

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

## Supplementary Table: Illustrative quotes in support of the twelve tips

### Tip 1: Establish registry independence as a foundational principle

“Once another university wants data, even within South Africa, there is some reluctance of supplying it... and I was always asked, what happens to the data... So, if you have an independent data system... It’s probably better.” AnP1

“Funding is problematic, but the registries that are funded by the surgeons and not by the industry are the successful registries.” S3

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

“So that’s something that I’ve looked at, but there, 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

“Emphasising the importance and the long-term outcomes to stakeholders is vital - people need to see the big picture to understand what the effort they put in now will accomplish in the long term (easier said than done!).” S3

### Tip 3: Offer adaptable registry procedures

“Yes, I think it will have to be mobile-friendly. We sometimes struggle with signal in theatre. This floor has... Wi-Fi, but they don’t have it downstairs. But I think that’s the main thing because you have to be able to sit in the clinic and look it up. Unfortunately, we don’t even have – there’s not even a single computer in the clinic.” AnP4

“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... So that’s the golden time... So, there’s a moment there, and I think if you have a reminder or somewhere for the person to trigger, I’ve just done the op note, now I’m quickly going to fill out the registry stuff, then that would be a good point to capture the patient’s presentation. Like we write that stuff anyway, their workup that they had, what operation was done.” AP3

### Tip 4: Institute clear-cut data governance principles

“If most of us work harder to join the registry and enter the patients and all the data, what will happen if somebody now wants to use the data and they haven’t raised a finger?” AP6

“Yes, if your unit contributes, but what if someone says I want to research thyroid nodules and the TIRADS correlation with cytology, or something like that, and it’s not someone who has been plugging the data in? Does it mean that they’re excluded? I don’t think so. I think that’s harsh. Look, the unit will obviously enter data, and anybody within that unit, or anybody from outside who requests permission to mine the data and has the necessary ethical clearance and the necessary approval, gatekeeper approvals, should be allowed access. That would be my feeling, so that you encourage rather than discourage people.” AnP3

### Tip 5: Use the registry as a clinical tool

“So, if they 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. So, then it will make it even easier for the people.” AnP2

“I also think that the big problem is a lot of people misunderstand registries. They think that registries are extra work. I think that’s 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

“Design the data collection system to be aligned with the service delivery platform and support health systems strengthening as an inherent part of the project in order to improve stakeholder support as well as improve quality of data.” S3

### Tip 6: Ensure consent and confidentiality

“It’s so difficult, because the thing is, you need to be practical... to do informed consent properly, it takes a few minutes. And you see what these clinics look like. You can’t like expect adding an extra let’s say five minutes, and that’s for someone who doesn’t have questions, and that is the minimum time.” Exp3

“They (clinicians) are worried about POPI, and they are worried about privacy and all those things.” Exp4

### Tip 7: Empower local champions to address resistance to change

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

“Strong, resolute leadership is vital, as there will be a multitude of opinions and criticism of anything new.” S3

### Tip 8: Ensure infrastructure is universally accessible

“The main thing is that it has to be something you can do quickly on your phone, because you know, a website that works on a mobile phone.” AnP4

“REDCap is useful. Its main use is, I think, you can capture different phases to a particular patient. It’s not in one snapshot. You can do the operative stuff, and then a week later, you can capture the outcomes, complications. So, it allows you to have multiple entries at different timepoints, linked to one individual through their code, or their record number. That is its strength.” AP3

### Tip 9: Tie participation to professional incentives

“They get listed as contributors to their data in their annual reports. There is a push from the community for them to do so, and everybody uses the data that we publish in our annual report for their planning and strategising. So, it’s in everybody’s interest to make the data as complete and as accurate as possible.” Exp4

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“That there rather should be a disincentive for not using it. A disincentive should have been our approach. I might still get to it, the funders, and say you should not reimburse this [operation] if it’s not logged. But then you need to give them something, they want the data or whatever. The robust registries in Europe, the Scandinavian one, they work on disincentives. You do not have a choice. There is no incentive to do it. There’s a disincentive for not doing it. So, you’re either not being credited, your hospital won’t be reimbursed, etc., etc. It shouldn’t actually be an optional thing.” ExP1

**Tip 10: Facilitate structured reporting across disciplines**

“It must be detailed in the form of, and I will tell you why. For instance, we get histological FNA. They don’t even say what Bethesda. They just tell you. When we get ultrasonography, they don’t report according to the TIRADS. We still have those things. If we say we want it to be strict tick, tick, you must tell us the Bethesda. It will fall along the cracks. But I think it must tell us, we need those details. This is the standard of reporting. So, it will force them as well.” AP2

“So, with colon, breast, lung, the big ones, everybody uses the CAP (Colleges of American Pathologists) datasets. Thyroid is a little bit less consistent. I use the dataset every time, because it’s also a much neater and faster way of reporting. Whereas the older pathologists still like to write the essays. So that’s a little harder to pull data out of that prose, kind of writing paragraphs.” AP4

**Tip 11: Provide robust registry support structures**

“We found that employing a person to capture data and follow up on missing data fields was the only way we could ensure good quality data for publication.” S2

“So again, I think that database really requires two full-time employees to maintain it... So, I think in general, you need to say we have a team that will drive this programme day to day, that is being paid. If that person resigns, that there will be someone appointed in that position with a salary, because as soon as you rely on someone that does it, you know, if you’re busy with a PhD or whatever, someone that does it for whatever reason, but then the reason goes away, then the continuity of that database falls apart.” AnP2

**Tip 12: Keep it simple**

“The system has to be absolutely foolproof and incredibly easy to follow/understand! If people struggle once, they don’t bother trying again.” S3

“Keep it simple. Don’t expect and rely on busy clinicians to enter data- they won’t!” S3

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