

# AKC2026

## Information Stream frequently asked questions

### 1) Are you building a registry?

- No, not really. A registry is a collection of information about a specific group of patients, or representative sample, who usually have consented to be involved in certain studies.
- The statewide kidney care dataset will integrate different types of data that we already collect – demographic, clinical, events, outcomes – and create a broad set of information that can be used for many purposes; mainly improvement, but also profiling, planning, and funding.
- It will also be housed with other data that is not kidney-care-specific, so we can observe kidney patients alongside other patients, and the conditions and events that kidney patients have that are not explicitly about their kidney disease.

### 2) But we already have ANZDATA!

- Sure, ANZDATA is highly valued and we do not propose ceasing your reporting to it as a longitudinal registry.
- As described in the answer to question 1, the scope will be broader, so we will have a more open view of kidney services and patients.
- Also, ANZDATA submissions and reports are infrequent, whereas the Queensland data set can be as current as we want and need it to be.
- It will also be easily accessible, so you can get your hands on the data you need about your service and patients and have flexibility to query data and to create custom outputs.
- Because submitting to ANZDATA is quite manual, in the future we might also be able to submit data that is already being captured elsewhere to ANZDATA electronically, instead of entering it twice.

### 3) Is this just another thing we have to report to?

- Not necessarily - we want to take data that is already being collected and integrate it into one place.
- For the data that is not being routinely collected now, we want to create systems that make it easy to routinely capture it, preferably as part of normal clinical care.
- Where data is not and cannot be easily captured routinely, we will evaluate the burden of collection against the value of the data's use and decide whether it is worth asking you to report that data.
- So, it will not be extra, except for some things we all think are worth it.

### 4) What's in it for me?

- Advancing Kidney Care 2026 (AKC2026) is all about improvement, and the Information Stream wants to give you visibility of your patients and services, so you can see how you are doing and where we

can improve. We all want the best for our patients and to deliver the best service possible. Having access to data can help us to do that.

- We also want to try to make data capture and reporting as easy and intuitive as possible, so hopefully you will not only be able to see aspects of your service you couldn't see before, but also be able to view information in a way that is less manual, giving you more autonomy.

## 5) What data will be available?

- The AKC2026 Clinical Stream asked clinicians and consumers and other kidney care stakeholders how we should measure quality. The answers were published in *The Queensland Health [framework for delivering quality care to people with kidney disease](#)*. These quality measures, plus some basic profile measures that describe the patients and the services, are our starting point. In 2019, we documented them in Business Requirements.
- Next, we needed to find out which measures we can report in the first year and which ones need to be developed in the future. That determined our initial scope. A statewide AKC2026 Information Stream Advisory Group (ISAG) helped us work out where to get the data for the initial set and agree on some definitions. Then we built it.
- It's called the Advancing Kidney Care Information Solution ([AKCIS](#)).
- The initial set of data was delivered in AKCIS in 2019-2020. In subsequent years, AKCIS has been expanded and further improved. Descriptions of the information available in AKCIS is described in the User Guides for each of the AKCIS reports, that are online.

## 6) When can we get access to this data?

- Now! AKCIS went live in June 2020. Go to the page [here](#) for more information about what is currently available and to apply for access.

## 7) Who can get access to this data?

- Only Queensland Health staff at this stage.
- We have implemented a data governance model that describes the type of uses of the data and matches those to different types of users. Basically, those who already have access to patient or clinician identifiable data under Queensland Health policies will have access to the same data, while those who are not authorised to access such detailed data will not have it. So, if you as a clinician would like a report on outcomes of patients under your care, then we will be able to provide this to you.
- Access to the data must be restricted enough so that it does not break patient privacy legislation and information security standards. Also, because one of our principles is that the data is used for care, the data should not be used punitively, which can erode clinician trust.
- On the other hand, transparency is a significant enabler of improvement and we can't improve what we don't know about.
- So, data governance tries to maintain a balance between the risks and benefits of opening up information to support our ability to improve.

## 8) But we all do things different ways...

- Being able to have a statewide view of data will be a challenge because around Queensland there are different models of care, information systems, human resources, and ways of managing services.
- Part of the work of the AKC2026 Information Stream is to standardise data elements where possible and produce a data dictionary that explains how data is sourced and how measures are derived and calculated for consistency.
- The level of differentiation will likely be a factor in deciding the scope of measures to report, because we want each HHS to have an equitable view of patients and services.

## 9) What if my hospital doesn't have ieMR?

- The Integrated Electronic Medical Record (ieMR) offers electronic capturing of more detailed data that will let us report clinical measures that we have not been able to report as accurately and easily before. So, the implementation of the ieMR presents new opportunities and will be a valuable tool for enabling improvement.
- That said, there is plenty of information already available in statewide datasets that we can leverage, such as appointment scheduling data and admitted patient data. Because the statewide kidney dataset will be built up over time, the initial scope focusses on the data that is available to everyone from these common sources.
- Our intention is to not include measures that require ieMR in the statewide scope until all sites have implemented ieMR, so that reporting is equitable.

## 10) Who is involved?

- The AKC2026 Information Stream is clinically led by Dr Magid Fahim, a nephrologist at Metro South HHS and Chief Clinical Information Officer for Metro North HHS. There is also a Business Analyst, Julie Sinclair and a Data Manager, Shruti Thakkar.
- The Healthcare Improvement Unit provides project management and governance oversight of the stream's objectives.
- We are also supported by the AKC2026 Information Stream Advisory Group (ISAG), who provides operational advice and offers customer perspectives from HHSs and Departmental planning and funding branches. ISAG helps us identify the detailed requirements, recognises available data sources and works through the detail of how we will report kidney-related data.
- Where needed, the team can also consult with the Statewide Renal Clinical Network and its working groups.

## 11) Who is going to clean the data?

- The statewide kidney improvement data set will be sourcing data from applications used in patient care. The data in these applications form the patient's medical record and should contain the most accurate information about a patient and their care.
- Collating and integrating this data into another location allows secondary use but does not mean that data will be 'cleaner' once its collated than it was when it was in its source.

- Often when data is aggregated and presented in a way it has not been viewed before, the quality of the data is exposed. If there are errors in the data, then AKCIS provides an opportunity to observe and improve data quality. Any inaccurate data should be corrected at its source (in the patient record), with changes flowing through to the collated set.
- In the initial phases of the project, most data will likely be sourced from established data collections, for which there is already a data validation process. As we increase the scope of the dataset, data will be sourced from a range of applications that may require data cleansing.
- So, the responsibility for cleaning the data is retained by HHSs who create and amend records in hospital-based applications. This is not an additional burden because the data will not be corrected in AKCIS, rather, data should be corrected in the original patient record. That way, every output that uses that original source will reflect a more accurate record.

Contact the AKC2026 Information Stream with questions at [AKC2026IS@health.qld.gov.au](mailto:AKC2026IS@health.qld.gov.au)