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ENDOCRINE SURGERY

Stakeholder engagement towards establishing a national thyroid cancer registry in South Africa

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Background: Patient registries in South Africa (SA) are not common. This study explored the perceptions and experiences of thyroid clinicians and members of existing patient registries in SA, aiming to establish a national thyroid cancer registry.
Methods: This was an exploratory qualitative study based on surveys and semi-structured interviews of participants' experiences treating thyroid cancer and using registries in general. Convenience sampling was performed for the surveys ($n = 27$) and purposive sampling for the interviews ($n = 20$). Data collection and analysis were conducted concurrently, facilitating an iterative process. The thematic analysis followed the steps outlined by Braun and Clarke.
Results: Four themes were identified. The South African healthcare system, the perceived value of a patient registry, the role of various stakeholders, and barriers to registry implementation. Participants expressed the value of registries in SA for both clinical and research purposes. However, concerns were raised regarding perceived challenges, such as resource and time constraints.
Conclusion: Developing a national thyroid cancer registry in SA requires responsiveness to national and local challenges and opportunities, necessitating an adaptable registry format. The principle of a registry is strongly supported by clinician stakeholders. The registry, as a clinical note-keeping system, will optimise clinicians' time efficiency in patient care, and standardisation of radiology and pathology reporting across a uniform platform will enhance patient care and data entry. The benefits of a registry strongly outweigh the challenges as it facilitates the development of local guidelines, improves patient outcomes, and promotes collaborative research among endocrine clinicians.
Keywords: patient registry, experiences, barriers, South Africa, thyroid registry

Introduction

Surgical registries in South Africa (SA) are limited. Establishing a thyroid registry could promote collaborative research among endocrine clinicians, aid in risk stratification, and predict surgical complications.[1,2] Clinical outcomes could be optimised by flagging high-risk patients for long-term surveillance while de-escalating the care of low-risk patients. A thyroid registry would facilitate the development of predictive scores and local guidelines, as current practices rely on recommendations from high-income countries (HICs).[1,3]

Several patient registries are currently operational in SA, including the National Cancer Registry (NCR), South African Heart Association Registry (SHARE) I and II, SA Renal Registry, Hernia Interest Group (HIG), and the SA Orthopaedic Association (SAOA) registry.[4-7] The absence of a thyroid cancer registry is a critical gap. An audit by the Thyroid Cancer Group of South Africa (TCGSA) reviewed thyroid cancer surgeries in the public sector and highlighted the advanced disease at diagnosis and the lack of standardised ultrasound (US) reporting.[8] The audit's retrospective design and public sector focus limited data quality and generalisability. Given SA's diverse population and healthcare landscape, ongoing real-world data collection and analysis are essential to inform context-appropriate approaches for managing thyroid conditions.

The Agency for Healthcare Research and Quality (AHRQ) developed a user guide for the development, implementation, and sustainability of registries.[1] Davids et al.[4] identified resource limitations as the most significant obstacle to the sustainability of the African Renal Registry. Unclear stakeholder roles and unstable funding are additional challenges.[9] Over the last decade, international endocrine surgery registries, such as the Collaborative Endocrine Surgery Quality Improvement Programme (CESQIP), the Scandinavian Quality Register for Thyroid, Parathyroid and Adrenal Surgery (SQRTPA), Eurocrine, and the United Kingdom Registry of Endocrine and Thyroid Surgery (UKRETS), have enabled collaborative research and outcome reporting.[10-13] These registries emerged from professional societies or healthcare institutions focused on measuring outcomes.[3] There are notable differences between health systems and countries. Clinician engagement on the risks, benefits, barriers and facilitators of registry development is essential. This study explored the perceptions and experiences of thyroid clinicians and members of existing patient registries in SA, aiming to establish a national thyroid cancer registry.

Methods

This explorative study gathered qualitative data through an open-ended survey and semi-structured interviews. A qualitative research design provided an in-depth understanding of barriers and facilitators to implementing a patient registry in SA. Using an interpretive paradigm, the principal investigator (PI) explored the nuanced contextual understanding of participants' attitudes and experiences with patient registries from their perspectives.[14,15] The PI, an endocrine surgeon at an academic hospital, met regularly with supervisors, facilitating reflexive processing during her PhD research.[16] Surveys and interviews among three different participant groups allowed for triangulation and verification of the data. These were Group 1: clinicians who were recently involved in the TCGSA audit (AP- audit participant), Group 2: clinicians who initially expressed interest in the TCGSA audit but could not participate (AnP – audit non-participant), and lastly, Group 3: individuals involved in existing patient registries in SA (ExP – experienced participant). Convenience sampling was used for the surveys, and purposive sampling for the interviews.[8]

