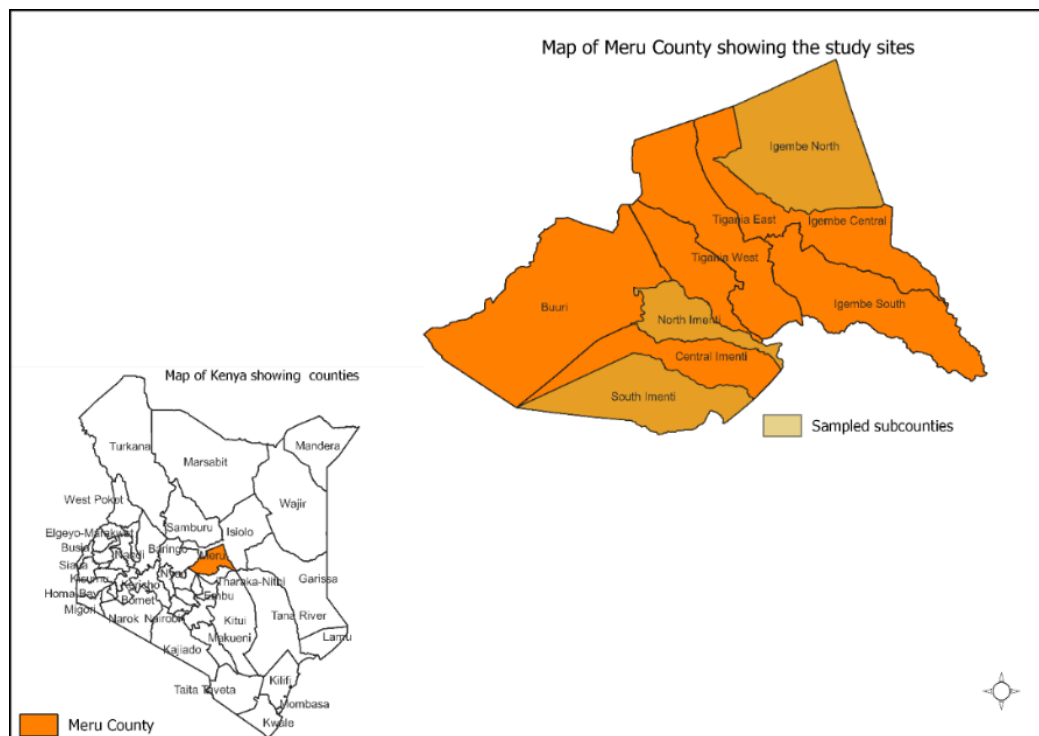
Figure 1.4 Map of Kenya showing the geographical location of Meru County in Kenya, and the selected subcounty study sites in Meru.

Meru County experiences seasonal temperature variations, ranging from 13.5^0 C in July to 22.9^0 C in April [72]. Few households have electricity, and most cooking is done over an open fire with limited access to improved cook stoves, another known exacerbating factor for chronic respiratory ill health [73]. The Kenya Demographic and Health Survey (2014) shows that in Kenya overall, use of electricity and gas as a cooking

fuel was low among rural dwellers, estimated at 0.1% and 2% respectively, while use of firewood was 84% in rural populations [74]. The burden of CRD in Meru, is not known.

Meru County has nine administrative sub counties: Buuri, Igembe North, Igembe South, Igembe Central, Imenti North, Imenti South and Imenti Central, Tigania East, and Tigania West. The map (Figure 1.4) shows these areas, and the PhD study sites. Each subcounty has a Subcounty Health Management team (SCHMT). Meru County has 15 level 4 facilities (subcounty hospitals).

Meru County was selected because it is one of the ten counties that collectively accounted for 50% of the TB burden in Kenya in 2016 [75]. This implied that it was among the priority counties for active screening of people with respiratory symptoms and suitable to explore public health system responses to people with CRD symptoms who sought care but were not diagnosed with TB disease. Importantly too, the County Health Management Team supported the study. Table 1.2. shows key trends in demographic and healthcare indicators in Meru County and at the national level between 2012 and 2015 [76].

Table 1.2 Trends in key demographic and healthcare indicators in Meru County and at the national level between 2012-2015

Population	Meru County, 2012	Meru County, 2015	National estimate, Kenya, 2015
Total Population	1,488,984	1,584,575	45,108,414
Male	736,264	783,532	22,422,667
Female	752,720	801,403	22,685,747
Children aged under five years old	212,925	226,594	6,936,691
Tuberculosis prevalence			
TB prevalence per 100,000 people	153	219	208
TB incidence per 100,000 people	78	117	79
Health facilities			
Public	103	139	4929
Non-governmental	2	5	347
Faith-based	56	58	1081
Private for profit	204	258	3797
Health personnel in public facilities			
Nurses per 100,000 people	55	66	55
Doctors per 100,000 people	15	17	10
Clinical officers per 100,000 people	14	22	21
Health financing			
Total government health spending per capita (KES)	923	806	1585
National Hospital Insurance Fund coverage as % of population	25	32.6	26.7

1.6. My role and position

I developed the concept, designed the study, and wrote the protocol, submitted for ethical approval, collected data, supported research assistants, conducted analysis and interpreted the data. My research assistant, Caroline Waithera and the field team members assisted in data collection. My supervisors each took a lead role in supporting analysis and writing in one disciplinary area (Egere- readiness assessment; Taegtmeyer- qualitative analysis; Wingfield- cost analysis; Meme- policy and county aspects).

1.6.1. Role in the research

My PhD was nested in the International Multidisciplinary Programme to Address Lung health and TB in Africa (IMPALA) programme (https://www.lstmed.ac.uk/impala). It was an NIHR funded consortium with 11 partner countries in Africa and 5 funded African doctoral fellowships investigating aspects of CRD and TB using complementary disciplinary lenses such as health economics, clinical medicine, policy, social sciences and health systems. I was appointed to the health systems doctorate post after a (highly) competitive process. In my first year, I conducted a policy analysis and key informant interviews with Kenyan policymakers in lung health as part of my Master of Research in Global Health training (Lancaster University) under the IMPALA programme. Two papers combining these findings with those of the other IMPALA countries have been submitted for publication from this work and I am a joint first author on one of these that is now published (see Appendix 2) [43].

For the work presented in this thesis I conducted a literature review, developed the study protocol, obtained ethics approval, and designed data collection tools alone. I was supported in data collection, transcripts quality assurance, coding and project management by a master's level research assistant, Ms. Caroline Waithera, and the six field team members. Transcribing and translation of English interviews was done by myself while Mr Bildad Omondi transcribed and translated Swahili interviews. Amos Ndombi supported me in programming the exit survey questionnaires on Open Data Kit™ (ODK) electronic platforms and supporting the data transmission process. All field team members were involved in testing the ODK system. After training the field team on the data collection processes, I managed the pilot study in Mutionjuri health centre and Miathene Subcounty hospital in Meru County (Tigania East subcounty). The healthcare workers and field team members were involved in reviewing questionnaires. I incorporated their feedback to refine the tools. I did data cleaning and analysis. Design, analysis, and writing were supported by my supervisory team.

1.6.2. Positionality statement

This section describes and reflects on my positionality in the research. I have included this statement in the introduction chapter as positionality frames the whole thesis. The way community participants and health facility staff perceived me, and the research team is relevant to each of the methods: facility readiness involved a team of KEMRI researchers using a checklist in a facility; exit interviews involved outsiders asking patients sensitive questions about finances and costs and finally the qualitative methods where I was involved in more open dialogue with key informants, health care workers and community members. The nature and quality of the relationship and conversation between the researcher(s) and the participants are an important underpinning of all these data and my positionality plays a role in this.

"The eye regards itself" [77]

Positionality refers to the reflections of how previous exposures e.g., professional, social, and personal biases of the researcher shape the research process. I have developed awareness over time about my dual identity as a qualitative researcher, driven by the need to understand various social phenomena, and as a research instrument through which these observations are processed and ultimately relayed to various audiences [78].

The perceptions of the study participants and other people involved in this study about me, the research team, and the aims of the study may have influenced the way they participated, particularly their decisions to share information.

Firstly, I am a Kenyan citizen, I have lived in Kenya all my life (except for brief trips outside the country for work and study). I have consumed public healthcare services, and this has inevitably shaped my thinking about health system problems, as well as my perceptions of healthcare services in Kenya. My undergraduate and postgraduate training were in health and shaped my thinking of health systems and the research approach.

I was affiliated to the Kenya Medical Research Institute, Centre for Respiratory Diseases Research (KEMRI-CRDR), as my local host institution for the duration of the PhD. KEMRI is a parastatal premier research organisation of the Kenyan government. It is well known and is widely respected internationally for its advisory role to the government on evidence-based policies. The KEMRI identity had significant implications on my overall PhD experience. Introducing myself as a researcher based in KEMRI may have provided me easier access to Meru County government and their data. This is partly because of the identity as a government institution 'insider'. During the data collection process, I got the feeling that some healthcare worker respondents perceived me as a fellow professional in healthcare service system. During interview discussions, it was common to hear respondents saying, *"Daktari, hata wewe si unajua hivi?"* ("Doctor, you are

obviously aware of this issue?"). Such responses suggested participants' expectations that some issues under investigation were known to me and therefore needed no further elaboration.

I had encountered some of the key informants, officials of Meru County during The Pan African Thoracic Society – Methods in Epidemiologic, Clinical and Operations Research (PATS MECOR) (https://panafricanthoracic.org/pats-mecor) conference in Durban, South Africa, in 2018. At that time my ideas were still at the conceptual stage, and I subsequently met them again and discussed and refined my ideas further at a policy stakeholder forum for lung health in Nairobi (2019). These encounters may have defined me as an insider, and therefore fostered trust, and shaped access to institutions, data, and development of important working relations in Meru County. Prior to exit interviews with patients, our study explored the clinical care pathways, and involved engaging the healthcare workers in identifying patients who were eligible for the study based on the symptoms. The healthcare worker would then introduce me, or another study team member (who sat within the consultation room) to proceed with the consenting process and subsequent recruitment of the study participants. These healthcare workers had been trained by me and the research team on how to fill in the data collection tools, including data on symptoms and physical examination. These exposures may have influenced the consultation process, for example through nudging the healthcare workers to think about specific details of symptoms in their history-taking, and possibly, more detailed documentation. This is further backed up by the qualitative interviews with frontline healthcare workers who said that the research questions made them rethink some aspects of diagnosis, for example spirometry and service provision for people with conditions like asthma.

In some instances, respondents looked at me as an "outsider", i.e., a researcher, working in an institution outside Meru, and who was there for a defined period. The research was perceived as an opportunity for them to air issues affecting their work, and I was perceived as one, who may channel their grievances to authorities higher up in government hierarchies: *"Please, when you go back to Nairobi (the seat of Government), please remember to tell them this: we are really suffering down here"*. On the other hand, my identity as an outsider may also have influenced how much the participants were willing to share. For example, questions about financial accountability are deemed sensitive, and there may be inclination to share less, or carefully framing responses to protect institutional reputation.

I got a similar feeling from patients' interviews. When we asked about the quality of services in one of the facilities, one said, *"the services have been good, since you came here".* These claims suggested that our study approach, i.e., facility surveys, where we asked questions about availability of drugs, diagnostic equipment, and services, may have influenced the process of delivery of services or the participants' perceptions of that delivery to some extent. I also wonder if the healthcare workers and facility administration teams may have felt as if we were auditing them. In retrospect, I do wonder if our mission was perceived as

fault-finding. We were however, staying in a facility for at least one month, people became familiar with our presence and 'normal' services quickly resumed allowing us to subsequently observe service delivery in the natural context. Our close interactions with the healthcare workers, sharing lunches and teas together and informal conversations also helped us to build trust, and understand contextual issues affecting service delivery in relaxed atmospheres of mutual friendship.

One of the healthcare workers at a primary care facility talked of the perceived power and professional differentials between the research team and healthcare teams and these may have been more widespread than we were aware of: *"Do we have data here that is worth a PhD?"* Similarly, participants in the focus group discussions asked me questions, e.g., about whether asthma was a communicable disease, suggesting there was the perception that the research team was more knowledgeable on these issues. A perception that may have affected how much they felt necessary to share. Reflecting on these encounters later, I felt that my identity and value attached to the research process (for PhD) may have shaped the support I got for this study, including the way responses were framed. Furthermore, my identity as a visitor from Nairobi, evoked cultural norms common in African communities, where visitors are welcome, and hosts feel obliged to help them, particularly when lost and asking for "direction".

The COVID-19 pandemic may have influenced study participation significantly. Our fieldwork ran from July 2019 to November 2020. The study team noticed a pattern of refusals to consent for interviews in March 2020, the time when the Kenyan government announced the first confirmed case of COVID-19 in Kenya on the 12th March 2020, and outlined containment measures [79]. Similarly, a general drop of health facility visits by patients significantly disrupted data collection activities and may have affected the study findings, for example the number of participants may have been lower, the distribution across facilities less balanced, and cost data collected may be less. This is partly associated to a government plea to people to stay at home, and only visit healthcare facilities for serious health conditions and emergencies only, during the COVID-19 pandemic. KEMRI played a central national role in communicating scientific facts about COVID-19 and in testing of people who had symptoms of the disease, and mapping hotspots that required extra measures, for example curfews and restriction of movements. Unfortunately, the Kenyan response to COVID-19 was characterised by stigmatising the people who were affected [80, 81]. In March 2020, the government also required quarantine for all people suspected to have contracted the corona virus, for at least 14 days, at their own private costs [82]. Multiple reports of difficulties in quarantine facilities were documented [83]. Expectedly, some people did not want to be tested for COVID-19. These developments may have influenced the perceptions of prospective study participants about our identity (due to association with KEMRI), and our real intentions in recruiting study participants. Some of the study eligibility criteria i.e., difficulty in breathing and

coughing were similar to COVID-19 symptoms. That we were investigating 'chronic' respiratory diseases may have been confused with 'corona', a commonly used term in the pandemic.

Meru is a patriarchal society, and therefore my gender as a male researcher may have influenced how participants perceived me. Whereas interviews with female healthcare workers may be perceived as conversations among professionals, gender considerations and my perceived identity as 'doctor' by some, may have affected how female members in community focus group discussions shared their perspectives.

Despite the issues outlined above, the research team endeavoured to build and sustain trust in our engagements with study participants and local decision makers. For example, we promised and maintained confidentiality in data collection and management processes. We reviewed the consenting process to emphasise key messages, including the fact that our study was interested in asthma, and not COVID-19, highlighting the fact that data collection started in July 2019, more than 6 months before the pandemic was officially proclaimed. In our interviews we reminded participants about the objectives of the research and that we hoped to learn from their experiences and knowledge. Overall, during the study, we conducted debrief sessions and kept reflexive notes about the research process, and these have been critical to enable my understanding of positionality, including my own, in the research process.

1.6.3. Rigour and Trustworthiness

Scientific rigor and trustworthiness are important considerations in demonstrating value, and credibility of qualitative research. Trustworthiness refers to the extent to which research findings reflect accurately the lived experiences of the phenomenon under investigation [84], while rigor refers to the deliberate research processes taken to ensure quality of data. Trustworthiness and rigor may be demonstrable through multiple ways, for example disclosure of the research objectives, methods of data collection, analysis and how these relate to the findings and conclusion of the study [85]. This study used different methods- qualitative and quantitative, to enhance rigor and trustworthiness. The preceding section 1.6.2 on positionality demonstrates effort to enhance trustworthiness, based on self-reflection by the principal investigator. This section describes other aspects of the research processes aimed at enhancing rigor and trustworthiness.

Prior to data collection, the tools were piloted, and refined based on the pilot experience. The research teams were trained on the data collection procedures and ethical conduct of the study. Data were collected in private, quiet places to protect confidentiality and enhance quality of the data collected. During the study, the research teams were closely supervised, involving frequent reminders of the procedures. Survey data were first collected and transmitted through Open Data Kit™ (ODK) platform, programmed and tested to enhance data transmission, and provide an effective platform for the principal investigator to review collected data.

Additionally, all the survey data were reviewed on the day of collection, and any identified mistakes corrected promptly. Similarly, all audio recordings were transcribed verbatim, and transcripts were reviewed and verified as true accounts of the interviews. Use of audio recording aimed to minimize distortion in data collection.

Triangulation of data collection methods, aimed at enhancing completeness of data collected, and also confirm perspectives of the issues under investigation [86]. Triangulation was achieved through use of both quantitative and qualitative methods, to quantify, as well as explore 'why', respectively. For qualitative methods, the use of in-depth interviews, focus group discussions and key informant interviews. These methods were used in engaging different research participant groups. By examining the unique perspectives of patients, healthcare workers, community members, and county policy decision-makers in healthcare access and service delivery, the study identified important underlying insights. In order to improve trustworthiness, data from individual interviews and focus group discussions, were compared in order to triangulate the findings [87].

The data collection plan also enhanced rigor and trustworthiness. Data were collected in one facility, for one month, before moving to the next. This provided opportunities to build rapport with the healthcare workers and county officials. The research team were allowed access into healthcare workers' service stations, enhancing opportunities to closely observe service provision in their natural settings. Consequently, the research team was able to explore issues in great depth including contextual factors. The PI led the qualitative interviews and provided opportunities for a second researcher (who was taking field notes), to seek clarifications on key issues, before end of the interviews. This provided important opportunities to collect comprehensive data, and systematically relate any patterns emerging from the process. Additionally, immediately after the interviews, the research teams debriefed together to identify key highlights e.g. emergent data, reflect on the interview process, and identify possible sources of new information. Subsequently, the interview guides were enhanced iteratively based on new information from previous encounters across multiple levels of the health system.

Data analysis was done by research team members competent in their respective fields, using statistical software- R, STATA and Microsoft Excel for the quantitative data and NVivo12 for the qualitative data. R and STATA have verifiable data analysis coding scripts, that enhanced shared understanding of the research findings. Through frequent meetings with the supervisory team, the research findings were discussed and questions emerging from these discussions guided the research process. In qualitative data analysis issues that were not clear were further clarified through phone calls with the research participants, or face to face discussions.

Chapter 2: Literature Review

Chapter 1 has shown the rising burden of CRD in LMIC and has outlined Kenya's policy response and devolved structures, setting the context for the thesis. In this chapter, I describe relevant health system conceptual frameworks and link these to health seeking, making the argument that any response for a chronic disease must take a holistic approach that integrates various health system levels with community and patient perspectives. This holistic view across the continuum of care has guided my review of literature on CRD in the sections that follow.

After describing my search strategies in section 2.1, I provide an overview of various conceptual frameworks relevant to the thesis in section 2.2, I critique these and justify the selection of aspects of the frameworks that contribute to the holistic approach taken in this thesis. I outline literature on the readiness of different aspects of health systems in LMICs to respond to the rising burden or CRD, relating this to the Kenyan context in section 2.3, I summarise the gaps in literature in section 2.4 and present a more person-centred framework for chronic care that guides the thesis.

2.1. Search Strategy

2.1.1. Sources and search terms

Both peer-reviewed publications and grey literature were searched. PubMed, Google Scholar, Web of Science and African Journals Online (AJOL) electronic databases were searched for peer-reviewed publications. Key search terms for health systems readiness included: health system readiness; chronic lung diseases; chronic respiratory diseases; decentralisation; devolution; management of chronic lung diseases; asthma management; LMIC; Kenya; and patient self-management. Search terms for person-centred care also included: community perceptions of asthma, healthcare seeking for chronic diseases; coverage of health insurance in Kenya; catastrophic costs; universal health coverage; out-of-pocket expenditures. The search was limited to content published in English, the official language of Kenya. All literature sources were reviewed for relevant content. Other sources were identified through a hand search of the reference sections of selected literature. The grey literature included government policy documents, and civil society publications including from media, academia, and non-governmental organisations. Grey literatures were searched electronically based on the key terms described above, using Google™ search engine. Some of the grey literature sources were also hand searched from the published literature references and other grey literature sources. Kenyan policy documents not available online were provided by government officials at national and county level (often during or after

key informant interviews). Printed newspapers were also reviewed online daily for relevant content, with relevant articles shared with the supervisory team and archived.

2.1.2. Justification of literature search time frame 2000 to 2019

The literature search focused on studies conducted from 2000 to 2019 (preceding data collection). Subsequent updates in literature are presented in the discussion chapter 6. This period saw a rapid rise in CRD and a major shift in the thinking about health systems globally. This is demonstrated by the development of the health systems building blocks framework [88], and the push for universal health coverage reforms [89-91]. Similarly, in 2010, the Package of Essential Non-communicable (PEN) disease interventions, for primary health care in low resource settings was introduced [92]. In 2015, Sustainable Development Goals (SDGs) were adopted by the United Nations and SDG 3.4 targets for reducing premature mortality from non-communicable diseases by a third by 2030 [93]. The high priority of non-communicable diseases (NCDs) in the global health policy agenda during this timeframe was further demonstrated by the endorsement of the Global Action Plan for prevention and control of NCDs by the World Health Assembly [39]. Kenya also saw major changes between 2000 and 2019 with devolution in 2010 and the key health system and financing reforms that followed (see section 2.3). This was reflected in both the peer-reviewed and grey literature searches.

2.2. Conceptual Frameworks

This study explores issues of health system readiness for CRD through a critique of the following frameworks: the six WHO Health systems building blocks; frameworks on the interface role of the community health workers; person-centred health systems frameworks including socio-ecological models.

2.2.1.   The WHO Health Systems Framework

The WHO defines a health system as "all the organisations, institutions, resources and people whose primary purpose is to improve health". This description encompasses deliberate efforts to "influence determinants of health as well as more direct health-improvement activities" [88]. I use the WHO framework of Health Systems building blocks [88] to assess what is known about system readiness in Kenya (section 2.3) and to ensure a comprehensive approach to the facility readiness assessments (objective 1; Chapter 3). The WHO framework has six core components as seen in (Figure 2.1). These building blocks interact in complex, dynamic ways such that a change in a building block affects the others [94]. This section describes each of the six building blocks in more detail; section 2.3 relates the building blocks to the Kenyan health system context.

THE WHO HEALTH SYSTEM FRAMEWORK

SYSTEM BUILDING BLOCKS

SERVICE DELIVERY

HEALTH WORKFORCE

INFORMATION

MEDICAL PRODUCTS, VACCINES & TECHNOLOGIES

FINANCING

LEADERSHIP / GOVERNANCE

ACCESS
COVERAGE

QUALITY
SAFETY

OVERALL GOALS / OUTCOMES

IMPROVED HEALTH (LEVEL AND EQUITY)

RESPONSIVENESS

SOCIAL AND FINANCIAL RISK PROTECTION

IMPROVED EFFICIENCY

Figure 2.1 The WHO Health System Framework

Source: WHO 2007 [88]

2.2.1.1.   Leadership and governance

Health systems need effective, committed, and sustained leadership and governance i.e., stewardship, to steer functions towards desired objectives. Governance denotes the rules that distribute roles and responsibilities among different actors and interactions towards desired objectives [95]. These actors include government agencies and managers, healthcare workers, patients, and civil society. Stewardship is a complex process affecting all the other five building blocks because it involves consideration of competing interests, some of which may conflict with the broad health system objectives. Stewardship must also be responsive to the socioeconomic and political context and entails development of policy, regulatory and accountability frameworks, standardised benefits packages, as well as mobilisation of resources and the resource allocation formulae needed to sustain the health system. A culture of good governance can drive the healthcare system towards good health for the people.

2.2.1.2.   Service delivery

The framework defines good services as those that "deliver effective, safe, good quality personal and non-personal care to those in need, and whenever needed with minimum waste" [88]. Effective services delivery depends on the successful coordination of other building blocks including adequate healthcare workers' capacity, reliable supplies of good quality medicines and equipment, and financing. Effective organisational management incorporating supervision and an appropriate mix of incentives to drive performance, and job

satisfaction are needed [96, 97]. Additionally, reliable services delivery demands infrastructural and logistical support, entailing buildings. Supply side service delivery needs to be complemented by demand for healthcare services, through for example, understanding users' perspectives and preferences, and socio-economic and cultural contexts that may impose barriers to healthcare access. Other important aspects of service delivery particularly important to chronic care (including CRD) include the development of integrated service delivery packages; the organisation of provider networks, to enhance continuity of care across levels of the health system and to avoid duplication or fragmentation of services. More details on person-centred care frameworks that address these aspects are described in section 2.2.3.

2.2.1.3.   Health workforce

The health workforce encompasses "all people engaged in actions whose primary aim is to protect and improve health" [88], implying professional frontline healthcare providers, managers and lay workers for example cleaners, plumbers and kitchen staff, who provide essential services. The healthcare workforce is the most important health system input (others are consumables and physical resources). Health system performance depends on workforce knowledge, skills, and motivation [98]. The health workforce needs to be available, competent, responsive, and productive. This is in turn influenced by adequate training, deployment, and retention of healthcare workers in sufficient numbers [99], and motivation to perform work through financial and non-financial incentives [88, 100].

According to the WHO, priorities for the health workforce include how to scale up healthcare workers' capacities, training the workforce to facilitate integration in service delivery, organising healthcare workforce across levels of care and strategies for retention of the workforce in the face of global health workforce shortages [101].

2.2.1.4.   Information

The WHO identifies "generation and strategic use of information, intelligence and research on health and health systems" as a necessity of health system stewardship. Timely generation, analysis and dissemination of accurate information, and regular use of this information in decision-making at different levels of the health system have significant implications on measuring health system performance, resource allocation decisions and accountability mechanisms [88]. Overall, a health information system would identify causes of ill health, how the health system is responding to health problems, and the outcome of health system interventions, respectively. The health system would also measure inequities in determinants, coverage and use of services based on socio-demographic data [102]. To work effectively, health information systems need to be "cohesive"; however, many country health systems are fragmented – an outcome of piecemeal development,

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reflecting complex administrative, socio-economic, legal or donor preferences [102, 103]. Much of the required data are generated outside the health sector [104], including national statistics offices and the civil society organisations. This implies variations in data formats, level of detail, ease of access, and accuracy as well as limited system interoperability.

2.2.1.5. Medical products, vaccines, and technologies

The health system should ensure equitable access to essential medical products, vaccines, and technologies. The most basic desirable attributes of these products, include quality, efficacy, cost-effectiveness, and their proper use. Critical drivers to these aspirations include development of national policies, standards, and guidelines; information and capacity to negotiate prices, reliable procurement systems, and support for rational use of the drugs through adherence [88]. In the case of CRD, equipment such as peak flow meters and spirometry machines and drugs including inhalers and nebulisers are required. As with other building blocks, the effective service delivery depends on training, supervision and reporting on their use. For example, providing peak flow meters or spirometry machines alone without training and recording may not have the desired impact on CRD care and they may sit unused.

2.2.1.6. Health financing

Health financing function is a supply side factor that entails mobilisation of revenues from different sources e.g., public, external partners or private; pooling of these revenues and purchasing of healthcare services [105] as is the case in Kenya. While supply side often dominates policy makers' thinking, a good health financing system ensures people can access healthcare services of sufficient quality, whenever they need it without exposure to catastrophic health expenditure or resorting to financial coping strategies [88, 106]. Reliable health financing systems that provide increased social protection coverage are essential to achieve universal health coverage [105]. These include strategies to reduce reliance on out-of-pocket payments, shifting to prepayment e.g., tax revenues and health insurance; improving efficient use of resources; and facilitating equitable access to healthcare services for the poorest and most vulnerable in society [107]. Enhancing efficiency and accountability in use of finances is a critical issue in health systems, particularly in consideration of the fact that health system resources are scarce, against many competing needs. Efficiency denotes using minimum possible resources, for maximum possible benefits. Similarly, efficiency entails design of funding flows, to enhance timeliness in disbursements and ease of access to these funds whenever needed. In the devolved health system in Kenya, the county governments have power to plan and prioritise healthcare services, and to manage finances in line with the Public Finance Management Act [108].

2.2.1.7. Limitations of the building blocks framework.

Several limitations of the building blocks frameworks have been identified. Firstly, the framework was modelled on supply side aspects of service delivery, but does not address demand side aspects e.g., at the community level, and social mobilisation activities. Furthermore the framework does not account for links between inputs, outputs and outcomes, and it is not clear which among the six blocks has comparatively more weight [109]. Also, the framework does not explain how the different health system components interact, and are influenced, within broader societal contexts. Additionally, the model does not account for population or individual-level behaviours and choices that affect the interactions across the building blocks [110]. These include local priority-setting by communities [109]. Overall, the WHO framework is not holistic in addressing CRD but is useful in framing aspects of health system readiness (Chapter 3). In section 2.2.3.2, we use the Innovative Care for Chronic Conditions (ICCC) model to further frame specific issues on chronic care [111].

2.2.2. Framing the interface role of community health system in CRD response

Alternative frameworks that better capture the relationship between the community and the formal health system have therefore been put forward and these are of relevance to the integrated approach I propose. Decentralisation of health services to the local community level can enhance engagement of service users. This can positively impact local prioritisation and utilisation of healthcare services. Decentralised health systems are well placed to support early detection, surveillance and sustained provision of care, sufficient drug and other technology supplies and psychosocial interventions for CRD [112]. This is because the proximity of provider facilities to the patients' homes reduces travel time and costs to facilities; it also enhances healthcare workers' knowledge of individual patients, families, and local communities to tailor strategies to their needs. Additionally, a local community environment helps in better definition of the population under coverage of a healthcare provider. This in theory, makes it easier to follow up and monitor patients and sustain continuity of care, including for comorbidities. Examples of chronic conditions that have been supported through decentralised health care systems include mental illnesses, HIV/AIDS and TB [113].

Accumulating research evidence shows that community health volunteers (CHVs) are important in the achievement of universal health coverage objectives. CHVs support healthcare delivery in hard-to-reach and underserved populations and expand coverage of essential interventions [114-118]. In NCD management, the informal community system provides an important opportunity for linking primary healthcare provision and effective self-management outside formal care [113]. An audit of primary healthcare facilities in following a quality improvement intervention for chronic asthma in Western Cape, South Africa, showed that only 11.2%

of the healthcare facilities had a written plan on self-management [119]. Informal community systems are characterised by the local arrangements and interrelationships between members of a geographical community and use of local resources to achieve heath objectives. Kenya initiated a community health strategy in 2006 [51]. This strategy highlights the role of households in the provision of healthcare services and supports the empowerment of communities to own health services through close interaction with the formal health care providers. This can be achieved through listening to community voices and engaging civil society groups in healthcare decision-making and by strengthening accountability mechanisms in healthcare provision. The CHVs are on the other hand, also bound by same cultural norms and values of the communities they serve, including perverse outcomes such as stigma [120]. Designed within a context of poor child and maternal health outcomes, a key objective of this strategy is to "strengthen health facility–community linkages through effective decentralisation and partnership for the implementation of Level 1 services" [51]. The basic model of a community health unit (CHU) consists of two community health assistants (CHA) working in partnership with 50 CHVs. The CHA are health professionals with formal health training and are employed to work in a primary healthcare facility whereas CHVs are residents of a community and are selected by a health facility committee. The CHA train CHVs based on priority learning needs. Each CHV is expected to cover 20 households accounting for approximately 100 people. In total, a CHU is expected to cover 1000 households, and a total of 5,000 people.

The CHVs are expected to play many roles in the community. These roles are broadly aimed at supporting health promotion e.g., family health and environmental sanitation and hygiene and prevention and treatment of key common diseases [51, 117]. Their activities are designed to target community members at all ages, from pregnant mothers and new-borns to the elderly. Examples of specific areas of focus include maternal and child health, exclusive breastfeeding, early childhood development, and reproductive health services. Other activities include control of malaria and HIV/AIDS and sexually transmitted infections. CHVs are also involved in promoting TB awareness, defaulter tracing and directly observed treatment short course (DOTS), home based care programmes for the elderly and awareness about chronic conditions e.g., diabetes [51]. However, identification and referral of people with symptoms of CRD are not explicitly mentioned in the strategy. While many programmes 'use' CHVs as their eyes and ears, their workload is large and there are no clear boundaries. It is therefore not clear if identification and referral of people with symptoms of CRD is included in CHV routine roles.

Kok *et al* reviewed 140 studies on factors that influence CHW performance in LMIC [115]. Key factors associated with positive outcomes include good working relationships with the healthcare workers, financial incentives, non-financial incentives e.g., recognition and respect in the community, trust by community members, and support by 'anchor' institutions in the community e.g., churches, mosques and women groups.

Some of the factors negatively affecting CHV performance include inadequate training and skills, poor supervision, and little confidence that people will get the services they needed in facilities even if they were referred, inadequate and unpredictable remuneration, and favouritism in training opportunities. Some community members prefer CHV who reside outside the community particularly for stigmatised conditions like HIV/AIDS. Other factors undermining CHV include poor communication and working relationships with healthcare workers, lack of clarity amongst CHVs about their roles, and low community awareness [115]. Evaluations of CHW programmes in primary health care shows that CHV are frequently overwhelmed by the broad range of tasks and heavy workload. This affects programme implementation because the CHV tend to select only tasks that are feasible [121]. It is therefore important to determine whether it would be feasible to add CRD-related activities to current CHV roles without distorting the community health system.

A subsequent conceptual framework (Fig 2.2.) for community workers' performance as a 'transactional social process' outlines the primacy of social relationships and power differentials within the health system [120]. Factors influencing CHW performance are broadly categorised into 'hardware' and 'software'. Examples of hardware are the WHO building blocks defined in section 2.2.1. Hardware includes technical, financial, and material resources e.g., infrastructure and equipment "shaped and driven by human choices and ingenuity". These system hardware affect processes such as communication, training, incentive structures and supplies of resources; and personal attributes such as adherence to instruction and competence [120]. Software denotes "ideas, interests, values, norms and relationships", including the interaction between software and hardware elements [122]. System software influences personal attributes such as agency, attitude, and self-esteem. Motivation and satisfaction are shaped by both hardware and software.
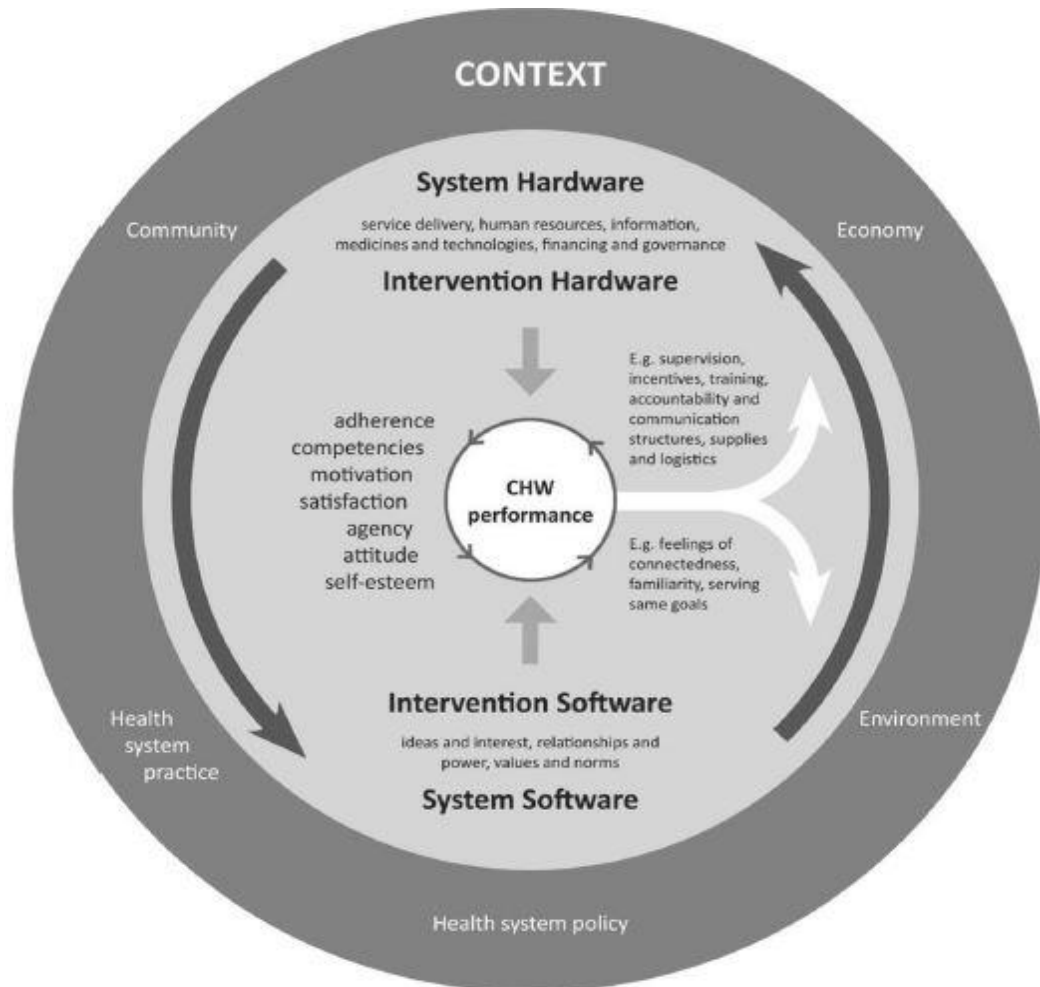
Figure 2.2 A conceptual Framework for community health workers' performance

Source: Kok MC et al. 2017 [120].

This framework emphasises the centrality of people in health system inputs, processes, and outcomes. Detailed discussion of person-centeredness is outlined in the next section (2.2.3). Despite the knowledge of CHVs' potential, the CHV network is not used optimally in Kenya. The Ministry of Health states that "there are no systematic linkages between providers of community-based care and health facilities" [22]. According to the Kenya Community Health Policy (2020-2030), by 2018, there were 6,087 community health units in Kenya, accounting for 59 % of the ideal number of community health units. Similarly, Kenya has 1,569 Community Health Assistants, out of an expected 10,379, equivalent to an 85% deficit. The CHV workforce is estimated to currently have 86,025 volunteers, accounting for 83% of the estimated workforce required [123]. These deficiencies have adverse implications on community health units' functionality. Community health unit functionality within the Kenyan context refers to the extent to which inputs, and outputs of a community

health system aligns to the community strategy. Functionality has been defined using various criteria. According to AMREF Health Africa, functionality is measured through 17 parameters. Inputs include training of CHV, Community Health Extension Worker and the committee; provision of CHV kits; enough supply of MOH 513 and 514 reporting tools; availability of MOH 100 referral forms; support for transport e.g., by bicycles, support supervision and provision of stipends. Output parameters include development of action plans, community health committee meetings, and CHV monthly meetings. "Cardinal elements" are the core components of the outputs that must at least be done in a CHU including: CHV monthly reporting (target: CHVs submit at least 80 % reports on MOH 514); convention of dialogue days involving community health committees, CHV and community members on quarterly basis; and monthly health action days, based on community health action plans. Community health units are scored as functional ($\geq$ 80% parameters available), semi-functional $\geq$ 50- $\leq$80%), and non-functional ($\leq$ 50%)[124]. The Kenyan Ministry of Health defines functionality of community health units using 11 criteria. The additional criteria besides those highlighted by AMREF Health Africa include availability of mechanisms for feedback, and local tracking; presence of a functional health information system; the community health unit registration in a master community health list, and frequency of conducting meetings, i.e. quarterly (dialogue days); monthly (health action days) and household registration once every 6 months [123].

The annual National Tuberculosis, Leprosy and Lung Disease Program (NTLP) report for 2014 showed that only 4% of people with TB reached healthcare facilities through referrals from CHV. Similarly, out of 47 counties, only 6 counties had more than 9% of people with TB referred to health facilities by the CHV [22]. However, it is unclear whether this is due to low referrals by CHV or poor recording of CHV referrals at the health facilities.

Political goodwill is important in realising the objectives of and sustaining the community health strategy but appears to be waning in Kenya. The Kenya National Health Accounts 2015/16 show a declining trend in government budgetary allocation for CHV programmes. Allocations fell 99% from 17 billion Kenya shillings (~US$146.5 million[2]) in 2009/2010 to 238 million shillings (US$ 2.05 million) in 2015/2016 [125]. In the financial year 2013-2014, the national government did not allocate funds for CHV programmes [126]. This is partly explained by the observation that political decision-makers in counties prefer 'visible' infrastructure projects, compared to preventive and promotive services [127] and institutional challenges posed by transition process to devolved government. Insufficient financing is one of the biggest challenges to the community health strategy because it affects accountability of CHV to supervisors. In addition, conflicts of interest

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[2] (**1 US$= Kenya shillings 116.4, based on Oanda**) (https://www.oanda.com/currency-converter/en/?from=USD&to=KES&amount=1) **forex rates on 18 June 2022**)

between personal priorities of the CHVs and county priorities affect service delivery plans [126]. Though donors partly support CHV work, their funding is often time bound and focused on specific vertical programmes.

A desired outcome of the community strategy is for CHV to enhance awareness of healthcare rights among community members and foster a culture of accountability in health services delivery. It is important to understand whether and how CHV are involved in the referral and management of CRD patients. This would inform the government decision-makers on how best to respond to community expectations.

The Kok framework [120] is limited in various aspects. Firstly, it does not address the legal implications of engaging community health volunteers as workers/ labourers- in which case, aspects related to formal human resources management e.g., development of legally binding contracts, defined salary scales and specific qualifications may be required. Additionally, the framework does not identify which intervention software or hardware components have most influence on community health workers' performance.

2.2.3. Framing person-centred health systems

2.2.3.1.   WHO framework on person-centred health systems

Health systems are social institutions, whose performance is shaped by people, occupying variable positions within the system, and consequently assuming multiple identities, for example as healthcare providers, suppliers of commodities, users of services, decision-makers [122]. Discourses on improving healthcare services have progressively shifted focus to the 'person'. "Health systems may be regarded as people-centred when the potential roles and capabilities, and the needs and preferences of individual actors (e.g., service users, health workers and health managers) and collective actors (e.g., whole communities and community groups) are recognised and given priority in the day-to-day operations of the health system" [95].

Person-centred care refers to the deliberate consideration of the preferences, decisions and needs, expressions, beliefs and contexts of patients, their families and communities, and their involvement as participants and beneficiaries of trusted health systems that respond to their needs in "humane and holistic ways" [128, 129]. Person-centred care implies tailoring of healthcare services to a patient's unique situation and requires educating and supporting people to make decisions about their own care.

The concept of integrated health services implies service delivery in a way that ensures a "continuum of health promotion, disease prevention, diagnosis, treatment, disease management and palliative care services at different levels and sites of care within the health system, and according to people's needs throughout their life course" [128, 130].

Person-centred care and integrated systems are expected to confer several benefits to the individual and their families, the community, health professionals and community workers, and health systems. Individuals and families will potentially have increased satisfaction and better relations with care providers, improved health literacy and more independence, increased self-management capabilities and control of chronic conditions, and better coordination of care across settings. Communities would benefit from enhanced access to care especially marginalised groups; greater influence and relationships with healthcare providers, to enhance trust in services, and care that is more responsive to community needs [128].

Understanding patients' views provides an opportunity for healthcare providers to collect important feedback on effectiveness of care, enhancing both patients' and healthcare providers' satisfaction, and enhancing efficient healthcare services delivery processes [129]. At the health system level, benefits include better prioritisation of resources, and equitable distribution of resources and services, enhanced efficiency; improved diagnostic accuracy and timely referrals, minimal unnecessary use of facilities, and reduction of waiting time for care [128].

The WHO proposes five interdependent strategies for enhancing person-centred care [128]. The first strategy is to empower people by providing opportunities, skills and necessary resources to co-produce health, healthy environments, and health policy. The second strategy prioritises strengthening governance and accountability among healthcare providers and managers. The third strategy aims at reorienting healthcare services to provide more efficient, stronger community and primary care with better focus on health promotion, disease prevention, and addressing the social determinants of health. The fourth strategy entails coordination of healthcare services based on needs at all levels of care. This strategy prioritises development of multi-sectoral networks and minimising or eliminating fragmentation of service delivery, and advocates for integration of public health functions e.g., surveillance and early detection. The fifth and final strategy champions development of enabling environments in which different stakeholders drive transformational change. This includes structural level changes for example in legislation, financial arrangements and incentives, and re-orientation of the healthcare workforce [128]. Successful implementation of these strategies demand sufficient political goodwill and stakeholder support.

