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Technical Capacity Reinforcement of the Oncology Unit at Nelson Mandela Academic Hospital: Impact on Access and Quality of Cancer Care

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FACULTY OF HEALTH SCIENCES

SCHOOL OF PUBLIC HEALTH

TECHNICAL CAPACITY REINFORCEMENT OF THE ONCOLOGY UNIT AT NELSON MANDELA ACADEMIC HOSPITAL: IMPACT ON ACCESS AND QUALITY OF CANCER CARE

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A research report submitted to the School of Public Health, University of the Witwatersrand, in partial fulfilment of the requirements for the degree of Master of Public Health.

July 2024

DECLARATION

I, Noel-David NOGBOU (2373930), declare that this research report is my original work. It is being submitted for the degree of Master of Public Health in the University of the Witwatersrand, Johannesburg. It has not been submitted before for any degree or examination at this or any other University. I am aware that plagiarism (the use of someone else's work without their permission and/or without acknowledging the original source) is wrong. I confirm that the work submitted for assessment for the above degree is my own unaided work except where I have explicitly indicated otherwise.

I have read the sections on referencing and plagiarism in the Wits Plagiarism Policy, and I have followed the required conventions in referencing the thoughts and ideas of others. I understand that the University of the Witwatersrand may take disciplinary action including suspension or permanent expulsion against me if there is a belief that this is not my own unaided work or that I have failed to acknowledge the source of the ideas or words in my writing.

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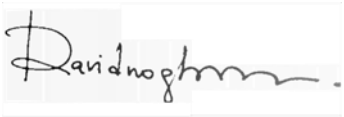

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ABBREVIATIONS

CI	Confidence Interval
COVID-19	Coronavirus Disease 19
EC	Eastern Cape
HICs	high-income countries
HIV	Human Immuno-deficiency Virus
IDIs	In depth Interviews
LMICs	low- and middle-income countries
NMAH	Nelson Mandela Academic Hospital
SSA	sub-Saharan Africa
WHO	World Health Organization

ABSTRACT

Background: Rural and remote areas suffer from inadequate resources for healthcare, including cancer care. In the bid to improve access to and quality of cancer care, the South African government initiated a policy of decentralising cancer care services. This study aimed to appraise the impact of technical capacity reinforcement on access to and quality of cancer care services provided at Nelson Mandela Academic Hospital (NMAH) in South Africa's Eastern Cape (EC) province.

Methodology: A concurrent mixed-methods study design through which a descriptive, quantitative cross-sectional design and in-depth, semi-structured interviews were adopted. The cross-sectional design served to describe cancer prevalence among patients attending NMAH, while the in-depth interviews explored patients' experiences with access and care quality before and after decentralisation. The statistical software analysis package Epi Info version 7.2.5.0 and the Advance Excel statistical analysis package version 2306 were used for the statistical analysis of quantitative data. While analysis of qualitative data was performed using the Robert codebook interpretation framework.

Results: Of the 120 randomly sampled participants for the quantitative study, 122 types of cancer were recorded. A total of 80.8% (n = 97/120) participants were female, and 94.2% (n = 113/120) were unemployed. Patients' ages ranged from 10 to 93 years, with a median age of 52 years (25th percentile: 42 years, 75th percentile: 67 years). Cervical and breast cancers were prevalent in 25.4% (n = 31/122; 95% Confidence Interval (95%CI): 0.2-0.3) and 23.0% (n = 28/122; with 95%CI: 0.2-0.4) of sampled records, respectively. The qualitative investigation enabled exploration of five main themes: cancer care context in the province, cancer care continuum at primary

care services, cancer's emotional toll and social experiences, unequal paths to healing: services before decentralisation, decentralization: perceptions of accessibility and quality in care and twelve sub-themes. Of the twenty interviewed participants, fourteen had cervical cancer. Participants reported that the change to NMAH as the point of care for chemotherapy, had improved access with significant financial relief for patients while maintaining a high standard of care.

Conclusion: Despite the current gap in cancer care services, available decentralise services provided at NMAH in the EC province are of high standard. Notwithstanding the improved accessibility, the provision to include radiotherapy will enhance services offered at this health facility.

ACKNOWLEDGEMENTS

The fear of the LORD is the beginning of knowledge. I thank my LORD, EWRADEH GNAMEH JESUS CHRIST,

To my daughter, Appata Kaleen Ningue NOGBOU, we refer to a set record not as a limitation but to bold the ability of humankind to overcome first themselves and second reaffirmed their superiority over the animal kingdom as the only species capable of self-improvement and self-determination. I hope this will serve as a starting point in your overachieving journey.

To my beloved friend, counsellor, and wife, Fatima DOUMBIA, my father, Appata NOGBOU, and my mother, Ningue AKA, I thank you for your continued support.

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Chapter One: Introduction

Background

Cancer is a recognised public health burden globally.[1,2] The term refers to any one of a large number of diseases characterised by uncontrolled cell growth and the acquisition of metastatic properties.[3] In 2020, cancer was recognised as the leading cause of death worldwide, with lung, colon and rectum, liver, stomach, and breast cancer identified as the most common causes of cancer deaths.[4] Despite this trend, an increase in risk factors has been observed in younger generations,[5] highlighting a similar trend for upcoming years. Most of this increase in the number of people living with cancer is expected to occur in low- and middle- income countries (LMICs).[6]

Patterns of cancer and availability of resources for cancer care vary across countries with different income levels.[7] LMICs generally have inadequate resources for healthcare, including cancer care.[8] This results in insufficient implementation of preventive treatments, a lack of early diagnosis, and subsequently insufficient treatment is common.[9] This reality is more severe in rural and remote areas within these countries, where insufficient healthcare infrastructure and a lack of qualified health personnel render cancer care scarce.[8]

Resources needed for cancer care can be specific to individual cancers, like test kits or specific drugs specific to cancer in general, such as radiation therapy or specialised medical personnel trained in oncology; and those not specific to cancer but affecting many types of medical care, including imaging facilities, surgical facilities, pathology, and laboratory medicine services.[8] In high-income countries (HICs), rather than the lack of resources for cancer care, it is the delivery of high-quality, affordable, and equitable care that is of concern to governments.[10,12] The financial burden imposed by

cancer care on national budgets pushes governments from HICs to re-evaluate their approach to a broader cancer care financing system and consider private health insurance initiatives as alternatives to cancer care.[13,14]

South Africa faces considerable disparities in its health system's capacity to address the cancer burden among rural populations.[14] In the Eastern Cape Province, the geographic location of well-equipped centres constitutes one of the major barriers to accessing quality care services for rural populations.[15] Dickens et al.,[16] in their study on breast cancer revealed negative associations between the proximity of cancer care services and the impact on cancer diagnoses, treatments, and outcomes. Another study[17] conducted in the Eastern Cape Province uncovered poor access to diagnosis and screening facilities for the communities in the rural area of the province,[17] while the increase in cancer incidence among these communities was highlighted.

Although data suggest that decentralised care has improved access and survival, it is, however, important to acknowledge that specialised and multidisciplinary cancer care is harder to avail of in remote areas.[18] Thus, specific interventions to reduce burdens related to frequent travel may significantly improve care quality.[15]

In the bid to improve access to and quality of cancer care, the South African government has since 2017 initiated a policy of decentralising cancer care services through the establishment of new treatment centres and reinforcement of the technical capacities of some tertiary, quaternary or central hospitals.[19] From this program, Nelson Mandela Academic Hospital (NMAH), as South Africa's only rural central hospital, has benefited, gaining the reinforcement of technical capacities and human resources to respond to the cancer burden within the Eastern Cape Province by

decentralising chemotherapy services from Frere hospital in East London (a tertiary hospital).[20]

Literature review

To some extent, cancer in sub-Saharan African countries reflects the socioeconomic inequalities and disparities within these countries, whereby a rapid increase in cancer among the most socio-economically disadvantaged population is of concern.[21] Yet, this population is facing considerable challenges in accessing cancer care services.[15] The malignant stage at which most of the cancer diagnoses are made, highlights the issue of access to adequate health facilities and technology for cancer care services among this population, mainly living in rural areas.[22,23] Rural areas still lack medical products, technologies, and qualified health workforces to effectively and efficiently address cancer.[23]

1. Cancer prevalence within the sub-Saharan African region

Cancer within the region is a growing public health concern.[24] Data projections suggest a double increase in mortality, from just over half a million deaths in 2020 to about 1 million deaths per year by 2030.[24] Female breast cancer and cancer of the cervix are the most prevalent cancers in Sub-Saharan Africa ranking first in 28 and 19 countries respectively.[25] These two cancers are also the most prevalent in sub-Saharan Africa (SSA).[25] This indirectly shows that women bear the burden of cancer in the region.[25] In men, prostate cancer is the most prevalent cancer in 40 countries, followed by liver cancer.[25] Although this data gives us an overview of cancer patterns within the region, the incidence rate varies from country to country, as does the incidence rate of specific cancers.[25] Oesophageal cancer is more common in East Africa, while lung cancer is a bigger concern in Southern Africa.[24] Additionally, Burkitt lymphoma is a disease

frequently seen in the tropical regions of sub-Saharan Africa.[26] The central and western regions of Africa have a high prevalence of breast cancer.[27]

