



Supplement Article

Coproduction in the management of individuals with cleft lip and palate in South Africa: the Ekhaya Lethu model

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Abstract

Objective: Cleft lip and palate (CLP), one of the most common congenital anomalies of the craniofacial complex, has a worldwide prevalence rate of 1 in 700 live births. In South Africa, a middle-income country, the CLP prevalence rate is 0.3 per 1000 live births in the public health sector. The complexity of the condition requires that individuals with CLP be treated by a multi-disciplinary team of health professionals, with the integral involvement of caregivers and families.

Methods: Between 2015 and 2018, we conducted a cross-sectional study entitled: *The epidemiology and care of individuals with cleft lip and palate in South Africa*, in fulfilment of a Doctor of Philosophy degree. The study setting consisted of 11 specialized academic centres (nine central hospitals and two specialized dental hospitals) that are situated in six of South Africa's nine provinces. The study used a combination of quantitative and qualitative methods and consisted of four distinct but inter-linked components. The first component consisted of a record review of CLP data over a 2-year period to determine the prevalence of CLP in the public sector of South Africa. The second component consisted of a survey of the leaders or heads of the health care teams in the 11 specialized centres to determine the current approach to CLP care provision. The third component consisted of a survey among CLP team members to measure inter-professional collaboration. The fourth component consisted of interviews with parents or caregivers on their perceptions of health service provision and support for children with CLP.

We draw on the findings of this large empirical study on CLP in South Africa's public health sector and the theory and principles of health care service coproduction to present the *Ekhaya Lethu* model for the management of CLP.

Results: The conceptual design of Ekhaya Lethu derives from the findings of each of the study components. We describe the possible application of the model in the coproduction of health care to examine the roles, relationships and aims of the multidisciplinary team in CLP management. We highlight both the implications and challenges of coproduction in the care and management of CLP for multidisciplinary health teams, the caregivers and families of individuals with CLP, and for health managers and policy makers.

Conclusion: The proposed Ekhaya Lethu model introduces a discourse on coproduction in the design and implementation of quality health care to individuals with CLP in South Africa and other low-and middle-income countries.

Key words: coproduction, cleft lip and palate, Ekhaya Lethu, quality of care, South Africa

Introduction

Globally, there is increased scholarly attention on the concept of coproduction and its potential to improve quality of care and patient safety [1, 2]. Coproduction is defined as the ‘interdependent work of users and professionals to design, create, develop, deliver, assess and improve the relationships and actions that contribute to the health of individuals and populations’ [1]: page 2. Although the movement on coproduction predates the three global quality of care reports published in 2018, the key findings of these reports build on these earlier contributions and underscore the importance of quality of care and people-centredness to the achievement of universal health coverage (UHC) [3–5]. The Lancet Global Commission highlights the importance of positive user experience, which includes incorporation of patient voice and values [3]. The report of the National Academies emphasizes the co-design and coproduction of health care between providers and patients and a ‘learning health system’ centred on patient needs and perspectives, as well as their empowerment and inclusion [4]. Similarly, the joint report of the World Health Organization, Organisation for Economic Co-operation and Development and World Bank reiterates a vision in which ‘all people have equal access to quality health services that are co-produced in a way that meets their life course needs’ [5]: page 54.

In South Africa, improving the quality of care has occupied the agenda of the democratic government since 1994, and there have been numerous health sector reforms to achieve this goal [6]. However, the South African Lancet National Commission found significant challenges in the achievement of high-quality UHC, including gaps in ethical leadership, management and governance and fragmentation of quality of care initiatives [7]. Among the key recommendations were a national campaign to educate patients and communities about their health rights and responsibilities and a broader programme of action on quality that involves patients and communities [7].

There is a significant literature on coproduction, focusing inter alia on conceptual models [1, 2, 8], enhancing the quality care of children with cystic fibrosis [9], coproduction in the design of oral health care services for older people [10], using coproduction to involve parents in defining research priorities on congenital anomalies [11], and the possibilities and challenges of co-production in health system-wide reforms [12]. More recently, Palmer has advocated for ‘a science of participation’, given the scholarly focus on coproduction [13]. Coproduction of and in health care has several advantages, including enhanced responsiveness to the needs of patients, improvements in health outcomes at both individual and population levels, health systems transformation and reduction in the power imbalances between patients and providers [1, 2, 8]. However, the scholarly discourse on co-production has been primarily in high-income countries in the Global North.

