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ENDOCRINE SURGERY

Twelve tips for setting up a national registry in South Africa: Principles and practice

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Background: Patient- and disease-specific registries provide valuable real-world data and often demonstrate greater generalisability compared to randomised controlled trials. A national thyroid surgery registry in South Africa (SA) can promote collaboration among surgeons nationwide, guide resource allocation, inform local guidelines, improve the quality of care, and support research. Although numerous global guidelines exist on creating and implementing disease registries, there is a paucity of data from SA. This study aimed to explore the perspectives and experiences of stakeholders to establish a national thyroid registry.
Methods: A qualitative study incorporated a survey and semi-structured interviews. Study groups included clinicians who (1) were recently involved in the Thyroid Cancer Group of SA (TCGSA) audit, (2) initially expressed interest in the TCGSA audit but could not participate, and (3) individuals who were involved in existing patient registries in SA. Participant perceptions and experiences with registries were discussed, and thematic analysis was performed on the transcribed data.
Results: Twelve practical recommendations were synthesised based on the participants' perspectives. The twelve tips emphasise establishing independent, well-governed, and accessible registries that clearly communicate their goals, encourage clinician use, ensure confidentiality, provide support, and promote simplicity and incentives to drive effective participation. This study is unique as the tips provided are based on stakeholder surveys and interviews, rather than relying solely on a literature review.
Conclusion: Our findings reflect South African realities, including clinicians' attitudes and administrative gaps, as well as experience-based tips. These stakeholder-informed, SA-specific recommendations can be adapted for use in other surgical disciplines aiming to establish a registry.

Keywords: national registry, disease-specific registry, framework, stakeholder input, South Africa

Background

Patient and disease-specific registries offer valuable real-world data and typically demonstrate greater generalisability compared to randomised controlled trials. Establishing a national thyroid surgery registry in South Africa (SA) can encourage collaboration among surgeons across the country, guide resource allocation, inform local guidelines, enhance quality of care, and facilitate research.

Poor data entry rates are major barriers to the success of patient registries.[1] Clinician and surgeon time constraints, along with increased administrative burdens in resource-scarce environments, pose significant challenges.[2] Duplication of note-taking and separating data entry from existing medical record keeping further complicates the process.[3] Funding to establish and maintain the registry, as well as a lack of stakeholder buy-in, have been identified as further barriers.[1] Improving participation in a national patient registry could involve raising awareness at conferences and publishing on optimal design and implementation.[2]

The guidelines put forth by Gliklich et al., published by the Agency for Healthcare Research and Quality (AHRQ), titled "Registries for Evaluating Patient Outcomes: A User's Guide", are among the most detailed and widely referenced for developing patient outcome registries, focusing on research methods, data quality, and transparency.[3] Many international guidelines exist for disease- or surgery-specific registries covering broad principles such as governance, sustainability, data quality, consent, information technology (IT), and stakeholder engagement.[2-6] However, the literature on establishing national registries in low- and middle-income countries (LMICs), especially in Africa, is limited, often describing barriers such as funding, staffing, and IT.[7-10] There are very few practical, tip-style frameworks that are directly drawn from stakeholders in an LMIC. When planning a surgical registry, it is essential to incorporate the views of clinician stakeholders and those with experience in registry establishment. This study sought to provide practical tips for establishing a national thyroid cancer registry.

Methods

The Thyroid Cancer Group of SA (TCGSA) collected data on 464 patients who underwent surgery for thyroid cancer across five provinces and 13 centres between 2015 and 2019.[11] The process was extensive, and multiple challenges were encountered, leading to valuable lessons. The study, its findings, and the discussions surrounding these challenges led to a qualitative study exploring stakeholder engagement towards establishing a national thyroid cancer registry in SA. The study primarily focused on input from the surgical community, as the emphasis was on patients undergoing surgery.

Qualitative research involves collecting, organising, and interpreting textual data through observation, interviews, focus groups or surveys, with insights filtered through the researcher's lens. This kind of research is approached systematically and meticulously, yet remains fluid and exploratory depending on the context.[12] This study included a survey and semi-structured interviews. Study groups included clinicians who were recently involved in the TCGSA audit (AP- audit participant),[11] clinicians who initially expressed interest in the TCGSA audit but could not participate (AnP- audit non-participant), and lastly, individuals involved in existing patient registries in SA (ExP – experienced participant). Data from face-to-face interviews were transcribed and thematically analysed,[13] and from this, twelve practical recommendations were synthesised, supported by illustrative quotes (Supplementary Table).