2. Cancer risk factors within sub-Saharan African region

The increase in cancer prevalence in Africa has been attributed to risk factors classified as external and internal.[24] The external risk factors encompass infection-induced and demographic-related cancer risk factors, while the internal risk factors encompass genetically associated risk factors.[26] According to the World Health Organization (WHO), Africa has the highest percentage of infection-induced cancer prevalence in the world.[28] On the continent, cancers such as liver cancer due to hepatitis B and C viruses; cervical cancer due to human papillomavirus; and Kaposi sarcoma due to HIV, account for 27% of the total cancer prevalence in all WHO regions.[28] Cancer demographic drivers in Africa are associated with the socio-demographic transition and changes in lifestyle observed throughout the continent.[29,30] The increase in adoption of “westernised” lifestyles, which involve physical inactivity and consumption of processed or unhealthy foods, alcohol, and tobacco, has been well documented as a driver of increased cancer incidence in the region.[29,30] Beyond the external factors, literature suggest that particular genetic markers increase the risk of specific cancers, such as breast and prostate cancers, among Africans.[31]

3. Cancer care accessibility in sub-Saharan Africa

The high cancer mortality within SSA is partly due to the inadequate availability and/or accessibility of cancer care services.[32] Resources to address cancer on the continent are less than adequate, and the reasons are complex and span diverse sectors.[33] Several countries in Africa are failing to adhere to the WHO’s recommended 15% budget allocation to the health sector.[34] The lack of funds allocated to the health sector

has a direct negative consequence on cancer services.[34] Specialised oncology treatments and medical technologies are lacking, and if available, they are at user fee cost.[35] The out-of-pocket fees as the main health financing mechanism render available cancer services unaffordable for most of SSA's populations.[35] Furthermore, the lack of trained health professionals for oncology care in SSA renders the availability of adequate and quality oncology services inadequate.[36] Additionally, the geographical location of most of the oncology care centres is within urban areas, worsening the already existing inequalities in accessing oncology care.[24]

4. Cancer care decentralisation

Decentralisation of cancer care services from urban to rural centres is thought to increase access, proximity, and positive impact on cancer diagnosis and clinical outcomes.[18] Literature highlight the difficulties of complete decentralisation of cancer care services, however, they recognise the possibility of availing some services in remote settings.[18] A complete cancer care services involve high skilled health professionals, specialise surgeries, costly chemotherapy, radiotherapy equipment such as linear accelerators, Cobalt-60 units and etc. that are not readily and/or easily available in remote settings due to infrastructural limitations, under-capacitation of remote health facilities and lack of trained health specialists in these areas.[33] To that extent, policymakers are approaching the issue of cancer care services with the so-called "targeted decentralised policy" for cancer care.

4.1. Cancer care decentralisation in Africa

Several scientific evidences support that decentralisation will strengthen African countries health system response to cancer burden.[37,38] Generally, on the continent cancer care services are located at tertiary or quaternary academic urban centres

leaving most of primary and rural cancer care facilities under-capacity increasing disparity, inequality and inequity in access to available cancer care resources.[37] Decentralisation of cancer services from national to regional hospital in Kenya resulted to an increased in access and services uptake through chemotherapy and surgical capacitation intervention of already existing cancer services at regional hospital and establishment of new units at health facilities within the immediate reach of patients.[39] A published report from the Ministry of Health of the Democratic Republic of Congo sustains that decentralisation of oncology services related to diagnosis and treatment to provincial hospital across the country will lead to improvement in access for cancer patients in Congo.[40] Concurring with the Kenyan study Jojo and Nkutu[38] in South Africa pinpointed in their report the fact that decentralisation of oncology services to rural health facilities in Eastern cape has improved access and patients outcomes.[38] However, all these reports investigated specific delocalised services within the cancer care continuum such as chemotherapy, diagnosis and simple surgical intervention that do not require advance and complex technical infrastructure and skills.[38,37,38]

4.2. Cancer care and targeted decentralisation

Cancer care encompasses highly specialised procedures and technical medical devices that are difficult to set up in resource-limited settings.[18] Targeted decentralisation is meant to bring cancer services closest to end users, thus improving accessibility.[41] Targeted decentralise cancer care is cancer care model in which specific medical technologies, products and services are brought closer to patients by making services that don't need specialised equipment or complex logistics available at local healthcare facilities.[41,15] This could include chemotherapy, diagnosis, and performing simpler surgeries. This approach is designed to specifically address and/or avail cancer services that can be setup in resource-scarce environments such as

those experienced in sub-Saharan African rural areas or reduce indirect costs related to accessing cancer care.[15] Decentralisation of cancer care is an urgent need that will enable improved patients management and timely access to specialised quality care services.[42,41] Targeted decentralisation can address the availability of cancer specialists in rural areas and/or the availability of cancer diagnostic and care equipment in remote settings.[15]

5. Cancer patients' views and experiences on decentralised cancer care

Decentralised cancer care aimed at enhancing health system performance while improving services experience of users. From patients' point of view decentralisation has remove several impediments related to access to care such as long travelling hours, high indirect cost while improving quality and range of services given at local oncology unit.[39,] In South Africa, patients have stated that their waiting time has significantly decreased due to clinical staff having less patients to care for, which increased provider-patient engagement.[38] The received services were deemed satisfactory.[38] In Spain, attending a decentralised cancer unit was decreasing transport cost while services given was of similar comfort as the one received at the central oncology services.[43] In Vietnam, patients attending decentralised cancer care unit were benefiting of community empowerment and education on self-detection of breast cancer.[44] Patients in this study described the service as holistic incorporating clinical treatment and social management of the disease.[44] There is an increase of evidence on positive patients experiences with decentralised cancer care.

Justification

Before the decentralised cancer program implementation at NMAH, patients attending the hospital for specialised oncology and radiotherapy services were referred to hospitals 3-5 hours away for cancer care.[45] Hospitals like Inkosi Albert Luthuli in the nearby KwaZulu-Natal province in Durban (±450 km away) and Frere Hospital in East London, also in the Eastern Cape province (±240 km away), were the referral hospitals where oncology patients from NMAH were transported for specialised cancer care services.[45] This was an anomaly as well, since NMAH is a quaternary level (central) hospital and Frere is a tertiary hospital.

Access to healthcare consists of services that can provide the needed care within an acceptable timeframe and the availability of a health workforce that can provide the care and coverage, or the means to access healthcare.[46,47] Targeted decentralisation consisting of specific interventions aiming to address the most prevalent cancers within a defined population may significantly improve care quality.[15]

This study sought to understand how decentralisation implemented at NMAH had impacted patients' access to care and what experiences these patients had of the new cancer delivery model in the province.

Research question

How has technical capacity reinforcement impacted access and quality of care for patients diagnosed with cancer at Nelson Mandela Academic Hospital in South Africa's Eastern Cape Province?

Aim and objectives

1. Aim

To appraise the impact of technical capacity reinforcement on access and quality of cancer care services provided at Nelson Mandela Academic Hospital (NMAH).

2. Objectives

1. To determine prevalent cancers among patients attending oncology services at NMAH in the Eastern Cape.
2. To explore patients' access experience of decentralised cancer care services at NMAH in the Eastern Cape.
3. To explore patients' satisfaction with cancer care decentralisation at NMAH in the Eastern Cape.

Chapter Two: Methodology

Study Design

This study adopted a concurrent mixed-methods study design. A descriptive, quantitative cross-sectional design was used to understand the profile of cancer diagnoses. Qualitative, in-depth, semi-structured interviews were used to gain insights on patients' experiences of cancer care services provided at NMAH.

Study Setting

The study was conducted at the oncology unit within the NMAH in the Eastern Cape Province of South Africa. The facility is a 512-bedded public central/quaternary level hospital and serves as a teaching hospital for Walter Sisulu University in Mthatha in the Eastern Cape. The oncology unit mainly provides services to people from the OR Tambo, Joe Gqabi, Alfred Nzo, and Chris Hani districts.



Figure 1. Eastern Cape provincial map with health districts (Nelson Mandela Academic Hospital in OR Tambo district).[48]

Study Population

The study population included all patients (in- and out-patients) attending the oncology services at NMAH for cancer care between July 2016 and March 2022.