The WHO conceptual framework for person-centred care and health services integration describes relationships between different components of the health system (Figure 2.3). People are at the centre of a service delivery context that promotes universal, equitable, people-centred, and integrated health services. The services are delivered through integrated networks and linkages within the health sector, with direct inputs from the communities. These events are embedded in a context of governance, health system financing and supply of resources [128]. The critical roles of inter-sectoral action (e.g. education, sanitation, social assistance, housing) in management of structural determinants of health, the vital need for an enabling policy environment, and variations in country and regional settings in terms of political factors, socio-economic development, governance and cultures collectively describe the environmental context [128].
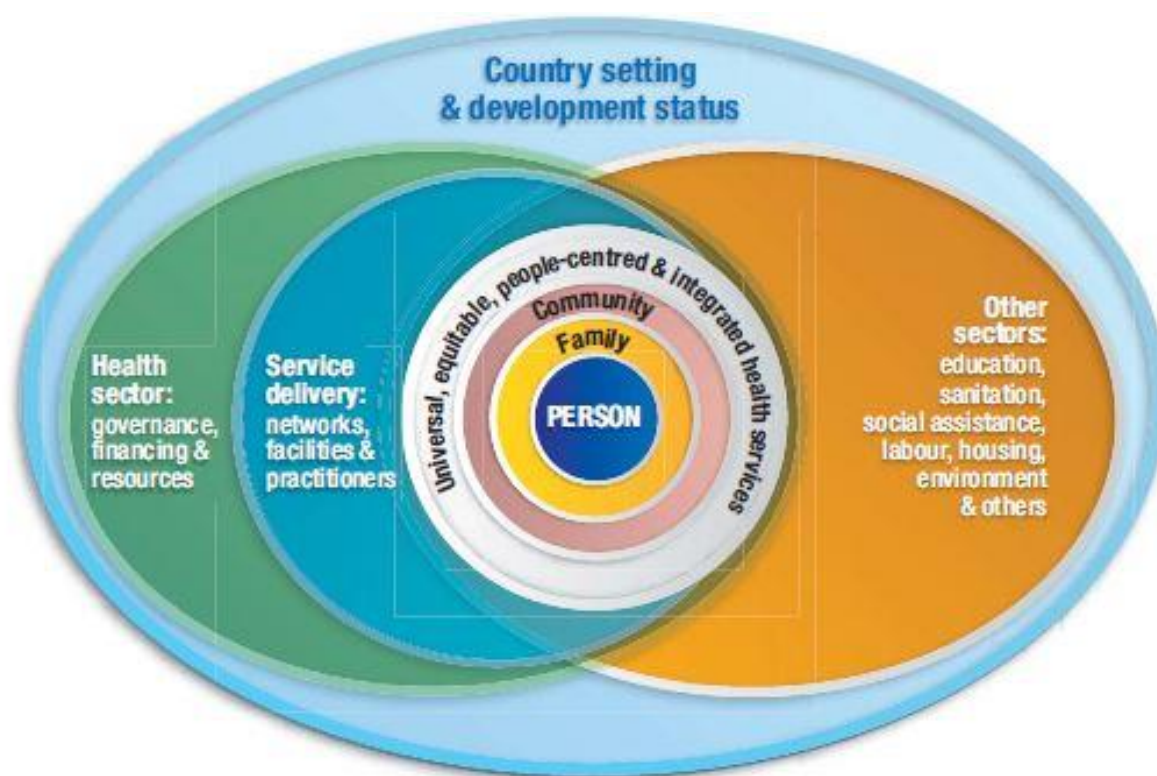
Figure 2.3 A conceptual framework for person-centred care and integrated health services

Source: WHO 2015 [128].

Practical provision of person-centred care entails involvement of healthcare workers, patients, and communities in co-designing service delivery. Consequently, empowered patients, communities, and civil society, can enhance integration, coordination and continuity of care. For example, these stakeholders can

jointly identify ways of circumventing barriers to care and identifying and addressing social determinants of health e.g. housing conditions [129]. Other considerations include a supportive work environment for healthcare providers. These include design of service points to provide easy access, privacy, and comfort, and mechanisms for measuring performance incorporating patients' feedback.

2.2.3.2.   The Innovative Care for Chronic Conditions

The Innovative Care for Chronic Conditions (ICCC) framework (Figure 2.4) proposes that to effectively manage chronic conditions, health systems must be redesigned differently, from models that were made for acute, episodic care, towards models that support extended patient support [111].
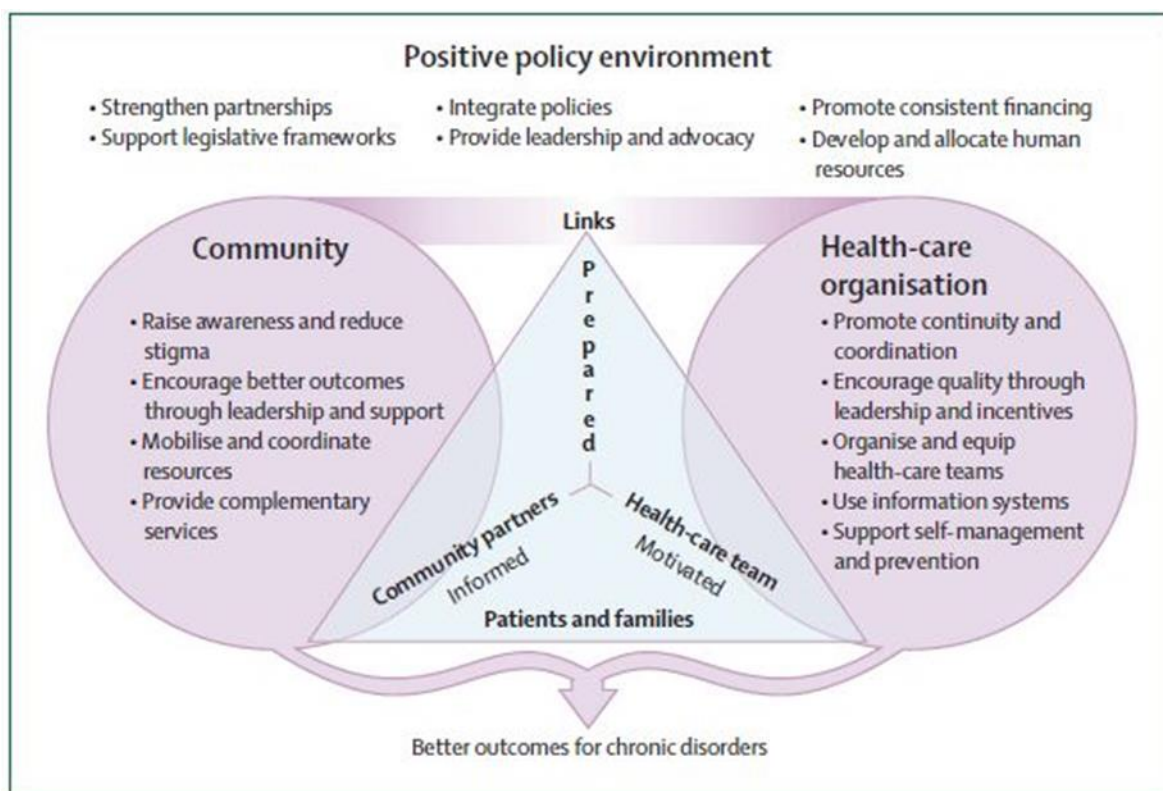
Figure 2.4 The Innovative Care for Chronic Conditions Framework

Source: Epping-Jordan, J. et al 2004 [131]

The ICCC framework reflects improvements to a previous model, the chronic care model (CCM) [132]. Unlike the CCM which had more focus on the USA context, development of the ICCC included perspectives of health leaders from Africa, Eastern Europe, Latin America, and Asia. This alignment to international realities makes the ICCC ideal in settings such as Kenya. Furthermore, whereas the CCM laid emphasis on partnership between patients and the healthcare teams in managing chronic conditions, the ICCC introduces focus on community partnerships and sustained care [131]. The Kenya national strategy for prevention and

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control of non-communicable diseases lists "establishment of the Innovative Chronic Care Model" as one of the targets within the strategic period of 2015-2020 [133]. Use of the ICCC framework, may therefore enhance coherence in communication about issues relating to chronic conditions.

The ICCC framework highlights the critical linkages and actions between household (micro), health facility (meso) and policy level (macro) actors important for management of chronic conditions. An effective care model for chronic conditions should be flexible and constantly evolving, to adapt to changing environments e.g., epidemiologic, political, cultural, and socio-economic. Furthermore, coordination between different levels of the health systems should enhance the seamless provision of services, beyond individual disease boundaries. The ICCC framework supports the integration of healthcare services [111].

The framework is gaining wide acceptance and application around the world as important in linking "informed and active patients" to "prepared and proactive health teams" [113]. By integrating the key aspects of this model, areas of strength and weakness in the management of chronic respiratory symptoms at the community, primary care and hospitals managed by the county will be explored.

2.2.3.3.   Healthcare equity and access frameworks

Health care access is a complex phenomenon that is closely associated to health systems performance. Cu *et al* [134] reviewed Levesque's framework (Figure 2.5), which defined health access as "the opportunity to identify, seek, reach, obtain or use healthcare , and to ensure the fulfilment of needs for these services" [135].

In this framework, access is viewed as multidimensional, and incorporating concepts such as approachability, acceptability, availability and accommodation, affordability, and appropriateness. *Approachability* means perceptions of people in need of care about the existence of services that they can reach. Approachability is in turn shaped by information about the services, and activities such as outreach. *Acceptability* is associated to social-cultural factors e.g., belief systems and values, that overall make services acceptable or not. The concept of *availability and accommodation* relates to physical aspects of services delivery that can be reached in a timely manner and is significantly dependent on resources with sufficient capacity to produce healthcare services. *Affordability* relates to the "economic capacity for people to spend resources and time to use appropriate services" [135]. Affordability is a function of direct prices of services, social protection coverage (such as health insurance like Kenya's NHIF) and opportunity costs including lost income and productivity time. Unaffordable care, which leads to catastrophic health expenditure and financial coping strategies, may dissuade from seeking care again in the future [107]. Lastly, *appropriateness* implies the extent to which available services fit the need of the clients: timeliness, amount of care, and technical and quality and adequacy of services [135]. The supply side attributes are in turn complemented by personal attributes, i.e., a)

ability to perceive availability of healthcare services, b) ability to seek, c) ability to reach, d) ability to pay for and d) ability to engage with the services.
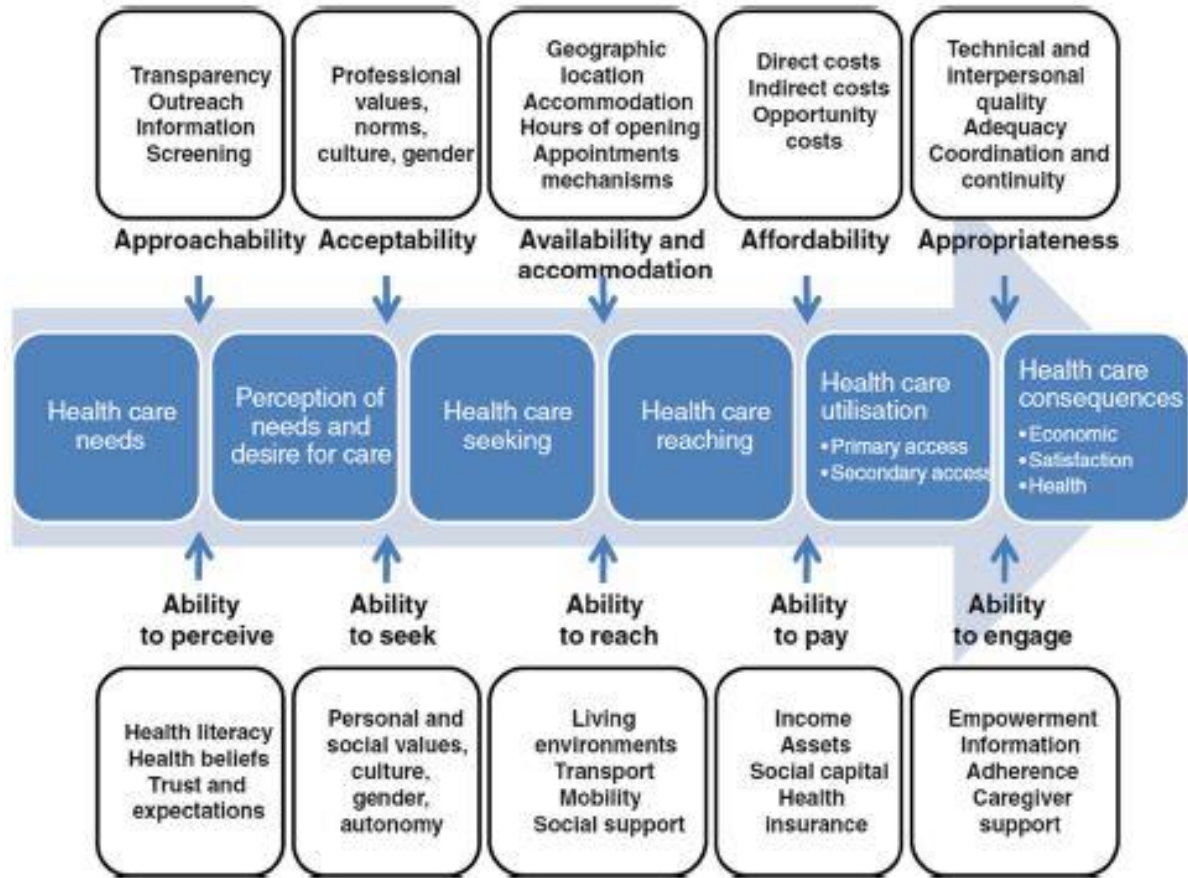
Figure 2.5 Levesque's Framework of access to healthcare services

Adapted from Levesque J-F, et al 2013 [135].

Access is shaped by supply side features of health systems and organisations, demand side factors of the population in need of services, and process factors describing how healthcare services are accessed. Finally, equity implies a situation where people access healthcare services according to need, i.e. the absence of systemic disparities across population subgroups including socio-economic factors such as gender, age, wealth, ethnicity, power, and geographical location [136].

2.2.3.4. The Social Ecological model

Social-ecological models [137] provide important insights in health promotion, and have been increasingly applied in designing interventions [138]. According to these models (Figure 2.6), individuals are embedded within broader social systems, and their behaviours affect, and are affected by their environments. Individuals

interact with their social environments at five different levels of influence, i.e. a) intrapersonal or individual-level factors, b) interpersonal processes, c) institutional/ organisational factors, d) community and e) public policy level factors [137]. These levels of influence shape the individuals' behaviours and ultimately, their health outcomes. Furthermore, delineation of these levels identifies possible points, and package of interventions.

Figure 2.6 The Social Ecological Model

Source: Adapted from Mc Leroy et al. 1988 [137]

First, Intrapersonal level factors such as knowledge, beliefs, values, education level and skills and other psychological factors affect the behaviours of people. An understanding of individual-level factors informs the design of interventions for example health education on risk factors for CRD, self-management plans and medication. Second, interpersonal processes entail relationships between individuals within formal and informal networks, and social support systems like family, neighbours, work groups, and other networks. These interpersonal relationships have important influences on behaviour and identity and may be associated with exposures such as smoking, and access to information, decisions such as seeking medical care, social support e.g., financial and coping with stressful events, adherence to healthcare professionals' advice, and preventive behaviours. An understanding of these interpersonal networks, and how individuals may belong to multiple networks can inform appropriate interventions. Third, focus on organisational factors acknowledges that people spend considerable time in their workplaces, and are affected by formal and informal policies, rules, and norms. Organisations also provide access to economic opportunities and incentives such as health insurance, restriction of harmful behaviours e.g., smoking that may promote positive health behaviours.

Organisational environments may however pose occupational risks for example dust, fumes, and smoke. The fourth level- community, entails social relationships encompassing formal and informal networks within a defined geographical space. Communities harbour important influences on individual's beliefs and attitudes; for example, local institutions e.g., religious groups and other organised community groups play important roles in information exchange, mobilisation, and support for local interventions. On the other hand, relationships between community organisations may enhance or undermine essential interventions, for example, competition for scarce financial and human resources may result in wasteful interventions. An understanding of how power is distributed, within community contexts is important in processes such as agenda-setting, resource allocations, and downstream intervention aspects [137].

The fifth level of influence- policy- refers to policies and regulations, and laws affecting people and institutions in which they operate. Enforcement of laws is vital, in protection against environmental pollution, access to healthcare services, safe housing, and exposure to harmful goods, including advertisement of harmful products, such as tobacco, and smoking [137].

The socio-ecologic model makes an important contribution to health promotion, by shifting from ideologies that place undue emphasis on "individual responsibility", lifestyle or choice, hence victim-blaming, to identify factors within an individual's environment, (and sometimes out of their sphere of influence) that affect their behaviours, and health outcomes. The socio-ecologic model builds up on the Alma Ata declaration [139] and Ottawa charter of health promotion [140], that shone the light on non-medical factors that influence health [141]. Some of these environmental factors are beyond the individuals' agency [141].

2.3. Health Systems Readiness to respond to Chronic Respiratory Diseases in Kenya

In this section, I outline health system readiness to respond to CRD in LMICs, viewed through the lens of the Kenyan health systems. This section mirrors the six building blocks outlined in section 2.2.1.

2.3.1. Readiness of leadership and governance for CRD in LMICs and Kenya

The call for health system redesign towards responsiveness to NCDs, including CRD [6, 113], is indicative of leadership or lack of it, depending on the context. For example, health system focus on NCDs has been more on treatment and long term clinical management, and dismal attention on primary prevention [142]. An expanding market in tobacco, will cause an estimated 8.3 million deaths in LMIC by 2030, emphasising the need for stronger leadership and governance mechanisms [143]. Although many countries have made commitments to invest more in health system responses to NCDs, including CRD, financial commitments

remain low. Civil society actions in framing and advocacy for NCDs reforms have been lacklustre, compared to other issues, such as HIV/AIDS [142].

The majority of the LMICs do not prioritise CRD and have weak institutions of governance. A study in East African countries showed that Uganda and Tanzania did not have a CRD strategy [44]. Research evidence shows that there are gaps in design of policies and very little budget allocations for CRD [43].

In Kenya, various changes in leadership and governance at the national level have implications on CRD. The change of the constitution is associated with a change of government earlier in 2002- the election of Kenya's third president the late Hon. Mwai Kibaki, and the reshaping of the development agenda through Vision 2030, Kenya's socio-economic blueprint [144]. The overall goal of Vision 2030 is to transform the country to middle-income-country status by 2030, while progressively and equitably improving the quality of life for the citizens [144]. During this period, Kenya experienced rapid shifts in development of health policies, including The Kenya Health Policy 2014-2030 [48], The Kenya National Strategy for the Prevention and Control of Non-communicable Diseases 2015-2020 [133], treatment and referral guidelines for common diseases at all levels of healthcare [38, 145, 146].

Kenya has demonstrated the need to enhance management of chronic respiratory diseases, through high level policy statements, and adoption of guidelines for healthcare delivery [48, 147]. The strategic aim of the health sector (2014-2030) is to "halt and reverse the rising burden of non-communicable conditions" and "enhance the quality of care for chronic lung diseases" [48]. Kenya has established the National Tuberculosis, Leprosy, and Lung Disease Program (NTLD) within the Ministry of Health. Nested within National Strategic Public Health Programs, in the Directorate of Preventive and Promotive Health, the goal of NTLD is "to accelerate the reduction of TB, Leprosy and lung disease burden through provision of people-centred, universally accessible, acceptable and affordable quality services in Kenya". The NTLD core mandate includes: policy formulation, setting standards, capacity development, resource mobilisation, implementation, supervisory, monitoring and evaluation roles for TB, Leprosy and Lung disease control programmes [148].

The National Strategic Plan for Tuberculosis, Leprosy and Lung Health, identifies the lack of a public health operational programme for the control and prevention of respiratory diseases in the Ministry of Health, as a key priority gap [149]. The Strategy prioritises establishment of a fully-fledged lung health program, to among other roles, "review and adopt lung health policy guidelines and training materials including development of a diagnostic and management programme for lung health", drive capacity development for healthcare workers and facilities, and establishment of reliable reporting systems for lung health [149].

Additionally, the 'Taking the Kenya Essential package of health to the Community' community health strategy, upon which community health systems are anchored, was developed [51], followed by the Kenya

Community Health Policy 2020-2030 [123], and the Kenya Community Health Strategy 2020-2025 [52]. A detailed description of community health aspects is outlined in section 2.2.2.

2.3.2. Readiness of service delivery for CRD in Kenya and other LMICs

Effective management of chronic disease programmes is dependent on well-functioning and equitable health systems [150]. Such systems would guarantee everyone access to appropriate, "good quality primary-care services, with referral to secondary and tertiary care when needed, without the risk of financial hardship" [150]. Service access encompasses availability, affordability and cultural acceptability of the services offered. Quality service delivery is dependent on health system readiness, to offer such services. An important aspect of this readiness is the capacity of the health facilities to offer the services. Key indicators of capacity include "presence of trained staff, guidelines, infrastructure, equipment, medicine, and diagnostic tests". Whereas health system readiness is a necessary condition for the provision of quality services, it does not in itself, guarantee that services will be provided or the services will be, of high quality [68].

Chronic conditions require continuity of care, i.e. access to services, and a reliable supply of affordable drugs [11], sustained provision over time, effective linkage with community systems and patient and community empowerment [5, 151]. Most countries in sub-Saharan Africa have weak health systems. These systems are characterised by inadequate diagnostic capacities. For example, in the ISAAC-3 study that involved 22 African countries [20], it was established that 50% of children with asthma had severe symptoms but more than 30% of these children "had never been diagnosed with asthma" [11]. The SSA health systems also grapple with unreliable supply chain systems for drugs, and human resource challenges [29, 42].

For healthcare systems to be responsive to chronic conditions including respiratory diseases, it is vital that specific weaknesses relating to country contexts are identified, and system is re-designed as appropriate. This requires political goodwill and sustained investments in health system strengthening, prioritising infrastructure, diagnostic capacities, medicines, and human resources.

Primary healthcare level is "the driver of the healthcare delivery system" [88] and has been identified as a strategic intervention point for NCDs [39]. A properly functioning primary healthcare system would ensure access to equitable care, that is culturally acceptable, incorporating community preferences [110] but in ways that are sustained and continuous, with effective linkages to higher level referrals to support provision of complex care [88].

Kenya has adopted various WHO clinical guidelines that detail CRD management at community level, i.e. Clinical Guidelines for Management and Referral of Common Conditions at level 1: The community [152] and at primary health care level i.e. Clinical Guidelines for Management and Referral of Common Conditions

at Levels 2 and 3: Primary Care [145] and Clinical Guidelines for Management and Referral of Common Conditions at levels 4-6 Hospitals [146]. In 2011, Kenya adopted the Practical Approach to Lung health (PAL) [22]. PAL is a patient-centred approach recommended by WHO. PAL aims to improve the quality of diagnosis and treatment of common respiratory illnesses at the primary health care (PHC) level. PAL also seeks to standardise the delivery of services by developing and implementing clinical guidelines within the district health system. Theoretically, PAL should result in coordination between different levels of healthcare, and enhance linkage between management of TB and other respiratory diseases [34]. Successful PAL implementation demands political commitment, adequate supplies of medicines, a reliable health information management system, and trained healthcare workers. However, minimal progress has been made in implementing PAL in Kenya [22]. Key steps achieved include the development of tools e.g., the PAL guidelines, training manuals, asthma registers, information, and education (IEC) materials e.g., posters and brochures on asthma and COPD and patient management cards. However, the Ministry of Health was unable to finalise the monitoring and evaluation plan for PAL as well as printing and disseminating the tools to facilities, due to financial constraints, and lack of political goodwill. Consequently, the PAL implementation was not evaluated. The supply of essential diagnostic equipment to deliver PAL was also hampered. Only 33 hospitals across the country were supplied with spirometers, peak-flow meters, and nebulisers [153].

A review of primary healthcare readiness for provision of major NCD services including CRD services identified challenges including: ill-equipped healthcare facilities, patients' lack of self-management awareness, low healthcare workers' capacities, weak referral and follow-up systems, and lack of information and education resources at the community level [110]. In Tanzania, a nationwide survey showed that only 10% of facilities had high readiness to provide diagnostic and treatment services for CRD [154]. In Kenya, a recent study involving public health facilities showed key service level challenges to be delays in diagnostic tests e.g., sputum tests, lack of chest x-ray services in lower-level public facilities, and lack of spirometry services. Additionally, healthcare workers were not trained on spirometry, and there were frequent drug stock-outs [43].

2.3.3. Readiness of Healthcare workforce in Kenya and other LMICs

As described in the introduction section,1.1.2, low capacity of the healthcare workforce is a big problem in LMICs. Recent studies on CRD in Kenya and four other Sub-Saharan African countries (Tanzania, Uganda, Sudan and Malawi) highlight specific problems, particularly in diagnosis, and treatment [43].

A Kenya Health Workforce Report [155] shows that the public healthcare system suffers significant deficiencies of the workforce, characterised by inequitable distribution across rural and urban areas. For example, contrary to the WHO recommendation of a minimum 44.5 skilled healthcare professionals (i.e.,

nurses, midwives and physicians) per 10,000 population [156], Kenya had only 13.8 health professionals per 10,000 population, inclusive of clinical officers [155]. The distribution of health care workers was highly inequitable. For example, Nairobi, Kenya's capital city had a 9.7:10,000 nurses to population ratio, while Mandera (one of the remote, arid counties) had a 0.1/10,000 ratio [155]. The distribution of doctors followed a similar trajectory. Several reasons are associated with this situation: challenges in absorption of trained healthcare workers into the public health system; difficulties in retaining healthcare workers in rural and remote areas; flight of healthcare workers from the public to the private practice; emigration of healthcare workers to foreign countries; and numerous, and prolonged healthcare workers' strikes [157-159] associated with dissatisfaction in career mobility, pay and working environments. The distribution of training institutions was also skewed in favour of the urban areas, particularly major cities. According to the report, counties with training institutions tended to absorb the graduates into their healthcare workforce [155]. This situation implies that availability and access for CRD services is mostly in urban areas, and counties where training institutions are located.

2.3.4. Readiness of Information systems in Kenya and other LMICs

The majority of LMIC countries have weak, fragmented health information systems. Trends of household surveys conducted in the African region show an upward trajectory, particularly from the year 2000. This is associated with global policy agenda such as the Millennium Development Goals (MDGs). The surveys are predominantly funded by external organisations [104], some focused on specific diseases [103]. This situation raises serious issues about data ownership and alignment of surveys to local priorities, efficiency in data collection processes particularly when multiple organisations duplicate and overlap issues, risks of bias, and strain on local country offices [104]. Health service statistics, show data on operational processes of health facilities, and include individual's health status, service provision, supplies and human resources available for service provision. These data are however "systematically under-analysed" and under-utilised for health system decision-making due to predominantly using paper-based media, incompleteness, timeliness, and poor quality of reporting. The data are also biased because they represent only people who access healthcare facilities [104]. Additionally, there is a huge gap in dissemination of epidemiological data because most health system outputs are intended for expert and specialist audiences [103]. This means that other important users of the information such as frontline healthcare workers, policy makers and patients may not understand the data, consequently limiting its utility.

The Kenya Health Sector Strategic and Investment Plan (2014-2018) identifies information as an important resource for aligning and coordination of healthcare resources [160], for instance, in many healthcare facilities, data is handled by unskilled staff. Scarcity of health records information officers in Kenya and other

Sub-Saharan African countries has been highlighted in a recent study [43]. There is suboptimal utilisation of health information at all levels of the health system [160]. Additionally, demands for data disaggregation place huge burdens on frontline healthcare workers [160]. Importantly, Kenya does not have population-based data on the burden of CRD, for all age groups. This situation undermines healthcare decision-making processes and is similar in many Sub-Saharan African countries [29].

The Kenyan Ministry of Health is implementing several reforms, including digitisation of health records and adoption of a Kenya Health Systems Interoperability Framework [161]. Key priorities include installing the information technology, training end users and conversion of paper-based data to digital formats. A survey of adoption of information technology among 58 county (subnational) health records information officers in Kenya showed that the information systems were mainly used for patients' administration and billing; laboratory and radiology departments had standalone systems and overall, the health system had varying levels of interoperability, usability of the system, resources and technical support and training were inadequate [162]. Although Kenya has made significant strides in adoption of important technologies such as the internet and mobile phones, these resources are not optimally used in the healthcare system [160].

2.3.5. Readiness of the Kenyan health systems to supply medical products and technologies.

The weaknesses of supply chains for CRD drugs in LMICs has been described in the introductory section, 1.1.2. Supply of drugs is determined mainly by price and availability. The cost of drugs constitutes a significant proportion of healthcare budgets in LMIC and drugs are unaffordable to many people, particularly when purchased out-of-pocket [163]. A survey of 52 LMIC showed availability of beclomethasone and budesonide inhalers in public facilities, was 19% and 16% respectively. Comparatively, private sector providers reported higher availability of beclomethasone (46%) and budesonide (58%) inhalers. Eight out of 14 LMIC that did not supply corticosteroid inhalers in either public or private facilities were in Africa. The drugs were unaffordable in some countries, for example, the cost of beclomethasone (100µg) inhaler ranged from an equivalent of half a day's wage in Afghanistan, to 14 days' wages in Madagascar. Prices of budesonide inhaler showed wider variation from half a day's wage in Jordan, 48 days (Burkina Faso), 51 days (Mozambique), to 107 days' wages in Republic of Guinea [163].

Kenya has the Essential Package for Health (KEPH) and has recently developed a healthcare benefits package. Additionally, Kenya has adopted the WHO essential Medicines List (EML). The EML contains "a list of minimum medicine needs for a basic health-care system, listing the most efficacious, safe and cost–effective medicines for priority conditions" [164]. Within the EML, essential medicines "acting on respiratory tract"

include: beclomethasone, budesonide, budesonide+ formoterol combination, epinephrine, ipratropium bromide, salbutamol, and tiotropium [164].

The Kenya Medical Supplies Authority (KEMSA) is the major supplier of drugs and medical technologies to county governments in Kenya. Following the adoption of the new constitution, the Kenyan government introduced the "pull" system in 2010, and conferred autonomy for the 47 counties to purchase their drugs based on local priorities [165]. This arrangement is different from the old "push" method, where districts health management teams procured drugs through drawing rights to KEMSA. Purchasing drugs through KEMSA conferred some advantages. Firstly, bulk purchasing enhanced efficiencies through economies of scale. Secondly, purchasing through a central government agency provided mechanisms for safeguarding quality assurance of drugs supplies [159, 166]. Importantly too, counties were not obliged to procure drugs from KEMSA only [159]. Additionally, in the early phases of devolution, low capacities in the county governments, exposed supplies systems to poor quality drugs, and corrupt practices [165].

Investigations on availability of drugs in Kenya's devolved context show mixed contextual perspectives. A study of availability of asthma drugs in eight counties in Kenya showed that whereas the majority of the people were diagnosed in public facilities (60%), more than 50% purchased drugs in the private hospitals, underscoring deficiencies in public supplies [167].

A study comparing availability of NCD drugs before and after devolution in Makueni County Referral Hospital (a secondary referral hospital), in Kenya showed that stock outs for asthma drugs were much longer during devolution, compared to the period before devolution [166]. Stock outs for salbutamol inhalers lasted 42 days (pre devolution), and 145 days, after devolution; budesonide inhaler stock outs lasted 143 days and 361 days pre, and after devolution, respectively. An earlier study on the early experiences of devolution at the Kenyan coast reported that drug supplies through KEMSA had improved, compared to pre-devolution era, underscoring contextual variations in experiences [159].

2.3.6. Readiness of the Kenyan health financing systems

Unlike acute unplanned care, financing for chronic diseases can be planned if the burden of disease is well understood and the standards and parameters of care agreed.

Health financing for NCDs, including the CRD has consistently been very low, worldwide. For example, in 2015, less than 1% of financial development assistance for health were channelled to NCDs [142, 168]. The Kenyan health system is financed through a combination of public, private, and external resources. Out-of-pocket payments account for a significant proportion of total costs of seeking diagnosis and care [169]. Important changes in the NHIF include coverage for outpatient services in hospitals and the inclusion of

healthcare services for chronic diseases in the benefits package. These benefits are provided as outlined in the clinical guidelines for management and referral of common conditions, for health facilities from level 2 (dispensary) to level 6 (national referral hospitals) [145, 146, 152].

Drugs covered under the NHIF scheme, are those listed in the Kenya Essential Medicines List (2019) [170]. The NHIF is the single largest purchaser of health services in Kenya and covers 88% of the insured population in Kenya [48]. Key services covered by NHIF include consultation, laboratory investigations, drugs administration and dispensing, radiological examinations, and surgical services. The NHIF benefits package covers drugs 'acting on the respiratory tract'. These include beclomethasone, budesonide, epinephrine injection, ipratropium bromide, and salbutamol. Coverage of chronic conditions in the NHIF package aims to lower financial burdens of accessing CRD care in public facilities but, given only 19% of Kenyans are insured with NHIF, is unlikely to have impact in its present form [171].

The current government regime, under the leadership of President Uhuru Kenyatta, has sustained the quest for universal health coverage, as one of the main flagship programmes of the 'Big 4 Agenda'. The four other development programmes, consist of manufacturing, affordable housing, and food security. The Kenyan government aims to achieve 100 per cent universal health coverage. Some of the targets include 100 per cent cost subsidy on essential healthcare services, and reduction of out-of-pocket payments by 54 per cent of household expenditure [41]. These reforms complement earlier Kenyan government policies to remove variable user fees at the dispensary and health centre levels, and substitution with flat rates of 10 and 20 shillings, respectively. The policy also exempted special patients groups from paying user fees in public facilities, i.e. HIV/AIDS, Tuberculosis, malaria, and maternal services, and children under five years [172].

Financing of health services for CRD is inadequate. Recent evidence from five Sub-Saharan African countries including Kenya shows that compared to communicable diseases such as HIV/AIDS, TB and Malaria, funding for CRD services is dismal. This situation is attributed to heavy reliance on financing from external partners, who have low interest on NCDs. Additionally, lack of healthcare service-level data on the burden of CRD influences low, or no budget allocation decisions, for drugs and diagnostic equipment for CRD. Lack of budget allocations for drugs and diagnostic services in turn undermine data collection at service delivery level, resulting in a vicious cycle that overall impedes health system responses to CRD [42]. Finally, apart from the field of TB, there is negligible data on the costs, lost income, and catastrophic health expenditure incurred by people with CRD symptoms who are unwell or seeking care.

2.4. Summary of evidence gaps and revised conceptual framework.

The literature review shows that, despite significant reforms that have been made within the Kenyan health system in the last two decades, there are several gaps across all the six building blocks of the health system

and relevant conceptual frameworks. These gaps can be summarised in key research questions that form the backbone of this thesis and are examined in more detail in Chapters 3, 4, and 5 respectively:

Chapter 3: What is the readiness of the devolved Kenyan health system to respond to the rising burden of CRD? Are the public healthcare facilities ready to provide chronic care and management for people with CRD?

Chapter 4: How do community understandings impact on the uptake of and adherence to existing diagnosis, care, and treatment pathways for CRD? What are the best ways of working with communities to increase awareness and uptake of services?

Chapter 5: What are the economic barriers and costs to people seeking care for symptoms of CRD? What is the role of the NHIF in covering the costs of care for CRD in public healthcare facilities?

Figure 2.7. below outlines the proposed study-specific conceptual framework for CRD care in Kenya's devolved healthcare system. This framework reflects the main issues from the literature review, and has been adapted to accommodate multi-level issues examined in this thesis from the national-level; county-level, the healthcare facility level, the community health system and finally, the individual level, i.e. people with symptoms of chronic respiratory diseases.
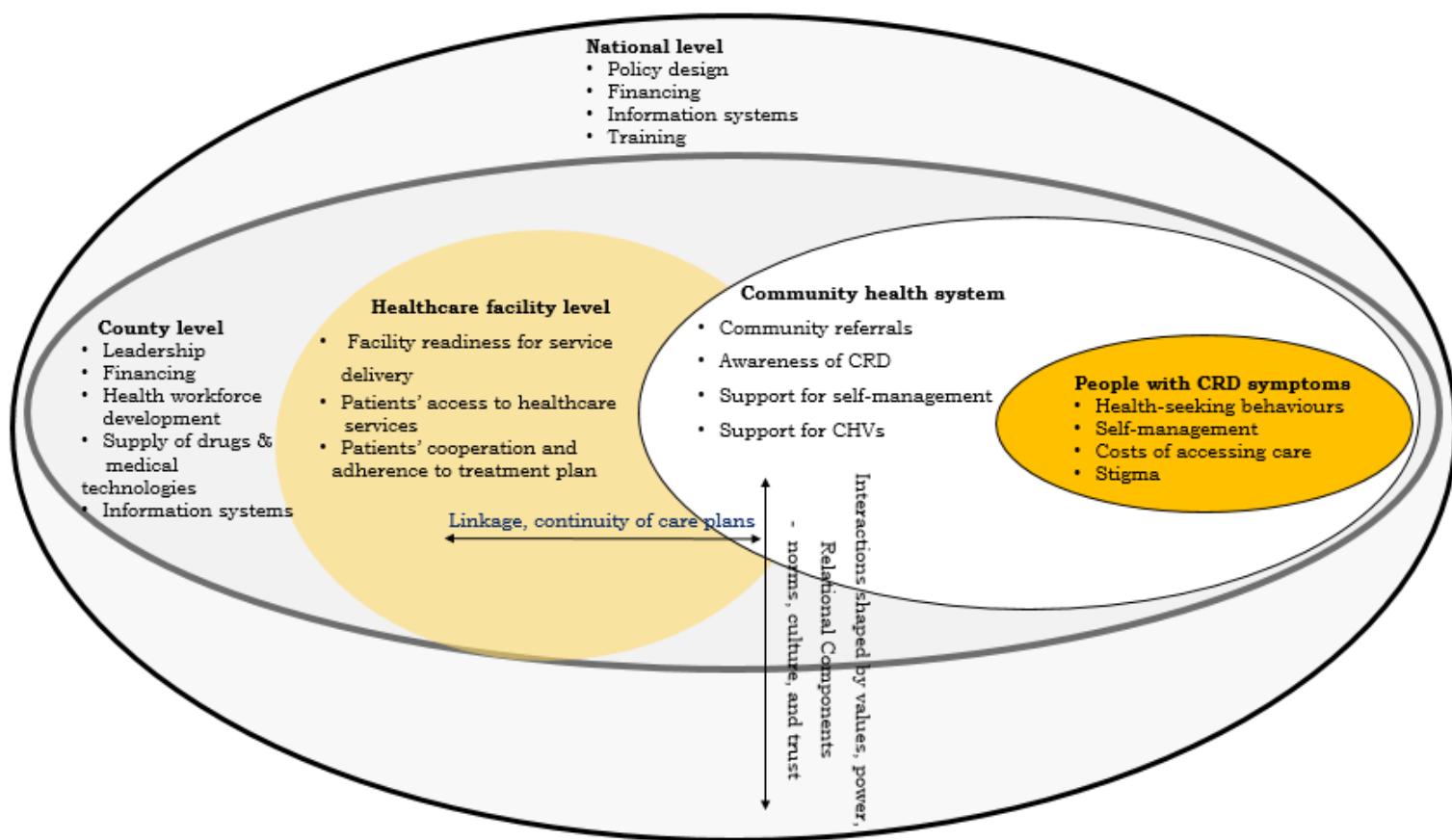
Figure 2.7 The proposed conceptual framework highlighting multi-level health system issues associated with care for chronic respiratory diseases in Kenya

This proposed conceptual framework places people at the centre of a community health system. The framework depicts people, with needs for healthcare services, and the health seeking behaviours, the various actions involved in self-management of symptoms of CRD, and key barriers i.e., costs and stigma. The CHVs are expected to support community referrals, awareness, and self-management of CRD. The CHVs in turn, need support e.g., finance, material resources and training, to perform their roles effectively. The community health system interacts with the healthcare facility levels through dissemination of information and supporting continuity of care plans. Within the healthcare facility level, the facility readiness to provide care for CRD incorporating all components of the WHO building blocks are explored. Patients' access to care, cooperation and adherence to treatment plans are also highlighted as important demand side factors for CRD.

The healthcare facilities and community levels are nested within the county government system, which is expected to provide local leadership and governance of the health system, financing, health workforce management and sustaining supply of drugs and medical technologies. The national level is depicted in line with its constitutional mandate, viewed through the lens of building blocks, i.e., policy design (leadership); finance, information systems, and training (health workforce).

Cross-cutting the community, health facilities, county and national subsystems, are interactions shaped by values, power and relational factors e.g. trust and norms.

Chapter 3: Health Facility and Health System Readiness

This chapter presents a standalone paper on facility readiness to respond to people with symptoms of CRD in Meru County. It uses asthma as an analytical lens by describing a case study of the diagnosis and management of asthma in five healthcare facilities in a devolved government context in Kenya.

3.1. Introduction

Asthma is one of the four major chronic respiratory diseases affecting over 350 million people globally, and accounting for at least 400,000 deaths [7]. The main risk factors of asthma include exposure to tobacco smoke, indoor air pollution from biomass fuels, environmental pollutants, lower respiratory tract infections and hereditary factors [8, 15]. Apart from death, asthma exposes the affected people and their households to poor quality of life and is an impediment to socio-economic development [173-175].

The true prevalence of asthma, especially in LMICs, is not known due to scarcity of reliable, up to date population-based research data, involving all age groups. It is however acknowledged that the burden of asthma is rising, particularly in LMICs [27]. A systematic review by Adeloye et al, shows that asthma prevalence in Africa increased from 74.4 million cases in 1990 (11.7% prevalence), to 94.8 million (12.0%) in 2000. In 2010, asthma prevalence had risen to 12.8 %, accounting for 119.3 million cases [17]. A survey of 839 households in Kenya established a 15.2% prevalence of asthma among adults [176]. Some of the factors contributing to increased asthma prevalence include an expanding market of tobacco products, exposure to pollution from biomass fuels, rapid urbanisation and demographic shifts that overall are associated with higher population growth and longer life expectancy [13].

The control of asthma, and other non-communicable diseases is a top priority in the global health agenda [8, 177]. The Global Action Plan for the Prevention and Control of Non-communicable Diseases emphasises the need to strengthen health systems to manage NCD through people-centred primary care approaches [39]. Chronic conditions require continuity of care, sustained provision over time, effective linkage with community systems and patient and community empowerment [5, 151].

We investigated the readiness of the public healthcare system of Meru County to respond to CRD using the lens of diagnosis, treatment, and management of chronic asthma. We went on to identify opportunities for improvement of asthma diagnosis and care among adults in Meru County. Apart from its high morbidity and

mortality globally, asthma was used as the lens for the case study because it is also a commonly used term by both clinical and lay persons when referring to symptoms of CRD.

3.2. Methods

3.2.1. Study Design

A mixed methods observational design was used. Facility readiness surveys were conducted first, to assess the preparedness of healthcare facilities to offer care for people with symptoms of chronic respiratory diseases based on the availability of human and other physical resources. The facility readiness surveys were followed by complementary in-depth interviews that explored in greater details some of the underlying issues identified for example, availability and training of healthcare workers, lack of drugs and essential equipment. Qualitative methods are important in exploring meanings that people attach to different social phenomena [178], therefore vital in contextual expositions.

3.2.2. Study setting and site selection

The study was conducted in Meru County as described in Chapter 1. At the health facilities' sampling stage, we requested information on the distribution of public health facilities from the Meru County Health Records and Information Office. At the time, Meru County had 21 health centres (level 3) and 15 subcounty hospitals. Three out of nine sub counties - Igembe North, Imenti South, and Imenti North - were sampled purposively based on consultations with officials in the Meru County Department of Health. Igembe North and Imenti South sub counties were identified as relatively higher prevalence sub counties in Meru County. Additionally, their healthcare facilities were relatively easier to access due to good road networks and were in areas with good security.

Igembe North and Imenti South sub counties are 79 kilometres apart. The sub counties differed by the type of economic activities and remoteness, as defined by proximity to the Meru-Embu-Nairobi highway (the highway), and Meru town, the 'seat' of the devolved government. Igembe North subcounty is located further from Meru town, and main socioeconomic activity is khat farming. Imenti South is closer to Meru town and is traversed by the highway. Key economic activities are farming of fruits and some tobacco farming. The third subcounty, Imenti North, is home to Meru town, and the Meru County government headquarters.

In each sub county, a health centre, and a subcounty hospital were sampled. These represent levels 3 and 4 healthcare facilities, respectively, in Kenya, and serve a predominantly rural population.

A health centre is a primary healthcare facility (level 3) managed by a nurse or a clinical officer (facility in-charge), and provides basic treatment for common diseases, health promotion, minor surgeries and short-term in-patient care such as maternity care [50]. Subcounty hospitals are first-level county referral facilities, and are headed by a Medical Superintendent [179]. They are normally staffed with medical officers, in addition to clinical officers and interns, and are expected to offer a wider range of laboratory services, radiography, major surgery, outpatient and inpatient care. Subcounty hospitals also manage medical outpatient clinics (MOPC) on specific days, for patients with specific chronic conditions.

The fifth facility, the Meru Teaching and Referral Hospital (MTRH), is the regional hospital, and is in Imenti North subcounty. The MTRH provides specialised care in addition to treatment of common conditions. The MTRH patient populations include urban residents within Meru town, closest to the facility, but its coverage goes beyond the geographical boundaries of Meru County. Overall management of the healthcare services within the county is vested on the County Department of Health (CDOH), comprising of the County Health Management Team (CHMT).

The key characteristics of the sampled facilities and distribution of respondents are shown in table 3.1.