Results and discussion: Tips

Tip 1: Establish registry independence as a foundational principle

A registry should operate independently of any third party, and registry members should retain full autonomy over decision-making and data access. This can ensure that hospitals and units are not excluded based on internal politics. During the TCGSA audit, some groups questioned why data should be sent to a specific university platform and expressed distrust of the underlying motives. Therefore, individuals from all regions in the country should be included in the team leading the registry, and the IT hosting of the data should be independent from any university and health system administration. Involvement of the whole community is essential for registry success. Housing the registry custodianship under a relevant national society was considered. In 2023, a group of endocrine surgeons deliberated and established the Endocrine Surgeons of South Africa (ESSA), a registered non-profit organisation. A registry steering committee, representative across SA and including the public and private sectors, was appointed with the vision and mission of designing and implementing a surgical thyroid registry, which will be hosted within the independent society.

Tip 2: Communicate aims, objectives and clear definitions from the outset

The successful implementation of a registry requires clearly defining its aims, objectives, and scope.[5,14,15] Participants suggested including all thyroid surgeries in the registry due to the high rate of diagnostic thyroidectomies and that thyroid cancer diagnosis is often made postoperatively on final histology. It was also noted that focusing and designing the registry around a clear scope is more effective than including multiple subspecialties within a single registry. However, a concern was raised that such specialisation might result in data being submitted only by specialised units.

Participants emphasised the importance of measurable, sustainable objectives and clear engagement strategies. One participant noted that if they did not understand the purpose of data collection, they would be less likely to contribute data. In the TCGSA, the definitions of some variables were not clearly communicated. Standard definitions for variables, such as operation type and whether repeat surgery was performed, were needed. This lack of clarity was evident in the results of the TCGSA study and reflected in the interviews with TCGSA participants. Consistent communication and motivation were suggested as ways to enhance contributions, based on the views of experienced participants.

An experienced participant emphasised that the primary value of their registry lay in advocating for resources by quantifying access disparities. The advocacy role, influencing the National Department of Health (NDoH) budgets, provincial resource allocations, and access to specialised care, is rarely highlighted in the literature and vital in SA.[14]

Tip 3: Offer adaptable registry procedures

During the interviews, it became clear that a patient registry needs various types of input to enable nationwide adoption. This is due to differences in clinical note-keeping systems and stakeholder priorities. Although many expressed positive attitudes towards establishing a registry, an experienced participant cautioned that there would not be immediate buy-in and that setting up a successful registry takes time. Significant variation exists in data processes across provinces, hospitals and sectors, making a uniform system impractical. Some centres rely on paper-based systems, others use electronic systems, and many operate with a hybrid system. Additionally, inconsistent internet access and the availability of digital records should be taken into account when designing data collection procedures.

A national registry requires flexibility to accommodate these differences. Key insights from study participants indicated that tailored pathology request forms with specific clinical fields could improve accuracy and linkage between cytology and histology results. Allowing provisional entries that could be completed later, enabling the uploading of PDFs or photos, and considering the use of data collectors or web-based systems might enhance participation. Incorporating follow-up data, such as post-thyroidectomy calcium and parathyroid hormone levels, along with long-term cancer outcomes, should be prioritised. Using paper tick-sheets, electronic entry, and delegating data-capturing responsibilities as part of daily routines could promote consistency. Strategies such as clinician reminders, repeated data cleaning, funding data collectors and marking cases lost to follow-up might address missing data. Overall, data collection methods must remain robustly adaptable to the infrastructure and needs of each site.

Tip 4: Institute clear-cut data governance principles

Data access and ownership were a significant point of discussion. All agreed that sites should have access to their data without any formal data application process. Some individuals require immediate access to data, as they intend to use it as a clinical note-keeping system. However, immediate access was not always a priority. All agreed that the logging surgeon should own the data, as it is clinical information from their patients. When data from other sites is requested, an application should be made to the registry steering committee. Although most participants felt satisfied with anonymised data being made available after application, which would include an ethics-approved protocol, some participants felt that only registry contributors should be eligible to apply for data access. Others believed that if all could apply, collaboration would be promoted, and they would be motivated to contribute.

