

Establishing and integrating datasets beyond instilling a culture of capture

SR Thomson,¹ DL Clarke²

¹ Division of Gastroenterology, University of Cape Town, South Africa

² Metropolitan Department of Surgery Pietermaritzburg, and the Universities of KwaZulu-Natal and the Witswatersrand, South Africa

Corresponding author, email: sandie.thomson@uct.ac.za

Whilst the double-blind, randomised clinical trial has established itself at the apex of the evidence pyramid for modern medicine, surgical research has always suffered from a degree of epistemological elitism and snobbery by the medical disciplines.¹ This is because the majority of surgical progress has been made as a result of the lowly surgical audit rather than the double-blind, randomised control trial (RCT). This is unfair as the benefits of clinical audit in surgery are manifest. Ambrose Pare was an early example of a surgeon who, out of necessity, applied his mind and came up with a pragmatic but radical solution to a pressing clinical problem. During the interminable internecine wars of the Renaissance period, he began to apply linen dressings to wounds rather than cautery, and so changed the practice of surgery for the better.² The same can be said of Semmelweis, an early adopter of surgical asepsis, at a time when the germ theory was still not conceived. Without any theory to support his praxis, he advocated hand washing for medical students returning from their morning post-mortem session, before beginning work in the maternity wards. His simple intervention radically reduced hospital-related maternal mortality rates. Semmelweis paid a heavy professional price for his radical disruption of vested interests. He was driven from Vienna and ended his days working far from the major hospitals of Vienna. He is posthumously referred to as the Saviour of the Mother.³

The basis of both these breakthroughs was the ability to observe an external reality and record it. Once this had been done, information was internalised. The surgeons involved then processed this data and generated a theory. This theory was then applied, and the outcomes recorded to establish a degree of validity. The basis of this very Aristotelean approach to knowledge was surgical audit. Its value is increasingly recognised as it provides real-world data in a longitudinal manner and in specific settings outdoes the RCT as a tool to improve clinical practice and inform health policy.⁴

As modern surgeons, we inhabit a world vastly different to that of Pare and Semmelweis. We have new and rapidly advancing technology and a massive body of basic science to support our ongoing attempts to solve complex surgical problems. The modern world provides us with new tools to augment and support surgical audit. The internet, smartphones, apps, and modern computing allow us to expand our ability to capture and analyse data. The last decade has seen the development of several electronic surgical databases or registries in South Africa. These take

many forms using a variety of university, commercial, or individually designed software and platforms. Many of these have been driven by enthusiastic individuals for research purposes in specific diseases or specialist disciplines, but few are integrated into the hospital informatics system as part of comprehensive electronic health record (EHR) for patient management and research. In this issue, there are perspectives on how three different systems have been independently developed in the Pietermaritzburg, Worcester and George hospitals.⁵⁻⁷ Some common themes emerge from the authors. Foremost, frustration that under-invested hospital informatics systems are not up to the task of providing a comprehensive discipline-specific health record that is clinically relevant. Data capture should be at the point of contact, and information should be focused on capturing continuous variables and fixed categorical information that are best served by drop-down menus only a click away. Narrative text should be limited. These efforts have undoubtedly improved clinical care in their respective institutions, provided useful information to guide health policy, and generated numerous publications and higher degrees. We believe that researchers and the country as a whole need to encourage the formation and integration of these individual databases, as does the Program in Global Surgery and Social Change, and the National Digital Health Strategy for South Africa 2019–2024.^{8,9}

Currently, there are many international efforts to generate large multi-national data sets.^{5,6} Often, these are developed by collaborative groups trying to provide a global perspective on a number of disparate topics. These include cancer care, paediatric surgical outcomes, and postoperative outcomes in general. Usually, these projects involve data collection from multiple sites, for a short period of time, ranging from a week to three months. Whilst these collaborative efforts are impressive and have produced high-quality publications, they are by definition limited and can only provide a snapshot view of a particular pathology.^{10,11} These projects help identify discrepancies in care and outcome between rich and poor countries. As such, they can provide a static gap analysis that can stimulate efforts to address such discrepancies. However, without a database which continues to function, any future review of the same pathology will necessitate a repeat multicentre effort to capture data. It is far better to have an ongoing data collection system which routinely collects data on the pathology under consideration. These diverse local systems which have been established

need to be integrated nationally, on the continent and internationally.

