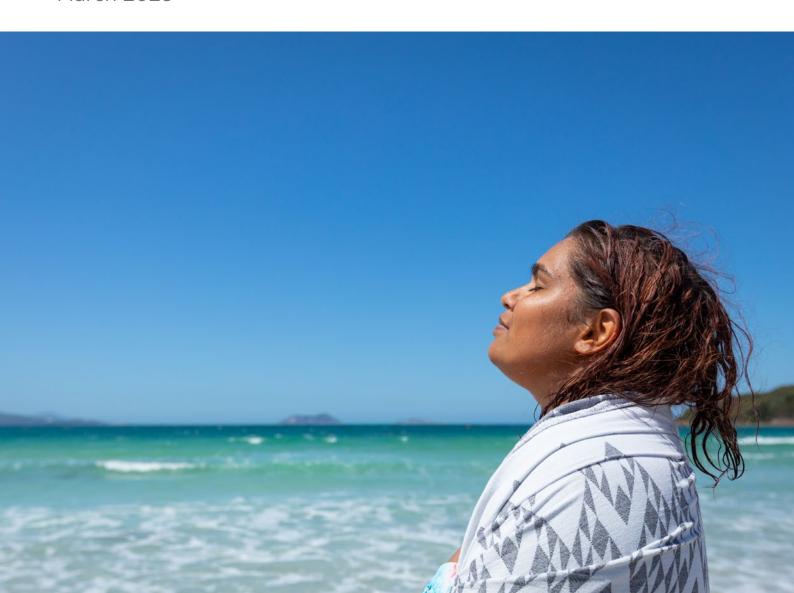


Data standards for interoperability

Supporting effective primary health care starting with health checks for Aboriginal and Torres Strait Islander people

Supporting ME, My Care, and My Wellbeing

March 2023



Acknowledgements

The Aboriginal and Torres Strait Islander Smart Health Project was funded by Australian Government Department of Health, through the First Nations Health Division.



Australian Government

Department of Health

We wish to thank the RACGP & NACCHO Partnership as well as all of the Primary Care Data Quality Foundations Collaborative Community who contributed their time, expertise, passion, and energy to deliver this phase of the programme.

We look forward to the community continuing to grow and working with you all to deliver resources and specifications to enable the meaningful use, exchange, and reuse of clinical information to support better health outcomes.

Foreword

Data standards for interoperability - following a common roadmap

Clinical software influences what healthcare is provided and how healthcare is provided and experienced. A common data interoperability roadmap addresses the ability of systems and services that create, exchange and consume data to have clear, shared expectations for the contents, use, context and meaning of that data.

The CSIRO Australian eHealth Research Centre (AEHRC) has been working with industry partners to develop a consistent methodology for data design and a common Data Interoperability Roadmap for Primary Healthcare.

This paper sets out to describe the roadmap for data interoperability of health data, focusing on a use case of high quality health checks for Aboriginal and Torres Strait Islander people. Data collected in health assessments such as the Aboriginal and Torres Strait Islander health checks (health checks) are a powerful use case to progress streamlining the secure exchange of healthcare data and enabling reuse to improve care delivery and experience. This demonstration project is mapping the data requirements of health checks and progressing development of data building blocks and technical components to support the foundation of a national infrastructure that supports data re-use and exchange.

Roadmap

Data building blocks re-used for quality reporting

Continue to expand – aligning with mental health/community and including HealthCheck in MyHR Work with industry to leverage re-usable building blocks. Review and streamline mandatory reporting requirements leveraging the agreed building blocks. Design will be guided by the principle of 'collect once, use many' 'build once, use many'.

Work with industry to implement reference implementations

Sector specific use data for local reporting

Work collaboratively with all stakeholders to educate and motivate broader implementation across primary care.

Develop and pilot SMART on FHIR reference implementation apps

Ensure app is fit-for-purpose

Develop an app that implements the data standards and launches the SMART on FHIR app pilot with early adopter GP systems and GP/ACCHO clinics.

Co-design data building blocks and exchange standards

Stakeholder engagement

Work with collaboritive and GP system vendors to develop, agree and publish clinical information models (CIM) and FHIR SMART Healthcheck, with agreed terminology/value sets.

Establish data governance

Data governance and sovereignty framework

Strong data governance that respects data sovereignty principles and supports collaborative data standards development will provide a strong foundation for adoption.

Figure 1. Common data interoperability roadmap

DATA COVERNANCE AND DATA STANDARDS DEVELOPANENT

Record the data that supports my care





National library of reusable models – CIM, terminology, FHIR IGs

Monitor my

progress and

authentication services



Data interoperability addresses the ability of systems and services that create, exchange and consume data to have clear, shared expectations for the contents, context and meaning of that data.