Study Sample

1. Quantitative sub-study

Using the patient registry of all patients seen at the oncology clinic between July 1, 2018 and December 31, 2021, all patients were assigned a number from 1 in chronological order. The sample size was calculated using the equation $n = \frac{p(100-p)z^2}{d^2}$, where n represented the minimum sample size and p, the proportion of cancer patients in the oncology unit who were managed in the unit before and after decentralisation, and who were receiving radiotherapy as part of the treatment. The radiotherapy was not part of the decentralised packages. As a result, patients receiving radiotherapy and chemotherapy still had to attend part of their care at Frere hospital in East London. Because this proportion of patients was not known, p was set at 50%, d represented the desired precision, and z is a constant that is 1.96 under the 95% confidence interval (95%CI) and the 5% level of significance. This yielded a minimum sample size of 96. To factor in for data entry errors, a further 10% was added, resulting in a minimum sample size of 116 and rounded off to 120 patients that were sampled using a simple random sampling strategy. All assigned numbers were entered into a computer programme to randomly sample 120 patients. The process was operationalised using Microsoft Excel 2020 software. In practice, the already existing electronic patient record at the NMAH oncology unit had 2297 patients with cancer as of June 3, 2022, and the de-identified database was labelled in ascending order from

1 to 2297. In Microsoft Excel, the function “=RANDBATWEEN (0,2298)” was used to select 120 random numbers from 1 to 2297.

2. Qualitative sub-study

Twenty (20) patients who received at least radiotherapy as part of their management plan were randomly selected for a semi-structure in-depth interview if they had been receiving cancer care before July 1, 2018. Semi-structured in-depth interviews (IDIs) were conducted during which participants were guided to discuss topics that enable researchers to evaluate the impact of the technical capacity reinforcement on the access and quality of cancer care services. This approach is detailed in appendices (Appendix: 2). Field notes were written, and audio recordings were done during the IDIs. Patients who only received chemotherapy and/or surgical interventions without radiotherapy were excluded. These patients were excluded because it would have meant that all their treatment would have been received at NMAH. Patients who were in respiratory distress, in pain, drowsed, or mentally ill were also excluded.

Data Collection

Two different sources of data were used for data collection. A review of patient records and in-depth interviews enabled us to achieve our objectives. The quantitative sub-study reviewed the patients’ registry to collect data related to demographic characteristics (sex, race, occupation, place of residence, and age), cancers diagnosed (type of cancer) and undergoing therapy on a standardised collection datasheet (Appendix 1). There was no age restriction in considering participants’ cancer unit record.

Once the study had acquired the necessary ethics approvals, the research access approvals from the Eastern Cape Provincial Health Research Committee, and the NMAH hospital management, the research team briefed nurses at the oncology unit about the study and requested their assistance. During each morning session, the research team was introduced, and patients were briefed about the study by the research team. Patients were approached to participate and gave voluntary, informed written consent to participate in the study. In-depth, semi-structured interviews asked patients about demographics, type of cancer they had, experiences of cancer care before and after decentralisation, changes noted with care after decentralisation and differences in care received at NMAH and Frere Hospital (Appendix 2). Participants also gave consent to the audio recording of interviews, which was supplemented with field notes. Only participants aged 18-year-olds and above were considered. IDIs lasted an average of one hour and were conducted at NMAH between April 17 and April 26, 2023, for convenience and aligned with the COVID-19 regulations and advisory.[49]

Reflexivity statement

As a black African researcher living in an upper-middle-income country, trained and working in resource-limited settings, I acknowledge that my personal and professional background may influence my interpretations of the data and the conclusions I draw from them. To mitigate this potential bias, I have made a conscious effort to engage with diverse perspectives and critically reflect on my own assumptions throughout the research process.

Reliability and trustworthiness

Standardised data collection forms have been developed and presented to experts (members of the Wits ethics committee) for approval.[27] To ensure the rigour of IDIs, the researchers ensured that the questions were clear and likely to produce accurate information and that the full scope of the area intended to be assessed was covered by the interview guide. The interview guide was pilot-tested on one patient with the least prevalent cancer. Subjects from the pilot test have not been included in the final analyses. Interview guides were translated from English to the local language (isiXhosa). All interviews were undertaken by four research assistants who have worked in the oncology unit, were trained on the interview guide and are fluent in the local language. Transcripts were translated from the local language (isiXhosa) to English and back translated from English to the local language using a different set of research assistants. Both transcript versions were peer-checked and approved by a data manager who was not involved with any of the translations and fluent in the local language to assess the trustworthiness of the transcripts.

Data analysis

1. Quantitative data

The statistical software analysis package Epi Info version 7.2.5.0 and the Advance Excel statistical analysis package version 2306 were used for the statistical analysis of quantitative data. Numerical data were explored for normality using the Shapiro-Wilk test. Numerical data were summarised using the median and interquartile range due to them not being normally distributed. Variables were summarised using frequency tables, percentages, and graphs. The 95% Confidence Interval (95%CI) was used for the precision of estimates.

2. Qualitative data

The combined inductive/deductive approach described by Roberts et al.[50], was used for thematic extraction. The developed codebook was double-checked by the researcher's supervisors (peer checking), and analysis was performed using the Robert et al.[50] codebook interpretation framework. This framework utilises the dualistic deductive and inductive approach while it also enables any unexpected themes to emerge during the coding process. This qualitative analysis technique, pioneered by Fereday and Muir-Cochrane,[51] focuses on the development and utilisation of a comprehensive codebook. The codebook is initially informed by the research question through a deductive approach. This means the codebook draws on the specific question the research aims to answer, existing knowledge about the topic, any relevant quantitative data, and preliminary insights from the raw data (e.g., interviews). Following this initial framework, the analysis employs an inductive approach. Here, the researcher closely examines the data itself to identify emerging patterns and themes. This allows for the discovery of unexpected but significant themes that might not have been anticipated in the initial codebook. The codebook evolves alongside the analysis, remaining flexible to capture the full richness of the data. Examples of developed codebooks are provided in Appendix 5.

Ethical approval

The study was granted ethical clearance from the University of the Witwatersrand human research ethics committee (medical) (reference: M220860) and from the Eastern Cape Provincial Health Research Committee (reference: EC_202302_010). Facility access approval was granted by NMAH management. Patients were informed that they could withdraw at any stage of the study, that they would not be incentivised

for participating, and that their care would not be affected if they chose not to participate. Moreover, the following basic ethical principles—autonomy, non-maleficence, beneficence, and justice—[52] were observed throughout the study. Autonomy resulted in the compulsory respect of participant self-determination regarding consent, refusal, or withdrawal at any stage of the research or interview. Non-maleficence addressed the obligation of the researcher to ensure that collected data will not be used to harm or in a manner that can compromise participants in any way. Justice was the ensuring of equitable treatment of participants and equitable provision of cancer care. The beneficence principle morally bounds the researcher to use collected data for the purpose of improving cancer care for the community. Permission to access the clinic registry was sought from the oncology unit manager. Participants in the IDIs gave consent by signing a consent form after being provided with information and offered a chance to ask questions. The data were only used for this research purpose.

Chapter Three: Results

In this study, 120 patient records were drawn from the patient registry as part of the quantitative sub-study, and 20 in-depth, semi-structured interviews were undertaken.

Quantitative sub-study

1. Demographic characteristics

Among the 120 records sampled, 80.8% (n = 97) were female and 99.2% (n = 119) were African. Patients' ages ranged from 10 to 93 years, with a median age of 52 years (25th percentile: 42 years, 75th percentile: 67 years); 94.2% (n = 113) were unemployed; 68.3% (n = 82) resided in the OR Tambo district (Table 1).

Table 1. Participants' demographic characteristics based on record review (N=120)

DEMOGRAPHIC DATA		N (%)
Sex	Female	97 (80.8)
	Male	23 (19.2)
Race	African	119 (99.2)
	Coloured	1 (0.8)
Age (years)	10-18	2 (1.7)
	19-39	23 (19.2)
	40-60	51 (42.5)
	>60	44 (36.7)
Occupation	Unemployed	113 (94.2)
	Formal employment	7 (5.8)
Residential District	OR Tambo	82 (68.3)
	Alfred Nzo	13 (10.8)
	Joe Gqabi	9 (7.5)
	Chris Hani	13 (10.8)
	Amathole	3 (2.5)

N: Frequency; %: Percentage

2. Prevalent cancers among sampled patient records

Two participants were simultaneously diagnosed with two types of cancer (Total cancer number were 122). Cervical and breast cancer were prevalent in 25.4% (n = 31/122; with 95%CI: 0.2-0.3) and 23.0% (n = 28/122; with 95%CI: 0.2-0.4) of sampled records, respectively. Two patients had two concurrent primary malignancies. Figure 1 summarises the prevalent cancers.