Table 3.1 Distribution of sampled healthcare workers in the five healthcare facilities

Category of healthcare worker	Health centres (n=2) (Level 3)	Subcounty hospitals (n=2) (Level 4)	Meru Teaching and Referral Hospital (n=1) (Level 5)	Total
Facility in-charges and senior management staff	3	4	2	9
Clinical officers and nurses	2	8	4	14
Laboratory personnel	2	3	1	6
Radiology personnel	0	1	2	3
Pharmacy personnel	2	4	1	7
Medical officers and Physicians	0	2	1	3
Medical Social workers		2		2
Total	**9**	**24**	**11**	**44**

3.2.3. Data collection

Data were collected from 16th July 2019 to 30th November 2020.

a) **Facility readiness survey (FRS)**

The FRS methodology was adopted from the WHO service availability and readiness assessment (SARA) methodology [68]. The SARA methodology uses availability of tracer indicators such as infrastructure, human resources, equipment to inform readiness of a healthcare system to offer specific services. This tool has been previously validated and was adopted with minor modifications for context based on pilot and reviewed by experts for clarity. For example, questions on availability of services, healthcare workers' specialisation, guidelines, drugs, and equipment were focused on TB and CRD-related services only. Examples of questions that were excluded in the tool include those relating to maternal and antenatal care, availability of landline telephones, infection control, processing of equipment for reuse, and waste management. The standard FRS questionnaire (Appendix 3) was administered in July 2019 by a trained assistant research officer (CK) to health facility management staff (n=12) in the five sampled facilities. They included facility-in-charges, heads of departments and facility administration staff. Key areas of exploration included human resources for healthcare (e.g., staffing and staff time), exposure to in-service training for CRD, availability of equipment and infrastructure to provide appropriate care for patients with symptoms of chronic respiratory diseases, guidelines, and medical supplies for CRD.

Data were collected on android tablets, on Open Data Kit™ (ODK) platform and transmitted to a secure server, same day of data collection. The survey tools (n=2) were piloted in Mutionjuri Health Centre and Miathene Sub county Hospital, both located in a subcounty different from the study sites (Tigania East). The surveys were done sequentially, starting with one subcounty and finalised at the MTRH. Data collection in health centres preceded the subcounty hospitals. In each facility, the survey was done within a day.

b) Qualitative interviews

We conducted in-depth interviews (IDI) with healthcare workers (HCW) in the five facilities, from August 2019 to November 2020. The HCW were sampled purposively based on their roles in managing the healthcare facilities and provision of clinical care to patients with respiratory symptoms, suggestive of asthma. During this phase, the study team also spent a minimum of 30 days at each facility. They engaged HCW in data collection activities for a sub study involving mapping of patient journeys within the clinical pathway for chronic respiratory diseases. The interactions between the research and healthcare teams enhanced trust and rapport, which provided useful insights in subsequent exploration of the healthcare system.

To understand contextual issues in more depth, we conducted key informant interviews (KII) with senior county officials i.e., the County Director of Medical services, the County TB Coordinator, County Pharmacist, a member of the County Public Service Board, the Chief Officer of Health and the County Health Records and Information Officer (HRIO).

We scheduled the interviews through verbal requests, phone calls, and e-mails, and conducted them within the healthcare facilities or county offices at times that were convenient to the respondents. Semi structured interview guides were used for IDIs (Appendix 4a-e) and KII (Appendix 5a &b).

Topics of discussion explored indicators used in the FRS in greater detail, i.e., availability of physical resources, such as health facility infrastructure, rooms with audio and visual privacy, the adequacy of healthcare workforce, health data collection and flows, availability and use of clinical guidelines, experiences in clinical decision-support, treatment, referrals and plans for continuity of care. We examined aspects of health financing, governance, and leadership, for example on decision-making, health workforce management, and other policy processes influenced by actors within the county system, as well as between national and county system. We also explored integration of healthcare services for CRD and TB, among key informants.

All the interviews were led by the principal investigator (SM) in English. This was important in progressively identifying important information emerging from subsequent interviews. SM has post graduate training and significant professional experience in social sciences research focusing on health systems and policy.

The discussions took place in quiet, private places, to ensure confidentiality, and minimise disruptions. The interviews were audio-recorded using SONY ICD-UX560F™ recorder. CK or fieldworkers took field notes during the interviews. Before completion of the interviews, they (CK/fieldworkers) sought clarification of key issues/questions emerging from the discussions. This approach was useful in collecting comprehensive data. Debriefing sessions were held immediately after the interviews and lasted approximately 10-15 minutes. In these sessions, the research team identified key issues, emerging from the interviews, to be explored in subsequent interviews. All audio recordings were transferred to a secure computer same day of interview and transcribed verbatim, on MS Word. The transcripts were subsequently read through by both SM and CK verified as accurate accounts of the interviews.

To enrich our contextual understanding of facility readiness to provide healthcare services, the research team members made unstructured observations of facility processes and engaged with the healthcare teams in informal conversations during the data collection period. These observations were recorded in field notebooks and discussed during debrief sessions, as well as weekly meetings by the research teams to review progress of data collection and important emergent information.

3.2.4. Data analysis

FRS data were analysed using Excel spreadsheets and involved tabulations of descriptive statistics in form of proportions and simple counts.

We adopted the analytical framework for readiness assessment from the SARA [68]. Data were analysed using the six components of the WHO building blocks framework. Data from the facility readiness surveys were scored using 'service-specific readiness'. First, 3 main domains with indicators relevant to asthma diagnosis, treatment and management were delineated. They were: 1) staff training (in-service) and availability of guidelines and treatment criteria, 2) diagnostics and equipment, and 3) drugs supply. Each domain consisted of specific tracer indicators of the basic requirements to diagnose and manage asthma and other CRD.

Assuming a cumulative score of 100 % for the three domains, each domain accounted for 33.3% (100/3). The next step involved determination of the scores for individual tracer indicators. For each domain, 33.3% (the dividend) was divided by the number of divisors (tracer indicators) in a domain. This step is denoted by the formula below:

Score (x)= a/b

Where x is score for a tracer indicator

- a- The dividend (33.3%)
- b- The divisor, i.e., number of tracer indicators in the domain.

The average scores per domain were also calculated.

The table 3.2. below shows the domains, and tracer indicators selected per domain.

A tracer indicator was scored either the quotient value of the division or 0 (zero), indicating availability or not, respectively. We assumed a score for all items reported as available, whether seen or not. For drugs, a score was given for available and valid, i.e., not expired. All non-valid drugs, were assigned a score of zero.

The readiness scores were computed by adding the availability scores in all the domains. A score of 50% and above was considered high and the health facilities were regarded as ready to deliver CRD services. Scores less than 50% were considered low, and the facilities regarded as not ready to deliver CRD services.

We analysed qualitative data using the thematic framework approach [180]. Both SM and CK read through all the transcripts to familiarise themselves with the interview data. Data were coded into analytical themes that mirrored the interview topics. Other themes emerged inductively as the data were coded. SM and CK developed the final codebook (Appendix 6a &b) jointly. CK subsequently coded the transcripts on NVivo 12. SM, HM, TW, UE, and MT reviewed the NVivo codes and discussed the interpretations and meanings of the findings. Divergent opinions were resolved through consensus.

3.2.5. Ethical considerations

The study received ethical approval from the Liverpool School of Tropical Medicine Ethics Review Committee, Research Protocol 19-003 (Appendix 7), and the Kenya Medical Research Institute (KEMRI) Scientific and Ethics Review Unit (SERU), SERU No. 3848 (Appendix 8). I applied for, and was granted permission to conduct the study, by the county government of Meru- Ref. MRU/MED/MRU/C.50 (Appendix 9).

3.3.   Findings

This section highlights key findings based on the domains in the readiness survey, complemented by findings from the IDI and KII. This approach is important in describing the findings using numerical measures, but also insights on underlying reasons for participants' perspectives on issues covered in the interviews.

Healthcare services for asthma patients were mainly provided in the outpatient departments. Interview data highlighted that, compared to other departments, the County Department of Health (CDOH) received significant priority and political support by the county government to enhance quality of healthcare services delivery. This was demonstrated by progressively increasing budgetary allocations, investments in physical resources, and recruitment of healthcare workers.

> *"Since devolution, the county government has invested heavily in infrastructure development… we have seen many health facilities come up, and existing ones being expanded… in fact the department of health has received the lion share of the budget allocations." (KII_county_official_19)*

Overall scores for facility readiness based on the three domains are summarised in the table 3.2 below, specific details of the individual indicators are highlighted in Appendix 10.

Table 3.2. Overall scores for facility readiness based on the three domains-training, equipment, and drugs

	Scores of domain indicators by facility				
Domains	**Mitunguu Health Centre (Level 3)**	**Laare Health Centre (Level 3)**	**Kanyakine Hospital (Level 4)**	**Mutuati Hospital (Level 4)**	**MTRH (Level 5)**
Domain 1: Healthcare workers' training in-service and guidelines availability	24.96	16.64	12.48	8.32	12.48
Domain 2: Availability of equipment	6.66	6.66	33.3	13.32	19.98
Domain 3: Availability of Drugs for CRD	22.2	22.2	33.3	33.3	33.3
Total Domain Scores*	**53.82**	**45.5**	**79.08**	**54.94**	**65.76**

*Score for each tracer indicator, domain 1 (4.16), domain 2 (6.66), domain 3 (5.55)

The readiness scores show that all the facilities scored more than 50 % on readiness, except Laare Health Centre (45.5%). Kanyakine Subcounty Hospital scored highest on readiness (79.1%). The following section provides details of the various health facility components. An estimation of average scores by domain shows that domain 1 (availability of trained healthcare workers and guidelines) scored least 15%, while domain 2 (equipment) averaged 16.0 %. Domain 3 (availability of drugs) scored highest in readiness (28.9%).

3.3.1. Limitations in infrastructure affect service delivery.

In-depth interview accounts show that all facilities - but particularly the health centres and subcounty hospitals - reported limitations in infrastructure that affected quality of service delivery for asthma patients. Examples of these limitations include lack of privacy for observation of patients e.g., during nebulisation for bronchodilator tests. These findings contradict the survey data that reported adequate private spaces for patients. In one subcounty hospital, there was no ward for male patients, consequently, all severe cases needing an admission were referred to other facilities. Pharmacies in all facilities dispensed drugs, including inhalers, through open windows in verandas that had limited privacy too. This negatively affected patients' care experience, as described in section 3.3.7, under stigma.

3.3.2. Availability of healthcare workers

Healthcare worker availability was highlighted as a limitation to delivering care for people with symptoms of CRD. For example, Mutuati subcounty hospital did not have medical doctors or radiographers, all health centres had only one lab technologist, and the entire Meru County had no pulmonologist/respiratory physician. In instances of staff absence, e.g., staff leave, laboratory services were not available. The inadequate numbers and HCW specialisation, adversely affected timely diagnosis and management of asthma, including higher level specialist consultations.

> *One chest specialist (a clinical officer) serves the entire subcounty and is only available in some days. (Frontline_HCW_44)*

In-depth interview accounts with HCWs showed that patients were frequently referred to facilities that had medical doctors or consultant physicians. These facilities are located further away from patients' areas of residence, exposing them to increased out-of-pocket travel costs and lost income and productivity. Similarly, referrals to private healthcare facilities exposed patients to financial strains.

Shortage of HCW also affected the subsequent reviews of patients diagnosed with asthma. Whereas there were regular, medical outpatient clinics (MOPC) for diabetes and hypertension, there were inadequate provisions for asthma.

I have rarely seen us book clinics for chest conditions. (Frontline_HCW_49)

Lack of available HCWs meant that people with CRD symptoms did not receive appropriate related counselling and health education e.g., on diagnosis, risk factors of asthma e.g., smoking and household air pollution, and proper use of inhalers. Clinical care providers reported that they were constantly under pressure by the long patients' queues and in some instances only prescribed medicines. Shortage of HCW also influenced decisions on the next review date. In some instances, patients who would preferably be reviewed for example within two weeks based on the doctor's assessment of severity were scheduled for their next review in four months. Consequently, there were reported delays in review of patients' progress. According to healthcare workers, when they finally came for clinical review, some patients showed signs of poor asthma control, e.g., acute exacerbations of asthma, and some were lost to follow-up.

A dearth of lung function tests undermined diagnosis of asthma and other CRD. The Meru County public health system did not have spirometers and the majority of HCW reported having no training in spirometry. Only two clinicians, at subcounty and MTRH, had been exposed to spirometry, pre-service, but also reported a lack of confidence in conducting lung function tests.

Spirometry? Last I saw that one in college, but in practice, not yet. We were taught more in theory but, practically, not involved. (Frontline_HCW_39)

Sometimes HCW experienced challenges when patients, in denial of a diagnosis of asthma based on history and/or clinical examination alone, asked for evidence of asthma backed by test results. In most instances, the HCW used bronchodilator tests to explain reversal of airways obstruction. According to a key informant, some tests may not be ordered because the HCW do not have the expertise.

Although the majority of the HCW reported confidence in diagnosing asthma based on clinical symptoms and patient history, interview narratives suggested that some HCW may not correctly diagnose asthma. In some instances, incorrect diagnosis was associated with inappropriate treatment decisions including repeat prescriptions of TB treatment for people with asthma or persistent symptoms of CRD.

The majority of the HCW workers indicated that for treatment decision-support, they depended on peer consultation with medical officers within the facilities or phone calls to specialists at the MTRH. Some HCW consulted their peers in private facilities or even their former teachers e.g., in medical training colleges, for a second opinion in diagnosing chest conditions. These engagements were usually done before decisions to refer patients were made.

> *At times, Meru General (MTRH) assists us in even managing patients .... if you make a call the doctor on the other side [they] may ask a few questions. If they feel that there is something that we can do, we agree that we try it first at our level. (Frontline_HCW_37).*

The majority of the HCW reported that overall, training opportunities were inadequate, and identified contextual challenges that were applicable across a range of training needs. Most trainings were conducted within the facilities, through weekly Continuing Medical Education (CME) sessions. CMEs involved HCW teaching their colleagues priority topics, e.g., differentiating mild from moderate asthma, and the appropriate management. CMEs lasted an hour, and each session covered a different topic (for example maternal care, child health), implying limited time to focus on a specific health condition in depth. Additionally, some staff may not attend CMEs due to conflicting priorities e.g., work shifts, or personal interests. Other opportunities for training included sessions e.g., on asthma embedded in TB trainings, *ad hoc* training by pharmaceutical companies, during their marketing campaigns and on occasions, HCW may access online resources e.g., by Global Initiatives for Asthma (GINA), through colleagues enrolled in such courses.

At the time of the data collection, the county government was rolling out an 'Integrated curriculum for lung diseases' that included asthma and COPD management, targeting all cadres of HCW. However, during interviews, it was reported that a low number of the total healthcare workers had been trained.

> *That Integrated Curriculum started last year. So, we have only, for the entire county, only 175 trained. Those are the people I can say now in terms of capacity to diagnose asthma and COPD, those people are well equipped. So, others unless we start doing CMEs and other sensitisation, yeah it is actually on the lower side. (KII County Official 12)*

Overall, the HCW reported fewer training opportunities during the devolution era, compared to pre-devolution. Although the county government supported school-based training by providing paid study leave to the HCW, several obstacles were reported. Firstly, some HCW may not afford fees for advanced training. Secondly, official county authorisation for the trainings were dependent on achieving minimum of three years of service to the county, and availability of substitute HCW to sustain healthcare provision. Thirdly, sometimes authorisation delayed and HCW missed such opportunities.

> *The approval is not easy; it takes time and most of the times you end up even not reporting because the reporting time is passed, and you don't have the approval; [you] cannot join course midway. (Frontline HCW 43)*

Several respondents associated difficulty in accessing limited government sponsorship opportunities with perceived cronyism in the selection process.

If there are any [programme places available], they are very rare; sometimes if they are there, you need to have connections [with key decision-makers]. (Frontline HCW 45)

For HCW on short, piecemeal contracts, decisions to enrol in advanced school-based training meant trade-offs with their employment opportunities, which were perceived as unaffordable. Interview data also revealed that there were inadequate incentives for HCW e.g., promotions, salary increments or new roles and responsibilities, post-training. HCW, particularly to those who financed their studies privately, perceived training to be a loss.

3.3.3. Data collection, policy, and guidelines availability

This study identified weaknesses in collection and management of clinical data, policy guidelines availability, and use (Table 3.3). Data collection tools were inadequate to accurately quantify the disease burden. For example, unlike hypertension and diabetes, there are no specific patient files with provisions for documenting asthma management. None of the sampled facilities had a dedicated asthma register.

Except for hospital revenue collection, data systems in the healthcare facilities are predominantly paper based, presenting difficulties in retrieval of clinical cards (usually filed in facilities) and portability, particularly in instances where patients may lose or forget the clinical cards at home. Such situations suggest difficulties in continuity of care.

Healthcare workers associated the shortage of professional Health Records Information Officers particularly at the primary care level to poor data quality. Clinical data were recorded into facility registers by nurses or volunteers and casual workers on short contracts. Sometimes, the casual workers/ volunteers may not record data written on the clinical cards correctly, or interpret abbreviations used by some clinical officers accurately. Interview narratives with healthcare workers highlighted instances of data gaps, e.g., missing diagnoses were reported on clinical cards.

We (records officers) find a lot of cards without diagnosis, but somehow the clinician was able to prescribe-after taking the history you just see the prescription- there is no impression (of the disease), there is no diagnosis, so you wonder, what are you treating? This patient got treated, but we don't know, for what? Others, you find blank cards in the consultation room- the clinician preferred to just write a prescription. (Frontline_HCW_55)

Missing clinical data were also associated to situations where patients may feel tired of waiting, and opt to go home, leaving their cards at service points.

The clinician may have requested for some test, but the patient does not come back.
(Frontline_HCW_55)

Challenges in collecting data from the service points, made it difficult to collate and document morbidity.

Now when you enter data in the '705 B' (outpatient register summarising cases by disease category),
that is where contradictions come in… maybe malaria we had 5, maybe URTI [upper respiratory tract
infections] we had 300, down there, there is a row where we are supposed to indicate all "other
conditions" which do not fall in any (disease) categories but because of missing data […] you will
find that is where we are reporting most of the cases you find that we have hundreds of 'all other
cases'[…]even if you want to analyse top ten conditions, you find that "all other cases" is number
one (laughter!) how do you even report? And that is our biggest headache! (Frontline_HCW_55)

Table 3.3 The distribution of readiness scores based on tracer indicators for training and guidelines availability.

Domains and Tracer indicators	Mitunguu Health Centre (Level 3)	Laare Health Centre (Level 3)	Kanyakine Subcounty Hospital (Level 4)	Mutuati Subcounty Hospital (Level 4)	MTRH (Level 5)
Domain 1: Training and guidelines availability					
1. Whether doctors were trained to manage CRD in-service	0	0	4.16	0	4.16
2. Whether clinical officers trained to manage CRD in-service	4.16	0	0	0	4.16
3. Availability of guidelines on case-management of asthma	4.16	4.16	0	0	0
4. Availability of guidelines on case-management of COPD	0	0	0	4.16	0
5. Availability of guidelines on case-management of chronic bronchitis	4.16	0	0	0	0
6. Criteria for the referral of patients with CRD symptoms	4.16	4.16	0	4.16	0
7. Clinical criteria for the diagnosis of asthma	4.16	4.16	4.16	0	4.16
8. Clinical criteria for the possibility of COPD	4.16	4.16	4.16	0	0
Total Domain 1 scores	**24.96**	**16.64**	**12.48**	**8.32**	**12.48**

Dissemination of policies e.g., treatment guidelines and training opportunities were not standardised. Formal channels of communicating policy included monthly meetings of the facility in-charges at the sub county level, and CMEs. Social networks such as WhatsApp™ groups, were used too, though some HCW doubted the authenticity of documents shared on these channels. While few of the HCW reported access to treatment guidelines for asthma; some described these as chance encounters while using the internet.

> *Hmmmm, ok, guidelines on chronic lung conditions, of late I have not had any experience with any. I have not seen anything on that. (Facility Manager 16)*

Some healthcare workers also perceived the guidelines to be too bulky to read, and preferred use of simple infographic tools.

3.3.4. Limitations in standardised treatment plans, referral processes and integration of services

The HCW accounts showed that there were no standard approaches to treatment of asthma. For example, some HCW prescribed medications that would provide faster relief, e.g., hydrocortisone, aminophylline, or adrenaline injections in the early stages of treatment. A few HCW were concerned that incorrect administration of drugs such as aminophylline may expose patients to other health risks.

> *They give these injections because they provide fast relief to patients… but aminophylline is supposed to be administered carefully, otherwise we could be exposing the patients to heart complications. (Facility_Manager_48)*

In some instances, HCW preferred injections because a facility nebuliser was dysfunctional. Some HCW also preferred oral salbutamol because they perceived it to be more affordable than inhalers. Patients, including those attending health centres, would have to purchase inhalers if they had run out of stock in the facilities. Nebulised asthma medications were reported to be progressively adopted in the public healthcare facilities compared to previous years.

> *Respondent: I can say the nebulisation machine has worked well for us. Initially we didn't have one, but we purchased one last year but one (2018), that one has totally assisted us managing this patient. […]it has assisted us a lot because initially we used to rely on injections which at times you give the patient injection, she/he doesn't respond, then you are left embarrassed and stranded on what next (both laugh!)*
>
> *Interviewer: Wow wow wow! So what injections were offered, which drugs were used?*

> *Respondent: Basically, we just used to rely on hydrocortisone, then there was aminophylline. Though nowadays is not that much encouraged. The first line you are supposed to do the nebulisation. (Facility_Manager_16)*

Key informants identified integration of TB and other lung services as important but difficult to achieve, because there were no policy structures and specific plans to support the integration. Although integration of care for asthma with TB has been suggested, some interviews identified barriers associated with professional boundaries protection.

> *Respondent: Guidelines are there, they integrated curriculum, it has everything, it is only that the coordination has not been streamlined yeah. [...] I remember there was a time I wanted us to start from here, we start it a xxx hospital, so I remember the one who was (a doctor), he told me, "you are just starting now a fight with the medical officers, if you are going to take the asthma patients" [...] (laughs) that one you know am starting a fight yeah, because we had even talked to purchase the inhalers for free and it was actually agreed so then he told take caution because you have started a fight with the medical officers.*

> *Interviewer: What issues were they raising?*

> *Respondent: I don't know, I don't know, you know if you pick all the patients and make them your patients (laughs) they think you are marketing yourself, they don't know you want to streamline the disease burden and ensure the patient gets the best of care KII_County_official_12)*

None of the case study healthcare facilities had a tobacco cessation programme. Smokers were counselled within routine consultation processes. Healthcare workers however reported that the approach was ineffective. Some patients tended to avoid clinicians who followed up on their smoking habits. It was also unclear how often people's smoking was reported or documented. Sometimes, asthma patients with a smoking history were not advised to stop smoking. Additionally, some patients ignored counsel to stop smoking, and presented to facilities with attacks.

Long, tedious referral processes may demotivate patients from seeking further care. Contrary to referred patients' expectations to see a physician at the MTRH directly, they may be directed to follow the normal outpatient processes i.e., from registration, consultation through clinical officers etc., and may not see the physician at all. In some instances, patients were discouraged to uptake referral services because of costs such as travel, and user fees that are charged at the higher-level facilities. Healthcare workers' interview accounts also showed that patients in need of specialist review may opt to go to other primary care level facilities, where these services were not offered. There were no structures or plans for feedback, from higher level

facilities to lower-level facilities, about outcomes and subsequent management plans for patients who had been referred for care. In some instances, HCW may follow up with patients at their own discretion.

3.3.5. Availability of equipment and other challenges in diagnosis of asthma

Inadequate diagnostic capacity impeded timely diagnosis and management of asthma. All surveyed facilities reported having functional nebulisers. Only one subcounty hospital reported having all equipment, and this was the only hospital with a peak flow meter. The MTRH reported availability of pulse oximeters, equipment for tracheal aspiration and pleural drainage, needles and equipment for transthoracic pleural biopsy, bronchoscope. Table 3.4. summarises availability of equipment in five sampled facilities.

Table 3.4 Availability of equipment in the five sampled facilities

Domains and Tracer indicators	Mitunguu Health Centre (Level 3)	Laare Health Centre (Level 3)	Kanyakine Subcounty Hospital (Level 4)	Mutuati Subcounty Hospital (Level 4)	MTRH (Level 5)
Domain 2: Availability of equipment					
1. Peak flow meter with mouthpieces	0	0	6.66	0	0
2. Spacer device for children/adults	0	0	6.66	0	0
3. Pulse oximeter	0	0	6.66	0	6.66
4. Oxygen sources (cylinder and/or concentrator and accessories)	0	0	6.66	6.66	6.66
5. Nebuliser with mask	6.66	6.66	6.66	6.66	6.66
Total Domain 2 scores	**6.66**	**6.66**	**33.3**	**13.32**	**19.98**

According to in-depth interviews, diagnosis of patients with respiratory symptoms prioritises sputum tests to rule out TB. Meru County has five GeneXpert™ machines, each distributed in hospitals located in highest TB burden areas. These included the three sampled hospitals. All the GeneXpert machines were module 4, except the one at MTRH (module 16), implying 2 hours' processing cycles of 4 and 16 samples, respectively. Although GeneXpert machines were perceived to have enhanced faster and more accurate diagnosis of TB, their capacities were deemed inadequate, due to high workloads. Additionally, transportation of sputum samples from the sub counties that do not have GeneXpert machines was hampered because of long distances, and occasionally, GeneXpert cartridges ran out of stock.

The other one, the GeneXpert they have placed there, they move very well, sometimes no cartridges to yeah so, we have been having gaps here and there. But if we could get GeneXpert for every subcounty that one will really close a very big gap and big challenges that we are experiencing as a county because of distances when it comes to sputum transport. We have tried to implement sputum networking in Meru County, but it is not working because of the distances (KII County Official 12)

In one sub county hospital, frequent electricity power outages and lack of 'Uninterrupted Power Supply' equipment reportedly ruined GeneXpert tests exposing patients to additional travel costs and inconvenience for repeat sputum testing. Some of these patients did not come back. The power disruptions were also associated with wasted personnel time and GeneXpert cartridges.

Some patients produced poor quality sputum samples e.g., very little sputum, containing saliva, food or *khat* particles, or blood. Such instances required patients to repeat samples. In some instances, patients who were issued with drug prescriptions for antibiotics and sputum test requests at the same time at consultation, may not present to the laboratory at all. According to HCW, such prescriptions were made, out of concern for patients who may have bacterial infection and were perceived as unlikely to return for test results and further treatment and follow-up. Healthcare workers were also cautious to minimise perceptions among patients that they did not receive treatment at the facilities.

You know if a patient comes here, I am not sure if it's TB. Now if I just send that patient without medication, how will it be, you know?! He or she may go, and the conditions worsen... then s/he goes elsewhere- I went to [a] facility, met a clinical officer, who just ordered a smear for me, no medication given (laughs)[...]so the only thing we try avoid is giving medication like augmentin, ciprofloxacin. These are used in treating multidrug resistance in TB (Frontline_HCW_01)

None of the subcounty hospitals provided chest x-ray services, at the time of the study. One hospital did not have an x-ray machine at all, while in second facility, the quality of chest x-ray images from previous tests were deemed poor, as they were not clear, and could not be used for diagnosis. Consequently, patients were referred to other healthcare facilities for chest x-rays; many of whom did not come back. Although the MTRH provided radiology services, the costs, particularly CT scan (7500 shillings= 64.4 USD) were unaffordable to many patients. Additionally, interview accounts suggested that some patients may not come back for their x-ray results especially if they required a radiologist's report that would not be provided on the same day.

3.3.6. Supply of drugs and medical technologies

The survey established that majority of the healthcare facilities reported availability of drugs. An analysis by healthcare level shows that health centres reported no availability of prednisolone and beclomethasone metred dose inhalers. All hospitals reported availability of all tracer drugs.

Table 3.5 Availability of selected essential drugs for chronic respiratory diseases

	Mitunguu Health Centre (Level 3)	Laare Health Centre (Level 3)	Kanyakine Hospital (Level 4)	Mutuati Hospital (Level 4)	MTRH (Level 5)
Domain 3: Drugs for asthma					
1. Prednisolone oral	0	0	5.55	5.55	5.55
2. Hydrocortisone for injection	5.55	5.55	5.55	5.55	5.55
3. Beclomethasone metered dose inhaler	0	0	5.55	5.55	5.55
4. Epinephrine (adrenaline) for injection	5.55	5.55	5.55	5.55	5.55
5. Salbutamol metered dose inhaler	5.55	5.55	5.55	5.55	5.55
6. Salbutamol solution for nebuliser	5.55	5.55	5.55	5.55	5.55
Total Domain 3 Scores	**22.2**	**22.2**	**33.3**	**33.3**	**33.3**

A comparison of the health centres, however, shows that one facility reported as 'never available', drugs that the other health centres reported as 'at least one valid'. These drugs were: dexamethasone oral, dexamethasone for injection, promethazine oral, beclomethasone nasal spray, beclomethasone metered dose inhaler, ipratropium bromide metered dose inhaler, and salbutamol ampoule for injection. Spacer devices were not stocked in two hospitals.

In-depth interviews established that the County government of Meru purchased drugs mainly from the Kenya Medical Supplies Authority (KEMSA), on behalf of the facilities, although private suppliers like the Mission for Essential Drugs Supplies (MEDS) were also involved in some instances. Drug requisitions were made from online essential medicines list (EML), circulated quarterly by subcounty pharmacists. This list is based on excel templates that contain drugs that may be ordered, and their unit prices. The excel spreadsheets are configured to sum up the value of drugs ordered within a given budget ceiling. For example, health centres

have a budget ceiling of 500,000 Kenya shillings (USD 4296[3]) for drugs, per quarter. The majority of the HCW strongly felt that supply of drugs had improved within devolved government context.

> *Since devolution came, there has been a good supply of drugs - plenty and even good ones- you can order what you want - that is also a thumbs up. There is an improvement of supply of drugs compared to [pre-devolution] national government. (Frontline_HCW_41)*

Key aspects of improved drug supply included timeliness of deliveries, and accuracy of orders. The facility survey established most facilities (n=3) had received their drug deliveries between two weeks to one month following their most recent order. Additionally, a wider range of quality drugs could now be purchased. Involvement of healthcare workers in prioritising drugs enhanced alignment of the supplies to local facility needs.

The county government negotiated with KEMSA to supply inhalers at subsidised cost. Consequently, inhaled corticosteroids (ICS) that would cost 1500-2500 Kenya shillings (13-21.5 USD) at market rates, were provided at 200 shillings (1.7 USD), at hospital level. For the health centres, drugs were provided free of charge, in line with the government policy of no user fees at the primary healthcare level. An exit survey (see chapter 5) confirmed that no patients paid for drugs in both the health centres. For one of the primary healthcare facilities however, the excel sheet for drugs requisitions excluded the ICS, so patients were required to purchase from private retailers.

> *Basically, there is a flat rate that is around not more than 200 shillings. This includes all inhalers. We offer them at subsidised rate, because the motive is not profit, but to offer access to inhalers. (KII_subcounty_decision_maker_HCW_28)*

The quantities of drugs are however perceived to be inadequate; frequent drug stock outs were reported. Some respondents associated drug stock outs to budget constraints at the facility level.

> *We get the average consumptions for a month, average monthly consumption then we multiply by 3. If we used like 10 tins of Ventolin in a month so we approximate we should order 30, multiply by 3 [**Interviewer:** ok, for the quarter] for the quarter but we are still limited with the funds such that when they exceed, we reduce a little bit like 25 we go reducing, reducing so that we can get the exact 500,000 shillings, Sometimes we are limited [may order less than needed] because it is like beyond our hands, so we just go with what we have been given. So that is why we experience some stockouts. (Frontline_HCW_02)*

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[3] (1 US$= Kenya shillings 116.4, based on Oanda) (https://www.oanda.com/currency-converter/en/?from=USD&to=KES&amount=1) forex rates on 18 June 2022)

Some HCW and key informants perceived KEMSA to have inadequate capacity to supply all the 47 counties. Alternative views were that KEMSA processed drug orders on a "first come-first-served" basis. This implied that KEMSA stocks may run out before a county's queued order has been processed. KEMSA therefore supplied drugs that were available and may substitute requisitioned drugs that were out of stock.

Surges in patient visits to facilities soon after drug deliveries were also associated to fast depletion of drug stocks. Additionally, lapses in communication to health facilities about drugs that may be ordered through KEMSA affected timely drug supplies. An invalid order may be corrected in the next round of quarterly supplies, meaning that stock-outs may last 3-6 months.

> *Yeah, yeah maybe you are ordering that drug, you are not getting, you ask yourself, 'why are you not getting that drug?', you hear (through informal channels) that it has been scrapped from that essential drug list. (Frontline_HCW_02)*

Healthcare workers reported the frequent unavailability of prescribed drugs and inhalers at the facilities had an adverse impact on their demand by patients. A HCW observed that some patients, accustomed to frequent stock outs, purchased directly from private retailers, and may not be aware of subsequent drugs availability, e.g., new deliveries at the health facilities.

> *Because some patients would come ask whether they (drugs) have been supplied? "no, not yet, not yet" (facility pharmacist) […] they (patients) end up going away, they assume we don't have. So, we are losing many (patients) even when we have the drugs supply patients wouldn't know because they have been asking for almost more than two months and we don't have the supply, so they end up just buying (from the private chemists) instead of coming and collect. (Frontline_HCW_02)*

Some HCW and key informant interviews shed light on contextual issues affecting drugs' supplies. In 2018, KEMSA stopped supplying drugs to many counties, including Meru, that had defaulted on payments due for previous supplies. To correct this situation, the national government passed a law in July 2019, which compelled all counties to purchase drugs from KEMSA. Alternative suppliers would be considered only if KEMSA did not have the required products. Although this law aimed to compel counties to offset their outstanding balances, it however limited counties' options, particularly in situations where KEMSA ran out of stock. According to interviews, the current Meru County government had resolved this problem, through adherence to an agreed payment schedule.

> *That one… KEMSA the time they never supplied we had a meeting, I understand there was a very big budget, a big debt that was not cleared. So, they could not supply, that one was cross cutting in almost all the Counties, there was that outcry. […] even some counties started diverting KEMSA and going to look for another supplier (KII_County_official_12)*

3.3.7. Health service delivery challenges: patient-related factors

The preceding findings sections have used a mix of facility readiness survey findings and qualitative IDI and KII to illustrate the key findings. The rest of chapter 3 findings are based on the KII and IDI findings only. In this section, we highlight challenges to health services delivery, with a focus on how patient-related factors i.e., stigma, perceptions, and poverty, undermine provision of appropriate care for CRD.

Perceived low awareness of asthma among patients, imposed barriers to service delivery. Healthcare workers reported that many patients were distraught and in denial by asthma diagnoses. These responses were associated with various forms of stigma for asthma. Health care workers observed that most people did not have adequate awareness about the risk factors of asthma, and associated asthma more to hereditary risk factors, compared to other exposures such as allergens.

> *You tell them that they have asthma, but they (patients) insist that 'no one in our family has asthma'. It becomes extremely difficult to proceed (Frontline_HCW_01)*

Some patients associated asthma to traditional beliefs, such as curses.

> *Sometimes our patients do not understand these conditions. It sometimes runs in family and when a patient comes does not want to be identified with some conditions because some say it is a curse, you know there are some those rumours and misconceptions about some conditions (Facility_Manager_18)*

Some people also perceived asthma to be contagious and associated with TB. Additionally, asthma was likened to other stigmatising chronic conditions such as epilepsy.

> *Any chronic illness in our setting has stigma. Epilepsy, asthma maybe the only ones they don't have much stigma would be diabetes and hypertension and I think it is because of the efforts towards public awareness but people don't understand what asthma is, even some healthcare workers (Frontline_HCW_26).*

People with asthma were also perceived by other people, to be weaklings, and may therefore be discriminated in jobs and marriage prospects.

Stigma for asthma affected the consultation process, diagnosis, and treatment plans. For example, healthcare workers reported that some patients may not disclose important symptoms, such as coughs during history taking, or may decline to produce sputum samples, or take tests. Healthcare workers responded mostly through assurances to the patients about confidentiality of information shared during consultations; additionally, HCW pointed out that stigmatised conditions like TB have cures, implying availability of

solutions for conditions like asthma as well. Other interventions included engaging CHVs to educate community members on the importance of communicating clearly and disclosing information about their illnesses to healthcare workers.

Some HCW underscored the importance of communication, and educating patients about asthma, sometimes by opening with discussion about allergies.

> *Before I even mention asthma, I usually start with the word allergy so that after I conclude I then tell them it's known as asthma. So, after I tell them about this allergy, I then tell them allergies can come any time. It doesn't have to go with the families. (Frontline_HCW_41)*

Secondly, some patients declined prescribed medication such as inhalers or use of spacers, particularly parents with whose children had asthma; they insisted on oral medication.

> *majority of these parents tend to develop that denial; they don't take it positively and they don't accept that the child could be developing asthma. So, you find that you do a certain prescription to this mother, and you give the health education and all the necessities that are required, you realise that this mother doesn't give the child the medication, they seek the attention from another facility or from another clinician and whenever they are told the same, they still don't accept. So, you find that by the time they come to the clinic to accept the recent condition, this child is in worse situation, the condition has progressed to severity. (Frontline_HCW_26)*

> *So, in my experience every time I tell a mum, even one who is educated that your child could be having asthma, they tell you, "no where did he get it?" So, they won't come for the next clinic (review), most likely they don't even buy the inhalers, they don't buy the spacers, they just disappear then they go to of course to maybe a Clinical Officer in a private clinic always being given steroids, because you see there are diseases which can always improve with steroid, so it becomes like a steroid dependent illness. (Frontline_HCW_26)*

According to the healthcare workers, stigma posed challenges to important processes such as demonstration of inhaler use. Furthermore, open spaces for drug dispensation at the pharmacies in all facilities limited audio-visual privacy, and appropriate communication of inhaler use. Some HCW observed that patients communicated in hushed tones when receiving asthma medication so as not to be heard by other patients waiting in the queue for medication. Thirdly, some patients may not come back for subsequent reviews or were presumed to see alternative providers. It was perceived as common, for such patients to attend at a later stage with acute exacerbations of asthma.

When you tell them it's asthma they say "no daktari no, (no, doctor) don't write asthma, in our family there is nobody who suffers from asthma, that's bad illness, I don't want to be associated with it", but after counselling most of them cooperate and I just advise them to take …. medication [and] they will get well. Then you find the clinics, they follow like some months and then they don't show up anymore, they come when there in attack the next time they visit. (Frontline_HCW_01)

Conflicting diagnoses and instruction by HCW affected patients' acceptance of inhalers in subsequent clinical encounters. Some HCW associated the denial of asthma diagnosis and inhaler use, to previous advice that patients may have received from other HCW, particularly at the primary care level.

The patient tells you, "I was told that this is not asthma". (Frontline_HCW_57)

Consequently, HCWs reported that patients preferred alternative diagnoses or disease labels such as 'bronchitis', 'pneumonia', or 'allergy'. In some patients' encounters, particularly in primary care facilities, HCW reportedly described inhalers as 'being too strong for the patient' and considered a last resort intervention, particularly for the most severe cases, which once started may create dependency. Additionally, some HCW preferred oral steroids e.g., prednisolone, perceived as a 'magic bullet' for lung conditions with inconclusive diagnosis. This however exposed patients to other health problems, including heart complications.

Some patients were also reported to have 'self-stigma' denoting, the internalisation by individuals, of negative attitudes the public may have about them, resulting in adverse consequences.

Others cannot afford the drugs, so the family finds it challenging to have such a person because when they have congestion they see it as a cost, thus a burden. When the patient observes these perceptions on them, they don't feel good. We have one such person in our family and it's a big challenge. (Frontline_HCW_40)

Self-stigma was associated with failure of patients to disclose their deteriorating conditions, and partly explained frequent incidents of patients presenting to the facilities in severe asthmatic attacks. Some patients were also anxious at the prospects of living with chronic conditions for the rest of their lives, risk of disability or death.

HCWs expressed divergent opinions on whether there was stigma related to asthma.

I have never experienced that, and I have not heard of it, stigmatisation against asthma yeah, I think it is because, both places and where I have worked, people, you know it is about knowledge, I think most of the people are knowledgeable concerning that especially asthma, so I have not felt any

stigmatisation against those people. I have not seen them being stigmatised not by clinicians, not by the community. (Facility_Manager_23)

Most of the time I don't see that stigma when it comes to asthma because the patient will come[...] they usually tell the day when they come, "I'm asthmatic." Or when you are enquiring from them whether they have any chronic illness, they usually tell you if they have asthma. (Frontline_HCW_45)

Even the hospital… stigmatises the clients because I used to be in xxx [facility name redacted] - the patients with asthma… they had direct access, if they are under [having an asthma] attack they should not queue, get in and they were allocated a room where they could get direct access but like here in our facility asthma patients they are just taken as any other patient, just queue, they are not given that attention. (Frontline_HCW_02)

Stigma around asthma was not limited to patients- even healthcare workers with asthma did not readily disclose to other healthcare workers.

Yeah, there is that stigma; it is there. It is there. I think it is almost everywhere in this Meru County. They have that stigma. Even those people who know that they have asthma, when they come to hospital, even as a medic, they will not be open to tell you that they have asthma. They try to beat around the bush; they don't want to say exactly that they have a chronic disease like asthma. So, there is that stigma. (Frontline_HCW_11)

Some HCW reported that children less than 14 years of age may come to the health facility unaccompanied and may not appropriately communicate important symptoms. Some diagnoses were missed.

I also have the challenge this community they are fond of a child who is less than 15 years go to the hospital alone, so this child may not be able to give proper history and when you know the history is the key thing to allow you to get the correct diagnosis, so you miss the history you may mess up the diagnosis. So that is one challenge I have seen in this community, the parents do really bring the children to the hospital, even a child of 7 years, you told send there, the child to the hospital, which becomes a challenge to us sometimes. Sometimes you may give these child drugs and this child may miss what was explained (Facility_Manager_18).

Challenges in patients' adherence to treatment plan and self-management

Effective control of chronic diseases requires that patients are empowered to self-manage their conditions, even as they adhere to the clinical review plans. Such empowerment may achieve the dual aim of generating or sustaining demand for appropriate healthcare services, as well as efficient use of healthcare resources e.g., healthcare workers' time.

Depending on severity of asthma, patients were scheduled for weekly and monthly reviews and treatment. Interview data with HCW showed that asthma patients were empowered to self-manage through education to identify and avoid risk factors like smoke from biomass fuels and tobacco, and allergens e.g., dust and cold. Patients were also taught inhaler use. Persons accompanying the patients to the facilities e.g., close relations received instructions on supporting patients, including with adherence to medication. Some HCW, at their discretion, shared their phone contacts with patients to respond to any issues that may arise.

The HCW narratives showed that patients' expectations, and assumptions, imposed barriers to individualised treatment plans, underlined by demand for certain treatment.

> *For example, some asthmatic patients expected to be given similar treatment to someone they know, not understanding that asthma is a spectrum. (Frontline_HCW_60)*

Patients reporting adherence to the treatment plans, or relief of symptoms expected HCW recommendations that they stop taking asthma medication during review. Such patients felt disappointed when they were urged to continue taking medication, or prospects of taking medication for long, which they perceived to be burdensome. HCW reported that many patients did not adhere to the asthma treatment plans. For example, some stopped using the inhalers or other asthma medication as soon as they felt better. One HCW associated this non-adherence to the 'free medication policy' at the primary care level (section 2.3.6).

> *Again, there are some people who are basically ignorant, they cannot complete the dosage. You give them they come here again, [Doctor]: "did you complete the dose?" [patient]: "No, I got healed I did not continue taking the drug" you see sometimes that is the challenges we experience here ...and you see for them they don't know. You are giving them this drug, they don't pay for these drugs you give them free; they go to use them in the manner they want but you know they are destroying themselves, [...] They are not taking drugs as prescribed because of ignorance and presumably because these things are given free, they are not paying any coin. Maybe you come back I will give you some more. (Frontline_HCW_17)*

HCW interviews suggested that self-medication was very common, especially amongst patients who did not prioritise additional clinician reviews. Some patients preferred buying drugs, including controlled drugs like steroids, over the counter without a doctor's prescription. The HCWs suggested that some of these patients consequently presented to health facilities with poor asthma control.

According to some HCW, many patients, particularly those who claimed no relief of asthma symptoms did not use inhalers correctly. The interviews showed that most of the facilities did not have dummy inhalers, which led to inadequate demonstration of inhaler use to patients. Some respondents observed that HCW too, may not know correct inhaler use.

> *If a healthcare worker does not know how to use it, (inhaler) then you don't expect patients to get anything. (Frontline_HCW_41)*

Additionally, it was established that some patients preferred nebulisers at the facilities, rather than to self-administer inhalers.

> *We have many people coming for nebulisation because they don't know how to use the (inhaler) device. (Frontline_HCW_41)*

One HCW worker observed that existing public health awareness about lung health, e.g., through media channels like TV, have focused too much on TB, neglecting other chronic conditions like asthma, therefore limiting public awareness.

3.3.8. Healthcare financing, leadership, and governance

The health services at Meru County are mainly financed through public sources, and out-of-pocket expenditures (OOP). According to key informants and some HCW, the county government determines budget allocations to the healthcare facilities, mainly based on facility workload data. These allocations are made every two months, and outline budget ceilings for facility expenditures. At the hospital level, county allocations are supplemented by user fee revenues, paid out-of-pocket (OOP). Since the facility workload data is reviewed every quarter, instances of low patient visits adversely affected subsequent county financial allocations and revenue generation from user fees.

