



Survey Questions – NFATSIH Response

Legal and ethical obligations

Does the VII Data Framework clearly set out the legal and ethical obligations for data users?

YES	
NO	X

What suggestions do you have on how the Department should communicate the legal and ethical obligations to data users?

Currently, the Framework reflects the Department of Health’s mandated requirements as per legislation, however these should not be the only factors guiding decision making in relation to how the VII data is acquired, used and handled. The Framework must incorporate and embed principles of Aboriginal and Torres Strait Islander data sovereignty. The data quality and its ethical use will be improved through transparency and clear communication about Aboriginal and Torres Strait Islander control over the collection and use of the data.

The Framework should also make clear who is collecting data, for what purpose and with whom it will be shared, for example pathology labs, research agencies, government publications, My Health Record and etc. Clearer advice is required for researchers and other data users about what data can and cannot be used, which will become more important as the secondary use of My Health Record data is established.

A focus on data users notwithstanding, communication and familiarisation must also take place within Aboriginal and Torres Strait Islander communities regarding the collection and use of data for Medicare (including both VII and information collected in practices/services. Consistent with principles of Aboriginal and Torres Strait Islander data sovereignty, information will need to be developed and delivered ideally by Aboriginal organisations and communities themselves. In order to be effective, this work should be properly funded and adequate time allowed for dissemination.

Uses of Voluntary Indigenous Identifier Data

Does the VII Data Framework sufficiently protect:

	YES	NO
Medicare Estimations	X	
Enrolment Data	X	

What suggestions do you have on how VII data should be used?

Although the current use is likely to be fine, a more significant issue that remains is the experience of Aboriginal and Torres Strait Islander peoples in how the data is collected. Identification data is sought via a number of means, for example via Medicare, practices/services accessing the Practice Incentive Payment Indigenous Health Incentive, hospitals, in addition to the other sectors that seek this data

This warrants a greater focus on Aboriginal and Torres Strait Islander data sovereignty and clear communication about the purpose and use of the data.



For Aboriginal and Torres Strait Islander people identifying to the VII, it must be made really clear what this data is, what it is used for, and how it is different to identifying via other means. Similarly, there may be a requirement for researchers and users of data to be really clear about the different uses of these data sets (especially as some of it gets into My Health Record and undergoes secondary use in research).

Owing to the multiple identification processes and varying levels of confidence in these systems, information in these datasets may conflict or be inconsistent. By way of example, patients known to a practice are likely to be more confident with sharing identification status than through an anonymous voluntary identification process. The RACGP is currently helping clarify the purpose of these datasets and how this information will be used.

Accessing Voluntary Indigenous Identifier Data

Is the Five Safes Framework an appropriate way to assess data requests?

YES	X
NO	

What else should be considered when assessing a request for VII data?

Principles of Aboriginal and Torres Strait Islander data sovereignty must be incorporated at all stages of collection and use of this data.

Protecting confidentiality

How would you assess the types of statistical data tables that can be released to data users?

Too much detail (could compromise privacy)	
About right	X
Not enough detail (could compromise usefulness)	

Please include any other comments about the VII Data Framework below.

The VII Data Framework must incorporate and embed principles of Indigenous Data Sovereignty.

Clear explanations about the collection and use of data in the VII are needed, including how this it compares with other data collected by health services, eg in General Practices and Aboriginal Community Controlled Health Organisations (ACCHOs); and descriptions of the source data included in reports compiled using VII or other sources of data (for example Practice Incentive Payment registrations. This is particularly important as the secondary use of My Health Record information for research purposes increasingly occurs in the future.

Communications about the Framework should not just come from the Department, but also from communities and ACCHOs. This work should be appropriately resourced to ensure it has meaning for both community members and data users.