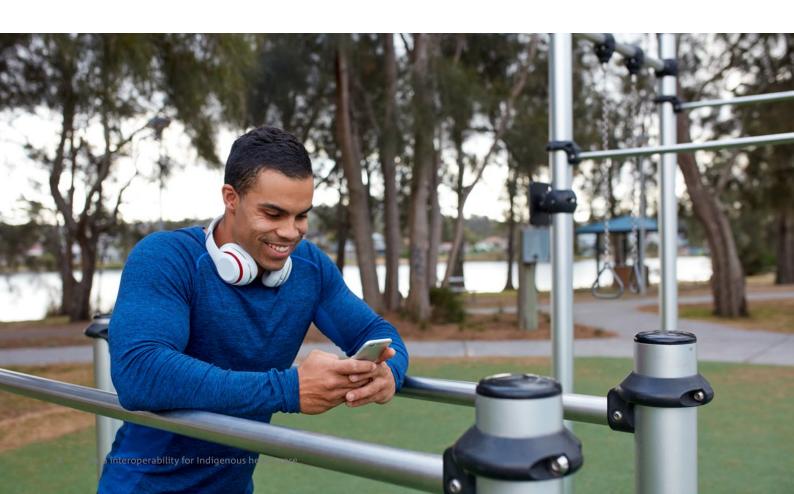
Data Interoperability Standards Consortium

The paper also identifies the key data standards (Clinical Information Models, HL7 FHIR and Terminology) required to ensure that data is recorded in a way that supports clear, unambiguous data exchange.

One of the CSIRO's key principles for data design is 're-use'. This means that the data building blocks, developed for the Health Check may be used for many other patient cohorts (including aged or primary care) and these same data building blocks can be re-purposed for collection of data during care delivery or automatically extracted for reporting. This not only streamlines data exchange, but also simplifies the work for busy clinicians, who can record the data once, and re-use the same data for ongoing care and monitoring or reporting.

Similarly, the national infrastructure and technical components identified and recommended for development through the health checks use case are re-usable and can be extended or applied to other purposes. This encourages adoption by vendors, given the same technical component can be re-used for other use cases.

With this first, in a series of papers, we will demonstrate how a consistent approach to data design, governance and standards can move the whole health sector rapidly forward towards the goal of data interoperability and the quadruple aim in healthcare – improving the individual patient care experience; improving the health of the population; reducing cost of healthcare, and improving provider experience by creating the conditions for the healthcare workforce to find joy and meaning in their work.



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Data interoperability for health assessment data

CSIRO is working nationally to develop a consistent approach to data collection and reporting for health check data that reflects the needs of patients and communities – starting at the beginning of the individual's health journey – collecting the data that reflects an individual's needs, preferences and social environment so that care can be appropriately targeted to deliver the best outcomes.

Our aim is to join-up the individual's health data story and ensure it has meaning to assist in effective primary care.

The role of local health services in providing primary care is critical. Peak healthcare bodies the Royal Australian College of General Practitioners (RACGP) and the National Aboriginal Community Controlled Health Organisation (NACCHO) have collaborated with Australian governments and health agencies to develop flagship resources that support effective, culturally safe and responsive primary healthcare that is valued by Aboriginal and Torres Strait Islander people. NACCHO and RACGP have collaborated to revise the recommended activities in annual Health checks for Aboriginal and Torres Strait Islander people. Health checks are a key activity in preventive healthcare and offer a framework in primary healthcare for health promotion and primary and secondary disease prevention through screening and health needs assessment. It is also an activity that supports collection of patient information that can inform healthcare at individual and population levels. The CSIRO work offers technology that can support health care teams to provide and plan for healthcare and the Health checks are a use case for this work.

Use case: Data interoperability supporting health care

Between the periods of 2009-10 and 2018-19, there has been an increase in the delivery of health assessments, Health Checks, chronic disease management plans, GP Management Plans (GPMPs) and Team Care Arrangements (TCAs) and general increases in episodes of care provided through Indigenous primary health care services.

With the quantity of services being delivered increasing it is imperative that thoughtfully designed digital health ecosystems improve rather than become a barrier to complex and high quality health care delivery.

The health checks use case seeks to provide a blue print for achieving this, which is applicable to the whole of primary healthcare.

Data governance and data sovereignty

Paramount to any work involving data gathering and ways to improve data sharing, there must be an acknowledgement of the importance to data sovereignty

Around the world, Indigenous communities are clearly articulating their concerns and demand ownership over what data is collected about them and how it is being used:

CSIRO and our partners acknowledge the importance of establishing mechanisms for data governance that respects these Indigenous data sovereignty principles. A strong data governance framework is required to support collaborative data standards development and to establish the foundations of trust that will underpin future adoption of these standards by healthcare organisations serving the needs of patients.

Data is a cultural, strategic, and economic asset for Indigenous peoples. Indigenous Australians have always been active in what is now known as 'data'. Yet in modern times we have been isolated from the language, control and production of data at community, state and national levels. This has resulted in data that are overly focused on Indigenous peoples as the problem. Existing data and data infrastructure does not recognise or privilege our knowledges and worldviews nor meet our current and future needs.... in Australia, Indigenous peoples should have the right to:

- Exercise control of the data ecosystem including creation, development, stewardship, analysis, dissemination and infrastructure.
- Data that is contextual and disaggregated (available and accessible at individual, community and First Nations levels).
- Data that is relevant and empowers sustainable self-determination and effective self-governance.
- Data structures that are accountable to Indigenous peoples and First Nations.
- Data that is protective and respects our individual and collective interests.