The PI emailed potential participants requesting survey completion (Addendum A – Survey). Informed consent was obtained electronically using the Research Electronic Data Capture (REDCap) platform. Individual in-person semi-structured interviews were held at locations convenient for the participants (Addendum B – Interview Prompts).[17,18] Interviews were conducted over 11 months, allowing for prolonged engagement with the research materials. Data collection and analysis were performed concurrently, allowing for an iterative process.[19-21] The interviews were recorded and transcribed by an independent professional transcriber. The anonymous survey included demographics and a question on "thyroid surgery annual volume" but excluded the province. The researchers analysed the survey and interview data inductively, identifying codes and themes. Thematic analysis, as described by Braun and Clarke, was followed.[22]

Results

Twenty-seven individuals responded to the survey, and 20 participated in semi-structured interviews. The survey response rate for Group 1 was 79% (11/14), Group 2, 86% (6/7), and Group 3, 83% (10/12). Table I provides an overview of demographic information and the professional experience of participants.

Four interconnected themes with subthemes were identified – the SA healthcare system, the perceived value of a registry, the role of various stakeholders, and barriers to registry implementation (Table II).

The following abbreviations are used for the identification of participants and their groups:
S1: Survey Group 1
S2: Survey Group 2
S3: Survey Group 3
AP: Audit participant (Group 1)
AnP: Audit non-participant (Group 2)
ExP: Experienced participant (Group 3)
For each theme, illustrative quotes elucidate the participants' experiences and perceptions.

Table I: Participant characteristics

	Surveys (n = 27)	Interviews (n = 20)
Specialty, *n* (%)		
Endocrine surgeon	9 (33.3%)	8 (40.0%)
General surgeon	11 (40.7%)	8 (40.0%)
Researcher	2 (7.4%)	1 (5.0%)
Epidemiologist	1 (3.7%)	0 (0.0%)
Administration	1 (3.7%)	0 (0.0%)
Surgical trainee	1 (3.7%)	1 (5.0%)
Specialist physician	2 (7.4%)	1 (5.0%)
Pathologist	0 (0.0%)	1 (5.0%)
Province, *n* (%)		
Gauteng	-	6 (30.0%)
Western Cape	-	9 (45.0%)
KwaZulu-Natal	-	3 (15.0%)
Free State	-	0 (0.0%)
Eastern Cape	-	1 (5.0%)
Northern Cape	-	0 (0.0%)
Limpopo	-	1 (5.0%)
Participant groups, *n* (%)		
Group1: AP (Audit participant)	11 (40.7%)	11 (55.0%)
Group 2: AnP (Audit non-participant)	6 (22.2%)	4 (20.0%)
Group 3: ExP (Experienced participant)	10 (37.0%)	5 (25.0%)
Healthcare sector		
Public	Anonymous	17 (85.0%)
Private	Anonymous	3 (15.0%)
Thyroid surgery annual volume of 17 endocrine surgeon paricipants, *n* (%)		
0–10	3 (17.6%)	-
10–20	5 (29.4%)	-
20–50	5 (29.4%)	-
50–100	3 (17.6%)	-
> 100	1 (5.9%)	-

Table II: Themes and subthemes

Theme 1	**The South African healthcare system**
Subthemes	1.1 General South African healthcare
	1.2 Thyroid-specific services in SA
Theme 2	**The perceived value of a registry**
Subthemes	2.1 Clinical audit and research
	2.2 Improved clinical care
	2.3 Educational opportunities
Theme 3	**The role of various stakeholders**
Subthemes	3.1 Clinical practitioners
	3.2 Registry managers
	3.3 Pathology services
Theme 4	**Barriers to registry implementation**
Subthemes	4.1 Time constraints
	4.2 Infrastructure and resource constraints
	4.3 Ethics board approval

Theme 1: The South African healthcare system (See Table III)

Subtheme 1.1: General South African healthcare

Discussions regarding private and public healthcare systems included access to healthcare, clinical record-keeping systems, and data availability to guide clinical decision-making. It was clear that patients' access to healthcare is significantly impacted by geographical location, with rural populations facing more challenges and sometimes travelling up to two days to reach hospitals. Limited resources in these areas result in compromised care. Clinical note-keeping incorporates diverse systems; electronic notes are mainly used in the private sector, while paper-based systems are employed in the public sector. In the TCGSA audit, fragmented electronic platforms for special investigations, such as separate systems for radiology and pathology, hindered easy access to patient records.[8] Existing registries were developed for private funder billing interests and mostly for administrative purposes. Ultimately, the lack of clinical data being captured, audited, and analysed limits the applicability of international guidelines to the SA population.

Subtheme 1.2: Thyroid-specific services in South Africa

Thyroid US and US-guided fine needle aspiration biopsy (FNAB) are seldom performed by clinicians. Radiology US reports are not standardised, although this varies significantly depending on practice settings. In some regions, pathology services are lacking, leading to thyroidectomy specimens being sent to other provinces for analysis. Furthermore, the reporting of pathology results differs across laboratories, and some cytopathologists have yet to adopt The Bethesda System for Reporting Thyroid Cytopathology (TBSRTC) to report FNAB results.