Cleft lip and/or palate (CLP) is the most common congenital anomaly of the craniofacial complex, with an estimated worldwide prevalence of 1 in 700 live births [14]. Given the complexity of the condition, individuals with CLP need treatment and care from a

multi-disciplinary team of health professionals. In addition, the long-term need for care necessitates the integral involvement of caregivers and families. In this paper, we draw on the findings of a large empirical study on CLP in South Africa’s public health sector and the theory and principles of health care service coproduction to present the *Ekhaya Lethu* (isiZulu for House of Care) model for the management of CLP.

Methods

Study design

Between 2015 and 2018, we conducted a cross-sectional, analytical study entitled: *The epidemiology and care of individuals with cleft lip and palate in South Africa*, which was done in fulfilment of the Doctor of Philosophy (PhD) degree of the first author and principal researcher (P.H.) [15].

Study sample and settings

The PhD study was restricted to the public health sector in South Africa, as it provides health care services to 83% of the population [16]. The study setting consisted of 11 specialized academic centres (nine central hospitals and two specialized dental hospitals) that are situated in six of South Africa’s nine provinces [15]. We assumed that our study setting included the universe of individuals born with CLP in the public health sector. This is because a child born with CLP needs specialized treatment and care given the obvious craniofacial defect, feeding and possible breathing difficulties and hence would need to be referred to and treated in one of these specialized academic centres. Multidisciplinary teams of health professionals are available at these CLP centres to provide specialized treatment and care. Further details on these specialized treatment and care centres are provided elsewhere [17].

Methodology

The study used a combination of quantitative and qualitative methods to maximize the strengths of each method and consisted of four distinct but inter-linked components. The first component aimed to determine the prevalence of CLP in the public sector of South Africa [17]. The PR used a data extraction form specifically designed for the study and conducted a record review of CLP data over a 2-year period at each of the specialized centres [17]. The aim of the second component was to determine the current approach to CLP care provision in the 11 specialized centres. Using an audit tool of all possible CLP services, the PR surveyed the leaders or heads of the health care teams at each specialized centre [18]. The third component aimed at measuring inter-professional collaboration (IPC) among CLP team members at each specialized centre, across the seven domains of care expertise, shared power, collaborative leadership, shared decision-making, optimizing professional role and scope, effective group function and competent communication [19]. Following informed consent, each

Table 1 Key findings on cleft lip and palate in South Africa's public health sector

- The estimated prevalence rate of CLP in South Africa's public sector is 0.3 per 1000 live births.
- The clinical profile showed that in females, cleft palate (CP) was more common, whereas cleft lip and palate (CLP) was more common in males.
- Surgical repair of the lip and palate (10/11 centres) and speech therapy (7/11 centres) dominated the type of CLP treatment provided in the public health sector.
- Although all 11 centres reported a multidisciplinary team approach for CLP care provision, there were gaps in the availability of certain categories of health care professionals (e.g. orthodontists), which in turn influenced the types of treatment provided.
- Only six centres provided written, standard treatment protocols for CLP.
- IPC was sub-optimal for all seven domains of care expertise, shared power, collaborative leadership, shared decision-making, optimizing professional role and scope, effective group function and competent communication.
- The highest mean score of 2.92 was obtained for care expertise, whereas effective group functioning obtained the lowest score of 2.55.
- The category of health care professional (e.g. doctor, speech therapist, etc.), to a lesser extent CLP centre, explained the differences in mean scores.
- The majority of caregivers of children with CLP were single, unemployed, women who had only completed primary schooling.
- Caregivers narrated their mixed feelings of shock, anxiety, and sadness at the birth of their children with CLP and highlighted the burden of care provision, amidst their experiences of health system deficiencies and insufficient social support services.

Source: Hlongwa, 2019: page 113 [15].

member of the CLP team completed a self-administered questionnaire on IPC, using the Interprofessional Competency Framework Self-Assessment Tool of the Registered Nurses Association of Ontario [20]. The aim of the fourth component was to explore the perceptions of parents or caregivers on health service provision and support for children with CLP [21]. The PR conducted in-depth interviews with 78 parents or caregivers across the 11 specialized CLP centres in six of South Africa's nine provinces, where these centres are located.