Communique, from the Maiam nayri Wingara Indigenous Data Sovereignty Collective and the Australian Indigenous Governance Institute, Canberra, 20th June 2018

The importance of data standards

Careful data design using contemporary techniques can streamline the flow of information between systems and unleash the power of health data collected in the process of delivery of care.

Inconsistent data design leads to a range of problems, which unfortunately are all too prevalent in our current systems. Busy clinicians find themselves continually needing to re-enter data already in their practice management systems because different forms require collection of the same data in slightly different format, using slightly different codesets¹. This not only impacts clinician time and patience, but also impacts data quality. Extraction of data into these forms or for reporting is often not automated and this will be difficult to achieve until there is greater consistency in data design.

Together with clinicians and industry we need to re-think our approach to data design, and the approach we are proposing starts with putting the patient at the centre. This approach is described in detail in the following sections but is conceptually summarised in Figure 1.

Good data design must:

- start by understanding ME (the individual patient themselves)
- focus on the data that supports MY CARE
- monitor the WELLBEING of my Community. The data required across these levels may vary in perspective or level of abstraction, but the core data models and standards should remain consistent.

Unfortunately, all too often data design has historically started at the other end of the chain – focussing on the requirements for reporting² rather than the requirements of the individual. We need to turn this around to ensure patients and their care are clearly at the centre of our data collection efforts.

Achieving the desired level of consistency will rely on industry collaboration and agreement to adopt (and further develop where necessary) a set of standards for data design, collection and exchange, including:

- consistent data building blocks (clinical information models CIM)
- a structured and agreed vocabulary (clinical terminology)
- streamlined mechanisms for secure exchange of health data (based on HL7 FHIR standards).

An international perspective

Both the US and the UK have recognised the importance of coordinated data standards across the health ecosystem.

Funded by the NHS, the Professional Record Standards Body (PRSB) have developed a range of clinical standards for health and care records in collaboration with industry and patients for the UK across the different care sectors. These standards are built around core components, such as medications, allergies, patient information, which are reused across the PRSB's portfolio of standards. The core components are reused multiple times across different standards as required by the information needed for each particular scenario. Reusing the core components across different sectors enables interoperability.

Similarly, the Office of the National Coordinator (ONC) for Health Information Technology within the U.S. Department of Health and Human Services has the United States Core Data for Interoperability (USCDI) which is a standardised set of health data classes and comprising of defined reusable data elements for nationwide, interoperable health information exchange.

¹ Aged care: put your data where the care is | InSight+ (mja.com.au)

² Data improvements - AIHW Gen (gen-agedcaredata.gov.au)

Start by understanding me

- lifestyle
- social factors
- emotional wellbeing
- mental health
- respiratory health
- oral and dental
- eye and hearing
- cardio-vascular



Focus on the data that supports my care

- vital signs
- medical history
- medications
- pathology
- allergies
- qoals
- care team



Monitor the wellbeing of me, my family, my community

- vaccination rates
- maternal and child health
- preventative health indicators
- chronic disease management indicators
- community goals
- regional goals
- national KPIs



Consistent data standards Data governance and sovereignty

Figure 2. Re-thinking our approach to Data Design

Structured and agreed

Clinical Terminology

Clinical terminology provides a standardised way to describe clinical concepts. The following are the main terminologies endorsed for use in Australian health information systems.

SNOMED CT is a comprehensive multilingual terminology that includes concepts covering clinical findings, procedures, observables, body structures, organisms and substances. SNOMED CT is much more than a dictionary or list of terms, it provides a map between concepts that can be used to drive intelligent decision support.

The Australian Medicines Terminology (AMT) is a formal subset of SNOMED CT-AU used to accurately describe all commonly used medicines in Australia and to support medication management activities, including prescribing, recording, review, dispense, administration and transfer of information.

LOINC is an international terminology used to support pathology, ordering and reporting.

Streamlining health data exchange

FHIR

FHIR (Fast Healthcare Interoperability Resources) is a standard for describing data models and elements (called "FHIR resources") and an API (application programming interface) for exchange. The standard was created by the Health Level Seven (HL7) international healthcare standards organisation.

FHIR APIs provide the interface between systems to enable direct exchange of health data.

FHIR is rapidly being adopted by industry because it is relatively straight-forward to implement and supports contemporary web-based technology that can work on a phone, tablet or across distributed mobile networks. Using FHIR resources and APIs, third party systems and apps can connect and interoperate with any electronic health record system, anywhere, anytime.

Consistent data building blocks

Clinical Information Modelling (CIM)

Clinical information modelling is a way of consistently capturing the core characteristics and meaning of health data. Together with terminology, these models provide the core building blocks for health information and can be used by software designers as the template for capturing data inputs in a way that is useful to clinicians/carers and supports unambiguous exchange of information with other systems.

For example, a CIM for 'medication order' will include the medication name, dose, frequency and route of administration. The CIM will also specify acceptable values for particular fields (eg dosage units) or require the use of standard terminologies.

The same model can be re-used in many different scenarios—for assessment, recording at the point of care or abstracted and collated analysis and reporting. Not all components of the model may be required in every scenario, but by consistently using the same core building blocks, users are able to share their data with others, confident it will be interpreted correctly.