Theme 2: The perceived value of a registry (See Table IV)

Subtheme 2.1: Clinical audit and research

Benefits of a registry include the development of context-specific guidelines, quantifying the burden of disease, and comparison of clinical management strategies. Several participants noted that an electronic registry could replace current manual labour-intensive data capture to facilitate local audits and promote research and collaboration across health sectors and provinces. Some participants believed establishing a registry could improve thyroid cancer management in SA, support uniform care, and help quantify

Table III: Theme 1: The South African healthcare system - illustrative quotes

Subtheme 1. 1: General South African healthcare

Inequitable access to health care

"The population is very poor. So, for them to get down to you from some of the far places… They will get a taxi to the hospital, they'll sleep the night at the hospital, then they'll come down to see you in the clinic for however long you see them for, and then they go back in the afternoon." AP7

"[Hospital name] drains semirural patients mostly. We get an urban population as well, but the semirural population is the bulk of it… the [patients] come with threatening airway obstruction. They leave their home, leave their children, pack their bags, get on the bus. Travel by bus from wherever they are." AnP1

Challenges with clinical record keeping

"Our hospital filing system is bad… patients who are coming in were operated... I have no clue what was done." AP2

"We sort of have a hybrid setting… some people do stuff online, and some stuff is then done paper based." ExP2

"You have to open like three systems at the clinic." AP10

"So, if you are with a patient, you have only got information of what you did during the admission. Once they are gone, you miss that information. Then the file is kept in the department for records; then the patient will come to us with the outpatient file." AP5

"It (the patient information) is somewhere in the store, and I must go through each page and look for those cases… I go and look at the number of thyroids that were done, take the numbers, and get back to my computer, enter the system, look at each and every patient that was collected that day, and see the history, the final pathology. If it's a cancer, then I will note that. At least I have a diagnosis." AP6

Lack of local data to guide clinical decision-making

"We find that a lot of clinical procedures are based on information that comes from Europe, that comes from America, not from our populations because we don't have data available." ExP3

Subtheme 1.2 Thyroid specific services in South Africa

Lack of thyroid ultrasound services

"… most of it (FNAB) is done by palpation because we don't have good ultrasound services." AP7

"Ultrasound services won't give you a TI-RADS classification." AP7

"When we get ultrasonography, they don't report according to the TI-RADS." AP2

Lack of pathology services

"They send their specimens to [hospital name in a different province] … We don't have [anatomical] pathology [services]. They can only do chemical pathology." AP2

"The older pathologists still like to write the essays… a little harder to pull data out of that prose, kind of writing paragraphs." AP4

"Going forward would be using synoptic reporting dataset, [a] minimum dataset." AP4

"For instance, we get … [an] FNAB. They don't even say what Bethesda." AP2

TI-RADS – Thyroid imaging reporting and data system, FNAB – Fine needle aspiration biopsy

Table IV: Theme 2: The perceived value of a registry - illustrative quotes

Subtheme 2.1 Clinical audit and research

Assist with audit and research

"You literally, if you need data, you need to go and draw it patient by patient." ExP3

"There's no way to index data. There's no way to combine data. You literally have to go and do it manually, which makes it completely impossible." ExP3

"It's the most basic of research. It's just clinical audit. You know, what is happening, where it's happening. The most basic of outcomes." ExP1

"As I was going through the data... I was just surprised that we had so many post-op hypocalcaemia's, post-op hypoparathyroidism." AP10

Development of context specific guidelines

"If there's a policy for SA, then people might think oh, this is actually cost-effective, or maybe it isn't for these limitations."AP3

"So it will just help people to, I think, institute local best practice, not necessarily international best practice." AP3

"Perhaps if you see how others are doing it, if there's like a national policy, that could change the way that we do things as well. If other people in SA have sat together and said we should work patients up like this, or this should be our surgical approach." AP3

Quantifying the burden of disease and comparison of management

"So that's a big thing for us, access to treatment, especially in the public sector, is very limited, and the registry allows us to put a number to it, and allows us to benchmark ourselves against other countries in the world." ExP4

"[Potential barriers are a] fear of being monitored." S3

"So we need to have a baseline of how are we managing this, so we can eventually move on to personalised or precision cancer management, particularly the thyroid cancers." AnP3

Subtheme 2.2 Improved clinical care

Simplified workflow (clinical note keeping)

"Our hospital filing system is bad… and the files are lost. So it will help … to capture also the theatre notes." AP2

"So if they [doctors] can take that and say please export this as a theatre report, and they can actually print that and put it in their file, then okay, great, I don't have to write something." AnP2