All health facility management teams (HMT) reported that they had autonomy to spend the revenues generated from user fees, subject to authorisation to incur expenditure from the County Department of Health (CDOH). Sometimes however there may be delays in the approvals. Additionally, hospitals accessed reimbursements from NHIF for claims for outpatient care and the free maternity care cover. These revenue pools could be used to respond to emergency facility needs for example purchase of essential drugs like nebulised salbutamol.

The process of budgeting is initiated by the health facility management team (HMT). This committee comprises senior facility management (facility in charge, nursing services manager and hospital administrator) and the respective heads of departments e.g., clinical services, laboratory, and pharmacy. Subsequent decisions on the budget are however made by the expenditure executive committee (EEC) comprising of the facility in-charge, the facility administrator, the head of pharmacy, nursing services manager and the accountant, and finally, the facility board of management comprising of members of the EEC and community representatives, appointed by the county government. Such decisions sometimes result in reducing departmental allocations e.g., on the quantities of drugs ordered.

Healthcare workers' strikes posed serious threats to healthcare delivery in Meru County. In 2019 for example, a nationwide clinical officers' strike started in November and lasted almost two months. According to healthcare workers' interviews, reasons for these strikes include delayed salaries sometimes lasting 2-3 months, and stagnation in promotions of HCW in some instances ten years. Key informant interviews linked these salary delays to late disbursements of funds from the national treasury to the county government treasury. Additionally, some HCW expressed concerns about financial accountability. For example, statutory payroll deductions were made on their salaries, e.g., to the NHIF and voluntary deductions (e.g., for personal loans from banks or credit societies), but were not credited to the appropriate accounts. Consequently, the HCW and their dependents defaulted on payments to NHIF and could not access NHIF cover for their healthcare expenses. This exposed them to financial strains associated with out-of-pocket payments. HCW were exposed to adverse credit scoring, for example when they defaulted on loans from banks and other financial institutions, implying difficulty in accessing future loan facilities. These problems in financial flows affected HCW motivation to work and provided some of the impetus to strike.

Interviews with healthcare workers and key informants on coverage and use of the NHIF to pay for healthcare services for CRD showed that the coverage and usage were inadequate. Although the county government and the NHIF representatives were reported to be creating awareness for the people to enrol in NHIF, enrolment into NHIF and use of the insurance to access outpatient care in Meru was reported to be generally low. Some of the reasons cited include unaffordable premiums, amidst general patients' expectations that all services would be provided without out-of-pocket payments. A healthcare worker observed that some of these patients have erratic, unreliable income patterns, and NHIF premiums are considered proportionately high to the income.

> They are the needy; the disadvantaged I mean. So, you find a person complaining, "I go for casual work. Maybe I work twice per week; that is a wage of KES 600. Sometimes a whole week I lack a job. So, telling me to pay KES 500 for NHIF, it is very difficult". We have tried (encouraged patients to enrol), but the challenge is still there. The response is very poor; very poor depending on the class of people I deal with. (Frontline_HCW_25)

In instances of poor quality of healthcare services for example frequent drug stock outs or lack of certain tests in healthcare facilities, NHIF members were obliged to pay out-of-pocket in other facilities.

> Most people find the NHIF premiums expensive yet when you sometimes go to some hospitals, they don't cater for all drugs nor all tests. Therefore, they view it as a loss to pay 500 bob (KES 500, the NHIF premium) then you are informed at the hospital that the NHIF card cannot cater for some services. (Frontline_HCW_40).

The recent reforms in NHIF allow patients to select two healthcare facilities, including private healthcare facilities. According to one HCW, some people preferred private facilities to public ones, mainly because the services were perceived to be of higher quality. This may partly explain the low coverage of NHIF membership recorded in the sampled public facilities.

> *We are neighboured with private hospitals, we have Consolata, we have St. Annes so people around they tend to think if I have my NHIF card and I can be served in either of the hospitals they prefer to go to the other hospitals. So, we are unable to get the expected population that we would want because people would be like why should I go a public hospital and there St. Anne and there is Consolata (private facilities) and am going to be given services (200521_1107_KII)*

> *As I said maybe they come, they needed and they were expecting a service to be delivered and we are telling them, "oh for now we don't have those services but for now", the you know, (you understand how government facilities work), Like for example patient comes over here and spends the whole, day waiting, without services, so, when they are finally served, they are told- "you will buy drugs in some other private facility". You are sent for x-ray like now, St Mary's ama St. Anne. You bring the result again back and you must pay from your pocket, remember transport costs also. So, they prefer to just go to the private facilities. (200521_1107_KII)*

Since NHIF members may only be covered for services in the two selected hospitals, this means that they would have to pay out-of-pocket if they accessed outpatient services in any other hospital. This may partly explain why patients felt frustrated at having to pay for services, '*yet they have NHIF cover'*.

> *Also, there is this other challenge, a patient maybe enrolled with NHIF but he or she has not chosen this hospital as an outpatient, as outpatient hospital. That means most likely if he/she comes as an outpatient he, the patient may be required to pay money from his pocket or her pocket. Yeah, so which again some patients don't understand. Eh, what are the issues? Maybe if it is possible and controlled people should be at a position to seek NHIF services in any hospital at any time. (HCW_200428_1218_)*

According to some healthcare workers, some patients did not perceive the risk of illness to be high enough to warrant an insurance cover.

> *Somebody just feels there is no need of having an NHIF cover. Some of them give funny arguments like, "I don't fall sick often. I fall sick like once a year. Therefore, I'm able to go and buy a few antibiotics from a clinic that is somewhere in my village". (HCW_200428_1218)*

Some patients had a low perception of risk of serious illness.

The other thing I can say is about ignorance because most of the client you approach; they already have the information, even through the media. But the person asks a question, "What if I won't get sick?" Ok I sacrifice my money. What if I won't get sick? So, some people are just ignorant. (HCW_1540)

Some people did not have documents required for registration, e.g., national identity cards or birth certificates, for their children. This was associated with widespread local perceptions that only the formally employed people were eligible for NHIF membership. Additionally, utility of identity cards was associated with services historically perceived to be elitist such as banking, although some people perceived identity cards to be useful mainly in voting during general elections.

I think for these patients [who are] asthmatic and these other [people with] COPD and even the TB patients, the enrolment to the NHIF is still very low, is very low yeah because we have even patients who have no ID cards up to this age. Like you know for TB patients, we are supposed to enrol them for NHIF, the MDR-TB, or DR-TB patients immediately we diagnose them, but out of my patients I think usually I do around 60% the ones am able to enrol comfortably. Why [are] the 40% not enrolled? They have no ID cards; they have children with no birth certificates. Yeah, so we have that challenge that is with us but those ones with the cards I have not experienced any problem when it comes to their treatment yeah. (190919_1317_KII_county)

Healthcare workers' interviews showed that although a hospital waiver system was in place for poor patients, it was not optimally utilised, partly because of low awareness among patients, attributed to poor linkage and communication between health facilities' frontline offices and the departments authorised to process waiver requests. To sustain waiver plans for vulnerable patients, it is important to conduct verification of patients' socio-economic status through household visits. Such visits entailed educating patients with CRD as asthma on risks-minimisation and provision of psychosocial support. Some HCW however reported constraints such as lack of vehicles and administrative support such as mobile phone airtime and allowances to conduct such verification processes. In some instances, the cost of conducting verification was more than the hospital bills and so the verification process was not pursued.

3.4. Discussion

This is the first study, to the best of our knowledge, to examine public healthcare facilities' readiness to respond to patients with symptoms of asthma, in a devolved government context in Kenya. By closely focusing on the lens of asthma diagnosis and treatment, and management plans, we contribute evidence on priority areas for managing other CRD. We identified critical systemic aspects that undermine health facilities' readiness, i.e., inadequate equipment and weak coordination of service delivery, limitations in

privacy due to infrastructural constraints, weak drugs' supplies, inadequate numbers of trained healthcare workers, and related missed opportunities for health education and counselling, gaps in access and standardised use of guidelines, healthcare financing and governance challenges. The study also identified patient-related factors such as perceived stigma related to asthma and factors that limited cooperation with treatment plans including self-management.

These findings underscore four main issues, i.e., health system strengthening for CRD in the context of chronic under-resourcing; implications of the study findings on person-centred care; priority setting and governance in a devolved government context and the adverse impacts of stigma on service delivery and patient-self management. We identified a few strengths. These systemic weaknesses also provided an opportunity for specific changes that actively demonstrate political goodwill to strengthen the health system. Examples include comparatively higher budget allocations to the County Department of Health by the county government of the day, aimed at enhancing healthcare services; investments in infrastructural development of healthcare facilities demonstrates responsiveness to identified needs in service delivery, rollout of an Integrated Curriculum for Lung Health in 2019, to enhance healthcare workers' capacities to provide care for CRD, involvement of healthcare workers in health facilities' prioritization mechanisms- this would in theory, enhance ownership of healthcare service delivery, and better alignment of quality drugs deliveries with health facility needs. The next section expounds in more detail on important weaknesses and highlights specific strengths.

3.4.1. Health systems strengthening in the context of chronic under-resourcing.

This study contributes evidence on the need to strengthen healthcare systems to be responsive to CRD, particularly in contexts of chronic under-resourcing like Kenya. Frenk outlines basic requirements for enhancing a health system that is responsive to legitimate expectations of people as consumers of health care services, providers of care, and, as citizens whose taxes finance operations of healthcare systems [181]. Responsive healthcare systems are driven by appropriate technology, embedded in sub-systems that coordinate resources and procedures that yield timely interventions. This study identified deficiencies in diagnostic and treatment technologies, as well as poor coordination of existing technologies with other scarce resources such as human resources, which collectively undermined the readiness of the health systems to respond to people with CRD.

We established the need to train HCWs, both preservice and in-service. In-service trainings should be complemented by effective policy and guidelines communication processes. Additionally, HCW will benefit from a package of education that supports them to find the literature they need if they have access to the

internet e.g., open access sites, current government policy, WHO PEN guidelines. These interventions would enhance standardisation of asthma treatment and management approaches.

The study found that inadequate drug supplies hamper effective healthcare responses to asthma - a problem widely acknowledged in other LMIC healthcare systems [182]. Frequent drug shortages were associated with low demand for inhalers by patients attending public healthcare facilities. This situation implies weakening of continuity of care plans and is associated with self-medication decisions. These findings are similar to another study that investigated access of Kenyan adults to NCD drugs [183]. Over-the-counter access to what should be regulated prescription-only medication exposes patients to health risks and represent a loss of opportunity to collect data e.g., on disease burden and health services utilisation in the public healthcare system. Consequently, this affects future resource allocation plans at the county level. GINA recommendations prioritise use of inhaled corticosteroids (ICS) in the management of asthma, to prevent exacerbations associated with inflammation [65]. This study established that adrenaline or aminophylline injections or oral steroids is often provided inappropriately at the first encounter with patients, because of lack of inhaled medications.

Unaffordable cost of drugs is a significant barrier to access of care [19, 184, 185]. It is therefore commendable that the county government of Meru negotiated a relatively low price of inhalers for public facilities. Initiatives to enhance access to NCD medications through subsidy programmes by pharmaceutical companies like Novartis™ have also been documented [186, 187]. There is need to explore and potentially expand such opportunities, including public private partnerships.

3.4.2. What does person-centred care look like?

This study highlights important aspects of person-centred care; our analysis shows that inadequate human resources constrained service delivery for people with symptoms of asthma. These constraints include limited time for communicating diagnosis appropriately and providing health education concerning, for example, common risk factors for asthma or indoor pollution from biomass fuels commonly used in rural areas in LMIC [13, 188], importance of inhaler use, and plans for patients' self-management. Healthcare workers seemed to prioritise faster turnaround times of patients from attendance to discharge over other elements of health service delivery. GINA guidelines recommend that depending on severity, an asthma patient should be reviewed 1-3 months after the start of treatment [65]. Decisions by healthcare workers to schedule patients' reviews much later contrary to their own professional preferences suggests gaps in continuity to care. The Meru County annual work plan 2019-2020 estimates a gap of medical doctors (n=11), pharmacists (n=23), pharmaceutical technologists (n=79), laboratory technologists (n=58), radiographers (n=19) and health records and information officers (n=98) [189]. By 2015, Meru County had 17 doctors per 100,000 people, and 66

nurses per 100,000 people. Although the healthcare worker per population ratio in Meru was higher compared to the national average (10 doctors and 55 nurses, per 100,000 people)[76], this was still significantly lower than the WHO minimum recommended thresholds of 21.7 doctors per 100,000, and 228 nurses per 100,000 [156]. These findings have significant implications on the prospects of patients' health education, self-management, and adoption of preventive behaviours.

This study established important gaps in diagnosis of asthma including, critically, a lack of lung function tests. GINA recommends that lung function tests using spirometry or peak flow meters, should be conducted at diagnosis and prior to treatment initiation [65]. Lung function tests are vital to consider alternative or concurrent diagnoses, estimate the severity of asthma and support clinical decision-making for subsequent treatment plans. None of the public facilities in Meru County provided lung function tests. Most interviewed HCW reported minimal pre-service exposure and therefore low confidence in conducting spirometry. These findings are mirrored in other studies from sub-Saharan Africa [190]. Lack of lung function tests have negative implications on patients' trust and satisfaction in the healthcare services. That some patients challenged healthcare providers to provide proof of asthma diagnosis signals difficulties in subsequent communication, for example about treatment and management plans, and prospects for future review. This situation also confirms a shift in patient-doctor relationships, and the growing emphasis on person-centred care [37, 129, 191]. We are also reminded that evidence-based medicine is not a preserve of professionals only - lay users too, demand both evidence and accountability in service provision.

That some healthcare workers may not know how to use inhalers correctly has negative implications on patient education, and effective monitoring of treatment. These challenges, coupled with the choice of some patients to not use inhalers because of stigma, means providing inhalers alone does not solve the issue. There have been instances of inhalers being provided and expiring in facilities or in KEMSA. These findings are consistent with other studies [192-194]. Inhalers have been described as among the "most complex devices in the pharmaceutical industry" [11]. Efforts to empower patients on inhaler use, and subsequently on self-management, must at the most basic, involve enhancement of healthcare workers' knowledge, skills, and confidence in using the inhalers. Consequently, healthcare workers would have confidence in their clinical decisions, and effectively persuade patients on the appropriate plans. Health systems are social institutions and are expected to be responsive, accountable, and empower the participants in the care process [195]. There is a need to educate patients the concept of chronicity, the need for individualised care plans, and the benefit of consistency in use of medications to avoid disease progression to severity. The preference for nebulisation services at the health facilities, rather than using inhalers is an indicator of low propensity for self-management by people with asthma.

The WHO advocates for integration of healthcare services to enhance efficiency, and sustain focus on the person, rather than disease [128]. Over the last two decades, significant resources have been invested in the management of HIV/AIDS and TB in Africa. The idea of leveraging NCD management on HIV/AIDS and TB care models is gaining traction among health care stakeholders [196]. For example, the Global Fund strategy for 2017-2022 includes health systems' strengthening among its four strategic pillars [197]. HIV/AIDS and TB care models are focused on chronic conditions, and therefore provide strategic opportunities for CRD management. It is thought that integration of services for NCDs at the primary healthcare level can potentially enhance efficiency in CRD management and minimise patient inconvenience [5, 15, 198].

3.4.3. Impact of stigma on facility services

This study findings support accumulating evidence of stigma related to asthma [199] and how such stigma undermines important processes in asthma diagnosis and treatment. Stigma related to asthma is a phenomenon that plagued high income countries several decades ago [200, 201] but which, surprisingly, is emerging as a big issue in Kenya [60] and other LMICs [202].

Stigma impedes effective communication during patients' examination, patient-doctor cooperation in developing a treatment plan, and patient adherence to medication and subsequent review appointments. All of these elements are contrary to the beneficial outcomes of person-centred care [128]. In this context, stigma seems to be driven mainly by lack of general awareness of risk factors for asthma, including the myth that asthma is contagious, like TB. Widespread perception of asthma as being associated more to hereditary risk factors, suggests feelings of 'helplessness' and lack of control over patients' situation. This phenomenon has been observed in patients with COPD and other chronic conditions [203]. Feelings of helplessness may undermine all practical behavioural responses e.g., patients' adherence to doctors' recommendations and obligations for self-management. Additionally, singular focus on hereditary risk factors may divert patients' attention and preventive actions from other important and widespread modifiable environmental risk factors such as exposures to smoke from tobacco or biomass fuels.

This study established that people with asthma feared discrimination related to diagnosis (or disclosure of diagnosis) and treatment (with a focus on inhaler use) – findings which have been observed in other contexts [204]. Previous studies have also demonstrated the association between stigma and poor control of asthma [205] and the need to incorporate psychosocial support in asthma and CRD response.

Section 6.2 discusses in more detail scope for applying lessons of stigma mitigation for HIV/AIDS and TB, to asthma. Possible interventions to reduce stigma for asthma include enhancing awareness about the risk factors of asthma, among community members. Through health education plans, community members may be

informed about other common exposures like smoke from biomass fuels, tobacco, and particulate matter e.g., dust and pesticide spray. Training of healthcare workers in their communications with patients about asthma diagnosis and treatment, may enhance understanding and perception of asthma among patients, as a treatable condition.

3.4.4. Priority-setting and governance in a devolved system

Devolution of health system functions has the potential to enhance priority-setting and governance processes [150]. Earlier studies from Kenya showed that the autonomy of healthcare facilities' managers for example in financial decision-making, purchasing of commodities and services, and decisions to hire casual workers diminished following devolution, resulting in a decline in morale among staff and operational difficulties that reduced the quality of healthcare services [59, 179]. The finding from this study that health facility managers had autonomy over revenues and in determination of priority expenditures, suggests a positive development in enhancing governance within the healthcare system. However, there is an urgent need to examine health system failures, particularly those relating to health workforce payments, accountability for payroll deductions, training, and career mobility prospects. These challenges have been associated with demotivation of healthcare workers and strikes. For more than ten years, the Kenyan healthcare sector has grappled with numerous healthcare worker strikes [157]. During these strikes, healthcare services delivery were disrupted, in some instances running into months [158]. Healthcare workers' strikes affected availability of quality healthcare services and were associated with poor health outcomes and patients' deaths [158]. Our analysis relates this situation to weaknesses in governance systems in Meru County. We contribute to the increasing calls to strengthen the governance of healthcare systems [206].

Inadequate healthcare infrastructure hampers effective provision of services. Lack of private spaces to observe patients, demonstrate inhaler use and dispense asthma medication may create anxiety among patients and act as a disincentive to seeking care. The lack of male wards in one subcounty hospital implies gendered inequities for accessing services. Beyond exposing patients to extra costs of accessing care through unnecessary referrals, the affected facilities lose opportunities for collecting vital data on service utilisation. Such hospitals are disadvantaged in resource allocations at the county level. Disruptions of electricity power supplies and their implications on sputum tests have been documented [207]. The findings of this study highlight the vital need for inter-sectoral collaboration, in this case in ensuring reliable supply of electricity.

Despite the challenges identified in this section, the study identifies various opportunities for provision of quality healthcare services to people with asthma. These include HCW perceptions of improved quality and choices of drugs supplies, based on the WHO EML [164]. Secondly, theoretically, the involvement of HCW in the planning and prioritisation of the facility budgets creates a sense of ownership in the process and is

likely to sustain better provision of services. Third, the use of data for facility workload in criteria for resource allocation decisions may provide incentives for proper data collection and management at the healthcare facilities. This may in turn, contribute to better estimates of disease burdens and disrupt the vicious cycle where lack of data undermines decisions that affect resource allocation, and service delivery processes[43]. These three issues demonstrate positive outcomes of the devolution process in strengthening the healthcare system and are important gains that the County government should consolidate in its quest for a responsive healthcare system. The challenges identified on coverage and use of NHIF for healthcare services are important in strengthening Kenya's strategy for universal health coverage. Chapter 5 complements these qualitative findings, through statistical analyses on patients' costs of care for the facilities' visits.

3.4.5. Strengths and limitations of this study

This study contributes evidence on specific strengths and weaknesses of the healthcare system affecting readiness to provision of care for asthma. These findings are applicable to other CRD and NCDs. The study uses a mix of quantitative and qualitative methods to quantify and explore the phenomena under investigation. This is important for both measuring and exploring underlying reasons why certain observations are made.

By investigating asthma in a high TB context, this study provides important opportunities to focus on other important respiratory diseases, which may be undermined by policy prioritisation of TB. This study also investigates health system responses for asthma in a largely rural context, and contributes to the evidence collected in urban contexts in Kenya [42].

This study had some limitations. The facility readiness survey was conducted on a small sample (n=5) of public facilities. The findings are therefore not generalisable to the entire county of Meru. This is however an exploratory study that has identified important issues that may be measured through larger scale, well-powered countywide or nationwide studies.

This study focused on public facilities only. Private healthcare providers constitute 50 % of healthcare providers in Kenya [208]. Exclusion of private providers therefore means that important perspectives e.g., on demand for services for asthma care, human resource functions, investment in infrastructure for asthma care and other CRD are missed. This study however aimed to understand weaknesses of public healthcare system, within a devolved government context. Public facilities are directly managed by the county governments, and therefore the lessons drawn from this study have direct bearing on public policy.

3.4.6. Conclusion and Recommendations

We conclude that, despite political prioritization of the healthcare system demonstrable through enhanced healthcare system investment by the Meru County government, deliberate efforts to make drugs for CRD cheaper through subsidies, and involvement of healthcare workers in drugs prioritization mechanisms at the healthcare facilities, inadequate resources and weak coordination mechanisms continue to undermine the public facilities' readiness to respond effectively to asthma. Stigma for asthma, and other patient-related factors are significant barriers to patients' demand, adherence to asthma treatment plans and self-management.

We recommend the following:

a) The healthcare workers should be trained on asthma management, including conducting lung function tests and inhaler use.

b) The healthcare worker teams at the facilities should enhance coordination of services to minimise inconvenience to patients and enhance access to all required services.

c) The county government should invest more in private spaces for patient review, drugs dispensation and wards.

d) The county government should strengthen drug supplies through better forecasting mechanisms and more allocation of finances for drugs.

e) The national government should strengthen drug supply chains through enhancing capacity of KEMSA and sealing loopholes for defaulting by counties.

f) The national government, county government and key stakeholders in lung health including the media, should also invest in enhancing awareness about asthma to the people, to minimise stigma.

g) The national government should ensure timely disbursement of funds to the county government.

h) The Meru County public service board urgently needs to strengthen governance and financial accountability mechanisms to reduce risks of healthcare workers' unrest.

i) The national government should lead the process of re-designing data collection tools, to provide for better collection of diagnostic data at the healthcare facilities.

j) The County government of Meru should strengthen its data collection and management system for lung health through employing and training professional health records officers particularly at the primary healthcare facilities' level, ensuring variables on chronic asthma as appropriately captured and regularly reviewing summary reports on CRD.

k) The county government of Meru should enhance supervision support at the health facilities to improve data management and quality.

Chapter 4: Community perceptions of asthma, health seeking behaviour and role of the community health system in supporting access to health services.

4.1. Introduction

The previous chapter examined readiness of the Meru County health system, to diagnose, treat and manage chronic asthma in public health facilities. In this chapter, the attention is shifted to the community health system, the most basic level of Kenya's public healthcare system [52, 123]. As in the previous section, we explore issues related to chronic respiratory diseases predominantly through the lens of asthma.

When properly managed, people with asthma lead normal lives [65]. Asthma is however often poorly managed in LMIC where high morbidity is associated with adverse developmental outcomes for example with children failing to thrive and missing school and adults missing out on employment, livelihood and social opportunities as a result of poorly controlled asthma [8, 28]. Like other chronic conditions, management of asthma requires a functional health system, characterised by proactive healthcare teams, informed patients, equity, and strong linkage between the community health systems and the formal healthcare systems [111]. Such linkages would enhance referrals of suspected asthma cases across the different levels of the healthcare system, according to need.

Community healthcare workers and volunteers have the potential to play important roles in asthma care through their responsibilities in supporting demand for healthcare services, access, self- management, and preventive interventions at the community level [117, 120]. The cadre are pivotal in enhancing reach of healthcare services particularly for communities living in remote, underserved areas [118]. Although many low and middle income countries initially focused community level-interventions on TB and HIV/AIDS, maternal and child health [209, 210], community health workers have increasingly supported NCD interventions, e.g. for cardiovascular diseases [211] and diabetes, and chronic respiratory diseases, including asthma [212].

Kenya initiated a community health strategy in 2006 [51]. CHVs in Kenya support health promotion, health prevention and treatment of some common diseases. While they have a specific focus on maternal and child health and nutrition, CHVs are also involved in promoting TB awareness, defaulter tracing and Directly Observed Treatment Short-course (DOTS), home based care programmes for the elderly and awareness about chronic conditions e.g. diabetes [51, 55]. The Kenya Health Sector Strategic Plan 2018-2023 outlines key strategies for strengthening the community health system [213]. These include provision for remuneration of community health volunteers, provision of resources to support CHVs' work in acknowledgement of the ever-expanding roles and expectations on the community health workers.

This study aimed to explore the current, and potential future, involvement of CHVs in supporting diagnosis and care of people with symptoms of asthma as characterised by a constellation of typical symptoms (difficulty in breathing, recurrent wheeze, chronic cough, and breathlessness) and where TB has been clinically and/or microbiologically excluded. The study also investigated the (overlapping) perceptions of asthma amongst CHVs and lay people at the community level and the perceptions of response to asthma at the healthcare facility level. Finally, the study explored systemic barriers and opportunities to achieving appropriate asthma management, examining the role of the community health system in referrals, experiences of access to healthcare and barriers and opportunities for adequately supporting people with asthma in Kenya's devolved government contexts.

4.2. Methods

Qualitative methods were used as this enables exploration of the underlying reasons and motivations of participants, based on their experiences, and perceptions, and attitudes within their unique cultural contexts [214]. We used in depth interviews (IDIs) as they are applicable in collecting data from individuals and are particularly appropriate when collecting sensitive data; key informant interviews (KII) to engage individuals believed to have deeper contextual understanding of issues [214]; and focus group discussions (FGDs) as they are able to reveal insights through the analysis of interactions among a group of participants [215, 216]. This study is reported using the Consolidated criteria for Reporting Qualitative research (COREQ) guidelines [217] to enhance transparency.

4.2.1. Study Setting and Selection of Participants

This study took place in Meru County between 27 June 2019 and 29 August 2020. The community health volunteers' roles include supporting healthcare promotion, and preventive activities, referral of people with any symptom of disease to healthcare facilities. The travel distance to health centres is approximately 5 kilometres, while subcounty hospitals may be 10-20 kilometres away. Asthma is a common condition in

Meru- possible risk factors include exposure to smoke from firewood, dust, cold, and other environmental pollutants[218, 219].

Study participants were sampled purposively (Table 4.1), for their roles in decision-making within the Meru County, community health strategy, support for the community health system, or service provision in healthcare facilities in the study sites. Community members and patients were also purposively selected because of their experiences in using services in the local healthcare facilities. Data were collected through KII with county and sub county officials, community health assistants (CHA); IDIs, and focus group discussions (FGDs) with CHVs supporting eight community health units linked to the sampled health centres and sub county hospitals (n=4), excluding the MTRH. We also conducted FGDs with community members living within five CHUs. FGDs consisted of 6-8 members and were stratified by gender as we knew perceptions of asthma might differ by gender and age. The community members' FGDs were further stratified by age i.e., young adults aged <35 and older adults aged 35 years and above. Stratification of focus groups by participants' characteristics such as gender, age, and race is important in enhancing free interactions between group members, who perceive each other as peers [215].

Table 4.1 Distribution of research participants

Participants	No of IDI/FGDs (participants)	Description of IDI/FGDs, age and/or gender composition
Community members	4 FGDs (n=32)	2 composed of adults > 35 years. 2 composed of young people 20-30 years. All FGDs stratified by gender
Patients	4 IDIs	2 males; 2 females
Community health volunteers	11 FGDs (n=75)	6 composed of female CHVs
	6 IDIs	4 male, 2 female CHVs
Community health assistants (CHA)	5 KII	2 females
County and subcounty officials	5 KII	4 males
Healthcare workers[4]	6 KII	3 males; 3 females
Total	133	

Due to COVID-19 disruptions and a government ban on community meetings, most of the community FGDs were conducted in one subcounty only. The first confirmed case of COVID-19 in Kenya was announced on 12th March 2020 [79].

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[4] Healthcare workers among those sampled in chapter 3.

4.2.2. Data Collection

To explore healthcare workers' perceptions and perspectives of CHVs, we included questions about the community health strategy, and their experiences working with CHVs in the healthcare workers' IDIs. Discussions were conducted in quiet, private locations convenient to the participants within the study area, i.e., community sites, healthcare facilities, and county offices. These sites provided audio and visual privacy. All FGDs were led by the principal investigator (SM), who has significant health systems and policy research experience; some IDIs were led by field research team members trained in qualitative research (CK and DM). Discussions involving community members and CHVs and patients were in Swahili, the most common language used by Kenyans, while key informant interviews (KIIs) were conducted in English. All discussions were audio recorded using SONY ICD-UX560F™ recorders. Field team members took field notes in different interviews. These notes documented key issues emerging from the interviews as well as contextual details relevant for this enquiry. The audios were transferred immediately after the discussions, to secure laptops, and transcribed verbatim, using MS Word. Swahili interviews were then translated to English, by a qualified translator. All transcripts were reviewed against the audio recordings and verified to be accurate accounts of the interviews.

Interviews followed semi-structured topic guides (Appendix 11& 12) and explored CHVs' awareness of chronic respiratory diseases, perceptions of chronic cough, their experiences in identifying adults and children with symptoms of asthma, referral of suspected asthma cases to healthcare facilities, subsequent roles in supporting asthma patients at the community level. The interviews also explored CHVs' involvement in raising awareness and promoting care for CRD. Specific questions focused on the linkage between the informal community health system to the formal healthcare system and how this worked (or did not work) in cases of asthma being referred from the community to the facility and vice versa. The discussions also explored CHVs' overall experiences in coverage of households within their respective community health units (CHUs), working relationships between CHVs and the CHAs and other frontline healthcare providers at the facilities, and CHVs' experiences in accessing training and supervision support on chronic asthma and other CRD. Finally, the interviews explored perceptions about county government of Meru support to the community health system e.g., on financing, training, and material resources. These discussions sought to understand CHVs' perceptions of successes and challenges in delivery of community health services. Community members and patients' interviews explored perceptions of chronic diseases, their awareness of asthma, including other community members' perceptions, their health-seeking behaviours, and their overall experiences of accessing services for CRD in public health facilities. Interviews with the county and sub county officials (Appendix 5b) focused on organisation, financing and decision-making for community health systems, experiences in supervising and supporting CHVs, community data collection and subsequent

information flows. Interviews with healthcare workers focused mostly on communication and linkage with CHVs, particularly on referral of patients and subsequently planning for future patients' reviews.

4.2.3. Data Trustworthiness and Analysis

The procedure of data collection, using digital voice recorders enhanced the quality of data, as well as transparency in the analytical process. Furthermore, by having two interviewers in the data collection process, it provided opportunities to probe better and collect comprehensive information as well as discuss emerging findings as a group, adjusting topic guides iteratively, if needed. Initial analysis ran concurrently with data collection. After every interview, we had approximately 15 minutes of debrief sessions. We reviewed perceptions of how the interviews went and the key emerging issues highlighted in the field notes, that were important to explore further. Additionally, we identified similar patterns arising from earlier interviews. Further in-depth analyses were done using a thematic framework approach as described by Ritchie and Spencer [180]. Both SM and CK read through all the transcripts to familiarise themselves with the data and analytical themes were developed deductively from the interview topics. Other themes emerged inductively from the data review. The final codebook (Appendix 13) was developed jointly by SM and CK and coded with the support of NVivo12, QSR™ software. Data were analysed iteratively, by reviewing findings from the interviews and relating these to reflections from the field notes. These iterations informed further development of the themes/ subthemes. Overall, 8 nodes and 53 sub-nodes emerged from the NVivo coding, representing major themes and subthemes, respectively. SM subsequently reviewed the NVivo codes and discussed the interpretation of the findings with MT, TW, UE, and HM. Divergent opinions were resolved through consensus. SM also called the CHV participants or subcounty officials by phone to clarify issues emerging from the analysis.

4.2.4. Ethical Considerations

The study received ethical approval from the Liverpool School of Tropical Medicine Ethics Review Committee Research Protocol 19-003 (see Appendix 7) and the Kenya Medical Research Institute (KEMRI) Scientific and Ethics Review Unit (SERU), SERU No. 3848 (Appendix 8). I applied for, and was granted permission to conduct the study, by the county government of Meru-Ref. MRU/MED/MRU/C.50 (Appendix 9). Prior to data collection, we engaged the head of the community strategy in Meru County and subsequently, the community focal persons (July 2019) about the study. All participants provided written informed consent. We also reimbursed all participants 500 Kenya shillings, for their time in the study.

4.3. Findings

The study overall showed that asthma was perceived as an important public health problem, however, community health volunteers had low awareness, and were not trained, nor supported to refer and support people with asthma; high levels of stigma and misunderstanding at the community level undermined asthma response. Timeliness of diagnostic tests, contextual challenges and inadequate health system financing and governance problems also undermined efforts within the community health system to support asthma care. The study highlights how various system hardware and software affected the extent to which people at different levels of the health system could respond to asthma. The subcounty and county level perspectives resonated with those of the CHVs, while some healthcare workers had divergent opinions from the CHVs on the roles of CHVs in supporting patients' care.

The findings are arranged around six emerging themes related to CHVs' roles at community level, community stigma, practical challenges, diagnostic challenges, contextual issues and resources. Interview excerpts have been used to illustrate the findings. The excerpts have been anonymised and in some instances gender attributes not included, to protect participants' identities.

4.3.1. CHV roles, training and supervision do not include chronic asthma.

According to IDI and FGD narratives, CHV tasks focused mainly on sanitation and hygiene, nutrition, maternal and child health, and TB case finding and treatment adherence. At the strategic policy level of the county, asthma and other CRD were considered low priority, and the community health volunteers did not have specific defined roles in asthma management. However, within their overarching roles, CHVs are expected to refer anyone with a cough of any duration to a healthcare facility, in line with national TB control strategies.

> *Asthma [is] not perceived to be a major problem- traditionally, we have focused on WASH (water, sanitation, and hygiene), malnutrition etc... Asthma was secondary (KII_county_official_08)*

Some key informants observed that CHVs had too many roles, many of which were ill-defined, and this undermined supervision and negatively affected their performance.

> *The whole range of health services at level 1(community health system) ultimately fall on the shoulders of a CHV, to be able to get to the household level, […]and if you look whole range of health services, all health issues there are too many. Too many such that sometimes you even sit down and wonder whether it is even realistic to expect that one individual targeting 100 households, covering*

100 households that they might even be able to manage to handle all those issues and handle them
effectively. (KII_county_official_08)

The majority of CHVs reported having inadequate knowledge about asthma. When asked whether they had ever seen someone with asthma, some CHVs described typical symptoms such as coughing, wheezing, difficulty in breathing, and chest tightness.

Symptoms? One, obstructed breathing, and if that happens, the patient even falls down[…]so I took
him to hospital and the doctors did their tests and said this is asthma ... he just fell when we were with
him [...] the doctors gave him some medicines, and was told to lie there, he started to breathing again,
and it was confirmed it was asthma. (CHV_IDI_01_Male)

Whereas most of CHVs reported that they had seen an inhaler, they did not know how inhalers worked. The few who expressed more knowledge on inhalers described personal experiences managing their own asthma or their involvement in supporting close relations who had symptoms of asthma.

CHV interview accounts depicted the need for more exposure to trainings on CRD. The majority of the CHVs and CHAs indicated they were not aware of 'Module 13', a new NCD-focused community health training module developed by the Kenyan Ministry of Health. Overall, the community health volunteers felt inadequately prepared to support people with symptoms of asthma in the community. Most stated they had not been trained on the identification and management of CRD.

As CHV we encounter these people, but do not really understand how to communicate this to our
people. If we had more knowledge, maybe it would help in reducing the diseases.
(FGD_CHV_07_Women).

Interview narratives by CHVs showed non-governmental organisations (NGOs) such as Red Cross and AMREF Health Africa had offered trainings on NCDs and establishment of patient support groups but with a focus on cancer, cardiovascular diseases, and diabetes. These trainings were however driven by the priorities of these NGOs, and involved few selected community health volunteers, implying limited exposures. Most healthcare worker respondents perceived training opportunities to be fewer compared to their experiences in the pre-devolution era.

Gaps in basic understanding were evident among patients as well as community health workers. This patient explained that for him misinformation came from health care workers in the facilities, as much as the community health workers.

There was once a doctor who told me… 'do not use inhalers. If you do, then you will depend for life on
them whenever you feel obstructed, so try to control your asthma without using inhalers'. He told me

that if I use [become dependent on] an inhaler, anytime I experience obstruction, no other remedy would work - yet the small inhaler costs 3000 shillings (30 USD). (Patient_022_Male)

As a result, patients and their CHV advisors favoured a range of local remedies. Interviews with community members and volunteers reported several self-management activities, that people with asthma commonly resorted to, to avoid symptoms and/or acute exacerbations. These included: keeping warm by wearing warm clothes, staying indoors during the cold seasons, avoiding cold water and – in extreme cases - emigration from their homes to warmer places either within Meru or to hotter, moister counties (such as the coastal city of Mombasa); and using traditional remedies such as consuming herbs, eating animal fat, or drinking hot water. There appeared to be limited information giving or structures to counter myths and pass on information, for example, there were no asthma support groups in the community, unlike conditions such as diabetes, high blood pressure, and cancer.

I have been involved in setting up a group for cancer people, even for diabetes, where we advise them for example not to share medicines, but for asthma, no, there are no asthma support groups. (CHV_IDI_01_Male)

4.3.2. High levels of stigma and misunderstanding at community level surrounding asthma

Like healthcare workers and patients' perspectives (chapter 3), the community-level interview accounts emphasised asthma as a highly stigmatised and stigmatising condition in communities in Meru County. Drivers of stigma include low awareness about asthma, for example fear of infection, and limited understanding of risk factors of asthma; perceptions of blame for people with asthma as weaklings, or unproductive, and being burdensome, and association of asthma with low socio-economic status.

According to interviews with community health volunteers and patients, asthma was widely perceived to be contagious, like TB or HIV/AIDS, and in some instances, not curable.

They do say that if someone for example has asthma and they cough next to you and you are eating from the same plate, you would also be infected (FGD_CHV_10_Women)

Local perceptions of asthma as a contagious disease were further exemplified through questions that CHV frequently encountered in their routine interactions with the community members.

They can even ask you a question such as if you meet an asthma patient, can they infect the others? So, you explain to them that only TB can be spread to the others, and that asthma is just for the affected person (FGD_CHV_02_Women)

Perceptions of asthma as a contagious disease based on symptoms such as coughing, also assumed gendered stereotyping, for example, in some community settings, affected young women were perceived to be commercial sex workers.

Some of these perceptions were partly attributed to previous interactions between community members and CHVs, that were sometimes characterised by stigmatising actions.

> *But initially these diseases such as asthma and TB, you know one (CHV) would sometimes talk to you (community member) from a distance because they (CHV) feared contracting the same diseases. But now we have been trained to know. (CHV_IDI_04_Male)*

Additionally, symptoms of asthma e.g., difficulty in breathing were associated to other locally stigmatised chronic conditions e.g., epilepsy, and mental health problems.

Our analysis of drivers of stigma suggested that, overall, there was low awareness about risk factors for asthma and other CRD in the study sites. According to interview accounts of CHVs, many community members associated asthma more to hereditary risk factors, generational curses or outcomes of witchcraft or punishment for engaging in vices like theft.

> *We normally see people with asthma in the community, and we view it as an inherited disease, it is there for life. We don't know if they come here, they can be treated but we just refer them. (FGD_CHV_05_men)*

> *Some feel that it is a curse and that they stole something[...] and they even leave some of their people to die without knowing what is going on. (FGD_older_Male_Community_Members_01)*

Some people perceived CRD generally, to be untreatable, and had low expectations for asthma to be resolved, and prospects of affected individuals to lead normal socially productive lives.

> *They say that the disease cannot be treated, and that the person will still just end up dying. (FGD_04_older_Women_community members)*

People with asthma were perceived to be burdensome financially, unproductive, and sexually weak and an inconvenience to others. Community members felt strained financially, for contributing direct healthcare costs of people with asthma, particularly in emergency situations at night. Similarly, some community members had anxieties about possibilities of asthma complications ruining social events like parties.

> *People feel that this sick person, they will consume their money. Sometimes people with asthma are rushed to hospital at night, they (benefactors) feel the money they are spending on transporting them to hospital is a burden (FGD_CHV_07_Women)*

Another thing about asthma, even the other 'work' in bed (sex) is hard.

(FGD_04_older_Women_community members)

Consequently, the affected people experienced discrimination for employment prospects and involvement in social activities.

Other forms of gendered discrimination were exemplified by reports of blame, regrets, and low prospects for marriage for affected people. The excerpt below describes the experience of a patient whose marriage was strained due to burdens of asthma.

Even my husband, I feel like the affection he had for me in the past, is waning…my husband nowadays regrets- he tells me he doesn't know what he could do to retain money in his pocket (rather than spend on me and my baby) that if I had disclosed my condition earlier that I have asthma, he wouldn't have married me (Patient_020_female)

Someone (an affected man) cannot marry quickly… So, if people know that someone has asthma, they don't want their girls to get married to someone with asthma (FGD_CHV_05_Male)

Apart from discrimination, stigma manifested in behavioural changes, mainly aimed at concealing the asthma conditions and symptoms, for example some people suppressed coughs, refused to use inhalers particularly in public, and tended to self-isolate e.g., by locking themselves indoors and generally avoiding other people.

I told him, just use it (the inhaler), there is no shame in having asthma. Otherwise, I could see him having difficulty trying to suppress the cough. (CHV_IDI_06_Male)

Healthcare workers' interviews showed awareness of 'self-stigma', an internalised form of stigma by the stigmatised person.

Self-stigma…some of the patients especially those I am helping; they pity themselves a lot. and they take as if they are being burdens to others. So, they stigmatise even themselves. Despite the family or community might have even stigmatised the patient, even them, their acceptance of their condition they still traumatise themselves also (Frontline_HCW_25)

Not all people experienced discrimination; a patient attributed his experience to widespread community knowledge and acceptance of their family as being affected by asthma.

No, I don't need to hide anything- asthma is normal, everyone in this area knows that many people in our family have asthma. (Patient_022_Male)

4.3.3. Practical challenges in supporting referrals, treatment, and subsequent engagement with community members.

According to the referral policy, community health volunteers should issue the 'MOH 100 Community Referral Form' (Appendix 14) to community members when referring them to a healthcare facility and retain a duplicate copy. The MOH 100 form contains: the name, area of residence, and description of symptoms of the patient; and the community health volunteer's name and mobile phone number. Ideally, after attending to the referred patients, the healthcare workers should write the key recommendations on the section B of the MOH referral form for onward management e.g., how the community health volunteers may support the patients in adhering to the doctors' instructions, including practical actions to prevent asthma exacerbations, medication plan and reminders of the next review date. In practice however, CHVs described numerous challenges particularly in referring patients from poor households to healthcare facilities. Some community members could not afford travel costs, or direct medical costs e.g., for consultation fees, laboratory tests, or radiology tests at the healthcare facilities.

The description of referral processes suggested that the community health system had weak linkage, poor communication, and relations with the formal healthcare facilities system. This situation posed serious implications on continuity of care, and data collection processes at the community level. The majority of the CHVs emphasised that some of the health care workers at the facilities had low awareness or acknowledgement of CHVs' roles within the public healthcare system. For example, some healthcare workers did not understand the community referral process. They reportedly tore the MOH 100 referral forms and discarded them in the presence of the patients (and in some instances of the CHVs who accompanied the patients).

> *The patient told me that the doctor has asked them [about the MOH 100 referral note] if they were a doctor, why did they not treat you? (FGD_CHV_05_men)*

> *Nurses don't recognise roles of CHV. We have tried to make them understand that the CHV are part of them. (Frontline_HCW_03)*

Divergent opinions drawn from healthcare worker interviews, showed that while some had low awareness of CHV roles, but others narrated aspects of collaboration with the community health volunteers. Examples include engagement with community members through fora such as community dialogues, which focused on aspects such as disease prevention.

> *We call them our 'madaktari mashinani' (community doctors) and we have engaged them, we have the trainings that we have been doing here and in that training there is the basics that they learn and*

then we tell them to go and educate back in their communities concerning like the cessation of tobacco smoking, even the use of this firewood because it is also a great risk factor to things like COPD and all that, so we are able to use the CHVs in the community level. (Facility_Manager_23)

Our analysis shows that considerations for professional values, and prioritisation of TB diagnosis over other conditions, somehow shaped views of healthcare workers and how they related with CHVs. According to some healthcare workers, CHVs were not professional healthcare workers. Consequently, there was a perceived need to limit CHVs' access to clinical information about patients, such as diagnoses made. Similarly, CHV narratives showed doctors were only likely to engage them to follow-up patients whose sputum samples tested positive for TB. This implied that for patients with negative TB test results, further engagement with CHVs somehow ended without a diagnosis of chronic respiratory disease (or asthma) being made or any treatment or follow-up initiated. These observations were corroborated in separate interviews as illustrated by the following excerpt from an interview with a healthcare worker.