The details of each study component are reported elsewhere [15, 17–19, 21]

Results

Table 1 summarizes the key study findings [15] in order to give context to the description of the Ekhaya Lethu model.

The Ekhaya Lethu model

The Ekhaya Lethu model derives from the empirical study findings of the PhD [15]. In addition, we have used various chronic care models including the House of Care model [22, 23], chronic care model [24], model for child and family-centred care [25] and the internationally accepted principles and concepts of the WHO on integrated models of care [26]. The *Ekhaya Lethu (House of Care)* model on CLP is shown in Figure 1.

The Ekhaya Lethu Conceptual Framework uses the analogy of a secure house with seven components and attributes, described below.

The *foundation* of Ekhaya Lethu derives from the study findings on the prevalence of CLP in South Africa's public health sector. We found that there was no updated information on prevalence of CLP and that there was lack of an updated, overall national policy framework on congenital anomalies in general and CLP in particular [17]. Hence, we propose that the foundation should consist of a population-based congenital anomaly surveillance system and national policy framework—together these two components will be context specific to South Africa and will inform health policy and practice on congenital anomalies.

The interviews with caregivers (Study Component 4) revealed their mixed feelings of shock, anxiety and sadness at the birth of their children with CLP [15]. They highlighted the burden of care provision, amidst their experiences of health system deficiencies and insufficient social support services, as well as stigma and discrimination from family members and the community at large [21]. IPC among team members (Component 3) was sub-optimal for all the seven domains of care expertise, shared power, collaborative leadership, shared decision-making, optimizing professional role and scope, effective group function and competent communication. Only 6 of the 11 centres provided written, standard treatment protocols for CLP (Study Component 2) [15]. The audit of treatment and care provision revealed gaps, and the types of treatment provided was influenced by the categories of health care professionals in each centre [18, 19].

Hence, in our proposed Ekhaya Lethu model, the *four walls* give structural support to the house, and each wall is represented by one of the four pillars to overcome the weaknesses identified in the study.

- *Parent and family coproduction and support*—Information about CLP, screening and genetic counselling, treatment information as the treatment starts from birth to 18 years (and beyond), active participation in and coproduction of care, reassurance and emotional support.
- *Community advocacy*—environment within which the child with CLP is born, public awareness to provide information on CLP and to reduce stigma and improve acceptance.
- *Health system responsiveness*—this includes safe, high-quality care that is effective and efficient, while being culturally sensitive at the same time. Such responsiveness also allows for coproduction of care, feedback and people-centredness.
- *Care environment*—availability of resources, appropriate access, training of health care professionals that are members of the CLP team, information and supportive treatment.

These three Study Components (2–4) [15] informed the proposal of the Ekhaya Lethu *roof*. The *roof* is protective and consists of a multidisciplinary team of specialized health care professionals that work together in a coordinated manner and collaborate with one another to ensure the provision of the necessary treatment to the individual with CLP. Importantly, the multi-disciplinary team is committed to coproduction of CLP care processes and encourages children with CLP (when old enough) and their parents or caregivers to partner with them in designing care that is culturally appropriate, sensitive and supportive.

The focus of the study was on CLP [15]; hence, the *contents of the house* are the child or individual with CLP who cannot be separated from their parents or caregivers and the broader community. The Ekhaya Lethu foundation, four pillars and roof provide assurance that the individuals with CLP are well secured.