"If we manage to have a database, then you can actually get historic information from a patient; that would also be helpful." AnP4

"The big problem is a lot of people misunderstand registries. They think that registries are extra work. I think that the trick to having a good registry is to fulfil a clinical need or to simplify a clinical need. Then you get good data capturing and valid data capturing." ExP2

"An electronic note system does not allow me to easily put in a search domain and find everyone that's got a thyroid cancer. So, there's a lot of manual work that has to go into extracting data, getting all the different fields, and then supplying that." AnP2

"We do have a surgical database, where we enter patient admission, and the operations; they are all recorded nicely. But now, it depends on who wrote the notes. So, some of the things, they are difficult to find there, like the cytology results, they are very difficult to find, because it's not clearly recorded in the admissions notes." AP8

"Theoretically, you can easily say, take this data and just generate a theatre report, which is then sort of a narrative form, but the person can then put that in their file." AnP2

Standardisation of clinical care

"It's the most basic form of research you can do, and it's actually for patient care and a little bit of quality control." ExP1

"It will be a good thing. It will help all of us; we will have more of an idea of what is happening with thyroid cancer, thyroid pathology. It will actually help everyone to improve and enquire about things. I think it's a bit of a standardised way of managing patients." AP8

"Junior staff training. So I think something to put out, maybe with an addendum or something, or just how to do a FNAB of a thyroid." AP7

"I'm not sure if we can really make a difference in terms of outcomes for the patient. But I think for the purposes of knowledge, and knowing sort of the epidemiology in our country, that can be useful." AP6

Improved follow-up and data validity

"We had 100% data and 100% follow-up… If somebody didn't pitch up for their chemo appointment, they'd ring them. Oh, no, we'll help you out. Let's make it for next week, and we'll help you with the transport." AP7

"So, we always got three phone numbers upfront. Every six weeks they'd ring them, the first phone number didn't work, then they'd try the second, and then the third, and then they'd find from the second person that the first one has changed their phone number and get the new phone number and ring them." AP7

"So, some of the complications, they are not recorded, so you don't get them." AP8

Advocating for better clinical care – advanced therapies

"Because it's expensive treatment, and not every country can offer it to everybody who needs it… now we have the numbers to back up that statement. Also, the registry allows us to pick up disparities in access to treatment." ExP4

"It's allowed us to get access to patients, to treatments, because we could show data. And if you can show a benefit of outcome and you can reduce things like costs for chemotherapy for example, then I think medical aids and funders in general start listening." AnP2

"It will be a very good way of motivating for more resources… Particularly when we're talking about newer modalities, molecular biological treatment, because we're seeing a lot of advanced cancers… both for oncology, for management of cancer patients, motivation for funds, motivations for treatment, motivations for, maybe in some instances, recombinant TSH when we want it." AnP1

Identification of preventative strategies

"In our case as well, it highlights the most common and important causes for [condition type], so that prevention efforts can be focussed on those diseases." ExP4

Subtheme 2.3 Educational opportunities
"She asked me questions, "What does this mean", so it was a lot of actual education for a medical student on cancer and thyroid surgery."AP3
"It allows us to identify things that are cost ineffective, and that we need to target in terms of education and training." AnP2
"[The aim of the registry is] to provide cancer information to organs of state and the public, for education and training, awareness and research." S3

SA - South Africa, FNAB - fine needle aspiration biopsy, TSH - thyroid-stimulating hormone

the burden of thyroid disease while allowing for regional and international comparisons. However, some expressed concerns that clinicians might fear being monitored, which could make them hesitant to input patient data. A more positive angle was that the registry could provide a baseline for management assessments and facilitate precision medicine tailored to the unique genetic, environmental, and lifestyle factors of individual patients.

Subtheme 2.2: Improved clinical care

The potential indirect clinical care benefits of the registry were discussed during the interviews. These included a note-keeping system that could simplify workflow, assist with standardised care, capture follow-up data and complications, and identify locally relevant and applicable advanced treatment and preventive strategies. Participants suggested that integrating clinical notes with the registry could mitigate limitations in current systems by enhancing record access, data quality and follow-up processes while avoiding duplication of efforts. Suggested features included standard operating procedures (SOPs) and templates for specific procedures such as thyroid US and FNAB, to ensure uniformity. While most participants agreed that the primary value of a registry lies in improving patient care and outcomes, some felt that another clinical note-keeping system was unnecessary. Those with existing registries reported better patient follow-up and data validity, with missing data prompting follow-ups, while improved patient contact details in the registry facilitated better patient care.

Subtheme 2.3: Educational opportunities

It was noted that the data collection process could be a positive experience because of the educational opportunity it provides, explaining the disease process when medical students are tasked with collecting data. Another educational advantage of the registry is its potential to identify target areas for education and training.