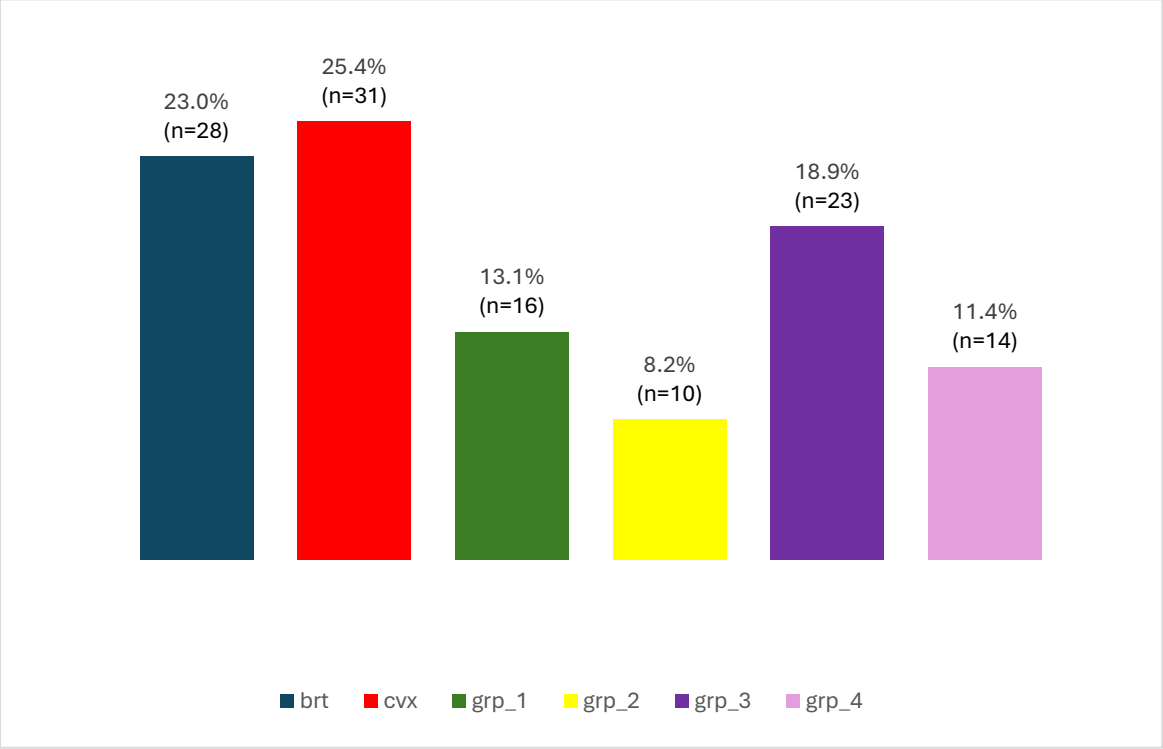

Figure 2. Cancer prevalence among study participants. *cvx: cervical; brt: breast; group_1* (*n = 1 for each of the following cancer: anal, bladder*, *castle man's disease*, *derma-fibrosarcoma*, *leiomyosarcoma, lung, malignant neoplasm*, *melanoma*, *oropharyngeal, parapharyngeal tumour*, *rectum*, *renal cell carcinoma, rectosigmoid, squamous cell carcinoma* (*neck*), *testicular*, *uterine*); *group_2* (*n = 2 for each of the following cancer: colon, ovary, hepatocellular carcinoma, conjunctiva, larynx, multiple*

myeloma)*; group_3* (*n = 3 for each of the following cancer: choriocarcinoma, non hodgkins lymphoma, prostate, vulva; n = 4 for each of the following cancer: metastatic endometrial, lymphoma,*); *group_4* (*n = 6 for the following cancer: Kaposi sarcoma*; *n = 8 for the following cancer: oesophagus*)

Qualitative sub-study

1. Overview of qualitative sub-study

The analysis of the semi-structured, in-depth interview of the 20 participants has enabled exploration of five main themes and twelve sub-themes. A summary table of themes and sub-themes are presented in Table 2.

Table 2. Summary of themes and Sub-themes on access and experience of received services

Themes	Sub-themes
Overview of cancer care context in the province	Context and respondents' demographic characteristics
Cancer care continuum at primary care services	Availability of cancer screening services
	Delayed presentation for care and limited screening for breast cancer
	Cancer diagnosis and diagnosis technology
	Continuity of care and referral pathways
	Limited cancer care capacity and skill
Cancer's emotional toll and social experiences	Feelings and reactions to a cancer diagnosis
	Social experiences due to cancer diagnosis
Unequal paths to healing: services before decentralisation	Barriers to access to cancer care
	Provided limited access to specialised services
Decentralisation: Perceptions of accessibility and quality in care	Respondents' perceptions on decentralisation
	Perceived quality of care

1.1. Overview of cancer care context in the province

Context and respondents' demographic characteristics

Interviewed participants were all African and female aged between 43 and 76 years old with a history of cancer care service attendance before and after the decentralisation of cancer care services at NMAH. These participants were all

unemployed and resided in rural areas (Figure 3). Twelve of the participants resided at OR Tambo district, six were from Alfred Nzo district, one participant was from Chris Hani and one from Joe Gqabi district. Before decentralisation, all the participants were traveling from their local clinics or hospitals to Mthatha Regional Hospital and NMAH, which are both in Mthatha, then transported from Mthatha Regional Hospital to Frere Hospital in East London, which is located almost 200 kms away (Figure 3). Some respondents mentioned that the initial transport from their local clinics to Mthatha Regional Hospital was done at their own expense, while others highlighted that there was an existing system of transport booking. The respondents suffering from cervical cancer (14), breast cancer (five), and thyroid cancer (one), mentioned that before decentralisation, receiving cancer care such as radiation, chemotherapy, reviews, and check-ups were initiated at Frere Hospital. However, surgical removal of cancer, reviews, and check-ups continued in either of the two hospitals in Mthatha.

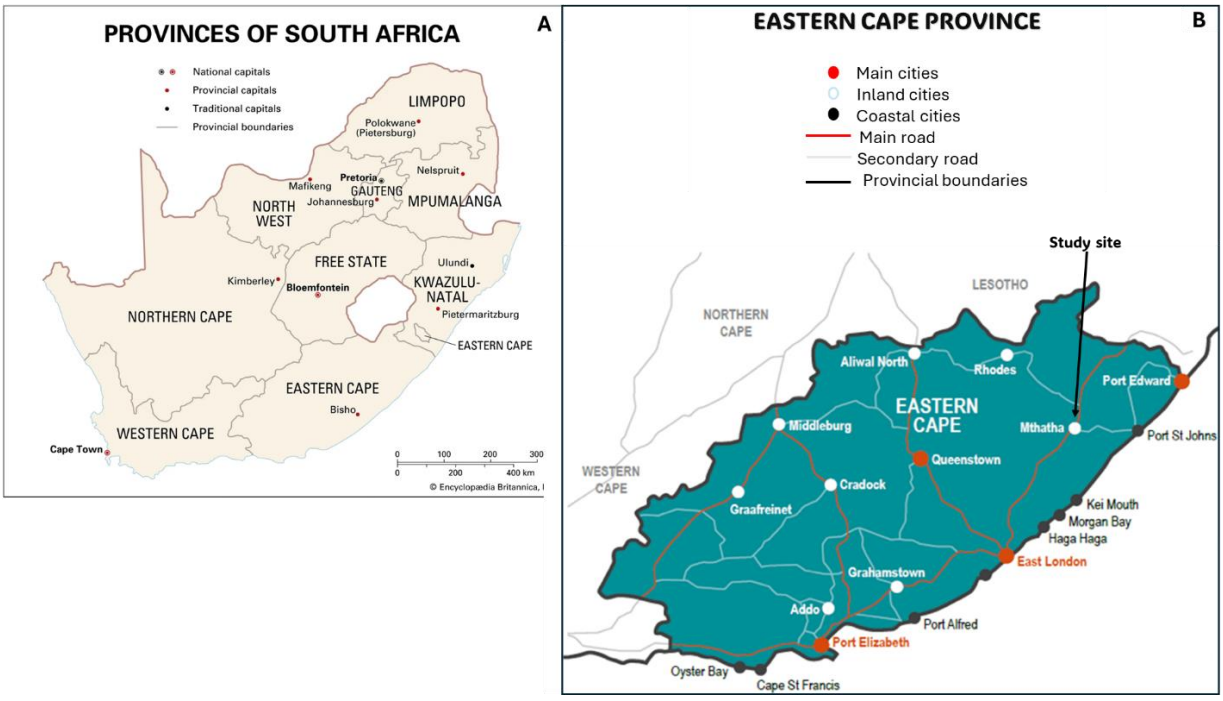

Figure 3. Geographical location of the study site in the Eastern Cape Province. A) South Africa provinces; B) Province and location of the study site

1.2. Cancer care continuum at primary care services

Availability of cancer screening service

Patients made use of cervical cancer screening services as accessed in their local primary care facilities. This would be in the form of a pap-smear that would mostly be undertaken by nurses. Upon acquisition of results, they would be referred to a hospital for further management.