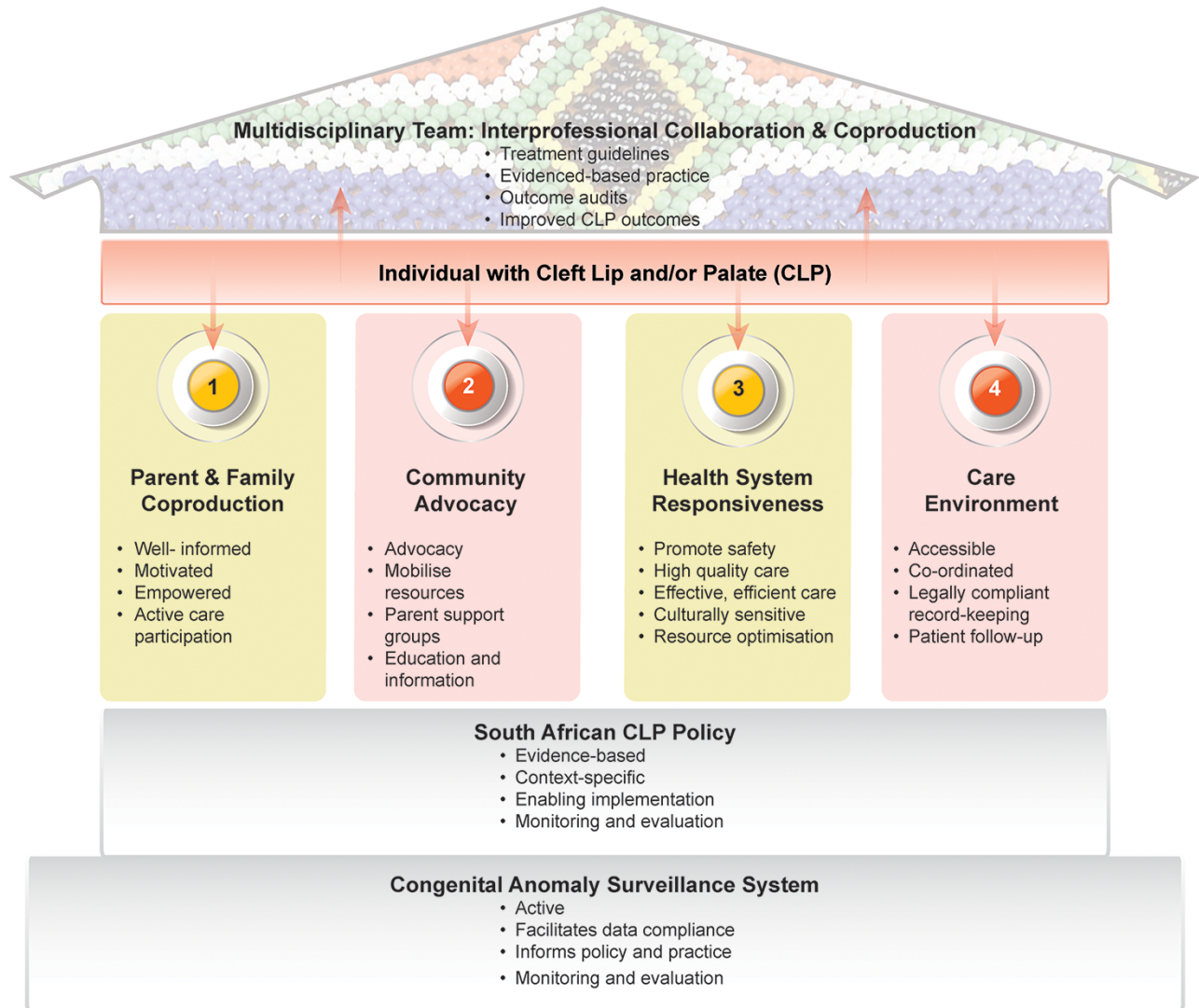


Figure 1 Cleft lip and palate Ekhaya Lethu model.

Source: Adapted from: House of Care Model [22, 23] and Principles of Coproduction [1, 2, 8] and informed by study findings [15].

Discussion

Statement of principal findings

In the Ekhaya Lethu framework, we propose that the foundation of CLP care should be a comprehensive national policy on congenital anomalies, informed by a population-based surveillance system [15]. However, our study found that this foundation is weak since the surveillance system does not exist and the national policy on congenital anomalies is outdated. This could be because of lack of capacity at the national government level and/or insufficient prioritization of congenital anomalies as these constituted a relatively small proportion of under-five mortality rates [27]. We propose that the Ekhaya Lethu model should inform the development and implementation of a population-based surveillance system on congenital anomalies that was envisaged in the 2005 national policy [28]. Such a population-based surveillance system will enable the country to obtain accurate information on the burden of, and risks for, congenital anomalies so that affected infants could be referred to specialized centres for treatment and care [29]. The surveillance system will also inform prevention programmes and assist with health policy development [30]. The implementation of the Ekhaya Lethu

model also provides an opportunity for government policymakers to coproduce the surveillance system with the academy, health care professionals and caregivers of individuals with CLP.