Most of them don't come for the results, especially negative results, we have [an] issue but we are not worried so much about negative results even if they don't come for them, we pile them for a month. (Frontline_HCW_15)

Weaknesses in healthcare delivery processes have been extensively described in chapter 3 on facilities' readiness. CHVs' and community members' accounts corroborated those findings and described how some weaknesses undermined CHV trustworthiness. For example, community members (who had been referred by the CHVs) felt inconvenienced, their time and money wasted when they encountered drugs stock outs at the facilities. The pattern of frequent drug stock outs drove community members to purchase drugs over the counter in retail pharmacies. The CHVs in turn felt their efforts to persuade community members to access diagnostic services and prescriptions through public healthcare facilities were undermined.

They didn't even have fare [money for transport]; you (the CHV) are the one who prompted him to go to hospital….so such a person goes and in the evening they come and tell you that "I went to hospital and was told that testing requires money, drugs must be paid for, and yet I did not have any money on me. I only had that 100 Shillings - it was meant for food (for the household). You told me to use the 100 shillings on fare. As CHV, you feel you have burdened him for nothing. (CHV_IDI_05_Male)

Some CHVs explained their 'status' and reputation was somehow 'lowered' when the patients did not get the expected services in the healthcare facilities.

I had confidently said "you go there you will get drugs". The patient comes back after not being able to get the drugs and asks, 'is this what you were telling me to go to?' (CHV_IDI_01_Male)

According to CHVs, patients' resolve to purchase medicines directly over the counter, undermined CHVs' education and plans or preferences for community members to be attended to by professional healthcare workers.

Interview accounts also showed some of CHVs' expectations were not met at the healthcare facilities, creating confusion about their identity and roles to the community members. For example, in past engagements (before devolution), CHVs were provided free access to medical care, including for members of their households, as an incentive for volunteering. Additionally, CHVs were not expected to queue for their own care at the healthcare facilities, since they were perceived to belong to the same team, as facility healthcare workers. Narratives showed CHVs expected that in instances when they had accompanied patients to healthcare facilities, '*their*' patients would be given preferential attention, for example, not having to queue like other patients. This, they explained, would help *their* patients to be seen faster, and free the CHVs earlier to attend to their private businesses. The CHVs also perceived queuing with *their* patients awaiting asthma services to dent their standing as 'community doctors' and created confusion about their identities and claims at the community level, to be part of the healthcare teams.

4.3.4. Challenges in accessing timely diagnostic tests.

We found that patients tended to present late because they knew that they would have to attend for repeated sputum examinations and many patients did not feel this addressed their needs. Chronic asthma was regarded as a diagnosis of exclusion based on symptoms once TB had been ruled out, rather than a diagnosis of inclusion. This pathway was perceived to lead to delays in diagnosis that were principally attributed to delays in getting their sputum test results. Interview accounts showed some patients went to healthcare facilities two or three times for their test results.

> *Some patients may go to the facility two, or three times and do sputum tests, but don't get results fast. In some instances, they may decide to go to another hospital. (FGD_03_men)*

Diagnostic delays were also related to late presentation due to access issues, HCW attitudes, and self-stigma. For example, at times the patient pathways included investigations other than sputum testing and some health care workers reported that '*fear of a reduced lifespan hampered patients'* uptake of chest x-ray services.

Communication problems between healthcare workers and patients were described as causing a number of issues for patients. Community members' narratives showed that some healthcare workers may not inform patients why sputum tests were ordered, which provoked patients' anxieties. Additionally, the handling and communication relating to sputum samples were fraught with risks of confidentiality breaches, as observed in the FGD below.

A doctor may ask loudly, 'why does this sputum sample have some blood stains?' Other patients get anxious to know the affected patient. (FGD_CHV_05_men).

4.3.5. Other contextual issues undermine CHVs' identity and trust in the community.

Trust between CHVs and the community was multi-layered, and events were often described in terms of how they affected trust, that in turn had wider impacts including on their ability to suspect and refer asthma. CHVs were not exclusively engaged by the county government- they also supported other community interventions by different civil society organisations. For example, some CHV were engaged to mobilise community members for a free medical camp for neglected diseases. In some instances, those activities were not coordinated well, exemplified by inadequate services like treatment. Consequently, this affected CHVs' relationships and trust with community members, in turn reducing community confidence in CHVs' ability to refer patients to services for chronic asthma. For example, people who did not access expected services in the free camps complained that their time had been wasted. Additionally, some community members perceived CHVs to be exploiting them, by exchanging personal data collected for payments.

They say that we are exploiting them, that we use the data they provide us in exchange of money. We tried explaining that we do this work for free, but some of them said that there is no way government can start any activity without allocating money there. (FGD_CHV_05_men)

4.3.6. Inadequate financing and resources: implications for community health services

The majority of the CHVs interviewed identified inadequate financing and resources to the community health system as a major problem, burdening CHVs, affecting their relationships with community members, and the CHA. Although the financing issue was not directly linked to asthma management, the discussions strongly suggested adverse implications cutting across any form of engagement with CHVs.

We have been lobbying for more resources to be set aside for community health work. 13 million [Kenyan Shillings-US\$112,000[5]] was secured for 2019/20 year. However, this is against the 70 million [Kenyan Shillings-US\$ 601,000] required, a 'drop in the ocean'. (KII_County_08)

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[5] (**1 US\$= Kenya shillings 116.4, based on Oanda currency converter- https://www.oanda.com/currency-converter/en/?from=USD&to=KES&amount=1) forex exchange rates on 18 June 2022)**

At the time of data collection, CHVs were not paid stipend. This was a recurrent issue in most of the interviews. CHVs explained that as volunteers, they incurred steep trade-offs with their private businesses. Additionally, they lacked essential resources such as airtime for phone calls and travel. The lack of stipends also compounded other problems that the CHVs encountered in their day-to-day voluntary work, often leaving them worse off. For example, when they felt obliged to support patients with travel and treatment costs using their own money, particularly when seriously ill. Such situations strained the CHVs financially. This aspect of volunteers incurring out-of-pocket costs was not limited to CHVs. In some instances, CHV leaders ended up providing fares to CHVs to enable them to move around in the community to undertake their roles.

Political factors were frequently identified as an important influence on CHV stipends. CHVs explained the previous county government regime had promised them monthly stipends (2000 Kenya shillings, equivalent to 17.2 USD). These commitments were however disowned by the current Meru County government regime, reportedly describing them as typical political promises made during election seasons to win votes, but which had no legal basis. Interview accounts with key informants established there were plans to create a local county law, providing for payment of monthly stipends to the CHVs. The formation of a parallel, but currently defunct, community programme consisting of post-secondary school youth (Meru Youth Service) that paid more than double the level of stipend promised to the current CHV cohorts, caused confusion and disillusionment among older CHVs who had served longer.

CHV narratives about the stipend problems suggested helplessness among the respondents. In almost all the CHV interviews, we frequently encountered the refrain *"God himself will pay us"*. Some CHVs, particularly the males, abandoned the programme, altogether to find paid employment. Consequently, the remaining CHVs had to readjust and cover more households, some, ending up covering more than 100 households. This meant the frequency of visits per household declined, and CHVs had to walk longer distances, with many giving up altogether. Consequently, some of the CHUs became inactive. Plans to develop more CHUs were further disrupted by COVID-19 pandemic and the government prohibition of public gatherings (important for selecting community health volunteers). The excerpt below suggests inadequate household visits.

CHV visits to the households are 'rare'. (FGD_Young_Female_Community_Members_04)

We explored reasons for the current CHVs staying on and established that CHVs viewed their roles as *'service to humanity'*, *'charity'*. According to a key informant, at the time of data collection, only two counties in Kenya, Turkana and Siaya were regularly providing stipends to CHVs from county budgets, demonstrating nationwide neglect of the CHV role. CHVs also continued working out of concern that if the health of a community member deteriorated, the burden of taking care of them would still fall back onto the CHVs.

CHVs also lacked reliable supplies of basic working tools such as CHV toolkit, identification documents and reporting tools such as MOH 513 and 514, the MOH 100 referral books. To document referrals, the majority of CHVs described having to photocopy official templates, using their own money. Alternatively, some improvised MOH 100 referral notes by hand-copying sections of the official templates in notebooks. This later situation may perhaps partly explain why healthcare workers may disown MOH 100 referral notes.

> *We were given empty bags, but no training. FGD_CHV_07_Women)*

While community members were receptive to health promotion messages by the CHVs, they expected to be given supplies of products, especially those promised to them in previous encounters with CHVs. Without these tangible benefits e.g., water treatment or de-worming tablets for household members many community members were less receptive to messages including important messages surrounding asthma diagnosis and care that might need referral.

4.4. Discussion

We found multiple community factors impacted the uptake of asthma care in Kenya leading to impaired wellbeing and a cycle of poor symptom control and health outcomes. Our analysis established that there is generally low knowledge among individuals, households, and community volunteers, about the common risk factors of asthma, and the appropriate methods to manage symptoms. Access to healthcare services was impeded by lack of medicines and poor coordination of services such as diagnostics, at the healthcare facility level, and household poverty that imposed barriers for travel and purchase of healthcare services. Traditional asthma remedies were thus preferred by many participants, although it was not clear to what extent these preferences affected health seeking behaviours in formal healthcare facilities. The uptake of asthma services and symptom control may therefore continue to be poor when people are not aware of what is available, services are remote and the perceived risks to the individual outweigh the benefit of health seeking.

Our analysis shows that the community health system has potential to support the response to asthma, but as currently structured, it is not fit for purpose, and cannot fill the decentralisation gap in chronic care for asthma. Reforms are needed in training the community health volunteers, and supporting them through provision of stipends and other basic working kits, and strengthening other systemic components outlined in the building blocks [88], particularly service delivery and supply of drugs. The county government of Meru is planning to institutionalise CHV payments through a local county bill and allocated 13 million Kenya shillings (111,683 USD) to the community health system in the financial year 2019/20, although this allocation was deemed inadequate by community health system stakeholders in our interviews. What is not clear nationally is if CHVs are to play a role in referring people with asthma, then what must be dropped from their overall workload? How can they be supported? How can it work if every programme adds tasks to them and 'uses'

CHVs? The tendency to add tasks to CHV workload without rationalising their overall responsibilities has led to reductions in quality of service, attrition of volunteers and the near collapse of previously functioning community health units [220].

The social impacts of asthma stigma have been described in other contexts where a multi-country review (of mainly high and middle income countries) revealed that high levels of stigma for asthma were associated with low awareness, fear of infection, social exclusion, poor health seeking, and difficulty in adhering to treatment [202]. Stangl et al's Health Stigma and Discrimination Framework describes drivers and facilitators as well as manifestations and practices [221]. Both were evident in relation to asthma at community level in Meru County, including people with asthma being excluded socially, finding marriage opportunities limited and difficulties to find work. Our analysis suggests that stigma for asthma was gendered, and contributes to findings by previous studies [222].

Cultural expectations to contribute financially when someone is acutely unwell led to people living with asthma being socially isolated (e.g., not being invited to gatherings) as people already living on the breadline feared having to donate their own money in case of an acute asthma attack. This intersectional nature of stigma highlights the complex, multi-level nature framing stigma and intervening in an under-resourced context [223, 224]. The association of chronic cough with TB is not surprising given the overlap of symptoms [225], but the fear of TB and the difficulty in clinical diagnosis in a system geared towards TB over asthma can lead to delays in diagnosis and increased morbidity and mortality [226]. Misunderstandings around the infectious nature of asthma exacerbate stigma and may result in serious psychological harm. A study investigating knowledge and perceptions of asthma among secondary school students in Tanzania revealed that most information about asthma had been passed on to students by their parents and non- asthmatic students. Most students presumed that asthma was infectious and therefore avoided interactions with students with asthma for fear of contracting it [35].

Self-stigma (the own adoption of negative societal attitudes) and anticipated stigma (expectations of bias from other people) were described as people presented late for asthma care, were worried about being seen with inhalers and were quick and vehement in denying the diagnosis. We found that stigma manifestations in turn influenced health outcomes as denial of care led to poor asthma control, more symptoms, and a vicious cycle of stigma. Chapter 3 (System Readiness) highlighted how stigma affected treatment and management of asthma from the health care worker perspectives with health care workers talking about their perceptions of how it impacted patients. Patients' interviews have added to this by showing how health care workers themselves may stigmatise patients or readily adopt community norms, colluding to deny the diagnosis, hide from inhalers and use problematic language.

Stangl et al argue that addressing drivers of stigma would the most appropriate point to pre-empt the process of stigma, otherwise intervention efforts should be channelled towards minimising the harmful effects to stigmatised people [221]. Achieving wellbeing for people living in with asthma in Kenyan communities requires a multipronged approach that combines knowledge, and advocacy with destigmatisation efforts. The findings of this study stress the need to shift the focus of management of asthma from solely individuals, to addressing wider contextual, socio-ecologic factors within the community and healthcare system [137]. Training of CHVs and systematic community sensitisation activities could help improve community perception about chronic cough. Clear messages about the causes of asthma and the availability and effects of treatment on controlling symptoms would help to destigmatise asthma. The transformative effect of seeing people being managed well with affordable medicines has the potential to be more powerful than being told about treatment effectiveness alone as has been the case in HIV care [227]. Words matter, and consistent framing and use of terms like 'people who have asthma' rather than asthma 'victims'; 'asthmatics' or CRD 'sufferers' can start to shift mind sets. There are lessons to be learned from community de-stigmatisation efforts with HIV in the antiretroviral therapy era, TB management [228] and, more recently, efforts being applied to COVID-19 related stigma [229] through multi-pronged approaches. These include provision of timely, accurate information about the disease, including transmission mode and risk reduction strategies; empowering the affected people with coping skills against stigma, e.g., through counselling; and mechanisms for enhancing contacts between unaffected people, and the affected people. This later approach aims to encourage positive attitudes towards the stigmatised diseases [230, 231].

While globally, there are concerns about the rising burdens of NCDs, asthma is not a national priority in Kenya, and our community findings show asthma is low down the list of priorities in community health systems. Priority setting in the context of devolution is affected by multiple issues, but the main issues are power, which in turn shapes governance, health financing and availability of complementary resources, including technical capacities [49]. McCollum and colleagues argue that higher priorities are given to "visible" interventions, particularly infectious diseases, and maternal care programmes. On the other hand, preventive and promotive interventions, that would yield huge benefits for asthma control, are low priority in Kenya's devolved context. Paradoxically, interventions that would ideally fall under "visible" and therefore priority investments such as inhalers, are preferred to remain invisible (by patients) because of community stigma for asthma. There is scope to explore citizen participation in local county agenda-setting, and how it influences priority setting processes for asthma and other CRD at the community health system level.

Any person-centred care system for a chronic condition requires an element of supported self-management and, provided stigma has been sufficiently addressed, self-management may be one way of task-shifting the control and treatment of mild asthma to the community-level. The innovative care for chronic conditions

(ICCC) framework, suggests self-management as an integral part of its proposed 'micro' and 'meso' levels [131]. Our analysis shows that the community members are poorly 'prepared', implying insufficient access to medication and equipment, self-monitoring tools and self-management skills. Whereas the ICCC model proposes that community health volunteers should 'echo' key essential messages about prevention and management, weak linkage between the community health system and the formal health facilities precluded this in the Meru context. Cost was identified as a major barrier to self-management in a recent study in Meru County [232]. Patient accounts of the costs of excluding TB before getting a diagnosis and of attending remote facilities for repeat prescriptions resonated with healthcare workers' observations (presented in Chapter 3) of the associated costs of travelling, sometimes repeatedly, to healthcare facilities, for financially constrained patients. We go on to explore patient and household expenditures in the chapter that follows (Chapter 5).

4.4.1. Limitations and strengths

Our study has several limitations. Asthma is a childhood illness, yet we did not interview children directly and focused our questioning on adults with symptoms (and to a lesser extent) adult caregivers. The analysis did not disaggregate by age. This study used qualitative methods and the findings are therefore not widely generalisable. Focus group discussions with community members were not conducted in one of the study sites, due to COVID-19 pandemic. Consequently, we may not have achieved theoretical saturation [233]. Additionally, the COVID-19 pandemic may have exposed community members to more information about respiratory diseases, for example on the symptoms, therefore exposing the study to the risk of bias. Despite these challenges, it is expected that triangulation of methods, investigators and data sources would minimise the limitations. We amplified the voices of different stakeholders in the devolved healthcare system, enhancing prospects of tailored policy responses based on the research evidence. Through using in-depth interviews, key informant interviews and focus group discussions, we were able to triangulate the study findings. Triangulation is an important method for enhancing rigor and trustworthiness in qualitative research [234].

4.4.2. Conclusions and recommendations

We conclude that the community health system is not prepared to support referrals and management of people with symptoms of asthma, based on multiple factors relating to human resources, financing, health system governance and contextual barriers, including high levels of asthma stigma, in the community. We recommend that the county government should: accelerate the process for paying community volunteers a reasonable stipend, with consideration for sustainability; train community health volunteers on asthma and other chronic respiratory diseases in destigmatising ways; provide community health volunteers tools required

for their work, for example stationery; strengthen drugs supply and coordination of asthma care at the health facilities, including enhancing working relations between healthcare workers and community health volunteers. The national government, county and other stakeholders should develop interventions against stigma for asthma and related medical technologies such as inhalers. Finally, self-management, a central tenet of chronic care may help to prevent attacks and reduce costs, a factor identified as a major barrier to accessing services for asthma care. We go on to explore the impact of the costs of care on patients in the next chapter.

Chapter 5: Catastrophic costs, coping strategies, and social protection coverage.

5.1. Introduction

Chronic respiratory diseases (CRD) are among the four main non-communicable diseases (NCDs) in the world, causing 80 per cent of premature NCD-related deaths globally [235].Without prompt diagnosis, effective long-term management, and sustained care, people with CRD may be exposed to chronic impairment of health and wellbeing, and negative socioeconomic impacts. The Sustainable Development Goal (SDG) 3.4 is to reduce the burden of premature deaths due to NCDs by 30 per cent by 2030 "through prevention and treatment" [93]. Key targets to achieve this include strengthening the primary health care system, increasing the coverage of social protection, and working towards reaching universal health coverage (UHC) to ensure everyone has access to the healthcare services they need [93, 236]. Specifically, policy recommendations on health financing for UHC emphasise the need for reforms that move away from patients' reliance on out-of-pocket payments towards wider access to and use of social protection platforms including prepaid mechanisms like health insurance, tax-based public financing, or a mix of both methods [237, 238].

The Kenyan healthcare system, which was devolved to 47 semi-autonomous subnational (county) governments following constitutional change in 2013 [38], remains heavily reliant on out-of-pocket payments. The Kenyan National Health Accounts 2015/16 show that out-of-pocket payments accounted for 31% of total health expenditure [239]. This reliance on out-of-pocket payments is likely to relate to the Kenyan government's health expenditure as a proportion of total government expenditure averaging 6.5% [239], which is substantially below the 15% mandated by the African heads of states meeting in Abuja [240]. This is important because out-of-pocket payments are a well-recognised barrier to accessing healthcare services, which can worsen inequalities and expose households to catastrophic health expenditures [107, 241, 242]. Catastrophic health expenditures have been defined using different thresholds correlating healthcare to household expenditures [243]. The WHO defined catastrophic health expenditures as out-of-pocket healthcare payments greater than 40% of total household monthly expenditure minus food, housing and utilities expenditure, or a household's "capacity to pay" [244]. In turn, catastrophic health expenditure can further compound impoverishment, especially amongst the most economically-vulnerable households [238]. Globally, the incidence of catastrophic health expenditure rose from 9.7 to 11.7% between 2000 and 2010, implying the socioeconomic impact on people seeking care is deteriorating over time [245].

Out-of-pocket costs and lost income for people with tuberculosis (TB), the archetypal social disease of poverty, are well documented [246-249]. A systematic review in 2014 suggested that up to half the costs experienced by people with TB are incurred prior to receiving TB diagnosis and initiating TB treatment [250]. It has also been found that lost income amongst people with TB and their households persists long beyond the end of TB treatment [251]. To address this, WHO's 2015 End TB Strategy included a global socioeconomic indicator of "catastrophic costs" (distinct to catastrophic health expenditure, catastrophic costs are defined as TB-related out-of-pocket costs plus lost income equating to >20% of a household's annual income or annual total expenditure), mandated cost-mitigation strategies including provision of social protection, and set the bold target that "zero TB-affected families should face catastrophic costs of TB by 2030" [252, 253].

Cost is a major barrier to diagnosis and treatment in rural Kenya, with 64% of Meru patients agreeing that they have a hard time paying for their medicines in a 2019 study on self-management of chronic diseases [232]. The Kenyan government has implemented a variety of social protection mechanisms to address user costs of seeking and accessing healthcare. Kenya's social health insurance scheme, the National Hospital Insurance Fund (NHIF), is central to achieving UHC in Kenya. Further details about NHIF benefits packages and the current reforms NHIF is undergoing are described in section 2.3.6 . The NHIF covers the costs of consultation, laboratory tests, radiology services and drugs, applicable at hospital level. For NHIF members in the informal sector, outpatient services are contracted to healthcare provider facilities through a capitation plan. Other social protection measures applicable within public hospitals include waivers of user fees for the poor and vulnerable on the recommendation of social medical workers based in the hospitals.

Kenya's drive towards UHC must be informed by up-to-date, context-relevant evidence on patients' costs of accessing care and social protection coverage. This study aimed to generate new evidence on the out-of-pocket costs, lost income, coping strategies, NHIF coverage and usage, and prevalence and drivers of catastrophic costs for people with CRD symptoms accessing public healthcare facility services in Meru County, Kenya.

5.2. Methods

We conducted a cross-sectional survey involving adults, attending five public healthcare facilities with symptoms of CRD.

5.2.1. Study Site

The study was conducted in Meru County. Details of the study site and sampling of the facilities are outlined in Chapter 1. According to Kenyan government policy, sputum microscopy for tuberculosis diagnosis and TB drugs for treatment are provided free-of-charge through a vertical programme subsidy in all public facilities.

Patients attending primary healthcare levels 2 and 3 (dispensaries and health centres, respectively) are only required to pay for consultation fees and other laboratory tests. At the hospital level (levels 4 and 5) all other services apart from sputum tests, are charged. Chest x-ray services are available in hospitals only. Similarly, based on the PAL plan, spirometry services should be provided at hospital level only.

In terms of geographical locations, Kanyakine subcounty hospital and Mitunguu health centre are 20 kilometres apart. Mitunguu health centre is 35 kilometres, from Meru Teaching and Referral Hospital, while Kanyakine subcounty hospital is 25 kilometres away, and averagely 45 minutes' express travel time by car. Distance between Mitunguu health centre and Kanyakine subcounty hospital was approximately 20.5 kilometres, equivalent to an estimated 30 minutes travel time. Laare health centre and Mutuati subcounty hospital are 10 kilometres apart, and are located approximately 67- 77 kilometres, respectively, away from the Meru Teaching and referral hospital (in Meru town). Travelling time to Meru teaching and referral hospital is estimated to be at least 2 hours.

5.2.2. Study Population Inclusion Criteria

The study included adults aged 18-64 years attending the outpatient departments in the five sampled public health facilities, who were found by facility clinical officers on clinical history and/or physical examination to have any of the following signs or symptoms, regardless of duration: a cough, difficulty in breathing, noisy breathing, wheeze, chest tightness (thought to be of non-cardiac origin), or blood in sputum. Severely ill patients, for example those presenting to the emergency care departments, or who were unconscious, were excluded because of practical and ethical challenges in gaining informed consent to participate in the study. Child participants (<18 years) were excluded from this analysis. Firstly, it was not practical to collect data on socio-economic status, because the children were presumed dependents, which precluded meaningful analyses of important variables such as occupation, assets' ownership, and household expenditures.

5.2.3. Data Collection

Data were collected on all eligible and consenting adult patients who visited the facilities between 5th September 2019 and 1st October 2020. Between 19th March and 15th July 2020, data collection activities were suspended due to COVID-19 related disruptions (see study limitations section). A nationwide clinical officers' strike paralysed healthcare service provision in public facilities (1st November 2019 to 15th January 2020) and further disrupted data collection activities. Data were collected at the facilities' consultation rooms and the point of patients' exit from the facilities.

In each facility, data were collected during standard outpatient opening hours (8 am to 5 pm) Monday to Friday for a cumulative period of at least 4 weeks. Prior to the survey, clinical officers in sampled facilities were trained to collect patients' clinical data, by completing a standard structured questionnaire. The questionnaires were adapted from the ENGAGE-TB toolkit [254] and reviewed by experts in respiratory and/or infectious diseases medicine and/or patient costs surveys based in Kenya and the United Kingdom.

Clinical officers identified eligible outpatients based on the inclusion criteria during routine history-taking and physical examination, assigned a unique ID and completed structured questionnaires (Appendix 15). The questionnaire included questions about the patient's age, CRD symptoms, diagnosis based on history and physical examination (i.e., upper respiratory tract infections, TB, asthma, bronchiectasis, COPD, post TB lung disease), and any recommended tests, investigations, or treatment. The study participants proceeded to other service points within the clinical care pathways with research team members strategically placed to document movement through the care pathways until the last service was accessed. Participants were then interviewed by members of the field team in Swahili (DM, RA, NC, ES, CM, DN) before leaving the facility.

Exit interview questionnaires (see Appendix 16) were adapted from the WHO TB Patient Costs Survey instrument [255], a previously validated tool which uses an itemised costing approach and was previously adapted and used in the Kenya National TB Patient Cost Survey [256, 257].The contextual modifications of the tool include collecting health expenditure data in Kenyan shillings, and health facilities' levels aligned to the Kenyan health care system. Examples of questions excluded from the Kenya National TB Patient Costs survey are body mass index (BMI), HIV status, nutritional support, modes of payment e.g., paying in kind, community-based insurance, and credit options, travel time to the facility, and number of visits. Participants estimated the: direct (out-of-pocket) medical costs, direct non-medical out-of-pocket costs, lost income, and coping strategies associated with their CRD symptoms, illness, and concomitant care-seeking; and the coverage and use of NHIF. Direct medical out-of-pocket costs included those for medical consultations, diagnostic tests (e.g., laboratory and radiological imaging), medicines, and any other medical procedures (e.g., bronchoscopy, pulmonary function testing). Direct non-medical out-of-pocket costs included one-way travel to the health centre, food, and accommodation, and were collected for both the participants and any persons accompanying them during healthcare seeking and facility visits. Lost income was calculated using a human capital approach of reported days of work lost multiplied by estimated daily income [258]. It was not possible to use an output approach to calculate lost income (e.g., household income prior to healthcare seeking minus current household income while healthcare seeking) as participant estimates of income prior to healthcare seeking were not provided.

Other data collected included socio-demographics (adults only), age, gender, socio-economic status, defined by occupation, educational attainment, monthly income, and monthly participants' household income, and

household wealth and coverage by, and use of the NHIF to pay for medical expenses during the specific healthcare facility visit. We also collected data on asset ownership including household furniture, electronic equipment, livestock, and amenities such as electricity and piped water; estimates of weekly household incomes; and household expenditure and consumption on food, rent, travel, amenities, and leisure. We explored socio-economic impact of the facility visits through estimates of lost income and use of coping strategies to mitigate financial shock including using savings, borrowing from friends and/or relatives, taking out loans, and/or selling assets or property.

The exit interview questionnaires (n=18) were piloted in Mutionjiri health centre and Miathene subcounty hospitals, both in non-study sub counties. Additionally, clinical officers in all sampled facilities piloted the tools on patients (n=20), providing feedback to the study team. Six trained field workers (2 males, 4 female) administered exit interviews. Data were collected using SAMSUNG Galaxy™ tablets (Model SM-T580) and transmitted on the same day to a secure server on the Open Data Kit (ODK) platform. All data were reviewed by the principal investigator within a day of collection to ensure accuracy.

5.2.4. Data Analysis

Statistical analysis was done using STATA v15 (Statacorp, TX, USA), R statistical package (version 4) and Microsoft Excel software. Data were analysed using descriptive statistics including simple counts, proportions, and mean or median averages depending on data distribution. In line with WHO and other patient costs surveys, continuous costs data were described using arithmetic means and standard deviations regardless of their distribution. Income or expenditure reported as "zero" was replaced with 1 Kenyan shilling per day [259, 260]. Mean total direct costs (total medical plus total non-medical direct costs), total costs (total direct costs plus lost income) and catastrophic costs were calculated. Catastrophic costs were calculated using an adapted and amalgamated version of WHO's catastrophic health expenditure and catastrophic costs definitions: a participant household's mean direct medical costs, direct non-medical costs, and lost income associated with seeking care for CRD symptoms exceeding 40% of the monthly household capacity to pay (e.g. the monthly household income remaining after subsistence needs including food, rent, and utilities have been met) [107]. This threshold was used for the following reasons: i) lost income and direct non-medical costs such as food and travel are both included in the WHO definition of TB-related catastrophic costs and were shown in the Kenyan TB Patient Cost Survey [256] and our own qualitative research in Chapters 3 and 4 to be major contributors to the socioeconomic impact of seeking care for CRD in Kenya; ii) the WHO definition of TB-related catastrophic costs uses a numerator of total out-of-pocket costs and lost income *throughout the entire TB illness and treatment (minimum 6 months)* and a denominator of *annual* household income, both of which were inappropriate time frames to examine the socioeconomic impact of care seeking

for CRD symptoms; and iii) the WHO catastrophic health expenditure definition is widely recognised and used, which would facilitate generalisability and comparability of catastrophic health expenditure prevalence of our cohort with others.

Sensitivity analyses were performed. These included using the standard definition of catastrophic health expenditure as being a household's mean out-of-pocket direct medical costs *(without the addition of direct non-medical costs, travel costs or lost income)* exceeding 40% of the monthly household capacity to pay [261]; and using recognised alternative catastrophic costs thresholds such as the total direct out-of-pocket costs of over 10% of the same household's monthly or annual income or expenditure [245].

To examine equity of distribution of costs and catastrophic costs, we used Principal Component Analysis (PCA) of asset ownership to derive a cohort-specific index of multidimensional deprivation (or poverty score), which was converted into poverty terciles for regression analyses [259, 262]. Univariable and multivariable logistic regression models generated unadjusted and adjusted odds ratios with 95% confidence intervals of the association of socioeconomic and clinical variables with incurrence of catastrophic costs.

5.2.5. Ethical Approval

This study was authorised by the Ethical Review Committee of the Liverpool School of Tropical Medicine 19-003- (Appendix 7) and the Scientific and Ethical Review Unit of the Kenya Medical Research Institute (KEMRI) protocol 3848 (see Appendix 8). We sought and were granted permission to conduct the study by the Meru County Department of Health-Ref. MRU/MED/MRU/C.50 (Appendix 9) who informed senior managers of the five sampled health facilities.

5.3.   Findings

Below, we describe the sociodemographic and health characteristics, the out-of-pockets costs and lost income, and the prevalence and factors associated with experiencing catastrophic costs of care seeking for symptoms of CRD.

5.3.1. Socio-demographic and health characteristics

Table 5.1 summarises the socio-demographic and health characteristics of the study cohort (n=296), by incurrence of catastrophic costs. The participants had a mean age of 36 years (SD 12), 58% (173/296) were female, and 55% (163/296) had only primary school education. The mean monthly participants' income was 4,166 Kenya Shillings (KES, equivalent to USD 36) and mean monthly household income 16,683 KES (USD 143). Under one third (84/296, 28%) of participants were registered NHIF members, with similar distributions

between participants whose households experienced catastrophic costs (25%) vs those that did not (32%). Compared to participants whose households did not experience catastrophic costs, participants whose households experienced catastrophic costs had a higher proportion of females (63% vs 53%), primary household income earners (29% vs 18%), people belonging to poorer households (38% vs 29%), and people seeking care from subcounty hospitals (29% vs 16.5%). An estimated 11.5% of the participants were diagnosed with a CRD, excluding TB. Most of the participants (55%) were seen at the health centre level.

Table 5. 1 Sociodemographic and health characteristics of the study cohort and by catastrophic costs incurrence

	All participants (n=296)	Participants whose households did not experience catastrophic costs* (n=133)	Participants whose households experienced catastrophic costs (n=163)
Sociodemographic factors			
Mean age in years (SD)	36 (12)	37 (12)	35 (12)
Age groups (%)			
15-29 years	103 (35)	44 (33)	59 (36)
30-44 years	117 (40)	50 (38)	67 (41)
45-59 years	60 (20)	31 (23)	29 (18)
60 years and above	16 (5)	8 (6)	8 (6)
Gender (%)			
Female	173 (58)	71 (53)	102 (63)
Male	123 (42)	62 (47)	61 (37)
Education level (%)			
Up to primary school completion	163 (55)	79 (59)	84 (51.5)
Up to secondary school completion	94 (32)	37 (28)	57 (35)
Above secondary school**	39 (13)	17 (13)	22 (13.5)
Mean monthly participant income in KES (SD)	4167 (18302)	2512 (6273)	5516 (23955)
Mean monthly participant income in USD (SD) ***	36 (157)	22 (54)	47 (206)
Mean monthly participant household income in KES (SD)	16683 (22376)	18569 (24231)	15143 (20690)
Mean monthly participant household income in USD (SD) ***	143 (192)	160 (208)	130 (178)
Participant is primary household income earner**** (%)	72 (24)	25 (18)	47 (29)

	All participants (n=296)	Participants whose households did not experience catastrophic costs* (n=133)	Participants whose households experienced catastrophic costs (n=163)
Multidimensional asset-based poverty score; n=275 (%)			
First tercile (poorest)	91 (33)	38 (29)	54 (38)
Second tercile	92 (33)	44 (33)	48 (34)
Third tercile (least poor)	92 (33)	51 (38)	40 (28)
NHIF			
NHIF members/registered	84 (28)	43 (32)	41 (25)
	All participants (n=296)	Participants whose households did not experience catastrophic costs* (n=133)	Participants whose households experienced catastrophic costs (n=163)
Final diagnosis (%)			
Acute upper or lower respiratory tract infection	188 (64)	91 (68.5)	97 (59.5)
No diagnosis	67 (23)	24 (18)	43 (26.5)
Asthma	16 (5)	6 (5)	10 (6)
Chronic bronchitis	14 (5)	9 (7)	5 (3)
TB	4 (1)	0 (0)	4 (2.5)
COPD	2 (0.5)	1 (0.5)	1 (0.5)
Post-TB Lung Disease	2 (0.5)	1 (0.5)	1 (0.5)
Bronchiectasis	2 (0.5)	0 (0)	2 (1.5)
Congestive cardiac failure	1 (0.5)	1 (0.5)	0 (0)
Health system level at which seeking care			
Health centre	164 (55.5)	85 (64)	79 (48)
Subcounty hospital	69 (23.5)	22 (16.5)	47 (29)
County hospital	63 (21)	26 (19.5)	37 (23)

*Total health-related costs >40% of monthly household non-food/rent/leisure expenditure also defined as a household's "capacity to pay"

**Including higher college and University

*** (1 US$= Kenya shillings 116.4, based on Oanda currency converter- https://www.oanda.com/currency-converter/en/?from=USD&to=KES&amount=1) forex exchange rates on 18 June 2022)

****Participant income contributes >50% of household income

*****1 congestive cardiac failure, 1 undifferentiated fever, 1 amoebiasis

5.3.2. Direct costs, lost income, and catastrophic costs of care-seeking for symptoms of CRD

Table 5.2 highlights mean direct costs, lost income and catastrophic costs incurred by participants seeking care for symptoms of CRD. The mean laboratory costs and travel costs were the largest contributors to medical (KES 133, USD 1.1, 34.1%) and non-medical (KES 157, USD 1.3, 69.8%) costs respectively. The mean total direct costs were KES 615 (USD 5.3). Compared to mean non-medical costs (KES 225, USD 1.9), mean medical costs (KES 390, USD 3.4) constituted a larger proportion (63.4%) of total direct costs. Lost income was KES 219 (USD 2). Mean total costs were KES 834 (USD 7.2). Direct costs constituted a larger proportion of total costs than lost income (73.7% vs 26.3%). More than half (142/296, 55%) of participants experienced catastrophic costs. Participants who experienced catastrophic costs were found to have higher lost income (KES 315, USD 2.7 vs KES 102, USD 1) and specific direct medical costs including medicines (KES 92, US 0.8 vs KES 51, USD 0.4), radiography (KES 116, USD 1 vs KES 79, USD 0.7), and laboratory costs (KES 170, USD 1.5 vs KES 88, USD 0.8), than those who did not experience catastrophic costs.

Table 5.2 Direct healthcare costs, lost income, and catastrophic costs

Cost in Kenya Shillings	All participants (n=296)	Participants whose households did not experience catastrophic costs* (n=133)	Participants whose households experienced catastrophic costs (n=163)
Direct medical costs participant			
Mean consultation costs (SD)	82 (65)	77 (63)	85 (66)
Median consultation costs (IQR)	50 (50-100)	50 (50-70)	50 (50-100)
Mean medicines costs (SD)	73 (152)	51 (110)	92 (177)
Median medicines costs (IQR)	0 (0-45)	0 (0-0)	0 (0-100)
Mean radiography costs (SD)	99 (277)	79 (222)	116 (314)
Median radiography costs (IQR)	0 (0-0)	0 (0-0)	0 (0-0)
Mean laboratory costs (SD)	133 (358)	88 (193)	170 (447)
Median laboratory costs (IQR)	0 (0-120)	0 (0-80)	0 (0-250)
Mean other procedure costs (SD)	3 (30)	2 (10)	4 (40)
Median other procedure costs (IQR)	0 (0-0)	0 (0-0)	0 (0-0)

Cost in Kenya Shillings	All participants (n=296)	Participants whose households did not experience catastrophic costs* (n=133)	Participants whose households experienced catastrophic costs (n=163)
Direct non-medical costs participant			
Mean food costs (SD)	16 (48)	18 (47)	15 (49)
Median food costs (IQR)	0 (0-0)	0 (0-0)	0 (0-0)
Mean travel costs (SD)	157 (180)	146 (149)	167 (202)
Median travel costs (IQR)	100 (50-200)	100 (50-200)	100 (60-200)
Mean accommodation costs (SD)	0.4 (6)	0.8 (9)	0 (0)
Median accommodation costs (IQR)	0 (0-0)	0 (0-0)	0 (0-0)
Mean other costs (SD)	3 (13)	4 (16)	2 (10)
Median other costs (IQR)	0 (0-0)	0 (0-0)	0 (0-0)
Direct non-medical costs carer/accompanying person			
Mean food costs (SD)	6 (35)	3 (20)	9 (44)
Median food costs (IQR)	0 (0-0)	0 (0-0)	0 (0-0)
Mean travel costs (SD)	42 (124)	38 (120)	46 (128)
Median travel costs (IQR)	0 (0-0)	0 (0-0)	0 (0-0)
Total direct medical costs participant			
Mean total direct medical costs (SD)	390 (582)	297 (436)	467 (670)
Median total direct costs (IQR)	95 (50-500)	70 (50-420)	150 (50-650)
Total direct non-medical costs (participant and carer/accompanying person)			
Mean total direct non-medical costs (SD)	225 (291)	208 (253)	239 (319)
Median total direct non-medical costs (IQR)	125 (60-300)	140 (60-260)	120 (60-300)
Total direct costs (total medical + total non-medical)			
Mean total direct costs (SD)	615 (763)	505 (595)	706 (868)
Median total direct costs (IQR)	325 (150-750)	250 (130-640)	400 (150-950)
Lost income (participant)			
Mean lost income (SD)	219 (825)	102 (274)	315 (1076)
Median lost income (IQR)	2 (1-50)	1 (1-32)	2 (1-72)

Cost in Kenya Shillings	All participants (n=296)	Participants whose households did not experience catastrophic costs* (n=133)	Participants whose households experienced catastrophic costs (n=163)
Total costs (total direct costs + lost income)			
Mean total costs (SD)	834 (1249)	607 (706)	1020 (1535)
Median total costs (IQR)	438 (151-987)	371 (151-751)	451 (171-1206)
Catastrophic costs incurrence			
Total costs >40% of the monthly capacity to pay of the household (%)	163 (55)	NA	NA

5.3.3. Coping strategies and NHIF coverage

The major coping strategies to pay for care-seeking due to symptoms of CRD (Table 5.3) were use of savings (173/296, 58%) and borrowing (91/296, 31%). Most (282/296, 95.5%) of households used at least one coping strategy and 37/296 (12.5%) used two or more coping strategies. Less than one third (84/296, 28%) of participants had NHIF membership, of which only 11/84 (13%) used NHIF to pay for care-seeking costs. The main reasons for not using NHIF were lack of discussion about the NHIF at the point of care (41%) and ineligibility for cover due to defaulting on monthly premiums (30%). Amongst those without NHIF membership (n=212), the main reasons reported were lack of affordability (92/212, 43%), unawareness regarding NHIF or eligibility to join NHIF (56/212, 26%), and lack of information including regarding enrolment processes (44/212, 21%). Other underlying reasons affecting NHIF membership and usage in payment for CRD services were reported in section 3.3.8.

Table 5.3 Coping strategies for healthcare expenditures, coverage, and use of NHIF in accessing CRD care.

Coping strategies, NHIF coverage and use	All participants (n=296)	Participants whose households did not experience catastrophic costs* (n=133)	Participants whose households experienced catastrophic costs (n=163)
Coping strategies (%)			
Use savings	173 (58)	71 (53)	102 (63)
Borrow	91 (31)	36 (27)	55 (34)
Money from other sources	22 (7)	7 (5)	15 (9)
Additional work	20 (7)	14 (11)	6 (4)
Sell property	11 (4)	6 (5)	5 (3)
Loans	7 (2)	3 (2)	4 (2)
Default on rent	1 (0.5)	1 (1)	0 (0)
Number of coping strategies used (%)			
None	14 (4.5)	10 (8)	4 (2)
1	245 (83)	112 (84)	133 (82)
2 or more	37 (12.5)	11 (8)	26 (16)
NHIF			
Participants with NHIF membership (%)	84 (28)	43 (32)	41 (25)
Used NHIF to pay for care (n=84)	11 (13)	3 (7)	8 (20)
Mean Kenya Shillings covered by NHIF (SD)	1278 (1327)	600 (529)	1532 (1472)
Did not use NHIF to pay for care (n=84)	73 (87)	40 (93)	33 (80)
Reason for not using NHIF to pay for care (n=73)			
Did not ask or was not asked about NHIF	30 (41)	15 (37.5)	15 (45.5)
Not up to date with NHIF premium payments	22 (30)	12 (30)	10 (30.5)
Facility not signed up to NHIF and/or NHIF card not taken	16 (22)	11 (27.5)	5 (15)
Forgot card or other required identification	3 (4)	1 (2.5)	2 (6)
Did not know services covered by NHIF	2 (3)	1 (2.5)	1 (3)
Participants without NHIF membership	212 (72)	90 (68)	122 (75)
Reason for not having NHIF (n=212)			
NHIF is unaffordable	92 (43)	38 (42)	54 (44)
Unaware of NHIF	56 (26)	18 (20)	38 (31)
Lack of information	44 (21)	24 (27)	20 (16)
Services/package offered is inadequate	2 (1)	2 (100)	0 (0)
Choice of facility is limited	0 (0)	0 (0)	0 (0)
Other*	18 (9)	8 (9)	10 (8)

5.3.4. Factors associated with incurrence of catastrophic costs.

Factors found through the multivariable regression to be independently associated with experiencing catastrophic costs included the participant: being female (adjusted odds ratio, aOR, 2.2, 95% CI, 1.2-4.2, p=0.011), being the primary income earner of the household (aOR 2.0, 95%CI 1.0-3.9, p=0.044), belonging to the poorest tercile of participant households (aOR 2.4, 95%CI 1.2-4.8, p=0.017), and having sought care from a subcounty hospital (aOR 2.5, 95%CI 1.3-5.1, p=0.008, Table 5.4). Using two or more coping strategies showed a borderline but non-significant association with experiencing catastrophic costs (aOR 4.1, 95%CI 0.92-18, p=0.065). Sensitivity analyses at varying catastrophic costs thresholds showed broadly similar associations as those in the primary regression analysis (see Appendix 18 for Supplementary tables 5.4 and Supplementary Figures 5a-d).

5.4. Discussion

To our knowledge, this is the first study to evaluate the prevalence and drivers of catastrophic costs for people attending public healthcare facilities with symptoms of chronic respiratory diseases in Kenya. Direct medical costs accounted for nearly two thirds of all out-of-pocket costs. Out-of-pocket costs contributed nearly three quarters of the total socioeconomic impact on those seeking care. More than half of people seeking care for chronic respiratory symptoms in Meru County's primary healthcare facilities and hospitals experienced catastrophic costs. Major predictors of incurring catastrophic costs were being female, being the primary income earner of a household, belonging to the poorest households, and seeking care from a sub county hospital. Less than a third of participants had NHIF membership, and even fewer used NHIF to pay for healthcare services. Our study adds to the accumulating evidence of catastrophic expenditures associated with health care among poor people living in Kenya [169, 256] and similar LMIC contexts, and contribute novel evidence on the current status of NHIF use for non-communicable diseases. Our findings will inform ongoing policy dialogue on health financing for NCDs and the use of NHIF to achieve UHC objectives in Kenya.