Delayed presentation for care and limited screening for breast cancer

According to some respondents, they sought care when they noticed an unusual physiological change in their body, such as abnormal vaginal bleeding, breast lump(s), or pain (in their body).

> Participant 7*: I first noticed when I went to relieve myself and when I pulled up my underwear, I noticed a spot of blood…I Went to Mt. Ayliff [local health facility].*

> *Participant 12: … I started feeling a lump on my breast in 2017, I went to the clinic…*

This also suggested that some patients were aware of changes in their bodies and were able to examine their breasts.

Cancer diagnosis and diagnosis technology

Some participants mentioned that their local health professionals correctly made the cancer diagnosis after performing procedures like pap smear or breast examination. In contrast to this, some respondents revealed that their local health professional could

not make the cancer diagnosis for their case. For them the diagnosis was established after referral to a health facility with adapted medical technology. For all respondents, diagnosis confirmation was made at either Mthatha Regional or NMAH after using advanced radiography and laboratory techniques such as mammography, biopsy, and colposcopy.

> Participant 2: …*the doctor could not perform the pap smear because I could not stop bleeding… he [the doctor] goes on to say that he cannot perform the pap smear because of all the bleeding and suggested that I go to the hospital and he suspects that I might have cancer.*

Such actions concerned patients as they felt that their care was delayed and without an alternative. Others on the other hand felt that there was an alternative offered when the screening test was not conclusive or negative in the presence of symptoms.

> *Participant 3: …I underwent a biopsy [at NMAH] because they have been doing pap smear tests [at the local clinic] but could not find anything, the results were always negative. So, at Nelson Mandela [Academic Hospital] they did the biopsy and the results confirmed that I have cervical cancer.*

Continuity of care and referral pathways

Based on respondents' storytelling it is the need for advanced health technology tools in diagnosis, expert opinion on cancer topic and treatment that led to referral of local patients to well-equipped health facilities in the province like Mthatha Regional and NMAH. These health facilities host cancer units and can provide diagnosis services using advanced medical technologies. From the local nurse the participants were

referred to a doctor who on his/her turn referred the participant to either Mthatha Regional or NMAH before treatment initiation at Frere Hospital in East London.

Limited cancer care capacity and skill

Several respondents pinpointed that some health professionals were not able to correctly suspect a cancer diagnosis despite evident clinical symptoms on their first visit. However, other respondents highlighted the lack of available medical technology to reliably and accurately screen and eventually diagnose their cancer at their local health facility.

> *Participant 8: …my breast had a lump. When I went to Danti Clinic, a couple of times I was told to drink hot water, and I was given panado, and the sickness was getting worse. I didn't know what it was, but the breast was painful and had a lump. Every time I went to the clinic, I was told to drink warm water and be given panado.*

> *Participant 3: …I went to my local hospital, and they kept on giving me pills until I met [a different nurse]. I told her my problem and she is a person who clearly knows about the workings of the oncology unit….*

A respondent highlighted that despite her evident clinical symptoms rather than being referred immediately to a specialised cancer unit, pap smear was still performed.

> *Participant 6: I went to my local hospital…, at the clinic I was told by the nurse who was attending to me that she will do a pap-smear on me. I was in pain below my stomach… the nurse told me that I have to go and see the doctor and*

I asked what is it (sic)? She said it is nothing bad, but you will hear from the doctor…

1.3. Cancer's emotional toll and social experiences

Feelings and reactions to a cancer diagnosis

Before their cancer experience, for some respondents, a confirmed cancer diagnosis was a death sentence. Their literacy on the topic of cancer was low. According to these respondents, stereotypes on diagnosis and cancer treatment prevailed within their community. Subsequently, the diagnosis confirmation led them to be very emotional, with feelings ranging from sadness to being shocked and/or scared of uncertainty about their future.

Participant 7: *My spirit was crushed because I used to hear that cancer kills… I thought I am going to die…*

Participant 16: *I was sad because I thought I was going to die, because cancer is incurable…I didn't believe that I would survive.*

Participant 14: *I was shocked to learn that I had cervical cancer because everyone typically says that people with cancer don't live long and eventually pass away from it…I was concerned that I would pass away sooner than anticipated…*

However, one respondent mentioned that the cancer diagnosis did not scare her.

Participant 20: *I accept myself, I never felt that I was going to die…Just because the doctors have discovered it, I told myself to let the doctors deal with it, that's all.*

Another one respondent mentioned that the cancer diagnosis did not surprise her because of her HIV positive status. The respondent mentioned that cancer was not scary as compared to HIV from her point of view.

Participant 19: *…I was diagnosed with cervical cancer. It did not surprise me because I recently tested for HIV, and I found out that I am positive...This doesn't scare me as much as that one [HIV positive status].*

Some participants feared the treatment side effects, such as radiotherapy that they had heard off. One participant mentioned being encouraged to consider alternative therapy for their cancer due to prevailing community stereotypes.

Participant 19: *…there are people who are telling me that I should go to a traditional healer, because in East London I will be ironed, I will not return, I will die if I go for radiation.*

Participant 13: *…I will not go there* [Frere Hospital]*, I am scared of the iron* [referring to radiation].

Social experiences due to cancer diagnosis

According to several respondents their family members were supportive, despite being shocked by such a diagnosis. However, one respondent disclosed that her marital relationship was negatively affected on the disclosure of her cancer diagnosis, while

another respondent mentioned how the disclosure of her diagnosis led to stigmatisation and abuse from community members.

Participant 9: …I was very hurt; I almost died being abused by the community, who told me I would die and I wouldn't survive. I was very abused (sic) before I went to East London.

Participant 15: …my husband thought I would die…his side woman said I will not make it to 2019… he was not fine with this whole thing…He did not leave me but when he wants to sleep elsewhere, he does …

Participant 10: … I am married, my husband didn't accept it, he treated me differently…

1.4. Unequal paths to healing: services before decentralisation

Barriers to accessing cancer care

Respondents mentioned several social, economic, and environmental determinants that hinder them from seeking or reaching cancer care facilities. According to some respondents, the major barrier to accessing care is financial.

Participant 11: …money is the most challenging thing …my child. The challenge is the money, my child.

Respondents noted that accessing cancer treatment services before decentralisation was not easy. Some of them boldly said that accessing cancer care required timely booking, availability of means of transport, and traveling long distances in uncomfortable conditions. The opportunity cost, the long time away from the

household, and the indirect cost due to money spent while traveling made access to cancer care resulted in high costs for respondents. This situation drove the respondents to be very concerned and expressing feelings of unhappiness, but persevered due to the lack of alternatives.

Participant 1: …I was not happy at all about it. East London is very far.

Participant 8: … East London is very far; you spend the whole week on the road.

Participant 15: …you have to sleep in the hospital, and it is not nice to sleep away from home.

Other respondents stated that factors such as protests within the transport sector and floods due to heavy rain hindered their access to care. Additionally, the insufficient number of buses to transport the increased number of patients referred to Frere Hospital was a barrier to accessing cancer care services. Finally, some respondents highlighted that the level of literacy in reading and writing for registration and itinerary filling for transport might be a barrier for some patients.

Participant 4: …we couldn't go to East London when there was a bus strike. The bridge in my village was affected by the floods; there was no road to head to the hospital.

Provided limited access to specialised cancer care services

According to respondents, before decentralisation, Frere Hospital in East London was the unique health facility with specialised and advanced cancer care infrastructures for delivery of quality and adapted services. This situation led to referral of all

respondents to this health facility. This was the status quo in the province before decentralisation resulting in all respondents to endure two to five days travelling to access care.

> Participant 6: *…I would be given a date and then go to Mjanyana, in Mjanyana the nurses would organise an ambulance, from there to Nyanga, in Nyanga I would take another ambulance to Mthatha and from Mthatha to East London [Frere Hospital].*

1.5. Decentralisation: Perceptions of accessibility and quality in care

Respondents' perceptions on decentralisation

Respondents' perceptions of decentralisation and the changes observed were diverse. For respondents who resided closer to Mthatha, decentralisation had come with a considerable change in the number of days travelled to the health facilities, a drastic reduction in the distances travelled and a reduction in the indirect costs that are associated with the period away from home. Even though respondents who resided further from Mthatha also noted some changes in relation to minor reduction in travel times, where it reduced by up to two days, they still spent as long as two to three days on travelling to access cancer care.