The *Ekhaya Lethu* model has proposed two essential pillars of care, namely health system responsiveness and a care environment that facilitate quality and patient safety. These pillars are weak, as the national policy is outdated, and some of the existing centres provide care to very few individuals with CLP [18]. This implies possible consolidation of limited number of centres of excellence in cleft care. This will reduce the 11 centres through a process of regionalization. The possible benefits and risks of centre consolidation through regionalization are shown in Table 2.

Hence, any decision on regionalization will require extensive consultation with all stakeholders, and analysis of financial and social costs, and careful change management.

The roof of the Ekhaya Lethu is proposed to be protective and consists of a multidisciplinary team of specialized health care providers that work together in a coordinated manner, committed to coproduction. This implies that patients and their caregivers are part of the team. However, the study found that IPC was

Table 2 Potential benefits and risks of consolidation of CLP centres

Potential benefits	Potential risks
<ul style="list-style-type: none"> • Increase in the critical mass of health care providers. • Enhance expertise in CLP. • Development of standard treatment protocols. • Cost-effectiveness for CLP treatment. • Improved quality of care. • IPC. • Coproduction of CLP care with caregivers and affected individuals. • Facilitate research or evaluation of long-term treatment outcomes audits. 	<ul style="list-style-type: none"> • Decreased training opportunities for health professionals at closed centres. • Reduced access to treatment and care for individuals with CLP. • Increased travel costs for caregivers. • Discontinuation of care due to long distances and lack of financial support. • Increased inequities in health care access and treatment between urban and rural areas.

Source: Adapted from Hlongwa, 2019 [15].

Table 3 Steps towards implementing Ekhaya Lethu

<ul style="list-style-type: none"> • Introduction of specialised orthodontic clinic for children with CLP. • Teaching dentistry students the importance of IPC and coproduction. • As part of teaching, requesting parents to share their experiences in living and caring for their children with orofacial cleft conditions. • Involving parents in decisions on treatment and care. • Inviting other members of the health care team to share experiences on CLP treatment and care.
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sub-optimal [19]. The teams of health care professionals who managed individuals with CLP appeared to work in silos, and doctors tended to dominate the health care teams.

The comprehensive management of the CLP condition and the long-term nature of treatment of individuals require a multidisciplinary team that collaborates with one another in a respectful and mutually supportive manner. The seven domains of care expertise, shared power, collaborative leadership, shared decision-making; optimizing professional role and scope, effective group function and competent communication could be used to guide practical strategies to enhance IPC in the existing CLP centres. However, IPC requires institutional support and leadership, as well as mentoring and coaching to unlearn certain behaviours [31]. Other strategies to enhance IPC include interdisciplinary discussions on care provision or patient management, as well as multi-disciplinary forums to continuing professional development [32].

Importantly, IPC and coproduction require leadership by example, even if small changes are introduced. Table 3 shows current initiatives introduced by the first author at the CLP clinic of one of the specialized academic centres.

The Ekhaya Lethu model proposes that the parents or caregivers should form one of the pillars and should be involved and should assist with the coproduction of the design and actual care of children with CLP. This implies that caregivers must be well-informed, motivated, empowered and prepared to participate in the care of children with CLP. Our study findings showed that the responsibilities for care of children with CLP fell mostly on caregivers who were single women, unemployed with only primary school education [21]. The health system deficiencies and lack of information and support exacerbated the emotional trauma experienced by the caregivers [21].

Hence, implementation of Ekhaya Lethu will require optimal functioning of the health care system and the provision of care that is culturally sensitive and appropriate. The model also requires that the information needs of parents and caregivers should be addressed [21].

Community involvement and support is another pillar of the Ekhaya Lethu model. In our study, caregivers reported widespread misperceptions from relatives and stigma from community members [21]. Ekhaya Lethu implies public awareness campaigns on CLP, as part of an updated national policy on congenital anomalies. The community plays an important advocacy role, which includes education to reduce stigma and discrimination, mobilization of resources, and supporting children with CLP and their caregivers. However, in Low-and-Middle-Income Countries (LMICs), government and non-governmental organizations would need to have dedicated programmes to assist and support poor communities.