Tip 5: Use the registry as a clinical tool

Suggestions to enhance data collection included aligning the data collection tool with clinician service delivery and preventing duplication of processes. Many participants suggested that the registry should not be an additional step but rather integrated into the clinical workflow. A suggestion was that the registry should double as a clinical documentation tool, offering a formatted operation note after data entry. The registry could also add value in providing International Classification of Diseases (ICD) and procedure codes to support the clinical workflow. As an explicit design requirement, the registry should offer output as a PDF or a summary, acceptable as the official operation note or clinic documentation. The registry should serve as the primary entry point for documentation in contexts where health record systems are fragmented.

Tip 6: Ensure consent and confidentiality

Evolving regulations related to patient privacy present a challenge for registries, limiting the ability to share data across centres and countries for evaluating rare diseases.[16-18] The most recent legislation in SA, the Protection of Personal Information (POPI) Act, requires researchers to implement practices that protect individualised information while enabling data sharing.[19] Since identifiable data is essential for tracking patients across departments, hospitals and provinces, as well as measuring outcomes, compliance with guidelines is crucial. Patient follow-up and, therefore, clinical care were improved when patient contact details were available in established registries.

The 2024 NDoH Research Guidelines mandate voluntary informed consent for the processing of personal information under the POPI Act.[19,20] To minimise adding to clinical workload, patient-informed consent for registry participation could be incorporated into the surgical consent process and collected by the operating clinician in paper format or through secure electronic platforms. It is important to ensure that the consent process is clear, as patients may not fully understand what they are consenting to.

To facilitate researcher access to data, a formal application process should be established, including the submission of a research proposal approved by the ethics committee. Appointing a data custodian, obtaining individual ethics approval, and releasing only de-identified data are essential measures. Additionally, secure data storage must be maintained to address concerns regarding confidentiality.

Tip 7: Empower local champions to address resistance to change

Often, more emphasis is placed on developing systems and processes (technology-focused) than on addressing human interaction (people-focused) with the system.[15] An experienced participant highlighted that resistance to change is common.[21] To secure buy-in from all stakeholders, employing a change management process was recommended. The focus should be on influencing behavioural change to facilitate registry adoption, rather than developing a 'perfect registry'.

One of the major challenges to registry implementation identified was human resources, or the lack thereof. A registry champion at each site – someone who can drive the registry, communicate its vision and provide local training – was suggested by many experienced registry participants. Many participants noted a lack of administrative and secretarial support as a barrier to participation. Dedicated administrative staff could ease this burden. Securing sustainable staffing through funded positions for registry tasks could reduce reliance on individual motivation alone. Administrative and data capture support could improve clinician involvement, as clinicians are often willing to supply data but less likely to capture it themselves; systems should support this division of roles. Strong leadership is crucial for sustaining engagement and ensuring accountability. Collaborating with other registries can provide IT support and guidance, leveraging partnerships. The future role of artificial intelligence in assisting with data entry was another discussion point.

Tip 8: Ensure infrastructure is universally accessible

Many stakeholders see IT solutions as the key to success, but several barriers remain. These include poor interoperability between registries and source data, balancing record completeness with user burden, and challenges with long-term follow-up, especially when patients are treated at multiple centres.[2,17] Suitable software infrastructure should adhere to FAIR principles – making data Findable, Accessible, Interoperable and Reusable.[22] Electronic devices are vital for registry operations, but availability varies across SA. Some public hospitals lack computers and/or reliable internet, creating data-capturing and connectivity issues. While some teams suggest supplying tablets for real-time data entry, others rely on personal devices, stressing that funding is needed for replacements to keep systems operational.

The choice of software platform is a common consideration and is often debated in registry discussions. When selecting software platforms, accessibility, user-friendliness, affordability, independence, and multi-user support must be prioritised. Options range from free tools (e.g., Google Forms) to costly specialised systems. REDCap (Research Electronic Data Capture) [23] was frequently highlighted as a preferred platform, valued for its security and widespread use, though some found institutional access difficult and the interface less appealing. To encourage uptake, the platform should be stable, simple to use, and supported by practical features such as a manual backup system, duplicate-entry alerts and a quick tick-sheet for mobile use. Consistency across centres is important, and using one shared platform will help standardise data entry. A unified registry platform across disciplines could streamline the workflow for general surgeons who need to record patient data in multiple registries. By using a single system, surgeons would avoid the inefficiency of repeatedly logging into separate platforms.