> *Participant 9: …I was very happy because Mthatha is close to home, and I will come and go back home the same day. I was very happy; at least here it is closer.*

Participant 1: Even though sleeping at these places still happens, nothing has significantly changed. Even now, I am going to sleep in Bizana [local hospital], wake up in the morning, and go home.

Perceived quality of care

In comparison to the services received before and after decentralisation, the respondents noted that the procedures carried out for the cancer treatment protocol were of similar quality at the two health facilities. The two health facilities had friendly personnel with a warm and good client service orientation. Respondents noted an improvement of their health status resulting from attending these health facilities, highlighting the efficiency of care given.

Participant 1: *I would say that they all do well, both in East London [Frere Hospital] and Mthatha [NMAH]… I see no difference in the way they do things…I am getting better.*

Participant 17: *In East London [Frere Hospital], they treated me very well... even in Mthatha [NMAH], they treated me very well.*

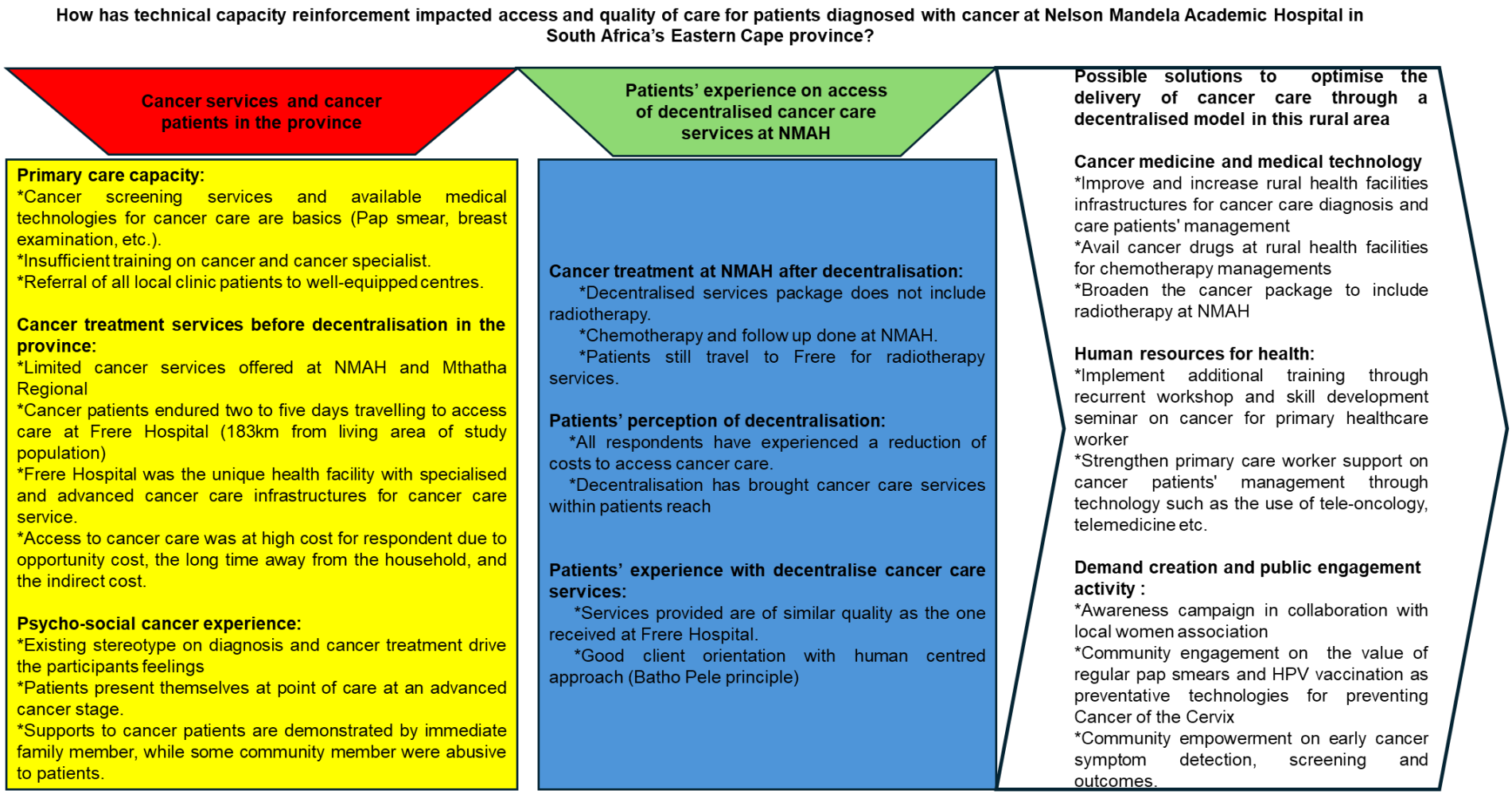

Figure 4. Summary of qualitative study and proposed approach for optimisation of cancer services in Mthatha district.

Chapter Four: Discussion

This study sought to describe prevalent cancers among patients attending NMAH, uncover the patients experiences with access before and after cancer care decentralisation, and explore patients' experience of decentralised cancer care services. The findings concurred with already existent communications on cancer prevalence in the EC province. Cervical cancer has already been mentioned as the most common malignant cancer with increased in incidence within the province.[53] The high prevalence of breast cancer reflect the national picture in which breast cancer incidence has steadily been increased over the past 20 years.[54] The presented data are as well consistent with global literature showing female breast and cervical cancer as the major contributors to the cancer burden in the world,[55,56] Causes like lower screening rate and low access to healthcare services have been indicated as reason for such observation.[54] However, vaccination such HPV vaccine, new digital screening methods, community awareness and empowerment campaign on topic like regular pap smear on cancer bear the potential to address some of these causes.[54] The results of this study, regarding the distribution of cancer cases by sex, are consistent with the existing South African state of knowledge.[38],[57]

Early access to cancer services has been identified as a determinant to decrease the high mortality and morbidity associated with cancer diagnosis.[58,59] Decentralisation means bringing services closer to the users, within a reasonable reach for underprivileged communities.[38] The findings of this study suggest that in the EC province, decentralisation has significantly reduced impediments associated with traveling long distances for care and eased access for underprivileged communities in EC province. Jojo and Nkutu[38] in their published communication on the same province concluded that decentralisation has improved access to cancer care services for rural

patients. Arenas et al,[43] in their study conducted in Spain emphasised that a satellite cancer care unit closer to remotely located patients implies a clear benefit for the comfort of the patients and an economic benefit by decreasing transport and other indirect related costs. The gathered evidence by Arenas et al,[43] revealed that cancer satellite units had considerably decreased stress and anxiety, improved access, and decreased challenges with significant financial relief for patients. The high unemployment rate among study participants emphasis the financial challenges faced by cancer patients attending NMAH. Although direct health costs were catered for by the government considerable indirect costs subsisted and were addressed by patients. These additional costs had placed an unbearable burden on these communities, already facing dire living conditions.[38,60] Cancer care decentralisation in the EC province has financially relieved patients on their care journey. The implemented decentralisation in EC province has enabled an improvement of NMAH cancer care unit infrastructures and widen services package delivered. However, the lack of radiation therapy in the available package of services maintains unmet needs that to some extent sustain some of the barriers Mthatha district patients faced before decentralisation. Arenas et al,[43] argued that despite the high technological requirements for a fully functional cancer unit, decentralising cancer care is feasible if technological needs and human resources are appropriately addressed. In South Africa rural health facilities experience a shortage of high-technology cancer equipment, and a lack of oncological expertise.[61,38,57] Universal Health Coverage includes that every patients received the full spectrum of essential health services without suffering financial hardship.[62] Therefor, the unavailability of radiation therapy technology within Mthatha district cancer patients immediate reach, is in discordance with equity in access principle and the initial motivation that drove South African

government to initiate this decentralisation policy.[19] Local and national health authorities should advocate and facilitate the availability of the full cancer services spectrum at NMAH.