Sharing of information between health IT systems to date has often focussed on the exchange of documents – with no way to accurately extract the individual data elements so that they can easily and quickly be used in computation, or to flag that a follow up is required.

In addition, this has generally only occurred during formal transitions of care, at discharge, or via a paper shared care plan.

Industry is now rapidly moving to the FHIR as the standard for secure health data exchange to enable the sharing of discrete health data. FHIR Implementation Guides (FHIR IG) provide an agreed set of rules about how data will be shared in a particular scenario (including standard definitions of agreed data models, specific data elements, required terminology and units).

Significant work is already underway internationally that Australia can leverage to accelerate this work. The Australian Digital Health Agency and the Australian Institute of Health and Welfare both endorse and publish a range of data standards for use in Australia. At the international level, WHO, HL7, IHE, SNOMED and OpenEHR International Standards Communities continue to consult and publish a range of relevant data standards. We are not starting with a blank page.

Australia is recognised as having fostered and developed world-leading expertise in health data standards at all levels of endeavour – from clinical, quality, health data modelling, health terminology, health data exchange and health statistical services. The key requirement is to bring this expertise to the table together to brainstorm and agree the standards and guidelines for use in Australia.

Applying consistent data design and clinical information modelling techniques at the earliest stages of development can help to ensure the ongoing utility and re-use of data, thereby maximising its value.

Sharing data not documents

FHIR Implementation Guides

Sharing of information between clinicians has historically been achieved by sending a letter or discharge summary – a document that embeds key data and provides contextual information relevant to their care ('content' in 'context').

Over time this information exchange has changed from being paper-based to electronic, but the format remained as a document.

In the digital world, the recipient often wants to extract key data from these documents for computation. However, sharing data out of context can result in it being misinterpreted. FHIR implementation guides (FHIR IG) describe a standardised, vendor-neutral format and guidelines for implementation of the information models and terminology that represent the clinical, research, analysis and reporting requirements.

FHIR APIs enable the sharing of content; FHIR IGs provide further context and constraints to ensure data can be correctly interpreted.

CSIRO's AEHRC has worked with Australian industry to agree on a FHIR IG for primary care practice-to-practice exchange of health records, and ADHA is working with WHO to develop FHIR IG for the international patient summary.

Good data by design

Start by understanding 'ME'

One of the first steps in improving care delivery must be to ensure we have mechanisms in place to document the individual needs of each client, including their health, functional, social needs and preferences.

By first assessing the individual's care needs, health providers are better placed to provide culturally appropriate care and support. With careful design, data collected during a clinical encounter can also be used to support planning and monitoring – but the individual comes first.

Healthcare providers should consider the individual context of their patients, their social history, their biopsychosocial risks, the patient as a person, in order to form a therapeutic alliance and to share power and responsibility. These are the hallmarks of the patient-centred healthcare professional. The social determinants of health may be broad and intersectoral, but patient-centred healthcare systems 'can and do yield health equity gains'.

National Guide to a preventive health assessment for Aboriginal and Torres Strait Islander people, Third Edition RACGP and NACCHO

A strong relationship between the individual and their health care team is important – not only during assessment but also to ensure that a realistic care plan is developed to meet the needs of the individual and that this plan can be monitored, with the individual supported over time to access the additional local services required to address their health needs.

Exploring the NACCHO-RACGP health checks use case

Health checks are now widely used throughout Australia and are an important way for clinicians to quickly document and record key elements of an individual's health story. Recommended activities for health checks have been developed by a NACCHO-RACGP Partnership Project and there is a one-page NACCHO-RACGP guide to *Useful high-quality health checks for Aboriginal and Torres Strait Islander people*³.

In 2019-20, 28% of Aboriginal and Torres Strait Islander people (about 239,000 people) had an Indigenous-specific health check conducted by their health provider.

Health checks are designed to ensure that data collection:

- is useful to the client and accurately reflects their individual needs
- identifies health needs including their health goals and priorities
- supports the individual to take charge of their health and wellbeing
- provides a framework for primary and secondary disease prevention through healthcare advice, risk assessment and other measures
- is provided by the regular healthcare provider
- includes a plan for follow-up of identified health needs, priorities and goals (as no follow-up will have no or minimal impact on improving health outcomes).

The health check marks the beginning of a health journey – recording key data in a way that can inform clinical service delivery and individualised care. With good data design and the help of technology, these Health checks can be used to personalise and better tailor health services to meet the needs of Aboriginal and Torres Strait Islander people; and by electronically recording and storing the data as discrete data elements (rather than as a document) the power of this data can be better leveraged. This requires consistent data building blocks, a common vocabulary and agreed standards for health data exchange.

Supported by funding from the Australian Department of Health CSIRO is bringing together world leading industry experts in health data and design with representatives from the Aboriginal and Torres Strait Islander health sector including from NACCHO and RACGP with the aim of transforming this paper-based assessment into an agreed and standardised electronic format. CSIRO is also working closely with primary healthcare providers and IT system vendors to identify what may enable, complicate or prevent integration of the new electronic Health check templates into practice; in order to remove barriers to adoption.