Limitations and strengths

The larger study was limited by its cross-sectional nature, which provided information on CLP at a point in time. Although all the CLP centres in the public health sector were included, we excluded the private health sector and the annual CLP campaigns by non-governmental organizations such as the Smile Train [15]. Many of the clinical records at the specialized centres contained missing and incomplete information. This limitation was overcome by piloting the record review form and excluding information that was not on collected (e.g. smoking or drinking during pregnancy). In addition, a 2-year period was selected, thus overcoming the problems of seasonal variation in births and health care utilization by individuals with CLP. The statistical analysis also took account of the limitation of missing data, by computing two prevalence calculation scenarios [15].

The Ekhaya Lethu model builds on other coproduction models of care provision but will require significant investment of time, leadership, unlearning old behaviours, risk taking and some limited financial resources to support change management.

The study has numerous strengths. This was one of the first comprehensive studies on CLP conducted at all specialized treatment and centres in the public health sector since the dawn of South Africa's democracy in 1994. The study has generated new knowledge on the prevalence of CLP, IPC, gaps in care provision and the perspectives of caregivers on CLP [15]. The methodological contribution of the study is the combination of quantitative and qualitative methods that incorporated the voices of caregivers of individuals with CLP. The various tools designed in the study could be used by other researchers in South Africa and adapted by those in other LMICs.

Interpretation within the context of the wider literature

The Ekhaya Lethu model has emerged out of the study findings (Table 1), while drawing from and building on other care models of coproduction [22, 23].

The implementation of Ekhaya Lethu is likely to face resistance to change in some specialized centres, because it challenges hierarchical models of care provision. Any change to the status quo implied by Ekhaya Lethu will require strong leadership that is committed to different ways of working and more egalitarian relationships with other members of the health care team and with patients and their caregivers.

The implementation of Ekhaya Lethu in the care of individuals with CLP also provides exciting opportunities to those willing to take risks, unlearn old behaviours, invest time and provide leadership to

support change management, and a new approach to collaborative care provision.

Implications for policy, practice and research

The study has policy and practice relevance and has generated knowledge that could be used to develop a more realistic national policy on congenital anomalies in South Africa [15]. Similarly, health care professionals, researchers or patient advocacy groups in other LMICs could use the Ekhyaya Lethu model to develop policies and care protocols that are context-specific, taking account of resource availability.

The Ekhyaya Lethu model provides a framework for care provision, and each of its elements could be implemented independently and be integrated and developed in a step-wise fashion over a period of time. The model could also be used to inform further research questions. For example research could be conducted to compare the clinical outcomes, perceived quality and responsiveness and cost-effectiveness of care provision between those centres that implement the Ekhyaya Lethu model and those that continue the historical model of care provision. Research could also explore the contribution of Ekhyaya Lethu to the chronic problem of human resource shortages in LMICs.

Conclusion

The complexity of the CLP condition and the long-term nature of treatment of individuals require a multidisciplinary team that are committed to and practise the principles of coproduction.

Hitherto, there is a dearth of studies on coproduction in LMICs. We have proposed the Ekhyaya Lethu model to contribute to the discourse on coproduction in the design and implementation of quality of health care to individuals with CLP. However, coproduction is a journey, rather than a destination, which will require health policymakers, health care professionals, caregivers and communities to unlearn certain behaviours and be willing to take some risks.

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Authors' contribution

P.H. and L.R. conceptualized and designed the PhD study. P.H. collected all the data, as part of her PhD. L.R. is the primary supervisor of the PhD. All authors contributed to the writing and editing of the manuscript and read and approved the final version of the manuscript.

Ethics and other permissions

The Human Research Ethics Committee (Medical) of the University of Witwatersrand, Johannesburg provided ethical approval for the study (Ref #M1501536). The Provincial Departments of Health, Chief Executive Officers of the specialized academic centres and the heads of hospital clinical departments also provided study permission.

All study participants provided informed consent. There was no coercion and participants were given the opportunity to withdraw from the study at any time without prejudice. Confidentiality and anonymity were maintained throughout the study.

Data availability

Data available from the University of the Witwatersrand website, <http://wiredspace.wits.ac.za>, <https://hdl.handle.net/10539/27981>.

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