Ineffective quality health care is predominantly occurring in poor rural communities.[63] Yet, this study suggests that patients receiving care at this rural decentralised cancer centre experience good quality care and satisfaction. This finding is aligned with a 2023 report investigating patient experiences with oncology services at the same decentralised location.[38] The report found that patients attending this centre had positive experiences. In this 2023 report participants highlighted reduced waiting times, kind and caring healthcare professionals, and overall satisfaction with the care they received.[38] Kruk et al,[63] highlighted that 58% of deaths in developed countries are attributable to poor quality healthcare received. The lack of advanced diagnosis technology tools, the insufficient training on cancer and cancer specialists within Mthatha district led to inappropriate cancer patients' management and/or delayed in cancer services delivery. It is evident that Mthatha district cancer patients before decentralisation did not experience high-quality cancer care. If decentralisation has brought closer quality cancer services to patients, the local clinics still need considerable improvement on quality cancer care offered such as screening, diagnosis, palliative care, follow-up etc. Although, the cancer care continuum is complex and might involve variety of medical personnel,[64,65] essential cares across this continuum should be made available at an accessible distance from patients home.[66] Literature supports that a well-trained and supported health worker through current available technology such as telemedicine can adequately and timely manage cancer patients presenting themselves at local clinics.[66] Tele-oncology can improve cancer care quality in prevention, early detection, and treatment by compensating for

the deficiencies of the health care workforce and infrastructure in resource-limited settings.[67] Tele-oncology can also serve in clinical decision support to optimise patient management[67] and providing remote chemotherapy supervision, symptom management, and palliative care as well as psychological support.[68] Implementing recurrent training and skill development workshop for primary health care workers in Mthatha district will help to improve and strengthen local capacity in cancer service while bringing decentralisation to local clinic level within EC province. The implementation of tele-oncology within this district can strengthen Mthatha district capacity on cancer patients' management.

The fear of the unknown drives' patients and community reaction toward cancer diagnosis.[69] The lack and/or misinformation on cancer topics have significantly altered the social and family experience of respondents. If personal health experience plays a role in health education, demand creation and community engagement activities to increase health knowledge and education on cancer for the local community might have the benefit of improving behavioural change and support towards patients.[70]

It is worth noting that the study did not sufficiently dive into the availability of medical technologies for cancer diagnoses at primary care facilities, the health care professionals' competences in accurate diagnosis were not sufficiently explored and the impact of decentralisation on patients' health status was not scrutinised. Notwithstanding the limitation, decentralisation implemented at NMAH has alleviated costs for cancer patients attending NMAH and improved access to cancer care services without altering the quality of services experienced by patients at an urban cancer care facility.

Chapter Five: Conclusion and Recommendation

Decentralisation of cancer care services at NMAH has helped to alleviate costs and significantly decrease barriers to access cancer care services while offering a good quality of care delivered to patients attending the decentralise unit. Decentralisation of cancer treatment in resources-limited and remote settlements, despite technical and operational challenges, can be implemented with a significant positive impact on patient access and experience of care.

The study highlights the fact that if resources and technical requirements for specialised cancer treatment are made available, remote cancer care facilities can make considerable differences in improving equity in access to and availability of cancer care services. A recommendation is made to implement similar initiatives in other provinces with similar population patterns, develop operational capacity of rural health across the health system building blocks on cancer care which will enhance the national move towards improvement in access to healthcare services for the less privileged population. Implement a robust program for monitoring, evaluation, and research of decentralised cancer services, to strengthen cancer care delivery and improve patient outcomes in rural areas. Considering the benefit that the decentralisation has brought to NMAH patients, recommendation is made to avail radiation therapy platform at NMAH which will increase benefit for patients attending this cancer care unit.

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Appendices

APPENDIX 1: Demographic characteristics collection data form

Date	Participant number	Sex	Race	Age	Place of residence	Occupation	Type of cancer	Cancer therapy undergoing

APPENDIX 2: IDIs semi structured questionnaire

Individual interview sheet and guide to evaluate the impact of the technical capacity reinforcement on the access and quality of cancer care services provided at Nelson Mandela Academic Hospital (NMAH) in the Eastern Cape.

Thank you so much for agreeing to answer some few questions on my research. I am doing a research study to evaluate the impact of the technical capacity reinforcement on the access and quality of cancer care services provided at Nelson Mandela Academic Hospital (NMAH). The study aims to understand more on how the decentralisation of cancer care services has impacted patients' access to care and what experiences these patients have of the new health services delivery regarding cancer care in the province.

You are being interviewed because you are a patient attending the cancer care services and has experienced the services offered before and after implementation of the decentralised cancer care services. The information collected from this interview are confidential and will only be used for research purposes. Your identity will not be at any stage disclosed to anyone. If at any moment you feel uncomfortable or wish to stop the interview, you are welcome to let me know, and we will stop.

If you are happy with contents of this document and agree with the process, could you kindly sign the consent forms and return to me before we start, if you haven't already done so. I am happy to answer any questions that you may have before we begin the discussion. Are there any questions that you would like to ask on the process before we start?

No	Area of Interest/ topic	Initial broad descriptive questions	Possible probing questions
1	Knowing the participant and his condition	Can you introduce yourself and the reason why you attend the oncology unit	+Can you tell us when the first diagnostic was made? +What was your feelings when you were inform of the diagnostic + How your family was reacting to the situation
2	Impact of the decentralise cancer care services at NMAH	Describe the process to access cancer care services before 2017 or before implementation of cancer services decentralization?	+What was the arrangement you had at the time to access cancer care? +Can you tell us more about the constrains you were facing due to this process to access cancer care before the new services at NMAH?
		Explain to us the process now you go through to access cancer care after 2017 or after implementation of	+How you personally have experienced these changes +Tell us more about the effect of this new policy in

		decentralization of cancer services at NMAH	your life and your family life
3	Quality of services	Tell us about your personal experiences with the cancer care services delivered at NMAH before the implementation of decentralization of cancer services?	+If you were to rate the services what will be the mark from 1 to 10; 10 be the best services you have received +What definition you give to best service
		How would you describe your personal experiences with the new cancer care services delivered at NMAH?	+Can you tell us more about the differences in care that you have noticed over the time that you have been attending to your cancer care +Is your definition or criteria to qualified services as good is met in the current offer at NMAH +Will you yes or no recommend the services to someone else? And why?

APPENDIX 3: Consent form

You are hereby kindly invited to participate in a study

Name of study: **Technical capacity reinforcement of the oncology unit at Nelson Mandela academic hospital: access and quality of cancer care implications.**

I, …… Confirm that I have read the information about the aims and objectives of the proposed study and was provided the opportunity to ask questions and given adequate time to rethink the issue. The aims and objectives of the study are sufficiently clear to me. I have not been pressured to participate in any way.

I am aware that this material may be used in scientific publications which will be electronically available throughout the world. I consent to this provided that my name or any of my personal identifiers are not revealed.

I understand that participation in this Study is completely voluntary and that I may withdraw from it at any time and without supplying reasons.

I consent to the audio recording of my interview

I grant permission to the researcher and his team to access my file once it generated for the study purpose every time that it will be necessary through the course of this research activity.

I know that this study has been approved by the University of the Witwatersrand Ethic Committee, the Nelson Mandela Academic Hospital central administration, and the oncology unit manager. I am fully aware that the results of this Trial / Study / Project* will be used for scientific purposes and may be published. I agree to this, provided my privacy is guaranteed.

I hereby give consent to participate in this Study ……

……

Participant Initial Signature of Participant

……..…..

Date

_____

Researcher initial and surname: N-D Nogbou Contact: davnogbou2@gmail.com/ +27792476203

Wits Ethic Research Committee Nº…….email:

Statement by the Researcher

We provided verbal and written information regarding this study. We agree to answer any further questions concerning the study as best as we are able.

We will adhere to the approved protocol.

Uyamenywa ngobubele ukuba uthathe inxaxheba kuphononongo

Igama lofundo: **Ukuqiniswa kobuchule becandelo le-oncology kwisibhedlele semfundo sikaNelson Mandela: ukufikelela kunye nomgangatho weziphumo zokhathalelo lomhlaza.**

Mna, ……. Ndiqinisekisile ukuba ndilufundile ulwazi malunga neenjongo kunye neenjongo zophononongo olucetywayo kwaye ndanikwa ithuba lokubuza imibuzo kwaye ndanikwa ixesha elaneleyo lokucinga kwakhona ngalo

mbandela. Iinjongo kunye neenjongo zesifundo zicace ngokwaneleyo kum. Khange ndicinezelwe ukuba ndithathe inxaxheba nangayiphi na indlela.

Ndiyazi ukuba le nto inokusetyenziswa kupapasho lwezenzululwazi oluya kufumaneka ngekhompyutha kwihlabathi liphela. Ndiyakuvuma oku ngaphandle kokuba igama lam okanye nasiphi na isazisi sam asityhilwanga.

Ndiyaqonda ukuba ukuthatha inxaxheba kwesi sifundo kungokuzithandela ngokupheleleyo kwaye ndinokurhoxa kulo nanini na ngaphandle kokunika izizathu.

Ndiyazi ukuba olu phononongo luvunyiwe yiKomiti yeYunivesithi yaseWitwatersrand, ikomkhulu lolawulo lweSibhedlele Sezemfundo iNelson Mandela, kunye nomphathi weyunithi ye-oncology. Ndiyazi ngokupheleleyo ukuba iziphumo zolu Vavanyo / uPhononongo / iProjekthi * ziya kusetyenziselwa iinjongo zesayensi kwaye zinokupapashwa. Ndiyavuma kule nto, ukuba imeko yam yabucala iqinisekisiwe.