The aim of this Smart Form Health Checks project is to ensure that the meaning of each data element of the Health check is accurately recorded first-time, in the right way, so that it doesn't need to be repeated when the question is asked in a different way or when the information needs to be used for a different (agreed) purpose.

Collaboration is key. Working with communities and health care providers, our aim is to get data collection right from the beginning – and to create re-usable data building blocks that can be used to consistently tell the story about an individual's health journey.

The Smart Form Health Checks Project is working with all stakeholders to codesign, deliver and publish the required CIMs, terminology and FHIR implementation guides (FHIR IG) to support this streamlined approach to data gathering and sharing.

The FHIR standards not only support traditional information exchanges (e.g. hospital to GP discharge summaries) but can also support innovations such as 'SMART questionnaires' that enable automated transfer of information collected via a questionnaire or health check form to other systems. Such SMART form technologies are particularly relevant to the implementation of electronic health checks.

Together these data standards and technologies provide huge opportunities for innovation not only by supporting standardised collection of data during a health check, but also through simplifying authorised sharing of information to ensure a complete health story.

Smart questionnaires

FHIR resource – questionnaire

Across health and aged care settings, questionnaires serve many different purposes including the capture of a clinical assessment, soliciting feedback or as a way for clients to document their preferences.

FHIR questionnaires define the questions to be asked, in what order, choices for answers etc. and provide guidance on organising and grouping these questions for extraction of data from the form for analysis and subsequent processing.

FHIR questionnaires, based on the standardised information model/terminology building blocks, will provide a standardised implementation to capture new data, auto populate from existing data, and potentially write back to source systems.

Focus on collecting the data that supports 'MY CARE'

Whilst health checks are a useful way to identify health issues and document individual goals and preferences, improving health outcomes also requires appropriate follow up of any issues identified during a health check. Armed with an understanding of their Aboriginal and Torres Strait Islander client's care needs as recorded during the health check process, health providers should be better placed to provide referrals to culturally appropriate services that meet each individual's expectation for high quality and safe care. Recalls and reminders can be electronically enabled, and ideally all health care providers should have access to a single care plan which can be actioned and monitored.

Aboriginal and Torres Strait Islander people who receive a health check can access up to 10 follow—up services per calendar year. The proportion of health check clients who had Indigenous-specific follow-up services within 12 months of their check increased from 12% to 47% between 2010—11 and 2018—19⁴. But with electronic monitoring and technology-supported workflows, these figures can be further improved.

Many of the data elements recorded during the initial health check will be relevant for occasional monitoring (e.g. smoking), but others require far more frequent and detailed monitoring (e.g. Glucose and HbA1c monitoring for diabetes patients). Different care providers will have different information needs and depending on the use case will be interested in different perspectives, even for the same data element. Therefore, data recorded during follow-up appointments should focus on the data that helps carers monitor and deliver the best possible care to their clients.

Even within the one clinic information silos may exist. For example, there are many similarities between the health check and the GP management plan (GPMP) – but data currently needs to be re-entered for each purpose. In the future these forms could be auto-populated from the EMR via FHIR technologies. Ideally these forms will also be stored in a shared record where they can be accessed by the care team. My Health Record (MyHR) has been developed to store key documents – including diagnostic test results and health summaries – but does not currently include health checks, the GPMP or other Care Plans.

⁴ Indigenous health checks and follow-ups, Overview - Australian Institute of Health and Welfare (aihw.gov.au)

Part of our recommended roadmap is therefore to ensure that in future these health checks plans are shared, for example in the MyHR. Of course, before this can be achieved, relevant stakeholders must be consulted to agree the data governance and sovereignty frameworks.

Solving the problems of interoperability between these information silos therefore remains a significant challenge for the health industry – but by working collaboratively with stakeholders and applying consistent data design and adopting the data standards identified in this paper, it should no longer be an insurmountable challenge.

Monitor the WELLBEING of the community

Aboriginal Community Controlled Health Services also have contractual obligations to report on national key performance indicators, several of which pertain to preventive healthcare delivery.

The National Guide can inform the evidence underpinning these indicators, and ensure they are 'fit for purpose' to support quality improvement. Indicators should be evidence-based, reflecting research, clinical expertise and patient values.

National Guide to a preventive health assessment for Aboriginal and Torres Strait Islander people, Third Edition RACGP and NACCHO

By using the data collected during health check as the starting point, and following the client through their health journey, health professionals will be far better placed to evaluate the health outcomes for the individual, and to assess the quality and appropriateness of their care.

Indicators may also unintentionally restrict clinical decision making if they prioritise the use of certain clinical tools over other equally suitable ones. Other unintended consequences may arise if indicators homogenise clinical decision making without considering the diversity of Aboriginal and Torres Strait Islander peoples and their health needs, thereby undermining patient-centred care.

National Guide to a preventive health assessment for Aboriginal and Torres Strait Islander people, Third Edition RACGP and NACCHO The goal of care delivery is always to ensure the best outcomes for the individual. With smart data design, IT systems can help monitor the wellbeing of clients at the individual level and the same data can then be abstracted and de-identified data for reporting at the local, regional or national level.