Direct medical costs relate to services within the control of decision-makers within the healthcare system, therefore there are important prospects for policy intervention. These findings differ from the first Kenyan Tuberculosis Patient Cost Survey, that ranked direct non-medical costs as the largest cost driver, while the direct medical costs were the smallest cost component [256]. This may relate to the prolonged TB treatment duration of six months, often with health facility-based DOTS, and TB medicines being subsidised at all health system levels in Kenya through a vertical programme.

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Despite TB and CRD sharing similar symptoms and diagnostic pathways, there has been little recognition of the socioeconomic impact or catastrophic costs or catastrophic health expenditure of people seeking diagnosis and care for CRD or symptoms consistent with CRD [263]. A study in Uganda showed that, amongst people with symptoms consistent with CRD who were not subsequently diagnosed as having TB, 11% incurred catastrophic costs [264]. In the Kenyan context, studies have focused on the leading NCDs: cardiovascular diseases, cancers and diabetes [47]. Subramanian and colleagues estimated patient costs of screening, diagnosis and treatment services for all the four main NCDs including chronic respiratory diseases in public and private facilities in Nairobi [147]. A key study limitation, however, was they used cost estimates from national surveys, Drug-Index price estimates and opinion of healthcare experts, rather than measuring costs incurred by patients directly. Drug-Index is a comprehensive source of information on distributor prices on drugs, in Kenya. The study established price variations of drugs between the Drug-Index and pharmacies. The study excluded estimates of non-medical expenses such as travel, and indirect costs e.g., loss of income that may significantly affect the overall cost of accessing care to the patients. The study was also based in Nairobi, the capital city and the findings may not be applicable to other parts of the country [147]. A household survey estimated that 82% of Kenyans incurred OOP costs to purchase medicines used to treat NCDs [19]. A study by Wang et al, [265], exploring economic burden of chronic conditions in Malawi, established similar results (60.8%). The Malawian study however was population-based, and explored costs incurred over one month. A different study by Sichali et al. in Malawi, identified travel and drug expenses as the highest costs of healthcare seeking for people with chronic coughs only [266]. This study collected similar data to our study, however the scope differed in that they explored cost of healthcare seeking pre-diagnosis, after diagnosis and treatment, through cross-sectional household surveys. Other cohort or health economic studies focused on CRD in sub-Saharan African contexts have largely investigated equity, availability, and affordability of medicines for asthma and other CRD [184, 267, 268].

The association of catastrophic costs with household impoverishment is well described [269] including catastrophic health expenditure of the poorest households in Kenya [270] and Uganda [271]. Moreover, the medical poverty trap is well exemplified by TB with the poorest households being those most likely to experience catastrophic costs [259]. Poverty stigma and asthma stigma are intersectional and any conditions that further impoverish people and their households will exacerbate stigma [223]. Family expectations and social interconnectedness in Meru means that any economic costs incurred by the person with CRD could lead to a ripple effect within their social circle, potentially setting up or exacerbating vicious cycles of poverty, asthma stigma and ill-health. A review of stigma experiences for chronic obstructive pulmonary diseases identified social exclusion, and loss of employment opportunities among other adverse outcomes [272].The economic impacts observed in this study risk perpetuating poverty and worsening outcomes such as morbidity

and mortality. Measures to mitigate these impacts and address asthma stigma would be crucial in breaking the cycle of poverty and ill-health, improving outcomes in subsequent generations. Additionally, unless stigma is addressed, poverty alleviation, social protection measures and free drugs may not improve the uptake of asthma care as was the experience of Novartis™ when supplying inhalers free at the point of use [37].

Other predictors of catastrophic costs, such as gender, invite more scrutiny. Our study found that being female was significantly associated with the risk of incurring catastrophic costs. This complements other studies that have focused on the gender differential of catastrophic costs associated with care-seeking for maternal health [273-276]. Whilst not ruling out completely the possible influence of maternal issues, this finding may be explained partly by consideration of health seeking behaviours by women, against social-cultural and economic norms. For example, women are most likely to take unpaid jobs or seek casual jobs because of other household responsibilities including lay caregiver roles [277]. Studies on drivers of TB costs in Kenya, including the National TB Patient Cost Survey, did not find gender to be a significant predictor of catastrophic costs [256, 257].

This study identified accessing healthcare services at the subcounty level (as opposed to primary care closer to home or at the more remote, but better equipped MTRH) as a predictor of catastrophic costs. This is because subcounty hospitals are critical levels of healthcare, where it is presumed that all referrals from the primary level should be seen, with very few referrals above this level. It is expected therefore that a substantial number of local populations will seek care at the subcounty level. This finding therefore has significant implications on financial protection.

Given the centrality of the NHIF in universal health coverage agenda in Kenya, the findings related to inadequacies in NHIF coverage and usage are topical and relevant to policy makers in the field of social protection both nationally and internationally. Coverage of NHIF was low among the study participants and, even amongst the minority of participants who were covered by NHIF, use of NHIF to access healthcare services was negligible. This low coverage and usage are likely to have contributed to the finding that NHIF membership was not a significant predictor of catastrophic costs. This is an important finding. Studies in Kenya and other LMIC have pointed out the disadvantage of health insurance as a purchaser of services, particularly rural communities working in informal sector [61, 62, 278]. This study established affordability and low awareness about NHIF as the main reasons for not enrolling in the scheme. This calls into question the prospects of using the NHIF as the preferred vehicle for universal health coverage in Kenya. There are increasing calls to identify alternative mechanisms for financial protection, for example shifting from health insurance to tax-funded healthcare purchasing models [279, 280].

5.4.1.   Strengths and limitations of the study

This study collected data on actual costs incurred for the facility visit, therefore enhancing contextual interpretation of these study findings in Meru County and similar contexts in Kenya. Collection of data same day that participants received healthcare services alleviated the problem of recall bias [281]. The inclusion of indirect costs in this analysis strengthens the estimation of risk to catastrophic costs, because it includes the 'hidden costs'[277] of accessing care. This study used a convenience sample of patients attending public healthcare facilities, additionally, we only investigated one county. Future studies should investigate population-based household samples on a nationally representative sample. We excluded data from children in the analysis mainly due to ethical and practical considerations. However, essential information such as occupation, household expenditure and lost income could only be collected from adults, therefore limiting the impact of excluding children.

The definition of catastrophic costs used in this study was adapted from two different WHO definitions: catastrophic health expenditure and TB-related catastrophic costs. The inclusion of non-medical costs such as food and travel, and lost income associated with illness and care-seeking may have elevated the prevalence of catastrophic costs in this study. Nevertheless, inclusion of these elements was evidence-based and perceived as essential by the research team to evaluate the true scale of the socioeconomic impact of care seeking amongst people with CRD. Sensitivity analysis showed varying the catastrophic costs threshold or definition did not alter findings on the factors associated with catastrophic costs such as gender, being the primary income earner of a household, and socioeconomic status.

This is a cross-sectional study that only investigated costs associated with a single episode of care seeking. Patients with chronic conditions require long term, and repeat engagements with the health system [263]. As the investigations on facility readiness (chapter 3) show, patients are usually required to come back for tests results (e.g., sputum tests) at a later date. Instances of unavailable results mean that the patients make additional visits and the costs of travel, and tests may be higher than the estimates provided here. We also assumed that recruited participants' costs were generalisable to the wider population of patients attending these services.

The COVID-19 pandemic and a healthcare workers' strike disrupted healthcare service provision for 6 months during which no data were collected. The research team noticed an increasing pattern of patients declining study participation in March 2020, when the first case of COVID-19 was reported in Kenya. The association of CRD prevalence with seasonal variation is well established [282, 283]. These factors may have also affected costs, such as travel or food costs or lost time and productivity, incurred at the time of the study.

5.4.2. Conclusion and Recommendations

The majority of people with symptoms of CRD incur catastrophic costs of care. Main predictors of incurring catastrophic costs include being female, being the primary income earner for the household, accessing services at the subcounty hospital level and belonging to a poor household. Direct medical costs account for a significant share of total costs of care. To cope with costs of healthcare we found most people use their savings. NHIF coverage and use in accessing healthcare services is low.

The government should identify drivers of direct medical costs, and design feasible mechanisms of subsidising these costs, particularly at the sub county hospital level. There is a need to reconsider strategies to increase community knowledge about NHIF eligibility and availability, optimise NHIF coverage and maximise NHIF usage within the UHC agenda of Kenya, tying this in to increased asthma knowledge and stigma reduction efforts. This may also require consideration of alternative pathways for reducing out-of-pocket user costs of accessing the healthcare system, particularly for most users who work in the informal sector.

Chapter 6: Thesis Discussion

This study explored the readiness of the devolved Kenyan public healthcare system in Meru County to respond to chronic respiratory diseases, through the lens of asthma. We examined patient-centred care and community aspects of our conceptual framework presented in section 2.4. We established that overall, devolution of healthcare services is associated with some positive changes in financing and management of the health system. Despite these positive developments, we found that the Meru County health system was inadequately prepared to respond to chronic respiratory diseases. This chapter provides a synthesis of the overarching issues, highlights the implications of these findings to health system response for chronic respiratory diseases and NCDs, and makes suggestions for future research studies. The chapter revisits the thesis conceptual framework (section 2.4) and discusses how well this and the Innovative Care for Chronic Conditions framework (section 2.2.3.2) fit for chronic respiratory diseases and offer our opinions for a revised and combined conceptual framework.

6.1.   Framing readiness to respond to chronic respiratory symptoms.

This study found significant gaps in the readiness of the devolved Kenyan public health system to respond to people with symptoms of CRD despite a rising burden of symptoms, a conducive policy environment and the availability of effective treatments for asthma control. Gaps were identified across the whole continuum of care from individual, and community to health facility, system, and policy level. The study highlights the perspectives and experiences of patients, community members, healthcare workers and local county level decision-makers in their respective roles as consumers, suppliers of healthcare services and policy level decision-makers. The articulation of different research participants' perspectives, and linkage of issues affecting multiple levels of the healthcare system (community, primary healthcare facility and referral hospitals) is critical in providing a comprehensive view and identifying priority issues and important opportunities for strengthening the health system.

The study finds that there is low awareness about asthma among patients and community members and various impediments to adherence to treatment and management plans; community health volunteers lacked training on CRD, were inadequately supported and experienced difficulties in linkage to formal healthcare facilities. The healthcare workforce is inadequately prepared to diagnose and manage asthma, frequent stock outs and unaffordability of drugs, poor coordination of services and inadequate equipment and infrastructure impeded optimal services delivery. Additionally, poor coordination of services eroded patients' trust in the public healthcare system and exposed patients to extra financial costs to access healthcare services. Health

care facility visits exposed majority of the patients' households to catastrophic costs. Key predictors of catastrophic costs included being female, belonging to a poor household, being a head of the household and attending sub county hospitals. Direct medical costs accounted for the largest share of costs of care. The coverage and use of NHIF in paying for chronic respiratory disease services appears to be inadequate. Governance problems within the Meru County health system affected healthcare workers' motivation and availability to provide care.

Health systems in LMICs are currently designed to respond to acute, mostly communicable, illnesses usually through disease-specific vertical programmes. There are increasing advocacy for health systems integration, and using multi-sectoral approaches [284]. Despite some adaptation to treat people living with HIV, these systems often respond poorly to chronic conditions such as CRD. Integration of NCDs with other disease programmes has potential to enhance efficiency in service delivery and enhance patients' experiences of care. TB for example, shares various social determinants with NCDs such as poverty, socio-cultural factors, and inadequate social protection [285]. Foo et al reviewed studies that investigated integration of TB and NCD services in LMICs. The review identified integration models involving screening and treatment services provided at the same facility, as the most appropriate for providing continuity of care. Key barriers to integration include lack of privacy for NCD screening, additional workloads and inadequate training of healthcare workers, out-of-pocket costs and inadequate financial allocations to healthcare services, long waiting times for screening and referral, shortage of staff and medical supplies. The review also identified lack of guidelines for integrating TB and NCD services as an important barrier [285]. The findings of Foo et al's review resonate with our study findings and other studies conducted in similar contexts [42, 286]. Based on the study findings, a practical starting point in integration of guidelines would be to embed pathways for diagnosing CRD within diagnostic algorithms for TB. According to our study, an important gap in integration of TB with chronic respiratory diseases, occurs at the point of communicating test results for TB to patients. Whereas active measures are undertaken to communicate positive test results for TB, communication of negative TB results, and possibly opening opportunities for alternate diagnostic tests, is discretionary and frequently neglected. Important aspects of the ICCC framework [111] that may be adapted for asthma and other chronic respiratory diseases include promoting continuity and coordination, for example of drug supply, sputum tests and availability of chest x-ray services, and community referrals. These aspects go hand-in hand with organising and equipping health care teams, for example through trainings on correct, timely diagnosis of asthma, counselling skills, and demonstration of inhaler use. The healthcare organisation should also support both short- and long-term self-management of patients.

6.2. Delivering person-centred care for chronic respiratory diseases in a resource poor context

The Global Action Plan for Prevention and Control of Non-Communicable Diseases emphasises on the need for enhancing patient-centred care plans in the management of chronic conditions [39], and reforming healthcare systems towards universal health coverage objectives. Our findings, drawn from investigating person-centred care for asthma, are applicable to other CRD, and to systemic aspects of chronic care models for other NCDs. Person-centred care means that the needs, preferences, beliefs, decisions, household, and community contexts of the patients are prioritised in the diagnostics, treatment, and management plans of patients [128, 129, 191]. Tailoring care plans to the needs of people with CRD symptoms is vital in optimising opportunities for patient *'co-operation'*, rather than *'compliance'* with the doctors' treatment plans, including adherence to medication, self-management and subsequently, better control of chronic diseases like asthma. This is likely to consolidate the trust of patients in the public health system. Cooperation implies adequate understanding and ownership of the situation and subsequent decisions and plans relating to the issues; compliance on the other hand implies responding to the influence of a dominant power. Prospects of sustaining a desirable outcome, are better in situations of cooperation, rather than compliance.

Provision of person-centred care requires that the patients' dignity, autonomy, and control, are respected. The concept underscores the recognition, and incorporation of "subjective experience of illness and collaborative approaches to self-management and care" [191]. It implies complementing the health system hardware such as human resources, diagnostic equipment, skills, and procedures, with relational aspects of care that deliberately focus on the human(e) in provision of healthcare services. Important aspects of service delivery that would focus on person-centred-ness for CRD include communication skills of healthcare workers for example in disclosing an asthma diagnosis, ethical and professional considerations, e.g., in handling sputum samples and maintaining patients' confidentiality; health education for the patients to help improve their understanding of CRD and minimising anxiety, engagement and working together in mutual respect between formal healthcare workers and community health volunteers particularly in referral, treatment and subsequent management of patients, privacy in provision of care e.g. in dispensing inhalers, demonstration of inhaler use, and specific measures to prevent inconvenience to patients. Person-centred care needs flexibility [191]. If healthcare workers proactively engage patients during care, it may help patients to understand the need for tailored services, and manage patients' expectations for care, better.

Addressing stigma is central to person-centred approaches. Stigma "is considered one of the major obstacles to public health, a barrier to provision of health services", and a driver of inequities [287]. In this study, stigma emerged as a significant issue in diagnosis, treatment and management of asthma, cross-cutting supply side

(community health system and healthcare facilities), and the demand side of the healthcare system (patients and their caregivers). Key drivers of stigma include low awareness about asthma especially on risk factors, social norms, and stereotypes, with implications on kinship, and gendered discrimination. We have reported these findings elsewhere [288]. According to this study, stigma affected the diagnostic processes and subsequent treatment and management plans. Miles et al have synthesised evidence of patients challenging the validity of an asthma diagnosis, and the deleterious effects on self-management [289]. In this study, such challenges were associated with denial of asthma diagnosis and stigma. The disconnect between supply side (Meru County government) efforts to obtain asthma medications at cheaper, subsidised prices, and the prospects of these drugs not being used by the intended patients, revolves around stigma, e.g., for inhaler use. Stigma for asthma has been reported in diverse settings in both low- and high-income countries [287, 290, 291], and has been associated with poor control of asthma. Effective interventions for asthma, must address drivers of stigma, across all the levels defined within the ecological framework, [137] i.e. individual, interpersonal, organisational, community, and public policy level.

Interventions to reduce stigma in HIV/AIDS and TB have been documented. Brown and colleagues established that interventions focused on HIV/AIDS-related stigma adopted several components including provision of information, development of skills to counter stigma, counselling and support for coping strategies, and mechanisms of enhancing contact between stigmatised populations and other people [230]. The authors however expressed uncertainty about the long-term effectiveness of the interventions. They identified scale, length of interventions, and gendered impacts as key issues for further research. A subsequent review [231], established that interventions were effective in 79% of the studies reviewed. The review however showed that majority of the interventions tended to focus on drivers of stigma, but neglected stigma manifestations e.g. shame and discrimination, or community-level attitudes and social norms that influence individual behaviours [231]. A review of interventions for stigma against TB showed that information campaigns, participation in 'TB clubs' or support groups, home visits by nurses were effective in varying extents, in reducing stigma [228]. These findings have important bearings on interventions against stigma for asthma and other chronic respiratory diseases, and align well with the ICCC framework [111] for community level interventions against stigma. The ICCC framework however fails to acknowledge meso-level factors (healthcare organisation) that may perpetrate stigma, for example healthcare workers' attitudes for asthma control. Suggestions for policy-relevant research focused on addressing stigma in healthcare settings [292] include measuring magnitude of stigma and examining contribution of stigma to delay in healthcare seeking, suffering and treatment dropouts [292].

6.3.   Capacity of the health system to respond to chronic respiratory symptoms in a devolved context.

This study was conducted five years (2013-2018) after healthcare services were officially devolved in Kenya. Devolution thus provides an important conceptual backdrop framing healthcare seeking, service delivery processes and policy decision making for NCDs including CRD within an evolving political process. Taking this into account in the analysis provides much needed evidence for policy processes aimed at strengthening devolution. The findings particularly highlight a vacuum in technical capacity following devolution; difficulties in responding to 'lesser priority' conditions that are not TB and are not vertically funded and the challenges and opportunities for governance that devolution poses.

6.4.   Technical capacity in the devolved system

Studies of the devolved healthcare system in Kenya, identified inadequate capacity, as an important barrier to decision-making and services delivery [50, 59, 127, 179]. This study identified capacity gaps specific to CRD, across health system building blocks. These include inadequate numbers of healthcare workers to deliver services. The Consolidated County Level Annual Work Plan for Meru County (2019-2020) highlights gaps in essential health worker cadres: 11 medical officers, 23 pharmacists, 79 pharmaceutical technologists, 58 laboratory technologists, and 98 health records officers [189]. Whereas the sampled healthcare workers in this study report knowledge of asthma diagnosis based on patients' histories and physical examination, this study establishes important skill gaps in conducting lung function tests, amidst widespread lack of peak flow meters and spirometry in public facilities. GINA guidelines recommend that lung function tests should be conducted, before a patient suspected of asthma is started on a treatment plan [65]. Inadequate diagnostic capacity implies limitations in tailoring treatment for example based on severity of asthma. Consequently, the collection, and measurement of CRD burden in healthcare facilities is limited [42]. Earlier research identified capacity constraints, poor coordination of training of healthcare workers, and lack of incentives for career progression, as important issues in the early year of devolution [159].

Capacity challenges in financing the Meru County health system affected the health system response for CRD. Firstly, the budget allocations to the healthcare system were inadequate, and associated to problems such as delayed salaries for healthcare workers, lack of stipends and other resources for community health volunteers, and constraints in drugs procurements. Latest estimates show a deficit of over 210 million Kenya shillings (1.8 million USD) in the Meru County Department of Health budget estimates. Pharmaceutical supplies accounted for approximately 51% of these deficits [189]. Weaknesses in drug supply chains suggest inadequate capacity in KEMSA to supply drugs to all the 47 counties effectively. This calls for assessment of relevant institutional

factors within KEMSA, that need to be strengthened to drive timely services. On the other hand, the delays by counties to pay also weaken KEMSA's capacities to supply drugs in time [293]. Priority setting for resources and finances at the county level, face difficulties because of weaknesses in information exchange, and governance issues. Weaknesses in data collection at the facility level have a negative impact on budgetary allocations and other county level priority setting for CRDs [42].

Health facility infrastructure needs re-design to align them to CRD management. Specific changes include provision of private areas for dispensing and demonstrating inhaler use. Assessed against the ICCC framework, these findings show limitations in promotion of consistent financing at the policy level, poor mobilisation and coordination of resources, and organisation and equipping healthcare teams [111].

6.5.   Responding to chronic respiratory symptoms that are not tuberculosis.

The study explored readiness of the Kenyan public health system to respond to chronic respiratory symptoms within a context of high TB burden. The lessons from the study will therefore illuminate a neglected but important condition, and hopefully spur prioritisation in the county agenda, and other contexts in Kenya.

Vertical programmes e.g., for TB, Malaria and HIV/AIDS, are associated with significant external donor funding, that have sharply increased since the year 2000. These programmes have had a huge impact in enhancing care for affected people, reducing prevalence of the targeted diseases, and strengthening health systems through infrastructural development, and enhancing diagnostic capacities e.g. through supply of equipment and other diagnostic resources [294]. Critics have nonetheless voiced shortcomings of these programmes [295]. The reasons include funding for vertical programmes being restricted to donor interests for specific diseases; losing opportunities for maximising efficient resources uses on broader health systems infrastructure and other resources development. Vertical programmes distort healthcare delivery e.g., they offer attractive packages e.g. salaries double what other public healthcare workers receive [295]. Consequently, these programmes 'siphon' scarce human resources from other important public healthcare services, creating in-country 'brain drain'. Furthermore, the vertical programmes have been associated with weakening of governments' priorities in public financing for programmes associated with donor funding. Further criticism is on vertical programmes introducing parallel monitoring and evaluation systems [296], consequently fragmenting information systems. By prioritising and amplifying issues on a specific disease e.g., TB, other important healthcare problems tend to be neglected. Donor driven initiatives consistently raise concerns about sustainability [297].

Our findings that TB care seems more prioritised compared to asthma resonate with these concerns on vertical programmes. This is demonstrable by the fact that healthcare workers were reported to actively follow up patients with positive test results for TB, but there is little or no follow up at all for patients with TB negative results. Our economic analysis shows that direct medical costs account for the highest cost of care for people with symptoms of chronic respiratory diseases. The TB cost survey in Kenya [298], on the other hand showed that other non-medical costs e.g. travel were the most significant. The differences in these study findings, despite the differing time periods of illness studied, may be attributed to the fact that TB drugs are subsidised by donors, and therefore provided free of charge, while drugs for asthma chronic respiratory diseases are not, except at health centre level.

There are opportunities for leveraging on the TB infrastructure to enhance response to asthma and other chronic conditions. The use of GeneXpert machines for the initial sputum tests is an example of the integration of care. Critical gaps however remain, including development of policy guidelines for integration of TB to asthma care, embedding pathways to diagnosis of asthma for people who have TB negative results. Supportive interventions will include designing of messages to create more awareness of asthma and other chronic respiratory diseases, investing in lung function test equipment, training healthcare workers and identifying mechanisms of subsidising further, the asthma medication.

6.6. Governance, priority setting, trust, and accountability in a resource-poor devolved system.

Governance and stewardship are important components that shape the performance of other health system building blocks [88]. Through governance, the 'rules of the game' are determined, which in turn create expectations among the different actors of a system and influence their behaviours [95, 102] towards desired outcomes. This study identified accountability in financial transactions e.g., delays in staff salaries and accountability problems in payroll deductions as important indicators of weak governance. Delays in disbursement of funds from the national treasury to counties is a recurring problem Kenya's devolved government system [165, 299, 300], and has been associated with disruptions to county planning, and timely payment for essential services and commodities [108, 293, 301]. The problems in accountability for payroll deductions call for further investigations and identifying mechanisms for strengthening local county governance structures.

Our analysis magnifies governance issues in community health systems, and adds to the growing literature on the need to understand political commitment and human resources policies as important contextual factors affecting community health workers' performance [302]. This study established that unfulfilled promises to

provide stipends for CHV, and lack of resources, ruined their trust in their engagement with the county government, and motivation to work. Consequently, CHV attrition negatively affected household coverage and further overloaded the remaining CHV. While volunteerism is acknowledged as an invaluable resource in many spheres of engagement, critics have questioned the 'voluntary' model of community health workers [303]. A study in Tanzania exploring motivations of CHV showed similar perspectives with our study. CHVs were motivated by both intrinsic (altruism, solidarity with community) and extrinsic factors (financial rewards, training, knowledge and material benefits) [304, 305]. Financial compensation is however widely cited in other contexts as a significant factor in CHVs retention [306-309]. Interestingly though, whereas CHVs in Kenya reported privately supporting poor community members e.g., with fare and food, the situation was different in Tanzania, where the CHVs themselves received support e.g., fare, from their household members and community members. For example, household members did additional paid work to compensate for CHV time in volunteering [304]. Both scenarios however imply that private resources are used to substitute public provisions. Other constraints that affect CHV trust by the community members, and need for recognition, have been documented [305]; they should be addressed, to enhance positive externalities of health system software [122], and optimising community health volunteers' roles as agents of social change.

It is commendable that the Kenyan government is driving legislative changes to entrench financial compensation of CHV in law. The Community health services bill is currently under consideration by the national parliament [123]. During data collection, we established that the Meru County Assembly was also deliberating a local legislative bill to provide for stipends for CHVs. These developments are important in sustaining CHVs work and demonstrate the importance of "leadership and advocacy" and consistent financing - both vital ingredients of a favourable policy environment for CRD [111]. In moving forward with these developments, it is important to carefully address sustainability [304], and wider legal implications of engaging CHVs as 'workers' rather than volunteers [303].

Governance also relates to priority-setting processes in contexts of donor- driven public health interventions e.g., TB vertical programmes. Additionally, the position, and visibility of chronic respiratory disease programmes within the NCD space deserves closer attention. According to our analysis, cardiovascular diseases, diabetes, and cancers seemed to receive more attention compared to CRD. This aligns with other observations about the low priorities to CRD, even within the NCD family.

6.7.   Gendered aspects of asthma and chronic respiratory diseases

Several gender-related issues emerged in this study, inviting closer scrutiny on how gender shapes socio-determinants of health, the health system response, and the interaction with other drivers of inequity and exclusion [310]. These include threats to marriage prospects or strains to marriage, associated with

perceptions of hereditary risks of asthma and a stereotypical view of people with asthma as weaklings including for example, sexual performance. The costs study identified the female gender as an important risk factor to incurring catastrophic costs. Most studies on gender have mainly focused on socio-economic aspects such as education, access to income-earning opportunities, underscored by differences in productive and reproductive labour. A review by Steege et al on the gender influences on the work of community healthcare workers showed that there was higher attrition among male CHVs, possibly due to their roles as breadwinners in their households [311]. This study too established that the main reason for male CHV attrition, is lack of stipends. Additionally, in LMIC contexts, women dominate low-paying or unpaid labour. The voluntary model in Kenya may serve to reinforce gendered disadvantages for CHVs. There is however a scarcity of research data on the intersections between gender and NCDs [312]. Future research should examine in detail intersections of gender and health outcomes for asthma and other chronic respiratory conditions.

6.8. Generalizability of the findings and exploration using the lens of asthma.

The decision to explore CRD using the lens of asthma have been outlined in section 1.2.Whereas these findings may have some limitations in generalizability across other CRD, they nonetheless identify important issues about how the Kenyan healthcare system responds to people who have CRD symptoms but are diagnosed as not having TB. The deficiencies in appropriate diagnostic equipment and healthcare workers' capacities imply that the difficulties in diagnosing asthma may be true for other conditions with similar symptoms such as COPD. Similarly, supply chain problems affecting asthma are applicable to other diseases as well. Baring contextual and procedural differences, the lessons from this study make important contributions to the health system reorganization to respond more effectively to other chronic respiratory diseases, as well as NCDs.

The selection of Meru County limits the generalizability of the study findings to other county settings, due to the small number of health facilities sampled, and the patient population. The case study design aimed to explore issues in greater depth, and this would not have been possible if the study covered many counties, given the resource and time constraints. Some key differences and limitations in generalizability may be due to contextual differences. The 47 devolved subnational governments are autonomous in management their respective healthcare systems. Priorities across counties may differ markedly, and the findings of this study may be applicable to counties with high CRD prevalence but may not be prioritised in other county settings. The findings of this study however resonate with findings from an earlier study conducted in Nairobi in 2018[43] , and which in turn were similar to observations in four other African countries in the Eastern region- Uganda, Malawi, Tanzania and Sudan, albeit with some contextual variations. The issues drawn from this

study are useful for informing health system preparedness for CRD in other county contexts. They include weaknesses in supply of medicines by KEMSA, low diagnostic capacities, the pervasive influences of stigma for asthma, weak community health systems and the problem of healthcare financing and governance in the devolved context.

6.9 Thesis strengths and limitations

During this study, several developments happened, that have significant implications on the chronic respiratory diseases at a local and international perspectives and were not considered in the design. This study was conducted before, and during the COVID-19 pandemic, and these findings are vital in health systems reforms in the 'post-COVID-19' pandemic era. The COVID-19 pandemic wreaked havoc on national and global health systems. The public health response revealed weaknesses in health systems in low- and high-income countries alike. Importantly though, the pandemic brought issues of lung health into sharp focus and has provided important windows of opportunity for pushing the agenda for reforms relating to lung health. Such reforms include improving diagnostic capacities for lung diseases, training of healthcare workers and community volunteers on lung health and increasing funding for infrastructural development and service delivery. This however would depend on the response of the policy communities on lung health.

COVID-19 disrupted our data collection. In the early phases of the pandemic, we witnessed a drastic fall of patient visits to the healthcare facilities. Besides disrupting data collection, it is possible that some patients who were eligible for the study did not visit the healthcare facilities. Additionally, we also witnessed declines in consent, which we associated to patients' anxieties about COVID-19 and KEMRI's role in the national COVID-19 response. It is also possible that some patients in the facilities concealed important symptoms which were associated to COVID-19, such as cough and difficulty in breathing, and therefore we may have missed these patients at the screening stage. There was also more awareness by the people about respiratory conditions owing to high publicity about COVID-19. This may have biased their responses. The government ban on community meetings affected the FGD data collection, in one of the study sites, therefore we may not in certainty, claim theoretical saturation for FGD data. Other disruptions due to healthcare workers' strikes were associated with a 7-month cumulative delay in data collection. This may have affected exposure to risk environmental risk factors that vary with season e.g., cold.

This study makes important contributions to the understanding of health systems response for CRD management in a devolved context in Kenya. These findings may be applicable to other non-communicable diseases, as relevant. Firstly, this study used and triangulated multiple methods - both quantitative and qualitative, to explore issues at different levels of the health system. By engaging community members and CHVs, patients, healthcare workers, and key informants, the study explored multiple perspectives of

consumers of healthcare services, providers of care and policy decision-makers at the county level. We got important insights on demand and access to care and complexities of management of health system within the devolved Kenyan context.

The data collection approach was designed to minimise bias. The facility readiness surveys were conducted first to explore the situation based on key indicators of service delivery. Similarly conducting exit interviews same day of facility visits aimed to minimise recall bias [313], particularly on the direct costs of the facility visits. We used voice recorders in all qualitative interviews, to enhance accuracy and quality of data collection. Additionally, we did member-checking through phone calls to seek clarifications on interview data. The duration of the study team in health facilities (at least a month), and interactions with healthcare workers provided important opportunities to learn and understand the contextual issues better. My experience in conducting health system research was an important factor in identifying important issues that arose in the interviews, as well as observing contextual events that enriched the interview experience.

This study involved only five sampled facilities, in one of the 47 counties. Additionally, we collected cost data from adult patients only, limited to the facility visit. These findings should therefore be interpreted with caution, as they are not generalisable to the Kenyan population. We however set out to have a comprehensive view of health system readiness, and focusing on Meru, a high TB prevalence county, was appropriate to understand issues in depth. Exclusion of children was informed by ethical considerations for parental consent, which was difficult to obtain in our research context. Practical budgetary constraints limited the scope of this study. Selection of Meru, a rural agrarian county complemented an earlier study conducted in Nairobi [42].

The study focus, on public facilities only, means that we missed out experiences of access and service delivery by private health care providers, who account for almost 50% of healthcare provision in Kenya. As our qualitative interviews showed, patients were frequently sent to private providers for services that were not available in the public healthcare facilities. Our study however, aimed to examine the readiness of public health care systems within the devolved government context, and private facilities operate autonomously from control of subnational government.

My own position (discussed in the positionality section 1.6.2) was not static during the data collection and analysis period. On 19th June 2021, drawing from relevant findings from this study, I participated in the National Asthma Management Guidelines Validation Workshop, convened in Nairobi. These guidelines have finally been published [314]. I am also privileged to have been invited, as an expert, in the first ever *WHO Technical Expert Meetings on Selection and Prioritization of Non communicable Primary-care Facility-based Indicators.* This was a rewarding experience towards strengthening the response to chronic respiratory diseases not only in Kenya, but globally as well.

6.9. Recommendations

6.9.1. Recommendations for the devolved health system

We recommend that where applicable, the national and county government should:

a) Enhance capacity of the health facilities, to make them ready to provide CRD care. Priority changes include in-service training and recruiting more health care workers, enhancing diagnostic equipment support, particularly peak flow metres, and drugs supply chains.

b) Redesign financing systems to be responsive to chronic diseases, for example subsidising care and NHIF membership using tax revenues and reducing out-of-pocket expenditures.

c) Enhance community awareness about asthma and develop interventions to confront asthma and CRD-related stigma amongst others, and drive demand for testing and technologies like inhalers.

d) Strengthen communication and working relationships between CHV and healthcare workers.

e) Train healthcare workers on asthma stigma and effective ways of mitigating stigma in healthcare settings.

f) Provide education and material support e.g., inhalers for long term self-management of asthma, including prevention and management of acute asthma exacerbations.

g) Improve mechanisms for CHV and primary healthcare workers' follow up and subsequent engagements of asthma patients.

h) Strengthen governance systems to ensure that health care workers, community health volunteers are paid their salaries and stipends in time, and problems in accountability are resolved.

i) Enhance the capacity of KEMSA, and strengthen institutional obligations of counties, to enhance drug supplies for inhalers.

j) Empower CHVs through training, on asthma, and provide tools to support referrals,

k) Destigmatise language around asthma borrowing lessons from HIV de-stigmatisation efforts.

l) Clarify roles and responsibilities of each health system level in relation to CRD care.

6.9.2. Recommendations for additional research

Future research should:

- Explore pathways for asthma and chronic respiratory diseases diagnosis and management in private facilities and across a public-private mix.

- Conduct a larger longitudinal survey on care pathways and costs of care for asthma incorporating household and facility-based data collection and is powered to yield generalisable results across counties in Kenya.

- Conduct research on the impact of decentralised and self-management on children, e.g., impact on the quality of life.

- Test interventions, co-designed across the health system levels, starting at the community, to create awareness about asthma and to minimise stigma, and enhance self-management e.g., inhaler use.

- Estimate direct and indirect costs of accessing asthma treatment including nebulisations in the health facility using the health system perspective.

- Explore alternative ways of financing and enhancing access to asthma care.

- Evaluate the impact of interventions that address a) stigma reduction and b) catastrophic costs both combined and separately (e.g., a four-armed trial).

6.9.3. Conclusions

When I set out to conduct this study in Meru County in June 2019, I was eager to learn how the Kenyan public health care system responds to chronic respiratory diseases like asthma. In this journey, I have encountered narratives, and listened to voices representing different levels of the devolved healthcare system from the community to the county level. I have learnt of the positive roles of devolution in enhancing priority-setting mechanisms, service delivery at the healthcare facilities, improving the quality of drugs supplies, amidst challenges of frequent stock-outs and financial constraints. I have also identified impediments standing in the way of a responsive healthcare system for chronic respiratory diseases. These challenges range from inadequate infrastructure, low capacity among healthcare workers - in numbers and in training for CRD; weaknesses in supply chains for drugs; lack of diagnostic equipment for respiratory diseases; and a despairing, and over-burdened community health system that appeals for more support. Weaknesses in governance systems, particularly relating to financial accountability, threaten every aspect of healthcare provision, not just

chronic respiratory diseases, but chronic respiratory diseases face the additional challenge of not being championed by donors, external agencies, or vertical programmes.

I have also learnt the adverse impact of asthma stigma on diagnostic, treatment processes and self-management of asthma, including inhaler use. This study amplifies an important disconnect between the supply side efforts to enhance inhaler use to manage asthma as championed by global leadership of GINA, on one hand, and the subversive influence of stigma on the other. I have learnt too, that rural Kenya is a society where one's physical strength to do manual work is an important social currency, leaving those with weak lungs feeling they are a burden to their community and families. Denial of symptoms and late presentation are therefore commonplace. At the same time health care use exposes people with symptoms of CRD to catastrophic costs and impoverishes their households, leading to further stigma by association. Even though the Kenyan government is reforming the health system to universal health coverage through the NHIF, critical design issues coupled with information asymmetries, stigma, and poverty, undermine effective insurance coverage and utilization for healthcare expenses. Combinations of these issues make the county health system inadequately prepared to respond to chronic respiratory diseases including asthma.

As   I penned these thoughts on the 25th of August 2022, I was struck by the timing of the completion of this study, and significant political events in Kenya. On this date, 45 elected governors in Kenya took oath of office, following nationwide elections on the 9th of August 2022, ushering in a new, third regime of government in Kenya, under the devolved government. Meru County has a new governor. Similarly, Kenya has a new president elect. There is hope, that a new regime, may bring in new ideas, new ways of doing things, and most importantly, be receptive to timely research evidence to support policy processes. I see important windows of opportunity to sustain the NCD agenda in Kenya and make practical recommendations to strengthen the Kenyan health system to support CRD care. Priority interventions should focus on health system weaknesses identified in this research relating to the supply side. These interventions should be complemented by demand side aspects, particularly on awareness and efforts to destigmatize asthma. Then, Meru County, and Kenya, will inch closer to the Universal values underpinning Sustainable Development Goals, to "leave no one behind"[315], in the quest for universal health coverage. The time to act is now.

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List of Appendices

Appendix 1: Glossary

Adults: study participants aged 18 years and above.

Asthma: as defined by the Global Initiative for Asthma (GINA)- "a heterogeneous disease, usually characterised by chronic airway inflammation. It's defined by the history of respiratory symptoms such as wheeze, shortness of breath, chest tightness and cough that may vary over time and intensity, together with expiratory airflow limitation" [65].

Asthma diagnosis: diagnosis of asthma, based on a decision by a clinical professional treating a patient.

Capitation: An advanced payment by a health insurance scheme, to a healthcare facility to deliver a set of services to a member of the insurance scheme for a defined period of time.

Children: study participants aged 5 years to 17 years old.

Chronic respiratory diseases (CRD) symptoms refer to coughs for more than two weeks' duration, coughs that persist after any treatment at a healthcare facility, coughs that continue, after a negative TB diagnosis, wheezing, difficulty in breathing, noisy breathing, chest tightness, blood in sputum.

Clinical care pathways (CCP) mean, all the essential service points in health facilities, through which patients with CRD symptoms must pass.

Community: A group of people living within the same geographical area.

Community health volunteer: (CHV) refers to a community member engaged by the county government of Meru, to voluntarily support community health services.

Community Health Assistant: A formally employed healthcare worker, based in a local healthcare facility managing a given community health unit and the CHVs, within the catchment area of the health facility.

County: a subnational devolved government unit, as defined by the Kenyan constitution. Kenya has 47 counties. A county government is led by an elected governor.

Devolution: a dynamic process of decentralization involving shift of power, administrative, political and fiscal responsibilities from national level to elected subnational governments (Bossert and Beauvais 2002).

County assembly: local legislative parliament at the county level.

Doctor: a healthcare worker providing any form of treatment to a patient.

Facilities- refer to the five public healthcare facilities (health centres, n=2; subcounty hospitals (n=2) and the Meru teaching and referral hospital, n=1), managed by the county government of Meru, and which were sampled for this study.

Health system: "A health system consists of all the organisations, institutions, resources and people whose primary purpose is to improve health" (World Health Organization 2007).

Healthcare workers: refers to all personnel involved in the provision of care within health facility settings and includes both clinical and non-clinical staff.

National government: refers to the central government of the Republic of Kenya.

Patients: persons presenting to healthcare facilities with symptoms of chronic respiratory diseases

Referral note: a document issued by a CHV to a community member, during referral to a health facility- the MOH 100.

Subcounty: a geographical zone nested within the larger county boundaries, and is administratively lower in hierarchy, in relation to the county.

Sputum test: laboratory test of sputum samples provided by patients.

Universal health coverage (UHC): a situation in which a population has access to quality preventive, promotive, curative and rehabilitative health care services in sufficient quantity, whenever they need it, without suffering financial strain.

Appendix 2: Peer-reviewed Publication on barriers to diagnosis and treatment for chronic respiratory diseases in five African countries

https://bmjopen.bmj.com/content/12/7/e052105.full?ijkey=IZ2Cq7XgczW4i9P&keytype=ref

Appendix 3: Facility readiness assessment checklist

Introduce yourself and the survey team to the health facility in-charge. Please explain the purpose of the readiness assessment and share the participant information sheet to the staff in the health facility being surveyed in advance of the assessment. Seek approval from the health facility in-charge to conduct the readiness assessment and arrange a suitable time to return to carry out the assessment, avoiding peak hours.

*On the day of the readiness assessment, introduce yourself again to the health facility in-charge and respond to any queries from the participant information sheet and complete consent with the health facility in-charge (or whoever is deputising for the assessment) **before** starting to complete the readiness assessment.*

Introduction					
001	Date	□□ / □□ / □□□□			
002	Assessor's name				
003	Name of facility				
004	Sub county				
005	County				
006A	Type of facility	Health centre 1 Sub-county hospital 2 County referral hospital 3			
006B	Facility opening times				
		Yes	**No**	**Don't know**	**Not Applicable**
007	Outpatient services only available	1	2	3	9
008	Is there a room with auditory and visual privacy available for patient consultations?	1	2	3	9
009	Do you have a bed where you can stabilize a very ill patient (e.g. acute asthma) before referral?	1	2	3	9
010	Does this facility have a functional ambulance or other	1	2	3	9

	vehicle for emergency transportation for clients **that operates from this facility**?				
011	Does this facility have access to a functional ambulance or other vehicle for emergency transportation for clients **that operates from another facility in close proximity**?	1	2	3	9
012	Is fuel for the ambulance available today?	1	2	3	9
013	Can the ambulance be used for transfer of a patient with acute asthma attack?	1	2	3	9
014	Number of inpatient beds	□□□			
015	Observe the drugs store, is there sufficient space to store all drugs and supplies?	1	2	3	9
016	Are drugs stored appropriately? I.e. is the drugs store well organised, drugs stored off the floor, clean and dry storage area?	1	2	3	9

Human resources			
017	Availability of health workers in the generalised care		
		Number present in health facility today	**Number expected to be present today**

			(including absentees)
017A	Doctor	☐☐	☐☐
017B	Clinical officer	☐☐	☐☐
017C	Nurse	☐☐	☐☐
017D	Community health worker	☐☐	☐☐
017 E	Pharmacist / Pharmacy technician	☐☐	☐☐
017F	Radiographers	☐☐	☐☐
017G	Laboratory technologist	☐☐	☐☐
017H	Other (specify)_____	☐☐	☐☐

Human resources			
018	Availability of health workers for managing chronic lung diseases (CRDs)		
		Number present in health facility today	**Number expected to be present today (including absentees)**
018A	Doctor	☐☐	☐☐
018B	Clinical officer	☐☐	☐☐
018C	Nurse	☐☐	☐☐
018 D	Specialist Doctors for CRD	☐☐	☐☐
018E	Community health worker	☐☐	☐☐
018F	Pharmacist / Pharmacy technician	☐☐	☐☐

018G	Laboratory technologist	☐☐	☐☐
018H	Other (specify)_____	☐☐	☐☐
018 I	Other (specify)_____	☐☐	☐☐
019	Are health workers trained to manage chronic lung diseases (CRDs)?		