Tip 9: Tie participation to professional incentives

A suggested approach to improve adoption was to incentivise data contribution. Proposed incentives ranged from monetary rewards to offering surgical status (i.e., based on the annual contribution of cases) and recognition as a contributor in reports or publications. However, it was mentioned that acknowledgement and co-authorship had previously led to conflicts. A suggested strategy to prevent disputes was to circulate the draft manuscript among all key contributors for input and approval. Interestingly, a participant highlighted that an existing registry in SA recognises surgeons who enter more than six patients annually. Others mentioned that co-authorship should depend on active input into the manuscript, not just data entry. One seasoned participant proposed a 'disincentive' rather than an incentive, as in their experience, monetary rewards alone were insufficient motivation for clinicians. Earning Continuing Professional Development (CPD) points could be a possible strategy to recruit contributors.

Tip 10: Facilitate structured reporting across disciplines

Laboratory coding practices were identified as a hidden barrier to registry implementation and could, in part, explain findings in previous national research on thyroid cytology.[24] During the TCGSA study, it was observed that thyroid cytology and ultrasound reports varied significantly and were not consistently standardised according to the reporting guidelines (i.e., Bethesda and ACR-TIRADS).[25,26] To promote standardisation, one participant proposed synoptic reporting for thyroid histology specimens. Developing a minimum dataset for thyroid pathology reporting was also considered. To enhance data quality, the reporting of diagnostic investigations, such as thyroid ultrasound and cytology, should be standardised. This would also help improve the healthcare system overall, as standardised reporting was mentioned as a potential role of a national registry. Concrete SA-specific integration with existing laboratory and radiology reporting systems should be considered where key elements are auto-populated according to a defined structure. Specimen coding practices should be addressed nationally. The registry has the potential to enhance standardised reporting at a national level and to clarify which dataset elements are uniquely important locally, even if they are not widely applicable in other countries.

Tip 11: Provide robust registry support structures

A registry should be financially sustainable, as many have experienced irregular and insufficient funding as major challenges to registry success. Some cynicism was voiced regarding financial gains within registries, suggesting that companies commonly expect financial returns before investing in registries. One participant mentioned that registries funded by surgeons, compared with industry-funded registries, are more successful. Suggested funding sources included the NDoH, research grant funding, the ethical sale of data, and sponsorship from pharmaceutical companies. Funds should be utilised for, amongst others, data collection and data cleaning, and sourcing funding for this was seen as vital.

Time constraints due to clinical duties and administrative tasks were viewed as a major obstacle. Clinicians who did not participate in the retrospective audit expressed particular concern about this. Reasons for non-participation included working alone in their unit and the lack of administrative support. It was perceived that increasing workload would specifically hinder participation. In addition to unit-based clerks that capture data, piloting a 'roving coordinator' model that conducts annual snapshots at participating hospitals by pulling files and validating data should be considered.[27] Such a model could address issues related to missing notes, paper folders, and variable IT.

Tip 12: Keep it simple

Too many variables at the time of data capture increase workload and discourage participation. Stakeholders emphasised limiting the dataset to critical clinical fields. Amongst the experienced participants, the importance of creating a smooth process before opening the registry to contributors was emphasised. They believed that if an individual struggles once, they will not try again and could be lost to the process forever. Some participants from the experienced group mentioned they had started with a large dataset, which is not advisable. As they attempted to improve buy-in over time, they refined their registry, resulting in a decrease in the number of variables. The suggestion is to use a lean dataset, as this will likely increase the chances of participation. The participants involved in the TCGSA also stated that the number of data points collected was troublesome, which may have contributed to the amount of missing data. A two-tiered system is proposed, with a core minimum dataset for routine capture (e.g., demographics, key diagnostics, procedures, complications, and essential pathology), and additional plug-in modules for sub-studies or a clinical note-keeping system.

Limitations

Surgeons were the only stakeholders treating thyroid cancer included in this study, as their role as the first contact with patients undergoing thyroid surgery positions them as crucial role players in this context. Future endeavours should include the perspectives of clinical administrative personnel, non-surgical colleagues, and patients.

Conclusions

Existing literature on surgical registries emphasises broad principles. These international best-practice guidelines provide a useful foundation but are often based on high-income contexts with well-resourced health systems. Our findings provide context-specific lessons from SA, including the importance of appointing registry "champions", tailoring data processes to local resources, addressing administrative gaps, and motivating clinicians through incentives such as recognition. Unlike purely literature-based tips, our insights are derived from stakeholder interviews, surveys, and audit data, capturing local attitudes, practical challenges, and possible solutions. These proposed recommendations can be adapted for use in other surgical disciplines and similar settings.

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Conflict of interest

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Ethical approval

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

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