Our aim is to ensure that this is done in the right way, building on the data already being collected during assessment and care delivery to derive a picture of the overall wellbeing of the Aboriginal and Torres Strait Islander populations and minimising the burden of data collection on our health workers:

- abstracting and grouping existing data for different levels of analysis
- documenting care plans and ensuring adequate follow-up occurs
- providing feedback loops to clinicians and the client themselves
- outlining the individual's perceptions of the quality of care they are receiving.

The same technology and data standards (SMART, FHIR, CIMs and clinical terminology) not only supports consistent data collection in primary care, but it also enhances the comparability of data used for statistical reporting at the regional/national level.

The health check is already being used for many things – but it risks becoming bloated with items only recorded because there is currently no other mechanism to capture data for reporting or to record workflows. There may be other more appropriate ways to collect this data, and care is required to ensure that the health check remains focussed on its core purpose, and that the data being collected is relevant to care delivery.

Often, for reporting only a more minimal data model is required. This is why historically governments have defined minimum data sets. However, these were generally designed from the perspective of the health statistician – and sometimes this proved inconsistent with the way data was being recorded at the point of care. Therefore, separate data collections appeared, with some collections having the sole purpose of recording data that was only used for reporting. By modelling data consistently from all perspectives – with input from all potential stakeholders – this problem can be avoided, and data required for reporting can be collected as a by-product of data being collected during care delivery.

The other major opportunity is to move from data that is several months (or even years) old before it is reported, to real-time analytics. Data has incredible power to highlight potential problems – identifying outliers and trends. We need to create a system capable of pro-actively responding to these issues. With new data standards and appropriate technologies this all becomes possible.

Reducing the burden of reporting

Moving from minimum data set specifications to re-usable data building blocks

With today's technology we can do much more than mandate adherence to a 'minimum' data set specification that will be used solely for reporting.

If we can agree on the core building blocks (CIM and terminology) through collaboration with industry partners and stakeholders, we can define varying constraints (through a FHIR IG) that can be applied to different use cases.

FHIR is both extensible and flexible – with very few 'mandatory' requirements. For national, mandatory reporting of the FHIR IG may tightly constrain some of the aspects of the building block (or FHIR resource). But the same building block can be re-used, perhaps in a more extended or complete format, for recording of information at point of care.

This approach reduces the burden of data collection and should also increase the accuracy and quality of data collected, because it has value for care delivery at the coal-face. In addition, new data collections can be far more rapidly constructed using these same clinical information model/terminology building blocks.

Real-time, not retrospective, reporting

Intelligent analytics

Most existing systems used to monitor aged care delivery and collate information for analysis, do so retrospectively. Many national reporting systems produce reports only annually. Such significant time delays make it more difficult to investigate aberrations and respond to trends in a timely way.

Enabling real-time collection and collation of data at both organisational and national levels through agreed data standards and FHIR-enabled systems will support a learning system capable of responding more rapidly to the needs of elderly. The ability to leverage this data for AI and predictive analytics provides even greater opportunity for improvement.

Consistent data standards

Implementing the agreed data standards

Having agreed the data standards and guidelines, the first step will be implementing these standards WITHIN the clinic completing the health check.

Current workflows and processes (as shown in Figure 2) are manual and require transcription from paper forms into the electronic medical records (EMRs).

Most GP practices and Aboriginal and Torres Strait Islander Controlled Community Health Organisations now use an EMR, but there are many different vendors and products used throughout Australia. Changing each of these systems for the sole purpose of enabling collection of the health check would be expensive, and any changes to the form in subsequent years would need to be reflected in system updates.

CSIRO is recommending an alternative approach using FHIR Smart Form technology, as shown in Figure 3. An app would be developed to collect the data in the preventive health questionnaire.

This app would be made available to industry and would connect to the practice EMR system through a standard interface (FHIR compliant).

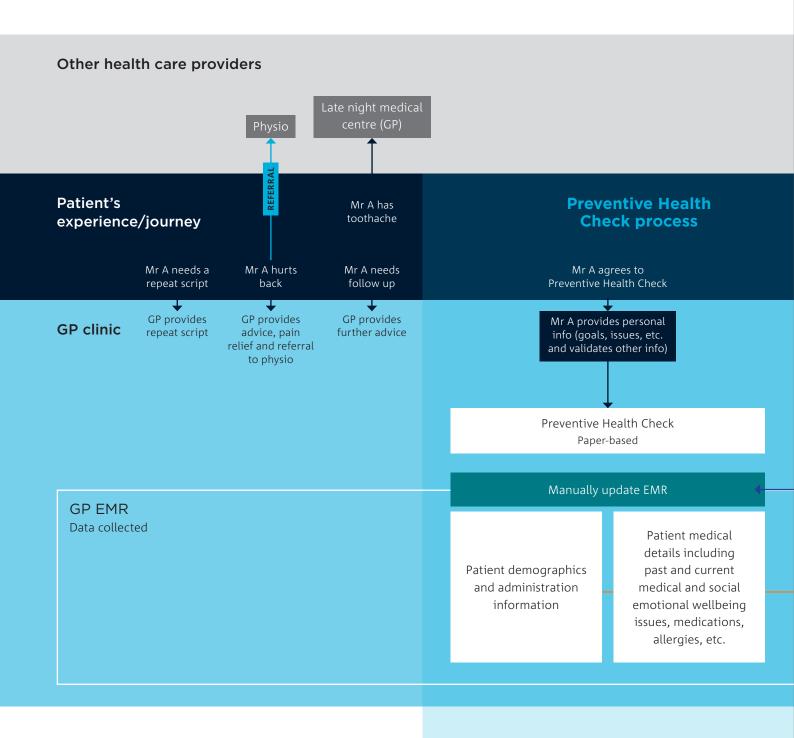
In the first instance (Horizon 1), this app will solely be used to support the health check process. But this is agile, contemporary ICT design, and in future it is envisaged that this same app can be used to launch a variety of forms and questionnaires to securely communicate with the GP EMR system for other agreed purposes (such as other management plans – Horizon 2, and KPI reporting – Horizon 3). Using FHIR technologies this can be achieved securely, and the required consent and de-identification processes can be built into the design of this single app.