		Trained during in-service training	Trained during pre-service training only	Never trained on CRD management
019A	Doctor	1	2	3
019B	Clinical officer	1	2	3
019C	Nurse	1	2	3
019D	Community health worker	1	2	3
019E	Other (specify)_____	1	2	3
019F	Other (specify)_____	1	2	3

	Supervision		
020	When was the last time this facility received a supervision visit from a higher level (CHMT or other)?	This month	1
		In the last 3 months	2
		More than 3 months ago	3
		Never	4
		Don't know	96
021	During the supervision visit, did the supervisor assess the following?	**Yes**	**No**
021A	Pharmacy (e.g. drug stock out, expiry, record keeping etc.)	1	2
021B	Staffing (e.g. staff available and training)	1	2
021C	Data (e.g. completeness, quality and timely reporting)	1	2
021D	Diagnosis and management of CRDs?	1	2
	Frequency of supervision		

022	How often do you normally receive supervision?	Regularly	1	
		Sometimes	2	
		Rarely	3	
		Never	4	

Service operation			
		Number of visits yesterday (from records)	**Number of visits last month (from records)**
		If don't know please write DK in box	If don't know please write DK in box
023	What is the total number of patient visits to the health facility for		
023A	Outpatient services?	☐☐	☐☐
023B	Asthma	☐☐	☐☐
023C	COPD	☐☐	☐☐
023D	Upper respiratory tract infection	☐☐	☐☐
023E	Post-TB complications	☐☐	☐☐
023F	Other chronic lung diseases	☐☐	☐☐
024	What is the total number of patients with	■	**Number of visits last month (from records)**
			If don't know please write DK in box
024A	Suspected TB	■	☐☐

024B	Confirmed TB	☐☐	
024C	TB negative with another diagnosis	☐☐	
024D	TB negative with no known diagnosis recorded	☐☐	
024E	Lost to follow up	☐☐	

Guideline availability

025	Are the following documents available within the facility (ask to observe)	**Reported available and seen**	**Reported available but not seen**	**Not available**
025A	Guidelines on case-management of acute respiratory infection for patients of all ages diagnosed with pneumonia	1	2	3
025B	Guidelines on case-management of asthma	1	2	3
025C	Guidelines on case-management of COPD	1	2	3
025D	Guidelines on case-management of chronic bronchitis	1	2	3
025E	Criteria for the referral of patients with symptoms and signs of respiratory conditions	1	2	3
025F	Clinical criteria for the diagnosis of pneumonia	1	2	3
025G	Clinical criteria for the diagnosis of asthma	1	2	3
025H	Clinical criteria for the possibility of COPD	1	2	3
025I	Criteria for the follow-up of asthma	1	2	3
025J	Criteria for the follow-up of COPD	1	2	3
025K	Standard treatment guideline	1	2	3
	Service availability			

026	Are the following services available at the facility?	**Yes**	**No**
026A	Patient counselling and education on smoking/ household air pollution	1	2
026B	Counselling and education of family members on smoking/ household air pollution	1	2

026C	Patient counselling for asthma management	1	2	
026D	Patient counselling for inhaler technique	1	2	
026E	Does this facility offer diagnosis of chronic lung diseases?	1	2	
026F	Does this facility offer management for chronic lung diseases?	1	2	
	Availability of equipment			
027	Complete for all health facilities			
	Is the following equipment available	**Available and seen**	**Reported but not seen**	**Not available**
027A	Sputum containers	1	2	3
027B	Peak flow meter with mouthpieces	1	2	3
027C	Inhalation chamber with masks (for children)	1	2	3
027D	Pulse oximeter	1	2	3
027E	Oxygen sources (cylinder and/or concentrator and accessories)	1	2	3
027F	Nebulizer with mask	1	2	3
026	Complete for sub-county hospital and County referral hospital			
	Is the following equipment available	**Available and seen**	**Reported but not seen**	**Not available**
028B	Centrifuge and incubator (if cultures for TB are performed)	1	2	3
028C	X-ray	1	2	3
028D	Spirometer	1	2	3
028E	Pulse oximeter	1	2	3
028F	Equipment for tracheal aspiration	1	2	3
028G	Oxygen sources	1	2	3
028H	Equipment for pleural drainage	1	2	3
028I	Needles and instruments for transthoracic pleural biopsy	1	2	3
028J	Blood gas analyser	1	2	3

029	Complete for Meru county referral hospital only			
	Is the following equipment available	**Available and seen**	**Reported but not seen**	**Not available**
029A	Bronchoscope	1	2	3
029B	CT scanner	1	2	3
030	Complete for all health facilities			
	Is the following equipment functioning?	**Functioning**	**Not functioning**	**Don't know if functioning**
030A	Peak flow meter with mouthpieces	1	2	3
030B	Inhalation chamber with masks (for children)	1	2	3
030C	Pulse oximeter	1	2	3
030D	Oxygen sources (cylinder and/or concentrator and accessories)	1	2	3
030E	Nebulizer with mask	1	2	3
031	Complete for subcounty hospital and the Meru Teaching and referral hospital			
	Is the following equipment functioning?	**Functioning**	**Not functioning**	**Don't know if functioning**
031A	Centrifuge and incubator (if cultures for TB are performed)	1	2	3
031B	X-ray	1	2	3
031C	Spirometer	1	2	3
031D	Pulse oximeter	1	2	3
031E	Equipment for tracheal aspiration	1	2	3
031F	Oxygen sources	1	2	3
031G	Equipment for pleural drainage	1	2	3
031H	Needles and instruments for transthoracic pleural biopsy	1	2	3
031I	Blood gas analyser	1	2	3
	Complete for Meru Teaching and Referral hospital only			
	Is the following equipment functioning	**Functioning**	**Not functioning**	**Don't know if functioning**

032A	Bronchoscope	1	2	3	
032B	CT scanner	1	2	3	
	Drug supply				
033	Who is the person responsible for managing the ordering of medical supplies at this facility?	Nurse Clinical officer Pharmacist Pharmacy technician Other (specify)_____		1 2 3 4 96	
		Yes	**No**	**Don't know**	
034	Which of the following mechanisms is used to determine this facility's resupply quantities?	1	2	3	
034A	The facility itself (pull distribution system)	1	2	3	
034B	A higher-level facility (push distribution system)	1	2	3	
034C	Other (specify)_____	1	2	3	
035	How are the facility's resupply quantities determined?	Formula Don't know Other means (specify) _____		1 2 3	
036	What is the main source of your routine pharmaceutical supplies?	Government MOH medical stores Joint medical stores NGO/donors Private sources Other (specify)_____			1 2 3 4 5

037	For the most recent order, how long did it take between ordering and receiving products?	Less than 2 weeks……..				1	
		2 weeks to 1 month……….				2	
		Between 1 and 2 months……….				3	
		More than 2 months……….				4	

		Observed available		Not observed			
	Are any of the following medicines for managing CRDs available in the facility today? **Check to see if at least one of each medicine is valid (not expired)**	**At least one valid**	**Available non-valid**	**Reported available not seen**	**Not available today**	**Never available**	**Alternative available (record name and strength)**
	Analgesics/antipyretics						
038	Acetylsalicylic acid oral	1	2	3	4	5	
039	Paracetamol oral	1	2	3	4	5	
	Antiallergics/ antihistamines						
040	Promethazine oral	1	2	3	4	5	
041	Chlorphenamine oral	1	2	3	4	5	
	Anti-inflammatory steroids (systemic)						
042	Prednisolone oral	1	2	3	4	5	
043	Dexamethasone oral	1	2	3	4	5	
044	Hydrocortisone for injection	1	2	3	4	5	
045	Dexamethasone for injection	1	2	3	4	5	
	Antibacterials						
046	Amoxicillin oral	1	2	3	4	5	
047	Amoxicillin + clavulanic acid oral	1	2	3	4	5	

048	Amoxicillin for injection	1	2	3	4	5	
049	Benzylpenicillin for injection	1	2	3	4	5	
050	Ciprofloxacin oral	1	2	3	4	5	
051	Ceftriaxone for injection	1	2	3	4	5	
052	Erythromycin oral	1	2	3	4	5	
053	Chloramphenicol for injection	1	2	3	4	5	
054	Phenoxymethylpenicillin (penicillin V) oral	1	2	3	4	5	
055	Sulfamethoxazole + trimethoprim (co-trimoxazole) oral	1	2	3	4	5	
056	Sulfamethoxazole + trimethoprim (co-trimoxazole) for injection	1	2	3	4	5	
	Are any of the following medicines for managing CRDs available in the facility today? **Check to see if at least one of each medicine is valid (not expired)**	At least one valid	Available non-valid	Reported available not seen	Not available today	Never available	Alternative available (record name and strength)
	Drugs for asthma, COPD and chronic rhinitis						
057	Beclomethasone nasal spray	1	2	3	4	5	
058	Beclomethasone metered dose inhaler	1	2	3	4	5	
059	Epinephrine (adrenaline) for SC or IM injection	1	2	3	4	5	
060	Ipratropium bromide metered dose inhaler	1	2	3	4	5	
061	Salbutamol metered dose inhaler	1	2	3	4	5	
062	Salbutamol solution for nebuliser	1	2	3	4	5	
063	Salbutamol ampoule for injection	1	2	3	4	5	
064	Theophylline/aminophylline oral	1	2	3	4	5	
065	Aminophylline for injection	1	2	3	4	5	
066	Spacer device for children/adults	1	2	3	4	5	
	Anti-TB drugs (administered under the control of the referral service)						

067	Ethambutol oral	1	2	3	4	5	
068	Isoniazid oral	1	2	3	4	5	
069	Pyrazinamide oral	1	2	3	4	5	
070	Rifampicin oral	1	2	3	4	5	
071	Streptomycin for injection	1	2	3	4	5	
072	Isoniazid + rifampicin oral combination	1	2	3	4	5	
074	Isoniazid + rifampicin + pyrazinamide oral combination	1	2	3	4	5	
075	Isoniazid + rifampicin + pyrazinamide + ethambutol oral combination	1	2	3	4	5	
	Other						
076	Furosemide for injection	1	2	3	4	5	

Policy and financing-			
082	Do patients (18 years old and older) pay the facility for medicines for CRDs?	Yes, full payment	1
		Yes partial payment	2
		No (medicines are provided for free)	3
083	If CRD medicines are provided for free or for partial payment, who subsidises it?	Central government	1
		Local government	2
		Social assistance plans	3
		Private insurance	4
		NGO	5
		Other (specify)_____	6
		Don't know	7
084	Do patients (18 years old and older) pay the facility for consultations for CRDs?	Yes, full payment	1
		Yes partial payment	2
		No (consultations are provided for free)	3
085	If CRD consultations are provided for free or for partial payment, who subsidises it?	Central government	1
		Local government	2
		Social assistance plans	3

		Private insurance	4
		NGO	5
		Other (specify)_____	6
		Don't know	7
086	Do patients (18 years old and older) pay the facility for diagnostic tests for CRDs?	Yes, full payment….	1
		Yes partial payment…	2
		No (diagnostic tests are provided free)	3
087	If CRD diagnostic tests are provided for free or for partial payment, who subsidises it?	Central government	1
		Local government	2
		Social assistance plans	3
		Private insurance	4
		NGO	5
		Other (specify)_____	6
		Don't know	7

Community links			
088	Are there any community activities to support CRD services provided at primary health care facilities?	Yes	1
		No	2
		Don't know	3
089	If yes, who is involved with providing community activities to support CRD services?	CRD patients	1
		CHWs and CHV	2
		Community leaders	3
		Religious leaders	4
		Traditional healers	5
		Pharmacists	6
		Other (specify)_____	7

090	What services are supported through community activities?	**Yes**	**No**	**Don't know**
090A	Identification of patients with possible CRD	1	2	3
090B	Referral of patients with possible CRD to health facility	1	2	3
090C	Patient peer support groups after diagnosis	1	2	3
090D	Community support groups to raise funds for treatment	1	2	3

Thank the respondent for their time and participation.

Appendix 4a-e In-depth Interview (IDI) guides for frontline healthcare workers

Chronic respiratory symptoms in adults and children in Kenya: how do health systems respond and what are the opportunities for health system strengthening?

Appendix 4a_ In-depth interview for healthcare workers: clinical staff e.g. clinical officers

1. Please describe to me your roles in this department (probe: how long have you been in this role? How big is your team? Please describe their roles?)

2. Do you see patients with chronic respiratory diseases? What conditions do you mostly see? How would you know if someone has CRD? What challenges do you face in diagnosing CRD?

3. What makes people with chronic respiratory symptoms come here? (probe- are they referred here? From where? Who refers them?) Please describe what happens to these patients from the time they come in. (Probe: Screening and diagnostics, treatment, follow up, health education).

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4. Do you have access to specialists to support your decision-making in management of chronic respiratory diseases? Please describe how it is working here?

5. How does referral work here? Where are patients referred from? Where to? How frequently do you refer patients? After referral, do you maintain contact with the patient? How? Do you get feedback? What happens after discharge?

6. Please tell me what has worked well so far in diagnosis of CRD patients

7. Please tell me what has **not** worked well in diagnosis of CRD patients. (For each of the observations, why do you say so?)

8. Please tell me what has worked well so far in treatment of CRD patients.

9. Please tell me what has **not** worked well in treatment of CRD patients. (For each of the observations, why do you say so?) Probe availability of drugs, timeliness of county governments, affordability of drugs, follow ups).

10. How do you ensure continuity of care for people with chronic respiratory diseases, after they leave this facility? (probe: in what ways do you support self-management of patients?)

11. Did you receive any training specific to CRD patients? When was that? (Probe: use of spirometers to diagnose chronic lung diseases) Do you have guidelines specific to CRD management? What are your experiences in implementing those guidelines?

12. What are your views of how services for CRD can be improved?

Chronic respiratory symptoms in adults and children in Kenya: how do health systems respond and what are the opportunities for health system strengthening?

Appendix 4b_ In-depth interview guide for healthcare workers: Pharmacist

1. Please describe to me your roles in this department (how long have you been in this role? How big is your team? Please describe their roles?)

2. I am interested in understanding the process of treatment for patients who come with chronic respiratory problems. Please describe how these patients get services from the pharmacy. (Probe: prescriptions, drugs access, demonstrations of using drugs/ inhalers?).

3. Please tell me about the preferred drugs for CRD. Which of these do you stock? How do you procure these drugs? What are your experiences of availability of these drugs? (probe: How frequently do you run out of stock? How long? what happens when stocks out?)

4. How do you manage your stocks? Do you use any electronic system? Please explain how this works? How does it work?

5. What is your experience about use of NHIF by patients to pay for their medication? What happens if a patient cannot pay for their medicine?

6. Apart from drugs, do you procure any equipment used in the management of CRD e.g. spacers?

7. Please tell me what has worked well so far in treating CRD patients.

8. Please tell me what has not worked well in treating CRD patients. *(Probe For each of the observations, why do you say so? availability of drugs, timeliness of county governments, affordability of drugs, follow ups).*

9. Did you receive any training on CRD management? (If yes: when?)

10. Do you have guidelines specific to CRD management? What are your experiences in implementing those guidelines?

11. What are your views of how services for CRD can be improved in this county?

Chronic respiratory symptoms in adults and children in Kenya: how do health systems respond and what are the opportunities for health system strengthening?

Appendix 4c: In-depth Interview guide for Laboratory staff:

1. Please describe your roles in this department (how long have you been in this role? How big is your team? What does your day to day job involve?).

2. Please describe how patients with respiratory problems get to the lab? Please describe what tests are done here? (probe: sputum, spirometry) On average, how many tests do you conduct in a day? Please describe the procedures involved in testing people with cough and/or breathlessness?

3. *For labs that conduct tests for other facilities* (Please describe your working arrangements with other health facilities in this sub county? How do you document tests from outside?

4. In your experience, what are the major outcomes of these tests? How long does it take to get results?

5. How are these results documented?

6. How are these results communicated to the patient? After lab, where does the patient go to?

7. Probe: what happens to patients with smear negative results for TB? What other tests are done for people with smear negative results? Are there patients who keep coming back to this facility? What do you do for them?

8. Please tell me what has worked well so far in testing people with chronic respiratory symptoms.

9. Please tell me what has not worked well in testing CRD patients. Why do you say so? (Probes: lack of reagents, problems with equipment, getting sputum from children)

10. For each of these challenges, how do you resolve them?

11. Did you receive any training on CRD management? (If yes: when?)

12. Do you have guidelines specific to CRD management? What are your experiences in implementing those guidelines?

13. What are your views of how services for CRD can be improved in this county?

Chronic respiratory symptoms in adults and children in Kenya: how do health systems respond and what are the opportunities for health system strengthening?

Appendix 4d: In-depth Interview guide for Radiology staff

1. Please describe your roles in this department (how long have you been in this role? How big is your team? What does your day to day job involve?).

2. Please describe how patients with chest problems are referred to this X-ray department? Please describe how tests are done here? How frequently do you conduct these tests?

3. (For CT scan) Please describe how patients with chest problems are referred for CT scan? Please describe how tests are done here? How frequently do you conduct these tests?

4. In your experience, what are the major outcomes of the tests? How long does it take to get results? Who interprets the X-ray?

5. How are these results communicated to the patient? After X-ray, where does the patient go to?

6. Are there patients who keep coming back to this facility? How frequently? (probe, e.g. in percentage).

7. Please tell me what has worked well so far in testing people with chronic respiratory symptoms.

8. Please tell me what has not worked well in testing CRD patients. (Probe for each of the observations, why do you say so? availability of equipment, personnel).

9. Did you receive any training on CRD management? (If yes: when?). Are there any specific differences in conducting chest X-rays/ Scans for people with symptoms of CRD, from other imaging you take here?

10. Do you have guidelines specific to CRD management? What are your experiences in implementing those guidelines?

11. What are your views of how services for CRD can be improved in this county?

Chronic respiratory symptoms in adults and children in Kenya: how do health systems respond and what are the opportunities for health system strengthening?

Appendix 4e: In-depth interview for health facility in charges and senior management staff

1. Please describe to me your roles in this department (probe: how long have you been in this role? How big is your team? Please describe their roles?)

2. What conditions of chronic lung disease do you mostly see? How would you know if someone has CRD? What challenges do you face in diagnosing CRD?

3. What makes people with chronic respiratory symptoms come here? (probe- are they referred here? From where? Who refers them?) Please describe what happens to these patients from the time they come in. (Probe: Screening and diagnostics, treatment, follow up, health education).

4. Does this facility have access to specialists to support your decision-making in management of chronic respiratory diseases? Please describe how it is working here?

5. How does referral work here? Where are patients mostly referred from? Where to? How frequently do you refer patients? After referral, do you maintain contact with the patient? How? How do you get feedback on patient condition? What happens after discharge?

6. Please tell me what has worked well so far in diagnosis of CRD patients? Probe- Please tell me what has **not** worked well in diagnosis of CRD patients. (For each of the observations, why do you say so?)

7. Please tell me what has worked well so far in treatment of CRD patients? (For each of the observations, why do you say so?) Probe availability of drugs, timeliness of county governments, affordability of drugs, follow ups). Please tell me what has **not** worked well in treatment of CRD patients.

8. How do you ensure continuity of care for people with chronic respiratory diseases, after they leave this facility? (probe: in what ways do you support self-management of patients? Do you have treatment supporters for patients with chronic lung conditions?)

9. Please describe how you prioritize which supplies should be brought to the facility. (Probe: how do you negotiate for essential supply for supporting the facility? Do you always get what you ask for? Please explain instances where your requisitions are not authorized)

10. In what ways has NHIF supported care of people with chronic lung conditions? How do you process claims for people who have chronic conditions? (probe- do the payments come to the facility directly, or they are channeled to the county)Are there services that are excluded? What are the caps to NHIF reimbursements for CRD?

11. What is your experience in enhancing staff capacity to diagnose chronic lung diseases? (probe: do you use guidelines? do you offer in-service training to healthcare workers)

12. What is your experience in enhancing staff capacity to manage chronic lung diseases? (probe: do you use guidelines to support management of diseases? do you offer in-service training to healthcare workers)

13. In what ways do you foster linkage between your facility [and the community health system (for health centre in-charges)] ; partnerships with other community partners/ stakeholders?

14. In what ways do you foster linkage between your facility and lower level facilities; higher level facilities (for hospital managers); partners with other community partners/ stakeholders?

15. Do you have smoking cessation programs in this facility? Please describes how it is working? Please describe challenges you face in running the smoking cessation program

16. What has worked really well in this county in so far as chronic lung diseases management is concerned?

17. What has not worked well in this county in so far as chronic lung diseases management is concerned?

Appendix 5a &b- Key informant interview guides- county level

Chronic respiratory symptoms in adults and children in Kenya: how do health systems respond and what are the opportunities for health system strengthening?

Appendix 5a_Key informant interviews for county government officials

1. Please describe to me your role in this department Probe [How long have you been in this role?] What are the main health problems in this county? (probe: please tell me about NCDs; other chronic lung diseases apart from TB- asthma, COPD, bronchiectasis…)

2. Please describe the current policies relating to chronic lung diseases? (probe: what does the policy say, in what ways did you contribute to the local policy design? who is supposed to implement?)

3. What has worked well so far in implementing policies related to lung diseases? Why do you say so?

4. What has not worked well in implementing policies related to lung diseases? Why do you say so?

Health care financing for chronic lung diseases

5. Please describe how healthcare facilities requisition for supplies in this county. (Probe: how does the supply cycle work? what are the timelines? Who receives these requisitions? What are the differences for health facility levels?- health centre, hospital?).

6. Do you receive requests from health facilities for supplies relating to chronic lung diseases? How frequently do you receive them? What is mostly requested? How have you responded to these requests?

7. Please describe the current plans for financing chronic lung diseases in this county? (probe: whether chronic lung diseases have been allocated a budget line, what is the share of budget, what is working well, what is not working well)

8. What is your opinion about use of NHIF by patients with chronic lung diseases in the county facilities? (Probe: is it high?/ low? What has worked well with NHIF? What has not worked well?)

9. What mechanisms does the county use to ensure that those who cannot afford treatment access healthcare services for chronic lung diseases?

Management of chronic lung diseases

10. In what ways have healthcare services for chronic lung diseases been integrated with routine heath care services? (Probe: How do you ensure continuity of service for chronic lung diseases?

11. What has worked well in terms of patient care pathways for chronic lung diseases? Why do you say so? (staff capacity, allocation of staff, medicines, equipment, patient cooperation for treatment, community support)

12. What has not worked well in terms of patient care pathways for chronic lung diseases- why do you say so? (staff capacity, allocation of staff, medicines, equipment, patient cooperation for treatment, community support)

Partnerships for management of chronic lung diseases

13. Who are your main partners in management of chronic lung diseases in this county? In what ways do these partners support you? (probe: finances, other resources, technical support, training, advocacy) how do you engage community?

14. In what ways do you engage communities in this county on issues concerning lung health? *Probe* chronic lung diseases?

15. In what ways does your office mobilize political support for chronic lung diseases program within this county? Are there any local legislations relating to management of chronic lung diseases?

16. Over the next 5 years, what are your priorities in NCD control? What about for chronic respiratory disease? What opportunities do you see? Generally, how do you plan to strengthen the health system to be more responsive to NCDs?)

Thank the respondent and end the interview.

Chronic respiratory symptoms in adults and children in Kenya: how do health systems respond and what are the opportunities for health system strengthening?

Appendix 5b_Key informant interviews for county government: community focal persons

1. Please describe to me your role in this department Probe [How long have you been in this role?]

2. What are the main health problems based on your experience in supporting community health? (probe: please tell me about NCDs; other chronic lung diseases apart from TB- asthma, COPD, bronchiectasis…)

3. Please describe how the community health system is responding to the problem of chronic lung diseases.

4. What changes have been made to the CHV curriculum to equip CHV with knowledge of chronic lung diseases? (probe: knowledge of module 13? What is the main focus?)

5. Have you trained CHV on non- communicable diseases? (probe: which ones?; in terms of coverage of training, what extent of training have you done?)

6. In what ways are you raising awareness in the community about chronic lung diseases? (Probe: steps taken to reduce stigma?

7. For Nurse: How do you ensure that patients suffering chronic lung conditions get good quality services in the facilities (diagnostics, medicines, health education, tobacco cessation programs). In what ways have you equipped your healthcare teams to provide care for chronic lung diseases?

8. What plans are in place to ensure that there is continuity of care for people with chronic lung conditions? (Probe: within the health system; at the community; how is care coordinated across the healthcare levels? (Probe, referral mechanisms, feedback between the levels)

9. How do you use information systems in decision-making for chronic lung diseases (probe: data collection, data analysis, examples of how information use has impacted on services delivery).

10. In what ways do you support self-management of people with chronic lung conditions? What can be improved?

11. What has worked well so far in implementing policies related to lung diseases? Why do you say so?

12. What has not worked well in implementing policies related to lung diseases? Why do you say so?

Management of chronic lung diseases

13. What has worked well in terms of patient care pathways for chronic lung diseases? Why do you say so? (staff capacity, medicines, equipment, patient cooperation for treatment, community support)

14. What has *not* worked well in terms of patient care pathways for chronic lung diseases- why do you say so?

15. Over the next 5 years, what are your priorities in control of chronic respiratory disease? What opportunities do you see? Any plans for integration? Generally, how do you plan to strengthen the health system to be more responsive to NCDs?)

Thank the respondent and end the interview.

Appendix 6a: Codebook for health system readiness: Healthcare workers and KII

Code book for Health systems building blocks

Themes and Subthemes	Description of essential information
1. Service delivery **1.1. Supply side issues (doctors' related)** ^^^ 1.1.1. Diagnosis of asthma, including tests# 1.1.2. Treatment and CRD management approaches**	^^^ Service delivery entails all the processes of ensuring patient gets service.

1.1.3. MOPC and plans for follow up and review of patients 1.1.4. Referral mechanisms and challenges 1.1.5. Availability of adequate space for Privacy and confidentiality 1.1.6. Community-based support and relationships= **1.2. Demand side issues (patient-related)** 1.2.1. Patient denial of CRD diagnosis & stigma 1.2.2. Patient cooperation with testing, treatment/ patient expectations++ 1.2.3. Self-management plans^^ 1.2.4. Affordability of medicines/ tests 1.3. Challenges in service delivery	# How CRD is diagnosed; tests, spirometry use, GenXpert and Chest xray ** includes preferences of healthcare workers e.g. injection vs tablets; demonstration of inhaler use and clinical decision support; antibiotics prescriptions =e.g. home visits by social med worker; perceptions of field workers ++ Include collection of test results ^^ Include inhaler use; adherence to doctor instructions and coming for review *** treatment continuation, nebulisation vs inhalers
2. Health workforce 2.1. Adequacy of healthcare workers, including records officers ^^ 2.2. Training of healthcare workers in CRD 2.3. Healthcare workers' strikes ** 2.4. Challenges 2.5. Others	^^ county plans to recruit more healthcare workers ** career development e.g. pay and promotion
3. Information 3.1. Data collection in health facilities –electronic vs paper based 3.2. Dissemination and access to policy guidelines 3.3. Information for decision-making e.g. ordering drug 3.4. Communication of referral decisions 3.5. Information flows from register to national health system 3.6. Challenges 3.7. Other	
4. Medical products and technologies 4.1. Supply of medicines- ordering and delivery ^^ 4.2. Quality and quantity of medicines ** 4.3. Affordability of medicines 4.4. Inhalers 4.5. Other challenges	^^ include decisions on which drugs are supplied e.g. HMT meeting ** stock outs and why
5. Sustainable financing and social protection 5.1. Sources of revenue ++ 5.2. Decisions on Budget allocation to a facility/ adequacy ^ 5.3. Health facility managers access to finances- (autonomy to spend) 5.4. Protecting the poor e.g. waivers, challenges 5.5. Challenges in financing 5.6. Other	++ budget allocations, facility user fees, NHIF ^ E.g. use of facility workload data !! amounts, timeliness,
6. Governance; leadership 6.1. Perceptions of current county government priority for health	

6.2. Relationships between county and national government 6.3. Accountability e.g. payroll deductions. 6.4. Incentives for healthcare workers 6.5. Challenges 6.6. Other			^^ Involving disbursement of finances, communication etc.

Appendix 6b: Codebook for Patients' interviews

	THEME & SUBTHEMES	Sub-nodes under each subtheme	Description of essential information**[6]
1.	Patients understanding and experience of asthma	• Understanding about chronic diseases generally • Understanding about CRD risk factors • Perceptions about cough & other symptoms of CRD ^ • How asthma affects daily lives**	^Symptoms of asthma What they call it e.g. baridi, kifua ** work, sex, school, healthcare
2.	Common responses to respiratory symptoms & health seeking behaviours	Remedies for asthma # Health facility visits**	#herbs, animal fat, hot water, warm clothing; who advised? **when started, who advised, how frequently, whether

		Access to tests and treatment at hospital	
3.	Stigma for asthma and mitigation measures	• Stigma manifestation** • Stigma outcomes • Patients reporting "no stigma experience for their asthma, and why	Actions and attitudes that show that there is stigma for asthma E.g. mental health stressors, isolation, ruin social relations

Appendix 7: Letter of Ethical Approval from the Liverpool School of Tropical Medicine Research Ethics Committee

Mr. Stephen Kikwe Mulupi
c/o KEMRI- CENTRE FOR RESPIRATORY DISEASES
P.O. BOX 47855-00100
NAIROBI

12 June 2019

LSTM
LIVERPOOL SCHOOL
OF TROPICAL MEDICINE

Pembroke Place,
Liverpool, L3 5QA, UK
Tel: +44(0)151 705 3100
Fax: +44(0)151 705 3370

www.lstmed.ac.uk

Dear Mr Mulupi,

Re. Research Protocol (19-003) Chronic respiratory symptoms in adults and children in Kenya: how do health systems respond and what are the opportunities for health system strengthening.

Thank you for your letter providing the necessary in-country approvals for this project. I can confirm that the protocol now has formal ethical approval from the LSTM Research Ethics Committee.

The approval is for a fixed period of three years and will therefore expire on 11th June 2022. The Committee may suspend or withdraw ethical approval at any time if appropriate.

Approval is conditional upon:

- Continued adherence to all in-country ethical requirements.
- Notification of all amendments to the protocol for approval before implementation.
- Notification of when the project actually starts.
- Provision of an annual update to the Committee.
  Failure to do so could result in suspension of the study without further notice.
- Reporting of new information relevant to patient safety to the Committee
- Provision of Data Monitoring Committee reports (if applicable) to the Committee

Failure to comply with these requirements is a breach of the LSTM Research Code of Conduct and will result in withdrawal of approval and may lead to disciplinary action. The Committee would also like to receive copies of the final report once the study is completed. Please quote your Ethics Reference number with all correspondence.

Yours sincerely

Angela Obasi

Dr Angela Obasi
Chair
LSTM Research Ethics Committee

Athena
SWAN
Bronze Award

INVESTORS
IN PEOPLE

Appendix 8: Letter of Ethics Approval from KEMRI- SERU

KENYA MEDICAL RESEARCH INSTITUTE

P.O. Box 54840-00200, NAIROBI, Kenya
Tel:(254) (020) 2722541, 2713349, 0722-205901, 0733-400003, Fax: (254) (020) 2720030
E-mail: director@kemri.org, info@kemri.org, Website:www.kemri.org

KEMRI/RES/7/3/1   May 29, 2019

TO: STEPHEN KIKWE MULUPI
             PRINCIPAL INVESTIGATOR

THROUGH: THE DIRECTOR, CRDR   *forwarded*
             NAIROBI   10/06/2019

Dear Sir,

RE: SERU PROTOCOL NO. 3848 (RESUBMISSION OF INITIAL SUBMISSION):
             CHRONIC RESPIRATORY SYSMPTOMS IN ADULTS AND CHILDREN IN
             MERU COUNTY, KENYA: HOW DO PUBLIC HEALTH SYSTEMS RESPOND AND
             WHAT ARE THE OPPORTUNITIES FOR HEALTH SYSTEM STRENGTHENING?

Reference is made to your letter dated May 13, 2019. The KEMRI Scientific and Ethics Review Unit
(SERU) acknowledges receipt of the following revised study documents on May 14, 2019;

1. Revised Protocol Version 3.00, 03.05.19 SERU.
2. Responses to Comments
3. Translation certificates for study information and consent forms, for parental consent forms
    (Swahili and Meru)

This is to inform you that the Committee noted that the issues raised at the 286th Committee A
meeting of the KEMRI Scientific and Ethics Review Unit (SERU) held on April 09, 2019, have been
adequately addressed.

Consequently, the study is granted approval for implementation effective this day, May 29, 2019 for
a period of one (1) year. Please note that authorization to conduct this study will automatically
expire on May 28, 2020. If you plan to continue with data collection or analysis beyond this date,
please submit an application for continuation approval to SERU by April 16, 2020.

You are required to submit any proposed changes to this study to SERU for review and the changes
should not be initiated until written approval from SERU is received. Please note that any
unanticipated problems resulting from the implementation of this study should be brought to the
attention of SERU and you should advise SERU when the study is completed or discontinued. You
may embark on the study.

Yours faithfully,

[signature]

ENOCK KEBENEI
THE ACTING HEAD
KEMRI SCIENTIFIC AND ETHICS REVIEW UNIT

In Search of Better Health

Appendix 9: Letter of Authorization by Meru County and renewals by KEMRI-SERU

COUNTY GOVERNMENT OF MERU
DEPARTMENT OF HEALTH

Telegrams: "HEALTH" Meru
Telephone: Meru 064-32370/1
Fax: 31242
Email: hospiralmeru@gmail.com
When replying should be to:
County Director Medical Services

Ref: MRU/MED/MRU/C.50

COUNTY DIRECTOR MEDICAL SERVICES
MERU COUNTY
P.O. BOX 8 – 60200
MERU

Date: 24th June, 2019

TO CEO- Meru Level 5,
    SCMOH,

IGEMBE NORTH (Mutuati Sub County Hospital, Laare H/C)
IMENTI SOUTH (Kanyakine Sub County Hospital, Mitunguu H/C)
TIGANIA WEST (Miathene Sub County Hospital, Mutionjuri H/C)

APPROVAL FOR CONDUCTING RESEARCH FOR STEPHEN MULUPI

This is an approval letter for the above named KEMRI / LSTM student conducting research in Meru County in the mentioned Sub County Hospitals and health centres.

The study topic is "Chronic Respiratory symptoms in adults and children in Meru County, Kenya: how do public health systems respond and what are the opportunities for health system strengthening?

The Principal investigator will pretest the questionnaire at **Miathene Sub County Hospital and Mutionjuri Health Centre in Tigania West.** Please give him all the support he requires as he conducts the study.

Don't hesitate to contact the office for any further information.

Note that on completion of the research, you are expected to submit one (1) hard copy and soft copy to this facility.

Thank you.

Dr. Lilian Karoki
Director Medical Services
COUNTY GOVERNMENT OF MERU
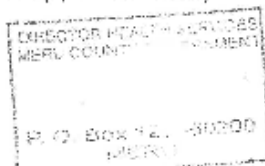
Appendix 10: Detailed summary of the 3 domains of readiness and indicator scores

Domains and Tracer indicators	Mitunguu Health Centre (level 3)	Laare Health Centre (level 3)	Kanyakine Subcounty Hospital (level 3)	Mutuati Subcounty Hospital (level 4)	MTRH (level 5)
Domain 1: Training and guidelines availability					
1. Whether doctors were trained to manage CRD in-service	0	0	4.16	0	4.16
2. Whether clinical officers trained to manage CRD in-service	4.16	0	0	0	4.16
3. Availability of guidelines on case-management of asthma	4.16	4.16	0	0	0
4. Availability of guidelines on case-management of COPD	0	0	0	4.16	0
5. Availability of guidelines on case-management of chronic bronchitis	4.16	0	0	0	0
6. Criteria for the referral of patients with CRD symptoms	4.16	4.16	0	4.16	0
7. Clinical criteria for the diagnosis of asthma	4.16	4.16	4.16	0	4.16
8. Clinical criteria for the possibility of COPD	4.16	4.16	4.16	0	0
Total Domain 1 Score	**24.96**	**16.64**	**12.48**	**8.32**	**12.48**

Domains and Tracer indicators	Mitunguu Health Centre	Laare Health Centre	Kanyakine Hospital	Mutuati Hospital	MTRH
Domain 2: Availability of equipment					
1. Peak flow meter with mouthpieces	0	0	6.66	0	0
2. Spacer device for children/adults	0	0	6.66	0	0
3. Pulse oximeter	0	0	6.66	0	6.66
4. Oxygen sources (cylinder and/or concentrator and accessories)	0	0	6.66	6.66	6.66
5. Nebuliser with mask	6.66	6.66	6.66	6.66	6.66
Total Domain 2 Scores	**6.66**	**6.66**	**33.3**	**13.32**	**19.98**

	Mitunguu Health Centre	Laare Health Centre	Kanyakine Hospital	Mutuati Hospital	MTRH
Domain 3: Drugs for asthma					
1. Prednisolone oral	0	0	5.55	5.55	5.55
2. Hydrocortisone for injection	5.55	5.55	5.55	5.55	5.55
3. Beclomethasone metered dose inhaler	0	0	5.55	5.55	5.55
4. Epinephrine (adrenaline) for injection	5.55	5.55	5.55	5.55	5.55
5. Salbutamol metered dose inhaler	5.55	5.55	5.55	5.55	5.55
6. Salbutamol solution for nebuliser	5.55	5.55	5.55	5.55	5.55
Total Domain 3 Scores	**22.2**	**22.2**	**33.3**	**33.3**	**33.3**
Total Domain Scores	**53.82**	**45.5**	**79.08**	**54.94**	**65.76**
Number of indicators in Domain 3 (6)					
Score for each tracer indicator 5.6 (33.3/6)					
Score for each tracer indicator, domain 1(4.2), domain 2 (6.7), domain 3(5.6)					

Appendix 11: CHV interview guide

Chronic respiratory symptoms in adults and children in Kenya: how do health systems respond and what are the opportunities for health system strengthening?

Appendix 11: Interview guide for Community Health Volunteers (CHV)

1. Please describe your roles in supporting healthcare in this community.

2. How many CHV are in your team?

3. I wish to understand more about chronic lung diseases (*Term used by the CHEW will be used here*). What do you think CRD means? Who gets CRD? What symptoms would they have?

4. Please explain what your work involves in helping community members with cough and breathlessness who do not have TB (Probe: awareness creation, how would you identify someone? Do you differentiate cases with TB from those with a cough but do not have TB? How do you refer of CRD cases? Who do you refer them to?).

5. How regularly do you communicate with the CHEWs about a patient with CRD that you have referred for care? How do you know if patient received care at the facility? Are there times that patients who you refer to facilities fail to receive healthcare (probe: diagnosis, treatment, any service at all)? In such instances, what actions do you take?

6. After a patient comes from the health facility, what happens next? (probe: do you follow up patients with chest problems, at their homes? Do you ever involve family members in caring for patients? Do you have patient supporters for any other disease, apart from TB?)

7. Have you ever received a call from a sub county hospital about a patient who comes from this community? What was the call about?

8. Did you receive any training on CRD management? When did you receive the training? Who provided this training?

9. What has worked well so far? Why do you say so?

10. What has not worked well? Why do you say so?

11. In your view, what should be done to improve your work as a CHV?

Appendix 12: FGD Guides Community Health Volunteers

Chronic respiratory symptoms in adults and children in Kenya: how do health systems respond and what are the opportunities for health system strengthening?

Appendix 12: FGD guide for Community Health Volunteers (CHV)

1. Please describe your roles in supporting healthcare in this community.

2. How many CHV are in your team?

3. I wish to understand more about chronic lung diseases (*Term used by the CHEW will be used here*). What do you think CRD means? Who gets CRD? What symptoms would they have?

4. Please explain what your work involves in helping community members with cough and breathlessness who do not have TB (Probe: awareness creation, how would you identify someone? Do you differentiate cases with TB from those with a cough but do not have TB? How do you refer of CRD cases? Who do you refer them to?).

5. How regularly do you communicate with the CHEWs about a patient with CRD that you have referred for care? How do you know if patient received care at the facility? Are there times that patients who you refer to facilities fail to receive healthcare (probe: diagnosis, treatment, any service at all)? In such instances, what actions do you take?

6. After a patient comes from the health facility, what happens next? (probe: do you follow up patients with chest problems, at their homes? Do you ever involve family members in caring for patients? Do you have patient supporters for any other disease, apart from TB?)

7. Have you ever received a call from a sub county hospital about a patient who comes from this community? What was the call about?

8. Did you receive any training on CRD management? When did you receive the training? Who provided this training?

9. What has worked well so far? Why do you say so?

10. What has not worked well? Why do you say so?

11. In your view, what should be done to improve your work as a CHV?

Appendix 13: Community health system interviews codebook

1 Basic information

1.1 Role

1.2 Team size

1.3 Number of households

2 What is CRD

2.1 Is CRD common in the CHU

2.2 Common CRD in community

2.3 Who gets CRD

2.4 Symptoms of CRD

3 Community health extension workers

3.1 Referral

3.1.1 Frequency

3.1.2 How referral works

3.1.3 Involvement in referral

3.1.4 Documentation from CHV

3.1.5 Records kept by CHEW

3.1.6 Coordination between hospital and community system

3.2 Involvement in follow up

        3.2.1 Feedback from patients

        3.2.2 Support in follow up

        3.2.3 Self-management

3.3 Tobacco cessation programs in the society

        3.3.1 is it available

        3.3.2 How does it work

3.4 Training

        3.4.1 Are you trained in CRD

        3.4.2 When

        3.4.3 Do you have any guideline for CRD

        3.4.4 CRD case management training

        3.4.5 Module 13 training

        3.4.6 Are CHVs trained

3.5 Additional support to patients

        3.5.1 Community outreach

        3.5.2 Frequency of outreach

        3.5.3 What is involved in community outreach

        3.5.4 Involvement of household members

3.6 Support from county government

        3.6.1 Financial

        3.6.2 Advocacy

        3.6.3 Technical support

        3.6.4 Other

3.7 Partners apart from county government

        3.7.1 International organizations

        3.7.2 Local organizations

3.8 What has worked well so far

        3.8.1 Training

3.8.2 Finances

3.8.3 County support

3.8.4 CHV

3.9.a What has not worked well

3.9.2 Training

3.9.2 Finances

3.9.3 County support

3.9.4 CHV

3.9.b Suggestion on improving partnership between community and health facility

4 Community health volunteers

4.1 Role of CHV in helping people with CDR

4.1.1 Awareness creation

4.1.2 Identify someone with CRD

4.2 Referral

4.2.1 How do you refer

4.2.2 Where do you refer

4.3 Care after referral

4.3.1 Do you communicate with CHEW after referring a patient

4.3.2 How you know if patient receive care after referral

4.3.3 Are there patients that fail to receive care after referral

4.3.3.1 Diagnosis

4.3.3.2 Treatment

4.3.3.3 Any other

4.4 Follow up of patients with CRD

4.4.1 Do you follow patients up after visiting a facility

4.4.2 Do you involve patient's family members in caring for them

4.4.3 Are there patient supports for other CRD apart than TB

4.5 Coordination with service providers

4.5.1 Do healthcare providers contact you about patients

5.2.1 Shop

5.2.2 Traditional herbalist

5.2.3 Health centre

5.2.4 Private health facility

5.2.5 Hospital

5.3 Experience with CRD

5.3.1 Have you ever suffered from CRD

5.3.2 How was it

5.4 Have you seen anyone with CRD in the community

5.4.1 Family member

5.4.2 Child

5.4.3 Neighbour

5.4.4 Relative

5.4.5 Other

5.5 What works well in CRD treatment in county health facilities

5.5.1 Medicine

5.5.2 Tests

5.5.3 Xray

5.5.4 Healthcare workers

5.5.5 Duration of service

5.6 Have you ever taken tests for chest problems

5.6.1 Sputum

5.6.2 Xray

5.6.3 No

5.6.4 Other

5.7 Procedure of taking tests

5.7.1 Cost

5.7.2 Results turnaround time

5.7.3 Diagnosis

5.8 What you do not like most in the county healthcare facility

      5.8.1 Medicine

      5.8.2 Lab

      5.8.3 Xray

      5.8.4 Healthcare workers

      5.8.5 Duration of services

5.9 Health education

      5.9.1 Are there groups that give health education

      5.9.2 How?

      5.9.3 Have you ever received health education in your home

      5.9.4 What do they talk about

            5.9.4.1 Smoking cessation

            5.9.4.2 Urged to visit the healthcare facility

            5.9.4.3 Hygiene

            5.9.4.4 Disease awareness

            5.9.4.5 Other

6.0 How to improve services in the health centre for people with CRD

      6.1 Healthcare providers

      6.2 Medicine

      6.3 Tests

      6.4 Health education

Appendix 14: The MOH community referral form

MOH 100: COMMUNITY REFERRAL FORM

REPUBLIC OF KENYA
MINISTRY OF HEALTH
MOH 100: COMMUNITY REFERRAL FORM

SECTION A: Patient /Client Data	
Date:	Time of referral:
Name of the patient:	
Sex: Male ☐ Female ☐	Age:
Name of Community Health Unit:	
Name of Link Health Facility:	
Reason(s) for Referral	
Main problem(s):	
Treatment given:	
Comments:	
CHV Referring the Patient:	
Name:	Mobile No:
Village/Estate:	Sub Location:
Location:	
Name of the community unit:	
Receiving Officer:	
Date:	Time:
Name of the officer:	
Profession:	
Name of the Health facility:	
Action taken:	
SECTION B : Referral back to the Community	
Name of the officer:	Mobile No:
Name of CHV:	Mobile No:
Name of the community unit:	
Call made by referring officer: Yes: ☐ No: ☐	
Kindly do the following to the patient: 1. 2. 3.	

Official Rubber Stamp & Signature _____

Appendix 15: Patient journey mapping tool

Chronic respiratory symptoms in adults and children in Kenya: how do health systems respond and what are the opportunities for health system strengthening?