Theme 3: The role of various stakeholders (See Table V)

Subtheme 3.1: Clinical practitioners

If clinicians are the main users and data capturers of the registry, their attitude is vital for its success, and challenges such as a resistance to change and their motivation for registry involvement were considered. One participant recommended that operating surgeons should enter the data to ensure and increase data accuracy. However, some experienced registry participants recalled doctors expressing dissatisfaction with the transition from paper to electronic notes as they had to learn a new system, which might hinder their involvement. Participants predicted challenges in securing buy-in from contributors and engaging clinicians as data capturers. One participant remarked that people would only be motivated to enter data into a registry if there was a clear aim or objective. While many viewed the initiation of a registry positively, one warned of the potential lack of initial buy-in and emphasised that establishing a successful registry requires time.

Subtheme 3.2: Registry managers

Registry managers' attitudes are vital for collaboration, data ownership, succession planning, and communication. Their attitudes were seen as an essential factor for its success, emphasising leadership with a collaborative mindset. An experienced participant highlighted previous conflicts over data ownership. Some felt strongly that individual passion without succession planning would negatively impact the long-term sustainability of a registry. Continuous communication between registry managers and contributors, along with external outreach, is key to success. One site did not participate in the TCGSA audit due to poor communication, as the task was assigned to a junior member, and subsequent communication between role players failed. Enhancing registry visibility through road shows and conferences has proven beneficial. Most participants recommended appointing a dedicated registry champion at each site to communicate the registry's vision and facilitate local training and motivation.

Subtheme 3.3: Pathology services

Pathology specimen types are coded upon arrival at the laboratory, after which the results are also coded once analysed. Participants mentioned how this practice differed across specimen types and laboratories, affecting the data quality. A participant indicated that coding precision would improve significantly once a cancer diagnosis was confirmed as accurate, coding was necessary for medical aid reimbursement, and added that the coding of diagnostic procedures would continue to be problematic unless there was a confirmed histological diagnosis. Another participant believed that the International Statistical Classification of Diseases and Related Health Problems codes (10th Revision) (ICD-10) are used infrequently in the public sector.

Theme 4: Barriers to registry implementation (See Table VI)

Subtheme 4.1: Time constraints

Lack of time was identified as a major problem, especially by participants invited to take part in the TCGSA audit, primarily due to the limited available time between clinical duties. The reasons for non-participation included feelings of isolation within their unit and a lack of administrative support. Most participants reported that an increased workload hinders participation in a registry.

Table V: Theme 3: The role of various stakeholders - illustrative quotes

Subtheme 3.1 Clinical practitioners

Clinical practitioner as data capturer

"The quality of the information is not clear, but luckily, because I was involved in most of the surgery, at least there is a bit of long-term memory, because the people come to the clinics." AnP1

"You can do the operative stuff, and then a week later, you can capture the outcomes, complications." AP3

"I think the best moment in time to capture data is just after the operation is done, when the surgeon sits down to do the operation notes. That's when they write down, and that's when they have a little bit of time before the next case is on the table." AP3

Attitudes towards change

"Surgeons having to learn a system that they are unfamiliar with, has been a major stumbling block." S3

"You need to direct your thoughts very intensively at change management, because that's going to be the key. If you design your platform and everything, it's okay. But even if it's a very simple platform of 10 data points, if you can't get people to fill it out, it's not going to happen." AP3

Clinician motivation

"I can't just do it. I need to collect certain things for certain aims. Like I must have an idea why I'm collecting all of this, otherwise it's just a troublesome collection of data." AP6

"Do not expect early buy-in as it takes about five years before a new registry starts to gain significant momentum. It does grow eventually and gain the momentum though! " S3

"Anything that comes to data recording and all that, there are also some challenges. It takes some people willingness to be part of it and participate. And obviously, it will take some time, which is sometimes a bit of a problem." AP8

"You need the clinician to supply that to you, and sometimes the clinicians are like yes, I'll send you the stuff, but they don't. So, in the end, it does come down to someone then needing to phone the patient and saying, did you have chemotherapy or not, or what happened with this?" AnP2

"The problem is people take shortcuts all the time. So then even something as simple as an ID number, they will not go look for it. They will just go to the default. You would be so disappointed if you see how disinterested clinicians are about this." ExP1

Subtheme 3.2 Registry managers

Collaboration

"It's got the support of the whole community. We spent a few years on it before we actually managed to get a countrywide round of data collection, and we published our first report." ExP4

Data ownership

"So big fights about to whom does it belong, and I think that thing of if you contribute something, I think one publication was in jeopardy because the one person said, because I've contributed patients to this, I need to be a co-author, for example." AnP2

Succession

"You've got one person that's been driving something very well and been keeping the ropes tight, and once that person now retires, the question is what's going to happen to that database after that. " AnP2