This approach would have many advantages:

- No need to change the many EMR systems out there, the same app can be rapidly deployed in any clinic or GP practice with a FHIR compliant system – 'build once, use many'.
- Vendors implementing these FHIR technologies can reuse the components to launch other forms or interfaces.
- Changes can be more rapidly deployed with changes only needing to be made to the one app or SMART form.

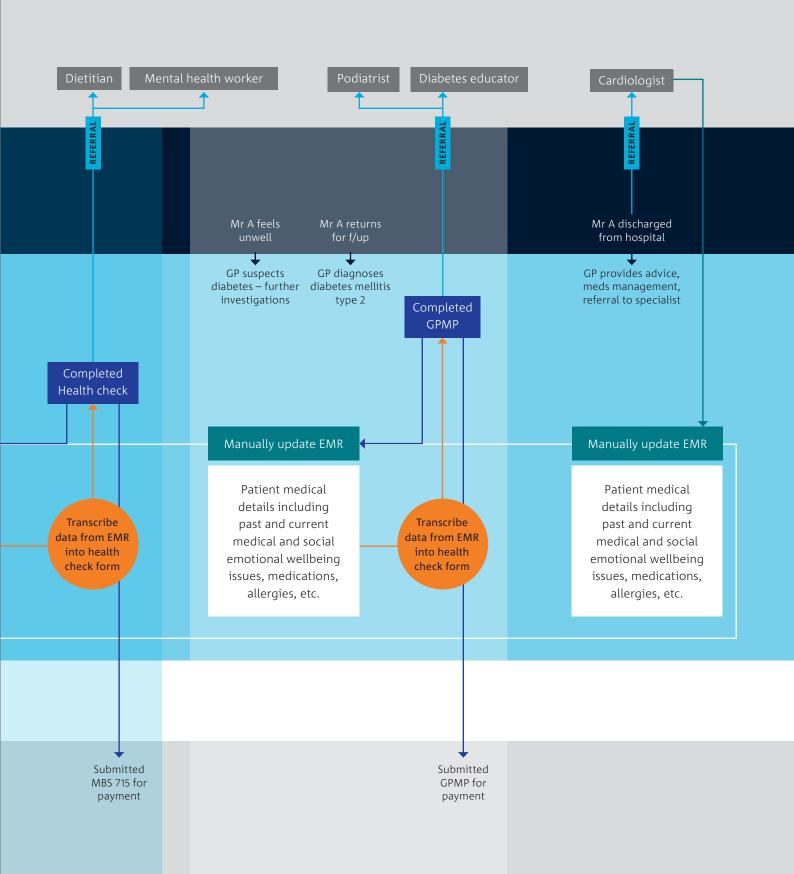


Current paper-based Preventive Health Check process within the patient health care journey