Ngokwenjenje ndinika imvume yokuthatha inxaxheba kolu phand

……

Oonobumba bokuqala begama lomntu othatha inxaxheba

……

Ukutyikitya koMthathi-nxaxheba

……....

Umhla

_____

Oonobumba bokuqala bamagama kunye nefani lomphandi: N-D Nogbou

Qhagamshelana: davnogbou2@gmail.com/ +27792476203

IKomiti yoPhando ngeeNqobo ezisesikweni yaseWits Nº…….

Imeyile:……

INGXELO YOMPHANDI

Sinikezele ngolwazi ngomlomo nangokubhaliweyo malunga nolu phononongo. Siyavuma ukuphendula nayiphi na eminye imibuzo malunga nesifundo kangangoko sinakho.

Siya kuhambelana nomgaqo-nkqubo ovunyiweyo.

APPENDIX 4: Detail on interviewed participants' age

Age (years)	Frequency	Percent
10	1	0,83%
14	1	0,83%
24	1	0,83%
25	3	2,50%
27	2	1,67%
28	1	0,83%
29	1	0,83%
31	1	0,83%
32	1	0,83%
33	2	1,67%
34	3	2,50%
35	1	0,83%
36	2	1,67%
37	1	0,83%
38	2	1,67%
39	2	1,67%
40	1	0,83%

41	1	0,83%
42	4	3,33%
43	4	3,33%
44	2	1,67%
45	5	4,17%
46	3	2,50%
47	4	3,33%
48	1	0,83%
49	2	1,67%
50	4	3,33%
51	4	3,33%
53	2	1,67%
54	2	1,67%
55	2	1,67%
56	1	0,83%
57	2	1,67%
58	3	2,50%
59	2	1,67%
60	2	1,67%

61	1	0,83%
62	3	2,50%
63	3	2,50%
64	3	2,50%
65	1	0,83%
66	1	0,83%
67	3	2,50%
68	2	1,67%
69	2	1,67%
70	4	3,33%
71	1	0,83%
72	2	1,67%
73	1	0,83%
74	3	2,50%
75	1	0,83%
76	1	0,83%
77	2	1,67%
78	2	1,67%
79	3	2,50%

80	2	1,67%
89	1	0,83%
91	1	0,83%
93	1	0,83%
Total	**120**	**100,00%**

APPENDIX 5: Example of developed codebook

Main codes	**Definition**	**Sub-codes**
Participant residing location	Place where participants live / stay	Village Townships (location around Mthatha) Suburbs
Type of treatment	What types of cancer treatment / management did the patient receive?	Chemotherapy Radiation Check ups Review
Type of cancer	What type of cancer was patient diagnosed with?	Cervical Breast
Access to cancer diagnosis technology	How easy or difficult it was to establish cancer diagnosis	Availability / lack of health technology for cancer care Availability / lack of qualified trained professional for diagnosis Several referrals before diagnosis establishment / confirmation
Cancer diagnosis	How was the cancer diagnosed	Pap smear Biopsy
Participant feelings about Cancer diagnosis	How did the participant react to the diagnosis	Not good Scared

		Lost (uncertain on the future) Very emotional
Family / community member respond to cancer diagnosis	How did participant family /community members respond to the diagnosis	Supportive Crying Sad Shocked Abusive Stigmatizing
Cancer literacy	Participant level of knowledge on cancer and cancer outcomes	Cancer diagnosis is a death sentence Cancer is incurable. Treatment can get you better Able of peer education on cancer
Access to cancer treatment services	How easy or difficult was it for the patient to get to the facility	Means of transport Time Opportunity costs Distance from where they live
Feelings about access before decentralisation	Participant emotional reaction to cancer care services access	Resigned (do not have any alternative) Not happy Very concern

		Worried
Participant socio-economic status	Socio-economic living condition of participant	poverty Unemployed
Barrier to Access cancer care	Social, economic and environmental determinant that hinder participant to seek or reach care facility	Financial (need for grant) Strike (bus strike) Travelling conditions Distance travelled Flooding Insufficient number of buses for transportation Level of education (read and writing literacy for registration and itinerary filing)
Response to decentralisation	Emotional response to decentralisation	Happy Indifferent
Perceived change after decentralisation	Participant experience on changes brought by the change of point of care to NMAH	No change Improved (accessibility, Cancer facility closer than before) Got worse

Perceived quality of care	Perception of participant on services received at cancer care facilities	Procedures carried out (similar to previous cancer facility) Client reception (Good) Friendly health personnel (pleasant) Warm

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG	HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

Office of the Deputy Vice-Chancellor (Research and Innovation)

TO: Dr N-D Nogbou
School of Public Health
Medical School
university

E-mail: davnogbou2@gmail.com

CC: Supervisor: Drs S Mabunda and W Chitha
<SMabunda@georgeinstitute.org.au>
and <HREC-Medical Research Office@wits.ac.za>

FROM: Mr Iain Burns
Human Research Ethics Committee (Medical)
Tel: 011 717 1252

E-mail: Iain.Burns@wits.ac.za

DATE: 2022/12/05

REF: R14/49

PROTOCOL NO: **M220860** (This is your ethics application reference number. Please quote it in all enquiries, oral or written, relating to this study.)

PROJECT TITLE: *Technical capacity reinforcement of the oncology unit at Nelson Mandela Academic Hospital; impact on access and quality of cancer care*

Please find attached the Clearance Certificate for the above project. I hope it goes well and that an article in a recognized publication comes out of it. This will reflect well on your professional standing and contribute to Government funding of the University.

MSWorks2000/Iain0007/Clearscan.wps

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

R49 Dr N-D Nogbou

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)
CLEARANCE CERTIFICATE NO. M220860

NAME: **(Principal Investigator)**	Dr N-D Nogbou
DEPARTMENT:	School of Public Health Medical School university
PROJECT TITLE:	*Technical capacity reinforcement of the oncology unit at Nelson Mandela Academic Hospital; impact on access and quality of cancer care*
DATE CONSIDERED:	2022/08/26
DECISION:	Approved unconditionally
CONDITIONS:	
NOTE:	If contact information regarding student study participants is required, please contact the Registrar's office - <Nicoleen.Potgieter@wits.ac.za>
SUPERVISOR:	Drs S Mabunda and W Chitha
APPROVED BY:	Dr CB Penny, Chairperson, HREC (Medical)
DATE OF APPROVAL:	2022/12/05

This Clearance Certificate is valid for 5 years from the date of approval. An extension may be applied for.

DECLARATION OF INVESTIGATORS

To be completed in duplicate and **ONE COPY** returned to the Research Office secretariat on the 3rd floor, Phillip Tobias Building, Parktown, University of the Witwatersrand, Johannesburg.

I/we fully understand the conditions under which I am/we are authorized to carry out the above-mentioned research and I/we undertake to ensure compliance with these conditions. Should any departure be contemplated from the research protocol as approved, I/we undertake to submit details to the Committee. **I agree to submit a yearly progress report**. When a funder requires annual re-certification, the application date will be one year after the date when the study was initially reviewed. In this case, the study was initially reviewed in **August** and therefore reports and re-certification will be due in the month of **August** each year. Unreported changes to the study may invalidate the clearance given by the HREC (Medical).

Signature of Principal Investigator _____ Date _____

Province of the
EASTERN CAPE
HEALTH

Enquiries: Yvonne Gixela TEL: 043 605 4540/4518

Email: ncebagixela22@gmail.com

Date: 15 February 2023

TECHNICAL CAPACITY REINFORCEMENT OF THE ONCOLOGY UNIT AT NELSON MANDELA ACADEMIC HOSPITAL: IMPACT ON ACCESS AND QUALITY OF CANCER CARE. (EC_202302_010)

Dear Dr. N.D. Nogbou

The department would like to inform you that your application for the above mentioned research topic has been approved based on the following conditions:

1. During your study, you will follow the submitted protocol with ethical approval and can only deviate from it after having a written approval from the Ethics Research Committee.

2. You are advised to ensure, observe and respect the rights and culture of your research participants and maintain confidentiality of their identities and shall remove or not collect any information which can be used to link the participants.

3. The Department of Health expects you to provide a progress update on your study every 3 months (from date you received this letter) in writing.

4. At the end of your study, you will be expected to send a full written report with your findings and implementable recommendations to the Eastern Cape Health Research Committee secretariat. You may also be invited to the department to come and present your research findings with your implementable recommendations.

5. Your results on the Eastern Cape will not be presented anywhere unless you have shared them with the Department of Health as indicated above.

Your compliance in this regard will be highly appreciated.

SECRETARIAT: EASTERN CAPE HEALTH RESEARCH COMMITTE

2030 NDP

TOGETHER, MOVING THE HEALTH SYSTEM FORWARD