Communication

"Yes, we did get the [ethics] approval. I think somewhere along the line, our communications got lost because I had said to you, we've got approval, and so [to whom it was assigned] was waiting for approval. I think [they] did register on REDCap, or didn't [they]? " AnP3

"The steering committee has hosted various interventions; the annual xxx congress and any sub-speciality meetings are usually targeted to host 'roadshows' to showcase the registry and how it operates." S3

"Assign registry champions at every clinical site to ensure ongoing registry use, facilitate quality control, and ensure staff training." S3

Subtheme 3.3 Pathology services

Obtaining thyroid specimen data

"But the problem with the NHLS and the government samples is none of them get ICD-10 codes. So, you would have to figure out another way of pulling those, because they don't need ICD-10 codes. So that would be an issue. It would be relatively easy in private to do it on the ICD-10 codes. In the state sector, the coding is almost non-existent." AP4

Coding the specimen

"Yes, it actually was quite simple to draw all thyroid cases, but that was dependent on a tissue code that we put in. In logging cytology specimens, they usually just use a broad code, and they don't use the thyroid code. So, you have to then go back to the ID number of the patient and then go back and find the cytology for that patient. So that was the main difficulty with regards to linking the cytology and the histology." AP4

"The logging people [codes the specimen], they're not medically trained. So, they will look at a request form like this, and they will see colon. So, they will code something with colon. The request forms don't always say thyroid on them. They say nodule left lobe of something, and maybe a drawing, but the logging person won't know. So, with cytology, there's even less information usually on the request form. There's generally a generic-like cytology code, that gets inserted sometimes. Sometimes not." AP4

Coding the diagnosis

"We're forced to use accurate, or as accurate as possible ICD-10 codes, especially with cancer, because the medical aids will not pay for the patient's therapy or surgery or radiology if the ICD-10 isn't correct. So you wouldn't be using tissue codes anymore. You would be using ICD-10 codes. ICD-10 codes, retrospectively, it was easier for us to just go thyroid, find a tissue code and get all of those, than to go each separate ICD-10 code, because there are quite a few of them." AP4

ID - identity document, REDCap - Research Eletronic Data Capture, ICD-10 - International Statistical Classification of Diseases and Related Health Problems (10th Revision), NHLS - National Health Laboratory Service

Table VI: Theme 4: Barriers to registry implementation - illustrative quotes

Subtheme 4.1 Time constraints
"They gave me some of the patients' information, but then it was a struggle: getting the histology from the lab, and then I realised no one was going to help me. I just ran out of time, basically." AnP4
"So, I think the biggest issue obviously is time. So, in a private practice, I have to run a business. So I have employees, I have to be a manager, and I have clinical workload, and I don't have anyone that shares that clinical workload… If I don't do clinical work, I don't earn money." AnP2
"I think clinical workload is the biggest challenge, in my practice. I have an exceedingly busy practice that has a huge workload. If I had people to help me, or let's say electronic systems were automated systems to collect the data, I would be very happy. I would encourage that data to be collected." AnP2
"That is because, I mean, we all have admin to do. But the private sector is very heavy on administrative duties. I had a half-day list today, and I've got a full page of admin from my receptionist that will take me till eight o'clock tonight, at least." AnP2
"The only reason that the database in the UK worked is that it was registrar-driven, and every consultant, after every operation, told the registrar, there's the computer, enter the patient." AP9
Subtheme 4.2 Infrastructure and resource constraints
"So, what happens is we call private companies to set up the databases, and on two or three occasions they have crashed. My experience with the databases? You need people to do the upkeep and if it's not there, then every few years, everything crashes." AnP1
"We struggle a lot with theatre time, and we've had a lot of challenges with our infrastructure and not having linen, and not having water. It's lots."AnP4
'Funding of registries is a global problem." S3
'The funding is a problem for us." ExP4
"People have very different resources, which also comes into – sorry, just to mention back, cytology. You've got cytology here that works. In all my years at [Hospital name], I think I only had two papillary cancers that were identified on FNAB."AP7
"Funding is problematic, but the registries that are funded by the surgeons and not by the industry are the successful registries." S3
Subtheme 4.3 Ethics board approval
"The existing research frameworks are limited to small studies. It is very difficult to get clear guidance from ethics committees based in single institutions for national registries." S3
"We've seen it now with the consent for the [TCGSA] study. Once another university wants data … there is some reluctance of supplying it. So, you need to somehow overcome this, I think. I mean, our consent process took so long, and I was always asked, what happens to the data. People were calling us… The problem was the internal processes at the universities take a long time, and there is also a bit of reluctance; now, what is [University name] doing with [University name] data, and is it safe? I think that must be addressed. So, if you have an independent data system … it's probably better." AnP1

UK - United Kingdom, FNAB - fine needle aspiration biopsy, TCGSA - Thyroid Cancer Group of South Africa

Subtheme 4.2: Infrastructure and resource constraints

Some participants voiced their concerns about the technical reliability and sustainability of systems they had used in the past. Many interviewees described limited financial and other resources as barriers to registry participation. Participants identified other constraints, such as a lack of water and clean linen in hospitals, and technological challenges, including issues with computer systems and internet connectivity. One view expressed was that surgeon-funded registries were more successful than industry-funded registries.