Internationally there are several ways of achieving this so-called merging of disparate data sets. This can be done using a data dictionary which records the individual datasets documented in each database. Using a data dictionary allows researchers to merge separate datasets and mine them. Currently, the Pietermaritzburg group are involved in a multicentre project with Australian researchers, merging three disparate data sets with the intention of comparing outcomes for blunt trauma between KZN and Queensland. This project will allow the identification of differences in patient load and outcome. In the UK, the National Cancer Registration Dataset in England is an excellent example of merged datasets and their analysis. The framework on how to make a start with merged datasets is described in their data resource profile article.¹²

On the African front, there have been several initiatives to establish national electronic health records systems.^{13,14} In South Africa, there is a systematic review of 15 studies in Africa that highlighted many technical, social and environmental barriers to the implementation of electronic health records.¹⁵ They made several recommendations: develop context-relevant strategies, dedicated budgets and legislation to implement EHR, involve all stakeholders in the EHR development, improve internet infrastructure, and attract and retain health informatics professionals by incentivising their career pathway. These recommendations are similar to those detailed in the National Digital Health Strategy for South Africa and synthesised in Annexure 13. These recommendations are meant to be implemented by 2024, but it seems unlikely that this deadline will be met. In the meantime, we believe that existing databases of health care can be integrated and amalgamated. This should be part of the strategy that enables enthusiastic health care practitioners and researchers to continue their development and thus provide real-world data that can improve clinical care.

REFERENCES

1. Horton R. Surgical research or comic opera: questions, but few answers. *Lancet*. 1996;347(9007):984-85. [https://doi.org/10.1016/S0140-6736\(96\)90137-3](https://doi.org/10.1016/S0140-6736(96)90137-3).
2. Paré A. The workes of that famous chirurgion Ambroise Parey (translated out of Latin and compared with the French). Ambrose Parey; printed Richard Cotes and Willi Du-gard, Sold John Clarke. London; 1649.
3. Kadar N, Romero R, Papp Z. Ignaz Semmelweis: "The Savior of Mothers" On the 200th anniversary of his birth. *Am J Obstet Gynecol*. 2018;219(6):519-22. <https://doi.org/10.1016/j.ajog.2018.10.036>.
4. Sherman RE, Anderson SA, Dal Pan GJ, et al. Real-world evidence-what is it and what can it tell us. *N Engl J Med*. 2016;375(23):2293-97. <https://doi.org/10.1056/NEJMs1609216>.
5. Clarke DL. Reflections on the development of the Hybrid Electronic Medical Registry in Pietermaritzburg. *S Afr J Surg*. 2022;60(2):146-147. <https://doi.org/10.17159/2078-5151/SAJS3919>.
6. Duvenage R. A surgeon's journey into the world of IT: the medwebtools.com database. *S Afr J Surg*. 2022;60(2):148-149. <https://doi.org/10.17159/2078-5151/SAJS3915>.
7. Stark H. The George Hospital Theatre Documentation and Information System. *S Afr J Surg*. 2022;60(2):150-151. <https://doi.org/10.17159/2078-5151/SAJS3914>.
8. Meara JG, Leather AJM, Hagander L, et al. Global Surgery 2030: evidence and solutions for achieving health, welfare, and economic development. *Int J Obstet Anesth*. 2016;25:75-78. <https://doi.org/10.1016/j.ijoa.2015.09.006>.
9. National Department of Health. National Digital Health Strategy for South Africa 2019–2024. Available from: <https://www.health.gov.za/wp-content/uploads/2020/11/national-digital-strategy-for-south-africa-2019-2024-b.pdf>. Accessed 27 May 2022.
10. Zargaran E, Spence R, Adolph L, et al. Association between real-time electronic injury surveillance applications and clinical documentation and data acquisition in a South African trauma center. *JAMA Surg*. 2018;153(5):e180087. <https://doi.org/10.1001/jamasurg.2018.0087>.
11. Mason SE, Scott AJ, Markar SR, et al. Insights from a global snapshot of the change in elective colorectal practice due to the COVID-19 pandemic. *PLoS One*. 2020;15(10):e0240397. <https://doi.org/10.1371/journal.pone.0240397>.
12. Henson KE, Elliss-Brookes L, Coupland VH, et al. Data resource profile: National Cancer Registration Dataset in England. *Int J Epidemiol*. 2020;49(1):16-16h. <https://doi.org/10.1093/ije/dyz076>.
13. Iverson KR, Drown L, Bari S, et al. Surgical key performance indicators in Ethiopia's national health information system: Answering the call for global surgery data. *East Cent Afr J Surg*. 2021;26(3):92-103. <https://doi.org/10.4314/ecajs.v26i3.1>.
14. Muinga N, Magare S, Monda J, et al. Implementing an open source electronic health record system in Kenyan health care facilities: Case study. *JMIR Med Inform*. 2018;6(2):e22. <https://doi.org/10.2196/medinform.8403>.
15. Katurura MC, Cilliers L. Electronic health record system in the public health care sector of South Africa: A systematic literature review. *Afr J Prim Health Care Fam Med*. 2018;10(1):e1-8. <https://doi.org/10.4102/phcfm.v10i1.1746>.