Appendix 15 Patient journey mapping

1.0	Date of interview	DAY [__][__] MONTH [__][__] Year[__][__][__][__]
1.1	Interviewer code / Initials	[__][__]
1.2	Name of facility (facility code)	( )
1.3	Sub-county name (code)	( )

Confirm inclusion criteria:

1.4. Please confirm these details about patients

Does patient have any of these symptoms?	Yes	No	
Cough	1	2	
Difficulty breathing	1	2	
Wheezing	1	2	
Chest pains	1	2	
Blood in sputum	1	2	
Other attributes			
If child, is s/he 5 years old or above	1	2	If <than 5 years, do not involve in study
If child below 18 years, is s/he accompanied by a guardian?	1	2	If child is unaccompanied, do not involve further in study

Proceed to consenting

INTRODUCTION: Hello, we are doing a study to see how much time it takes patients who have lung problems to go through all the service points within this facility. Our staff would like to record the time taken for each activity you go through today till you leave the facility to go home. Should you leave the facility for another activity, e.g. to go to the shops or other services e.g. x-ray, we will also record the time it takes before you resume other services at the facility. **We will NOT take your name, test results, or any personal information.** You can identify our staff by the green name badges they are wearing. If you need care tomorrow, we wish to record the time you will take in getting various services again. If you do not with to participate in this activity, please feel free to say so. This will not affect the care you receive in this facility today or any other day.

May I record the time it takes to complete the activities you go through at the facility today?
    1- Yes   2-No

2. STATION 1:

2.1. ID number *Give patient ID badge*	___ ___ ___	Date (dd/mm/yy)	___ ___/___ ___/___ ___
2.2. Time of arrival:	___ ___: ___ ___	2.3. Time of departure	___ ___: ____ ____
2.4. Purpose of visit:	___ ___ **2.5. Respiratory symptoms NOTES:**	**2.6. Age of patient** (write the age) [	] **2.7. Gender:** 1- Male 2- Female	**2.8.** Patient is alone/ accompanied? 1- Alone 2- Accompanied by another person(s) - specify number 3- Child accompanied by an adult(s) - specify number
Station 1	**RECEPTION**	**Indicate station number:**	
Step 1	**Enter activity e.g. payment/ registration/**		
TIME IN	___:___	TIME OUT	_____:____
Payment for outpatient services/ card Confirm from Appendix 3 b, all the activities involved at this station	Enter all activities involving patient care in step 1 (E.g. recording name)		
STEP 2	**Enter activity e.g. Triaging**		
TIME IN	___:___	TIME OUT	___:___
Registration	Enter all activities that happen in step 2.		
Station 2	**CONSULTATION- please indicate room number**		
TIME IN	___:___		_____:____

Please indicate the following

2.1. History of cough:

1- <2 weeks
2- 2-7 weeks
3- 8 weeks
4- >8 weeks

2.2. Physical examination: Other symptoms

1- Difficulty in breathing
2- Wheeze
3- Chest tightness
4- Blood in sputum
67_Other (please specify)

2.3. Diagnosis made at **this** first consultation?

1- Yes
2- No (skip to 2.6)

2.4. Specify diagnosis
1- TB
2- Post-TB lung disease
3- Asthma
4- COPD/ Emphysema
5- Bronchiectasis
6- Acute causes
67__Other (Specify)

2.5. Was patient prescribed medication?

1- Yes (Specify_____,_____, _____ skip to 2.8.)
2- No

2.6. Any tests recommended?

1- Yes
2- No (Skip to 2.8)

2.7. Tests recommended

1- Sputum test
2- Chest x-ray
3- CT scan
67_ Other-specify

2.8. Other decision made?

1- Referral to another service point within facility (please specify)
2- Referral to other facility e.g. for x-ray (please retain this form)
3- Admission
67_ Other (specify)

2.9. Was client given counselling/ health education?

1- Yes
2- No

TIME OUT___:____

STATION 3 TEST: LAB (please indicate room number)

TIME IN			

3.1. Tests conducted:

1- Gene Xpert
2- AFB test
   67_Other (Specify0

3.2. Is the gene Xpert test conducted at the healthcare facility or referred to another facility?
1- Conducted at facility
2- Referred (specify date when sample is likely to be dispatched_____/_____/2019)

If Gene Xpert is conducted out of the facility, please retain this questionnaire and inform the research team member.

TIME OUT____:_____

STATION 4 TEST: X-RAY (please indicate room number)

TIME IN	___:____		

This is applicable only to patients taking x-rays within the facility.

Was x-ray conducted
1- Yes
2- No

TIME OUT_____:_____
Please indicate where patient is referred next

STATION 5: DIAGNOSIS- : please Indicate room number-

TIME IN			

This is only applicable to patients sent for tests

Please indicate date of diagnosis____/_____/_____ (Day/Month/ Year)

5.1. For Xray tests and Gene Xpert tests, please indicate date when the test was done, based on documentation from Xray or lab

1- Date of x-ray

2-Date of Gene Xpert test

3-Date of AFB test

5.2. Specify diagnosis
- 1- TB
- 2- Post-TB lung disease
- 3- Asthma
- 4- COPD/ Emphysema
- 5- Bronchiectasis
- 6- Acute causes
- 67__Other (Specify)

5.3. Was patient prescribed medication?

- 1- Yes (Specify_____,_____, _____)
- 2- No

5.4. Any **further** tests recommended?

- 1- Yes (Specify)
- 2- No (Please indicate the next service point for patient)

5.5. Other decision made?

- 1- Referral to other facility(specify)
- **2-** Referral to Medical Officer/ Pediatrician for further consultation (**Applicable only to Sub county and Meru Teaching and Referral Hospital)**
- 3- Admission
  67_ Other (specify)

TIME OUT_____:_____

6. Medical Officer/ Pediatrician Only(please indicate room number)

TIME IN_____:_____

6.1. Please describe the differential diagnosis for this case

6.2. Any further tests recommended?

    1- Yes
    2- No (skip to 6.3)
Please specify

6.3. Medical prescription?
Please list prescribed medication

6.4. Is patient referred to another service point within facility?
    1- Yes (specify_____)
    2- No

TIME OUT_____:_____

6.5 NOTE FOR CONSULTATION

Please note final decision made about patient:

1: Await test results (Date?)
2: Diagnosis made
3: Treatment decision
    a. Prescribe drugs for facility pharmacy
    b. Referral to another facility (indicate name of facility)
5: Next appointment (Date)
6: Linkage to CHV?

STATION 7: PHARMACY
Please indicate Room number:

FIRST ENCOUNTER- CONFIRMATION OF DRUGS IN STOCK

TIME IN	____:____	

Pharmacy:

7.1. Please list all drugs prescribed for patient

Drugs prescribed		Availability 1- Yes 2- No
1.		
2.		
3.		
4.		

TIME OUT_____:_____

8. CASH OFFICE

TIME IN	_____:_____	

Drugs purchased		Cost
1.		
2.		
3.		
4.		
Total cost		

TIME OUT_____:_____

9. PHARMACY	**COLLECTION OF DRUGS**		
TIME IN	_____:_____		

EXIT POINT

Confirm that this is the last service point for the patient today.

Please note the time and, request the patient to leave the tool with you.

TIME OF EXIT			

FOR RESEARCH TEAM NOTES (circle appropriate answer):

1- **Tool complete**
2- **Tool incomplete**

Reasons:

1- Patient did not present it to all points
2- Some areas not filled
3- Other- specify

Appendix 16: Exit interviews questionnaire for patients

Chronic respiratory symptoms in adults and children in Meru county, Kenya: how do public health systems respond and what are the opportunities for health system strengthening?

Appendix 16_ Exit interview questionnaires for patients.

INTRODUCTION SECTION: Health facility and patient details

0.1. **Sub county name [code]**	
0.2. **Date of interview**	**[dd/mm/ yyyy]**
0.3. Day of the week	1- Monday 2- Tuesday 3- Wednesday 4- Thursday 5- Friday 6- Saturday
0.4. **Health Facility Name [code]**	**1-Meru Teaching and Referral Hospital**

		2-Kanyakine Sub county Hospital 3-Mitunguu Health Centre 4-Mutuati Subcounty Hospital 5-Laare Health Centre
0.5.	**Category of treating facility:** 1. **Health centre** 2. **Subcounty hospital** 3. **County hospital**	
0.6.	**Patient name**	
0.7.	**Patient registration number in facility register**	
0.8.	**Sex: 1. Male 2. Female**	
0.9.	**Age of patient** (years)	
0.10.	**Area of residence:** 1- **Sub-county** 2- **Location** 3- **Sublocation**	
0.11.	**Time of interview [Start/ End]**	
0.12.	**Interviewer name (Code)**	
0.13.	**Results Code**	Completed- 01 Partially completed- 02

SECTION 1: SOCIO-DEMOGRAPHIC DATA

1.1.	(Adults only) What is your marital status	1- Monogamous married 2- Married Polygamous 3- Living together 4- Separated 5- Divorced 6- Widow/ widower 7- Never married
1.2.	What level of education did you reach, and grade completed?	1- Pre-primary 2- Primary 3- Post Primary, vocational 4- Secondary / A level 5- College/ middle level 6- University undergraduate 7- University, postgraduate 8- Madrassa 96—Other (Specify) 99__Don't know For all current students (1,2,3, 4 skip to section 2)
1.3.	What type of work do you do as your main job/ business (the last 7 days?) **Describe** the main occupation in at least 2 words e.g. Primary school teacher, General shopkeeper, college teacher, computer programmer etc.	(Write a description here) (For student, skip)
1.4.	Who is your main employer for the job/ business?	1- National government agencies 2- County government 3- Private sector enterprise 4- International organizations/ NGO 5- Faith-based organization 6- Self-employed- modern 7- Self- employed- informal 8- Small scale agriculture (employed) 9- Self-small-scale agriculture 10- Pastoralist activities (employed) 11- Self-pastoralist activities 12- Individual/ private household 13- Schools' board of employees 96_Other-specify
1.5.	What is your working pattern in your main job/ business?	1- Regular (skip to 1.8) 2- Casual

1.6.	For how many days did you do casual job in the last one month?	Specify
1.7.	What is the average daily wage you received during the days worked as casual labour in the last one month?	(Estimate cash value for any in-kind payment received)
1.8.	How much were you paid as salary the last one month?	Specify
1.9.	On average, how much money in Kenyan shillings, does your household spend per week on	1- Food 2- Rent 3- Travelling 4- Medication 5- Leisure Other, specify
1.10.	Does your household have any of the following? (tick all that apply)	1. A table 2. A chair 3. A sofa 4. A bed 5. A cupboard 6. A clock 7. A non-mobile telephone 8. A mobile telephone 9. A radio 10. Electricity (If no, skip to question 1.11) 11. A solar panel 12. A television 13. A refrigerator 14. A microwave oven 15. A DVD player 16. A cassette or CD player
1.11.	What means of transport do you mainly use?	1- Walk 2- Bicycle/ Motorbike/ bodaboda 3- Own bicycle 4- Tuk tuk 5- Matatu 6- Bus 7- Employer-provided 8- Private vehicle 9- Not applicable
1.12.	Do you own agricultural land?	1- Yes 2- No
1.13.	How many acres of land do you own?	1- Acres (specify) 2- Plot size (Square feet) 99_Don't Know
1.14.	Do you own any farm animals	1- Yes 2- No

1.15.	Which farm animals do you own (specify number)?	1- Local cattle 2- Exotic/ grade cattle 3- Horses/Donkeys 4- Goats/sheep/pigs 5- Chicken/ turkeys/ ducks 96_Other- specify
1.16.	Do you own your current dwelling?	1- Yes 2- No
1.17.	Do you own the land on which the dwelling is built?	1- Yes 2- No
1.18.	Does your household receive any form of assistance/ cash transfer from the government?	1- Yes 2- No (Skip to Section 2) 99_dont know (Skip to section 2)
1.19.	For what reason does your household receive a cash transfer or social assistance?	1- Orphaned children 18 years and below 2- Elderly persons 3- Person with severe disability 4- Urban food subsidy 5- Health voucher 6- Food/ cash for work 7- School feeding 8- Hunger/ safety net program 96_Other (Specify)

SECTION 2: DECISION TO ATTEND HEALTH FACILITY AND DIAGNOSTIC SERVICES RECEIVED

2. **This section contains questions about the experiences of patients with chronic cough in the healthcare facility.**

2.1.	How long have you (or child) been coughing, or had difficulty in breathing before coming here today?	1- Less than 2 weeks 2- 2-4 weeks 3- More than 4 weeks 99_ Don't know
2.2.	Is this the first time you have visited a health facility because of coughing or breathing difficulty??	1- Yes (skip to 2.4.) 2- No
2.3.	Where else did you go, for healthcare before coming to this facility, for this coughing or breathing problem?	1- Self-medication(drugs over the counter, borrow friends or relatives) 2- Visited another public facility 3- Visited a private facility 4- Visited traditional doctor 5- Faith healing 6- CHV 96_Other (specify)
2.4.	Who advised you to come to this facility?	1- Made own decision

			2- Friends/ family 3- A community health volunteer/ worker 4- Referral from another facility 96_ Other (specify)
	Experience with diagnostic tests		
2.5.	For this problem (CRS), were you asked to undergo any tests?		1- Yes 2- No (Skip to section 3)
2.6.	Please explain whether you have been tested		

	Test	Test requested
		1- Yes
		2- no
			Test completed
			1- Yes
			2- No
				Reasons for not completing
				  1- Cannot afford
				  2- Service not available in facility
				  3- Have been referred to another facility
				  4- Don't think it is important
				  96_ Other-specify

	1. Sputum tests			
	2. Chest X ray			
	3. CT scan			
	4. Blood test			
	5. Spirometry			
	6. Other			

2.7.	Have you received the results of the test?		

Test	1- Yes	2-No (Skip to 2.11)
1. Sputum tests		
2. Chest x-ray		
3. CT scan		
4. Blood tests		
5. Spirometry		
6. Other		

2.8.	Did the doctor say what the diagnosis was?	
	1. Yes 2. No (skip to 3.1.)	
2.10.	What was the diagnosis?	
	1. TB 2. Post-TB lung disease 3. Asthma 4. COPD/ Emphysema	

	5. Bronchiectasis 6. Acute causes 7. Other (specify)	
2.11.	If 'No' in 2.7, did someone in this facility tell you when you should expect to receive the results for the tests that you have done today for your chest/ breathing problem?	
	1- No they didn't tell me 2- Later today 3- Tomorrow 4- Within a week 5- More than a week 96_Other, specify	

SECTION 3: EXPERIENCE ABOUT TREATMENT RECEIVED FOR THIS HOSPITAL VISIT

3.1.	Did you receive any treatment today for this breathing/ coughing problem?	
	1- Yes 2- No [skip to 3.3.]	
3.2.	What treatment did you receive in this facility for your breathing/ coughing problem?	
	1- Drugs for TB treatment 2- Other antibiotics 3- Bronchodilators 4- Inhaled steroids 5- Oral steroids 6- Inhalers 96_ Other (Specify)	
3.3.	What decision has been made about your breathing or coughing problem?	
	1- Have been asked to come back another day (skip to 3.5) 2- Have been referred to another facility 96_Other (specify)	
3.4.	If referred to another facility, where have you been referred to ?	
	1- Public subcounty hospital 2- Public county referral hospital 3- Private provider facility 4- Private, retail pharmacy 5- Other (Skip to 3.7)	
3.5.	Do you plan to come back to this facility on the appointed day?	
	1- Yes (Skip to section 4) 2- No 99 Don't know	
3.6.	If 'No' in 3.5, what are the main reasons you may not come back on the appointed day?	

	1- I would have other things to do (e.g. work, travel) 2- I cannot afford fare 3- It depends on partners' decision 4- I don't think it is necessary/ hope to feel better 5- I plan to go elsewhere 96_Other (Specify)	
3.7.	Do you plan to seek healthcare anywhere for this coughing/ breathing problem?	
	1- Yes 2- No	
3.8.	Where else do you plan to seek for healthcare?	
	1- Public facility 2- Private facility 3- Retail pharmacy 4- Traditional doctor 5- Self-medication 6- Faith healing 96_Other- specify	
3.9.	Why do you prefer the provider mentioned in 3.8 above?	
	1- Availability of diagnostic tests 2- Availability of medicines 3- Cheaper prices 4- Closer to home 5- Availability of doctors 96_Other (specify)	

SECTION 4: OWNERSHIP OF HEALTH INSURANCE AND PAYMENT FOR EXPENSES INCURRED FOR THIS HEALTH FACILITY VISIT

4.1.	Are you enrolled in any health insurance scheme?	
	1- Yes 2- No (skip to 4.3)	
4.2.	Which insurance scheme are you enrolled in?	
	1- National Hospital Insurance Fund (NHIF) 2- Community Based Health Insurance (CBHI) 3- Private health insurance schemes 4- NHIF + other insurance (applicable to either Private or CBHI) 96_Other (Specify) (Skip to 4.5)	
4.3.	Do you know if you are eligible for NHIF?	

	1- Yes 2- No (Skip to 4.5)
4.4.	Why don't you have NHIF insurance? 1- Lack of information 2- NHIF is unaffordable 3- Services offered in the benefit package are not adequate 4- Choice of facility is limited 5- Other

Direct Medical costs incurred for this health facility visit

4.5.   Please describe the expenses that you have incurred for this health facility visit.

4.5.1. Medical out-of-pocket payments, (Total per visit) **(A)**					
Consultation fee A1	Lab tests A2	Radiography and other imaging A3	Other procedures[7] A4	Medicines A5	Medical payments, total in Shillings (sum) ΣA1 to 5 (If patient does not remember specifics of A1 to A5, indicate the **TOTAL** amount spent)

Direct non-medical expenses for hospital visit for patients/ persons accompanying them

4.5.2. Non-medical out-of-pocket payments for patient[8] , (Total per visit) **(B)**				
Travel B1	Food costs during visit B2	Accommodation B3	Other expenses e.g. phone services B4	Non-medical out-of-pocket payments (Total) ΣB1 to 4 (If patient does not remember specifics of A1 to A5, indicate the **TOTAL** amount spent)

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[7] Based on the facility survey, indicate any other procedures that the patient undergoes…
[8] In case of child patients, the direct costs and income lost for the

4.5.3. Non-medical out-of-pocket payments for person accompanying patient, (Total per visit) (C)				
Travel C1	Food costs during visit C2	Accommodation C3	Other expenses e.g. phone services C4	Non-medical out-of-pocket payments (Total) ΣC1 to C4 (If patient does not remember specifics of C1 to C4, indicate the **Total** amount spent

Payment for Healthcare Services using NHIF (Skip to 4.5.8, for those without NHIF)

4.5.4.	(For those with NHIF) Did you use NHIF to cover for any medical expenses for this coughing/ breathing problem?	Instruction: emphasis should be for this hospital visit
	1- Yes 2- No (Skip to 4.5.7)	
4.5.5.	Which services were paid for by the NHIF?	(Specify amount)
	1- Consultation 2- Tests (lab) 3- X-ray / CT scan 4- Medicines Don't know	

4.5.6.	In total, how much money was paid for by the NHIF?	(Specify amount) **Skip to section 4.6 (Economic costs)**
4.5.7.	Why do you think your medical expenses for this hospital visit were not covered by the NHIF?	
	1- Not fully paid up 2- Forgot card/ other identification requirements at home 3- Did not ask/ was never asked for card 4- Didn't know services covered by NHIF 5- Other- specify	

4.5.8. Total Direct Expenses incurred for this treatment episode (This section to be filled by the field worker based on responses indicated in Questions 4.5.1. to 4.5.6.).

Out-of-pocket payments (A+B+ C) (Gross) (D)	Health Insurance reimbursement or waiver (E)	Net out of Pocket payments for the treatment episode (Difference between Gross OOP and Heath insurance reimbursement (D-E)
Total out-of-pocket payments (ΣA1 to 6) + (ΣB1 to 4) + (ΣC1 to 4)	Health insurance reimbursement, specify: 1- NHIF 2- Private 3- Community-based 4- Waivered	

4.5.9. Impact of facility visit on individual and household income:

a) What is your household's daily income? *(Explain household to mean all the people who live under one room and share meals from one pot).*

b) How many days of your individual income would you estimate this visit cost you?

c) Have you had to do any of the following to pay for this health facility visit ?

Actions taken to pay for Hospital visit	1- Yes 2- No
1- Use savings	
2- Take out a loan	
3- Borrow money	
4- Sell property e.g. household item, livestock or other asset	

5- Do additional work to earn some more money	
6- Default on regular payment (e.g. child school fees)	
96_ Other (Specify).	

SECTION 5. PERCEPTION ABOUT THE QUALITY OF CARE:

I wish to understand how you feel about the services that you have received here today. I will read through various statements, please choose the option that best describes how you feel.

	Statement	1- Strongly Agree	2-Agree	3- Neither agree or disagree	4- Disagree	5- Strongly disagree
5.1.	I am satisfied with the services I have received here today					
5.2.	The health worker talked to me in a way that made me feel comfortable					
5.3.	The healthcare worker allowed me enough time to explain my problem					
5.4.	The consultation happened in a private place					
5.5.	The healthcare worker explained to me all the tests that will be conducted					
5.6.	The healthcare worker explained why s/he was examining me					
5.7.	The healthcare worker explained to					

	me what my problem was				
5.8.	The healthcare worker explained to me the likely causes of my problem				
5.9.	The healthcare worker explained to me the next steps of care				
5.10.	I received all the medicines that I needed in this facility				

SECTION 6. EXPOSURE TO TOBACCO SMOKE

Now I want to ask you some questions on risk factors for chronic respiratory conditions

	Smoking tobacco	
	Currently Tobacco smoking status	
6.1.	Do you currently smoke on a daily basis, less than daily or not at all?	
	1- Daily (Skip to 6.4) 2- Less than daily 3- Not at all (skip to question 6.3)	
	Past Daily smoking status	
6.2.	Have you smoked tobacco daily in the past?	
	1- Yes 2- N0 99-Don't know	
	Past smoking Status	
6.3.	In the past, have you smoked tobacco on a daily basis, less than daily, or not at all?	
	1- Daily (skip to 6.7) 2- Less than daily (skip to 6.7) 3- Not at all 99—Don't know	
6.4.	On average, how many of the following products do you smoke per day?	
	1- Pipe 2- Chewing tobacco 3- Shisha 4- Cigarettes 96_Other (Specify)	(Indicate number of cigarettes NOT packs smoked per day)
6.5.	Have you discussed anything about your smoking habit with a healthcare worker today?	
	1- Yes 2- No	
6.6	Did these discussions mention how you can quit smoking/ services available to support you to quit smoking?	
	1- Yes 2- No Skip to 6.8	
6.7.	(For respondents who smoked in the past, 6.3)When did you stop smoking? (The year)	
	Instruction to the interviewer_ Compute the number of years since stopped smoking, by calculating the difference of (2019- year)	
	Exposure to Second hand smoke (For respondents who don't smoke/ stopped smoking)	
6.8.	Does anyone smoke in the house?	
	1- Yes 2- No	
6.9.	How often does anyone smoke inside your house?	
	1- Daily 2- Weekly	

	3- Monthly 4- Less than monthly 5- Never 99—Don't know	

SECTION 7: EXPOSURE TO HOUSEHOLD POLLUTION FROM BIOMASS FUELS

7.1.	What type of fuel do you mainly use to cook in your home? (all that apply)	
	1. Firewood 2. Electricity 3. Liquid petroleum gas (LPG) 4. Biogas 5. Paraffin/ Kerosene 6. Charcoal 7. Agricultural crops 8. Straw/ shrubs/ Grass 9. Animal dung 10. No food cooked in household 96_ Other (specify)
7.2.	For choices (1-9) in 7.1. Is the cooking usually done in the house, in a separate building, or outdoors?
	1. In the house 2. In a separate building 3. Outdoors in open air 4. Outdoors on the Verandah 96_Other (specify) (2,3,4,& 96, skip to 7.5)
7.3.	Do you have a separate room in the house that is used as a kitchen?
	1- Yes 2- No
7.4.	Who does most of the cooking in the house
	1- Myself 2- Another household member (Skip to 7.6)
7.5.	Averagely, how many hours do you spend cooking every day? (Specify)
7.6.	For child patients only (Averagely, how many hours do you spend with your child in the kitchen while you are cooking?
	1- All the time 2- Most of the time 3- Very few times 4- Never

Thank the respondent and end the interview

Appendix 17: Collage of media headlines in Kenya

Appendix 18: Supplementary Table 5.4 & Figures 5a - 5d

Supplementary File 5.4: A priori sensitivity multivariable logistic regression analysis and post-hoc descriptive analyses

Sensitivity multivariable logistic regression analyses and post-hoc descriptive analyses were performed at both 10%- and 40%-thresholds with i) the addition of lost income to the numerator as per WHO TB Patient Cost Surveys[1] and ii) the inclusion of *only* direct medical costs of participants and *not* non-medical costs of participants and any accompanying person in the numerator.

Post-hoc supplementary, descriptive analysis were performed using Kruskal Wallis or ANOVA (Tables & Figures 5a-5d) where appropriate to examine the relationship of socioeconomic and clinical variables and costs incurred with level of care sough (i.e. health centre, subcounty hospital, county hospital). Supplementary table 5.4. shows the results of sensitivity analysis at the 10% and 40% thresholds.

1. **Supplementary Table 5.4: Total costs sensitivity analysis showing univariable and multivariable logistic regression of health and social factors associated with catastrophic health expenditure**

	Catastrophic health expenditure at 10% of monthly total household expenditure threshold						Catastrophic health expenditure at 40% of household monthly capacity to pay threshold				
	n/N (%)	Unadjusted univariable odds ratio; n=296 (95%CI)	p value	Adjusted multivariable odds ratio; n=275 (95%CI)	p value		n/N (%)	Unadjusted univariable odds ratio; n=296 (95%CI)	p value	Adjusted multivariable odds ratio; n=275 (95%CI)	p value
Age groups											
15-29 years	34/103 (33)	REF		REF			59/103 (57)	REF		REF	
30-44 years	34/117 (29)	0.83 (0.49-1.5)	0.53	1.1 (0.46-2.8)	0.79		67/117 (41)	1.0 (0.59-1.7)	0.99	1.4 (0.72-2.6)	0.34
45-59 years	20/60 (33)	1.0 (0.52-2.0)	0.97	1.4 (0.49-3.9)	0.55		29/60 (48)	0.70 (0.37-1.3)	0.27	0.94 (0.44-2.0)	0.88
60 years and above	3/16 (19)	0.47 (0.13-1.8)	0.26	0.42 (0.065-2.7)	0.37		8/16 (50)	0.75 (0.26-2.1)	0.59	0.81 (0.24-2.7)	0.74
Gender											
Male	51/123 (41)	REF		REF			61/123 (50)	REF		REF	
Female	40/173 (23)	0.42 (0.26-0.70)	0.001	0.88 (0.43-1.8)	0.72		98/173 (59)	1.5 (0.92-2.3)	0.11	**2.3 (1.3-4.0)**	**0.004**

	Catastrophic health expenditure at 10% of monthly total household expenditure threshold						Catastrophic health expenditure at 40% of household monthly capacity to pay threshold				
	n/N (%)	Unadjusted univariable odds ratio; n=296 (95%CI)	p value	Adjusted multivariable odds ratio; n=275 (95%CI)	p value		n/N (%)	Unadjusted univariable odds ratio; n=296 (95%CI)	p value	Adjusted multivariable odds ratio; n=275 (95%CI)	p value
Education level											
Up to primary school completion	37/163 (23)	REF		REF			84/163 (52)	REF		REF	
Up to secondary school completion	37/94 (39)	2.2 (1.3-3.8)	0.005	0.76 (0.32-1.8)	0.54		57/94 (61)	1.4 (0.87-2.4)	0.16	1.1 (0.59-2.1)	0.76
Above secondary school**	17/39 (44)	2.6 (1.3-5.5)	0.01	1.6 (0.52-4.7)	0.43		22/39 (56)	1.2 (0.60-2.5)	0.58	1.1 (0.44-2.6)	0.9
History of smoking											
Never smoker	75/253 (30)	REF		–	–		143/253 (57)	REF		–	
Current or past smoker	16/43 (37)	1.4 (0.72-2.8)	0.32				20/43 (47)	0.67 (0.35-1.27)	0.22		

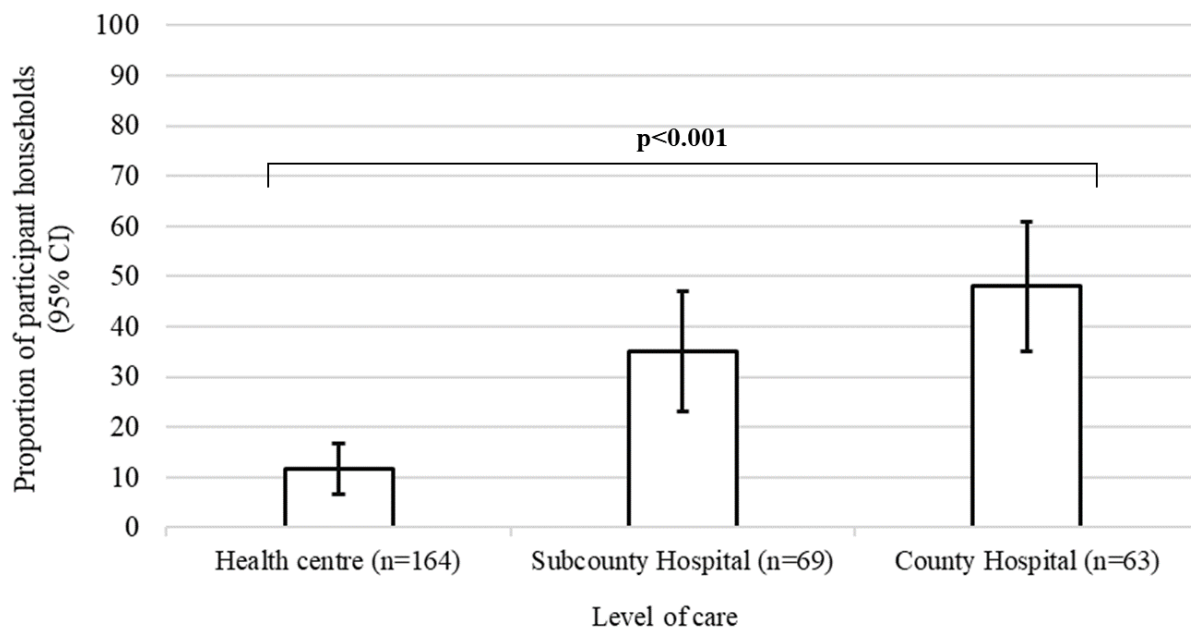|	Catastrophic health expenditure at 10% of monthly total household expenditure threshold						Catastrophic health expenditure at 40% of household monthly capacity to pay threshold				
	n/N (%)	Unadjusted univariable odds ratio; n=296 (95%CI)	p value	Adjusted multivariable odds ratio; n=275 (95%CI)	p value		n/N (%)	Unadjusted univariable odds ratio; n=296 (95%CI)	p value	Adjusted multivariable odds ratio; n=275 (95%CI)	p value
Primary income earner											
No	54/224 (24)	REF		REF			116/224 (52)	REF		REF	
Yes	37/72 (51)	3.3 (1.9-5.8)	<0.001	**4.1 (1.8-9.5)**	**0.001**		47/72 (65)	1.8 (1.0-3.0)	0.047	**2.0 (1.0-3.9)**	**0.043**
Accompanied during healthcare seeking and visits											
No	59/237 (25)	REF		REF			128/237 (54)	REF		–	
Yes	32/59 (54)	3.6 (2.0-6.5)	<0.001	1.8 (0.80-4.1)	0.16		35/59 (59)	1.2 (0.70-2.2)	0.46		
	Catastrophic health expenditure at 10% of monthly total household expenditure threshold						Catastrophic health expenditure at 40% of household monthly capacity to pay threshold				
	n/N (%)	Unadjusted univariable odds ratio; n=296 (95%CI)	p value	Adjusted multivariable odds ratio; n=275 (95%CI)	p value		n/N (%)	Unadjusted univariable odds ratio; n=296 (95%CI)	p value	Adjusted multivariable odds ratio; n=275 (95%CI)	p value

	Catastrophic health expenditure at 10% of monthly total household expenditure threshold						Catastrophic health expenditure at 40% of household monthly capacity to pay threshold				
Multidimensional asset-based poverty score (n=275)											
First quintile (least poor)	15/55 (27)	REF		REF			24/55 (44)	REF		REF	
Second quintile	23/55 (42)	1.9 (0.8.6-4.3)	0.11	**5.6 (1.8-18)**	**0.004**		27/55 (49)	1.2 (0.59-2.6)	0.57	1.4 (0.63-3.3)	0.39
Third quintile	9/54 (17)	0.53 (0.21-1.4)	0.19	1.1 (0.33-3.5)	0.91		23/54 (43)	0.96 (0.45-2.0)	0.91	1.1 (0.48-2.6)	0.82
Fourth quintile	12/51 (24)	0.82 (0.34-2.0)	0.66	2.9 (0.87-9.9)	0.083		35/51 (69)	2.8 (1.3-6.3)	0.011	**3.5 (1.4-8.7)**	**0.006**
Fifth quintile (poorest)	11/60 (18)	0.60 (0.25-1.4)	0.26	2.5 (0.74-8.6)	0.14		33/60 (55)	1.6 (0.76-3.3)	0.22	**2.3 (0.94-5.4)**	**0.067**
NHIF member											
Yes	26/84 (31)	REF		–	–		41/84 (49)	REF		REF	
No	65/212 (31)	0.97 (0.57-1.7)	0.96				122/212 (58)	1.4 (0.86-246)	0.17	1.1 (0.61-2.1)	0.69
	Catastrophic health expenditure at 10% of monthly total household expenditure threshold						**Catastrophic health expenditure at 40% of household monthly capacity to pay threshold**				
	n/N (%)	**Unadjusted univariable odds ratio; n=296 (95%CI)**	**p value**	**Adjusted multivariable odds ratio; n=275 (95%CI)**	**p value**		**n/N (%)**	**Unadjusted univariable odds ratio; n=296 (95%CI)**	**p value**	**Adjusted multivariable odds ratio; n=275 (95%CI)**	**p value**
Number of coping											

	n/N (%)	Unadjusted univariable odds ratio; n=296 (95%CI)	p value	Adjusted multivariable odds ratio; n=275 (95%CI)	p value		n/N (%)	Unadjusted univariable odds ratio; n=296 (95%CI)	p value	Adjusted multivariable odds ratio; n=275 (95%CI)	p value
strategies used (%)											
None or single coping strategy used	74/259 (29)	REF		REF			137/259 (53)	REF		REF	
Multiple coping strategies used	17/37 (46)	2.1 (1.1-4.3)	0.035	0.96 (0.34-2.7)	0.9		26/37 (70)	2.1 (1.0-4.4)	0.051	1.6 (0.69-3.8)	0.27
Diagnosis											
Any diagnosis	65/229 (28)	REF		REF			120/229 (52)	REF		REF	
No diagnosis	26/67 (39)	1.6 (0.91-2.8)	0.11	0.49 (0.21-1.2)	0.11		43/67 (64)	1.6 (0.93-2.9)	0.09	1.3 (0.65-2.5)	0.48
	Catastrophic health expenditure at 10% of monthly total household expenditure threshold						**Catastrophic health expenditure at 40% of household monthly capacity to pay threshold**				
	n/N (%)	Unadjusted univariable odds ratio; n=296 (95%CI)	p value	Adjusted multivariable odds ratio; n=275 (95%CI)	p value		n/N (%)	Unadjusted univariable odds ratio; n=296 (95%CI)	p value	Adjusted multivariable odds ratio; n=275 (95%CI)	p value
Health system level at which seeking care											
Health centre	22/164 (13)	REF		REF			85/164 (48)	REF		REF	
Sub-county hospital	30/69 (43)	5.0 (2.6-9.6)	<0.001	**10.3 (4.0-27)**	**<0.001**		37/63 (59)	1.5 (0.85-2.8)	0.16	**2.6 (1.3-5.2)**	**0.007**

| County hospital	39/63 (62)	10 (5.3-21)	<0.001	31 (9.9-99)	<0.001	47/62 (69)	2.3 (1.3-4.2)	0.006	2.1 (0.97-4.5)	0.059

2. **Supplementary Figure 5a: Distribution of Catastrophic health expenditure at 10% of total monthly household expenditure threshold by level of care**

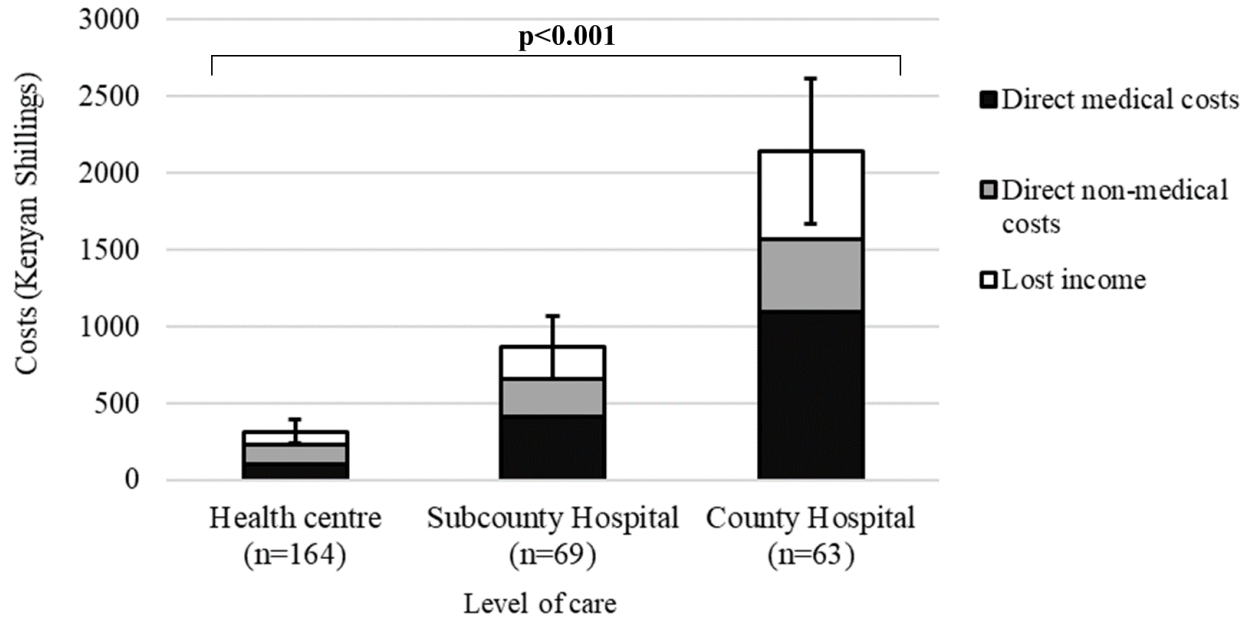*Legend: p value from one-way Anova test across levels of care*

3. Supplementary Figure 5b: Catastrophic health expenditure at 40% of total monthly household capacity to pay threshold by level of care
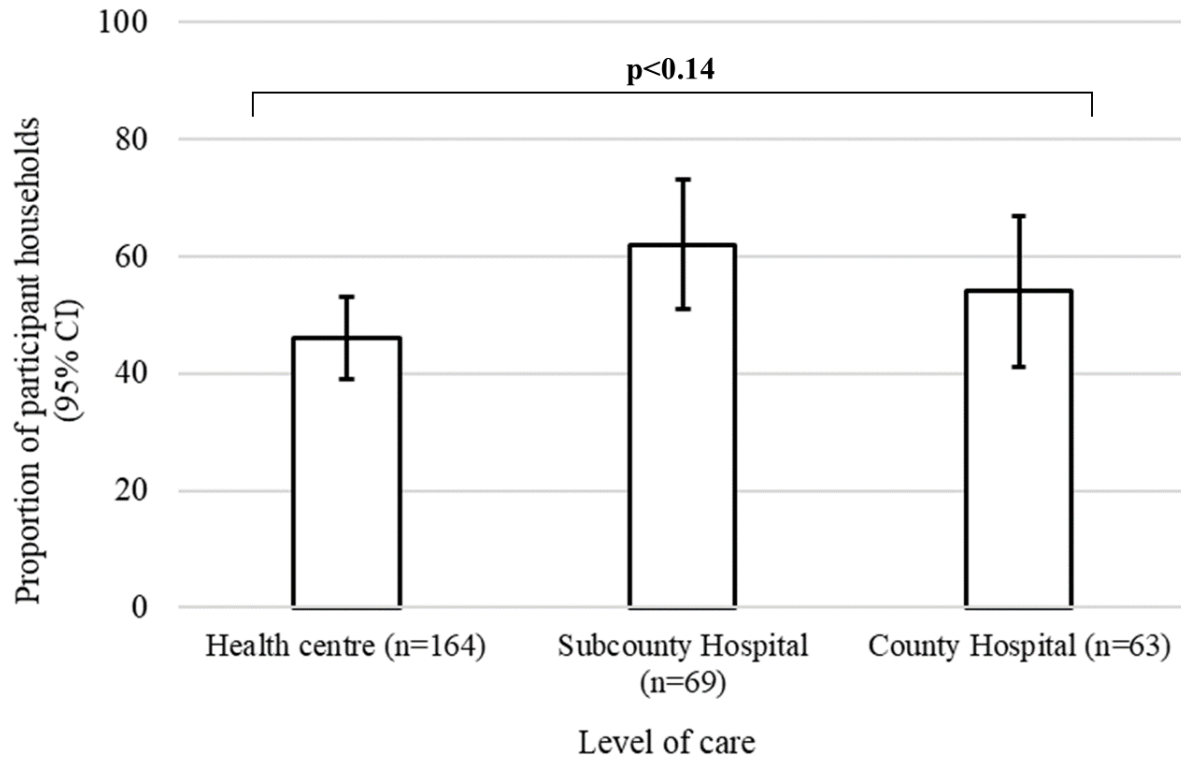
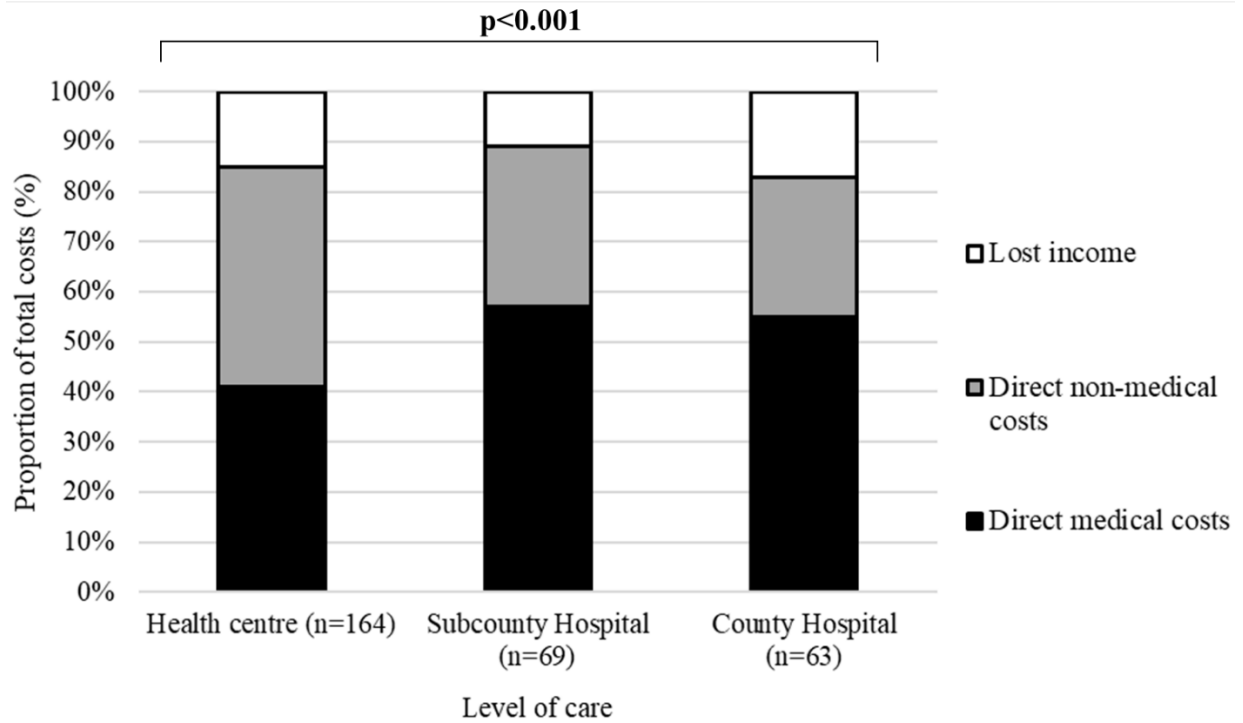*Legend: p value from one-way Anova test across levels of care*

4. Supplementary Figure 5c: Distribution of mean direct medical costs, direct non-medical costs, and lost income of participants by level of care

Legend: p value from Kruskal-Wallis test across levels of care

5. **Supplementary Figure 5 d: Direct medical costs, direct non-medical costs, and lost income as a proportion of total costs of participants by level of care**

Legend: p value from Kruskal-Wallis test across levels of care