Subtheme 4.3: Ethics board approval

Multisite ethical approval was identified as a barrier to national research. Obtaining multisite ethics committee approval for the retrospective research proved challenging, contributing to some sites opting out of the TCGSA audit. Updated guidance from ethics committees regarding individual institutions approving national registries was suggested.

Discussion

Establishing a national thyroid registry in SA is complex due to health inequalities, varying clinical practices, availability of specialist services between the public and private sectors, and rural and urban locations. Patients often rely on small government grants and struggle to afford childcare, transport to a hospital, or maintain a reliable contact number. A study of 27 490 people in Gauteng Province showed that income and place of residence did not affect healthcare access, whereas quality of healthcare, employment status, medical insurance, and immigration status did.[23] Another study showed that only 86% of South Africans have access to emergency surgical care within two hours, emphasising the need for equitable surgical access.[24] Additionally, the reported geographical variability in thyroid cancer subtypes further supports the development of an adaptable registry.[8]

This study revealed non-standardised US and FNAB reporting in some SA practices, affecting clinical decision-making. In the TCGSA audit, only 19.6% of US adhered to American College of Radiology, Thyroid Imaging Reporting and Data System (ACR TI-RADS) reporting, confirming our findings.[8] Promoting clinician-performed US can improve access to US-guided FNAB for thyroid nodules. Following the ACR TI-RADS improves diagnostic accuracy and reduces unnecessary biopsies.[25-27] TBSRTC improves communication between pathologists and clinicians, preventing unnecessary surgery.[8,28]

All participants unanimously supported the principle of a registry, recognising its scientific value and role in improving patient care. This aligns with others who noted the clinical benefit of tracking patients across disciplines and centres, saving time and enhancing the quality of care.[29] The African Perioperative Research Group (APORG) identified the creation of a minimum dataset surgical registry among the top ten priorities to reduce perioperative mortality risks.[30]

Barriers and facilitators to registry implementation varied across health systems and regions. Lazem identified the most critical barriers to maintaining a patient registry as inadequate budgets, poor manager performance, low data quality, and low stakeholder interest.[31] The clinician's commitment to adding data to the registry was seen as one of the biggest potential challenges.[31] Participants in this study shared that other factors, such as technical and infrastructure challenges and financial and resource constraints, can influence clinicians' lack of motivation. Clinical group demonstrations can significantly increase registry involvement.[7] Our findings concurred that insufficient financial resources and registry setup difficulties, such as data management and technological constraints, are more common in developing countries.[31] Strategies for improvement include carefully designing an online system, establishing clear data definitions, user guides, real-time chat support, and co-opting junior doctors to enter patient information.[2,32] Our study participants, from both the public and private health sectors, identified insufficient time as the most significant barrier. Other studies, including those from HICs, have recognised insufficient time and increased workload as barriers.[31-33] Funding could help employ data collectors and registry managers to address this time constraint.

A pertinent barrier identified in this study, from both the public and private sectors, is the fragmentation of data sources. Most clinicians mentioned that they do not always have access to past clinical notes, although some have more efficient paper or electronic systems. No participant had access to a unified system integrating radiology, pathology, and nuclear medicine imaging. The TCGSA study also faced significant delays because clinicians needed to gather information from multiple sources for data entry.[8] Participants suggested a registry as a potential platform for storing patient information and serving as a clinical note-keeping system. A unified platform can provide knowledge on outcomes, track patients across departments and healthcare facilities, save clinician time and strengthen the healthcare system.[34-36]

Ethics board approval is essential for registry research. Multi-institutional approval poses a significant barrier, preventing some interviewees from participating in the TCGSA study due to a lack of institutional ethics approval. This challenge is also noted in Lazem's systematic review.[31] In SA, exploring national registry ethics approval is necessary, focusing on standardising multi-institutional ethics applications, with guidance from the National Health Research Ethics Council (NHREC).

Given the varying practices and workflows nationally, a one-size-fits-all approach to data entry may not be feasible. The registry should accommodate diverse data input methods, with each site tailoring its procedures based on internal systems, staffing, and workflows. To ensure accurate data collection, customisation is necessary to allow for local variations while meeting overall objectives. The suggested registry champion at each site could assist in streamlining this process.

Strengths and limitations

Various stakeholders are involved in clinical registries, each with distinct influences on and objectives for the registry. Although patient participation in registries is often promoted in the literature, this was not mentioned by any interviewee. In addition, several stakeholders, including policymakers and hospital managers, were also not included. Further exploration should seek their respective input. The PI's positionality as a colleague in endocrine surgery may have influenced responses.

Conclusions

Establishing a national thyroid registry in SA requires adaptability to unique challenges across practices, systems and provinces. The principle of a registry was strongly supported by clinician stakeholders, appreciating the clinical and scientific value. Additionally, constituting the registry as a clinical note-keeping system would save clinicians' time. Standardising radiology and pathology reporting on a single uniform platform would improve patient care and data entry. The benefits of a registry outweigh the challenges, aiding in local guideline development, enhancing patient outcomes and promoting collaborative research among endocrine clinicians.

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Conflict of interest

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Ethical approval

This study was approved by the Health Research Ethics Committee of the Stellenbosch University (S23/05/115).

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Addendum A: Surveys

GROUP 1-2:

What do you do? (general surgeon, ENT surgeon, endocrine surgeon, pathologist, medical student, medical officer, intern, other)
Where do you work? (Please feel free to omit this field if you prefer)
How many thyroid procedures are performed/evaluated by your unit/lab per year? (0–10/10–20/20–50/ 50–100/ > 100)
How many thyroid procedures do you personally perform/evaluate per year? (0–10/10–20/20–50/ 50–100/ > 100)
Did you take part in the retrospective audit on thyroid cancer in SA? Yes/No

If Yes = Group 1:
What has been your experience with data collection and data entry of the retrospective audit?
How many patients did you enter?
What has been your previous involvement in patient registries?

If No = Group 2:
You were part of the discussions around this audit, but eventually did not complete the process up to completion of data collection.
What were the reasons or what limited you to take part in the retrospective audit?

Thyroid surgery registry (focusing on thyroid cancer). For everyone to complete please.

Would you like to be involved in setting up a prospective thyroid surgery registry with a focus on thyroid cancer?

If Yes: Involvement
In what capacity would you like to be involved?
What will you be able to contribute to the registry in terms of skills, resources, source of funding or experience?

Feasibility of the Registry
How do you think a thyroid registry can be funded?
What barriers will prevent you from entering each patient into a surgical thyroid registry?
Are you available for an in-person interview with the principal investigator to discuss a surgical thyroid registry in more detail? (Yes, No, Maybe)
If you agree, you will be contacted and the principal investigator will visit you at a place of your convenience and this will take up about 15 mins of your time.

GROUP 3:

What do you do? (specialist physician, specialist surgeon, researcher, administrative support medical officer, pathologist, other)
What registry are you involved with?
How are you involved in this registry and what is your role?
What is the aim of the registry?
How long has the registry been in existence?
Who was involved with the formation of the registry, and how did it start?

Technicalities day-to-day functioning of the registry
How is the registry funded?
What IT infrastructure/software do you use? Who is responsible for maintaining the registry?
What process is followed for informed patient consent?
Who has access to the data, and how is this controlled?
Is the registry data validated, and if so, how?
Do you compile annual reports? Yes, No

Experience
What are the main issues you have encountered in your work related to disease registries so far? Can you give some detail about the barriers as well as the facilitators you have experienced?
What advice can you give a team starting up a new surgical registry?

Addendum B: Interview prompts

GROUP 1:

1. What has been your experience with the data collection and entry of the retrospective audit?
2. What has been your experience with other disease registry systems?
3. What are your thoughts on a prospective thyroid surgery registry? In your opinion, what will the challenges be in setting up and maintaining such a registry?
4. Can you help me understand the data collection process you will have to follow to be part of such a registry?
5. What has been making the data collection process difficult for you, and can you share some examples?
6. Are there any positive experiences with registries that you would like to share?
7. Will a thyroid surgery registry contribute to your day-to-day practice? If yes, why and how? If no, why not?

GROUP 2:

1. Can you explain to me what prevented you from taking part in the retrospective audit, and use some examples?
2. What has been your experience with other disease registry systems?
3. What are your thoughts on a prospective thyroid surgery registry?
4. Can you help me understand the data collection process you will have to follow to be part of such a registry?
5. Will a thyroid surgery registry contribute to your day-to-day practice? If yes, why and how? If no, why not?
6. Are there any positive experiences with registries that you would like to share?

GROUP 3:

1. Which infrastructure platform, in your opinion, should be used for data collection? Why?
   a. How does or how should the data collection process flow?
   b. Should this registry include private hospitals, or only academic institutions to promote research?
   c. Do you think it is valuable for the registry to be established by a society, and what are the advantages or disadvantages of this?
2. Can you explain the day-to-day processes of the registry?
3. What would you have done differently with what you know now?
4. What advice can you give a team starting up a new surgical registry?