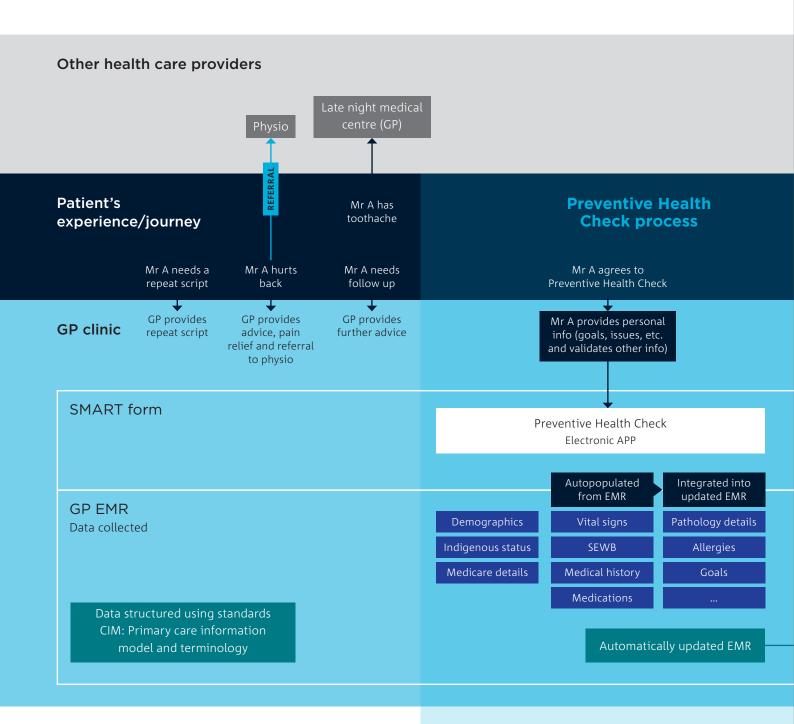


Medicare

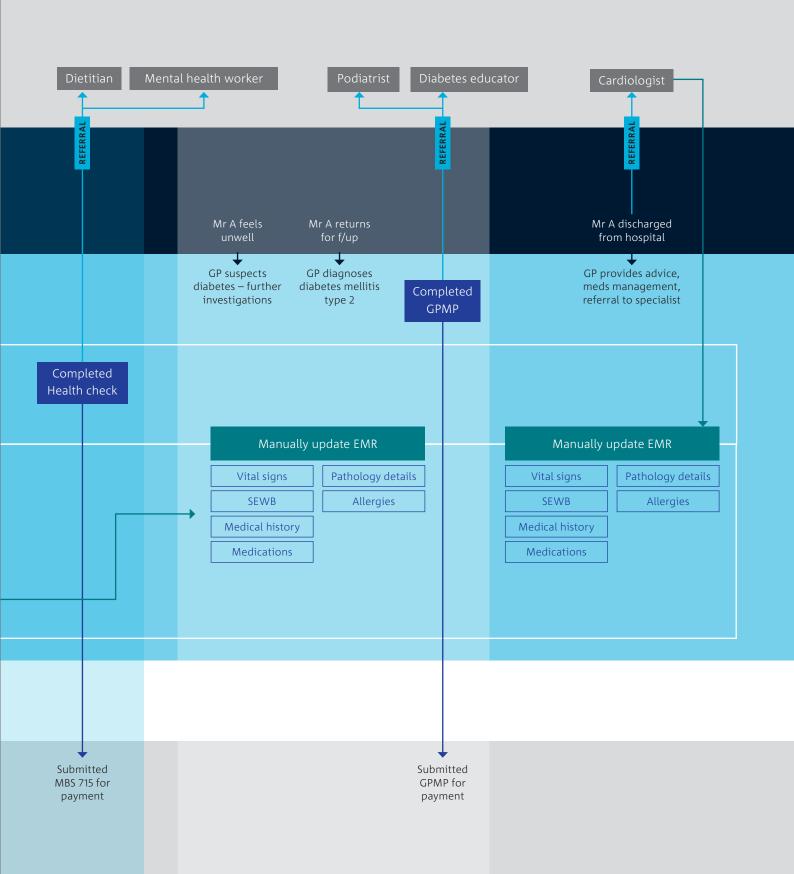
Figure 3. Current paper-based health check process



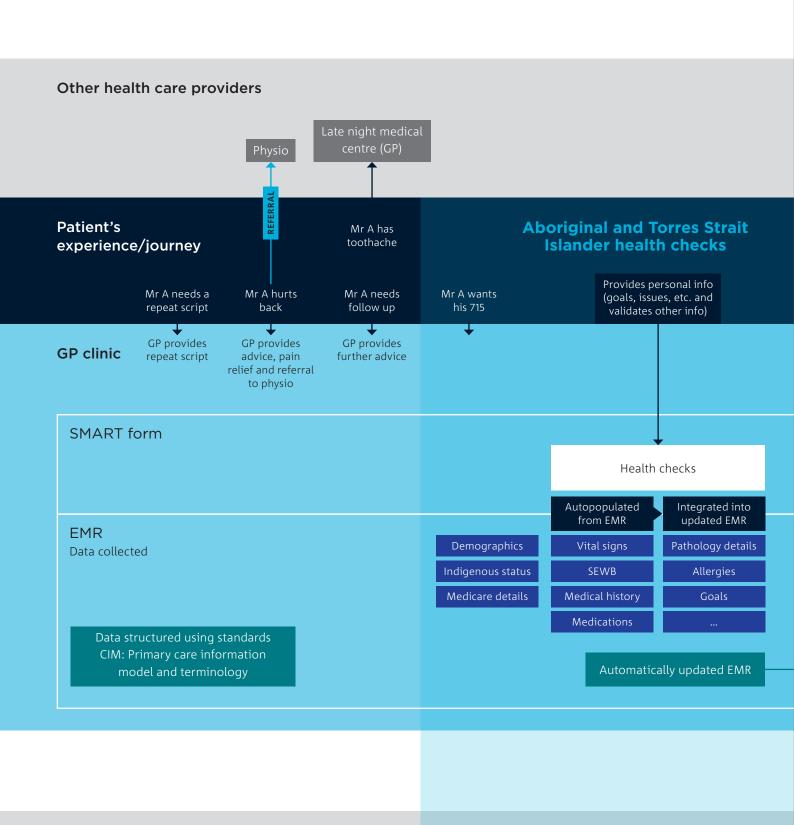
Horizon 1: FHIR enabled SMART questionnaire - Preventive health check process



Medicare

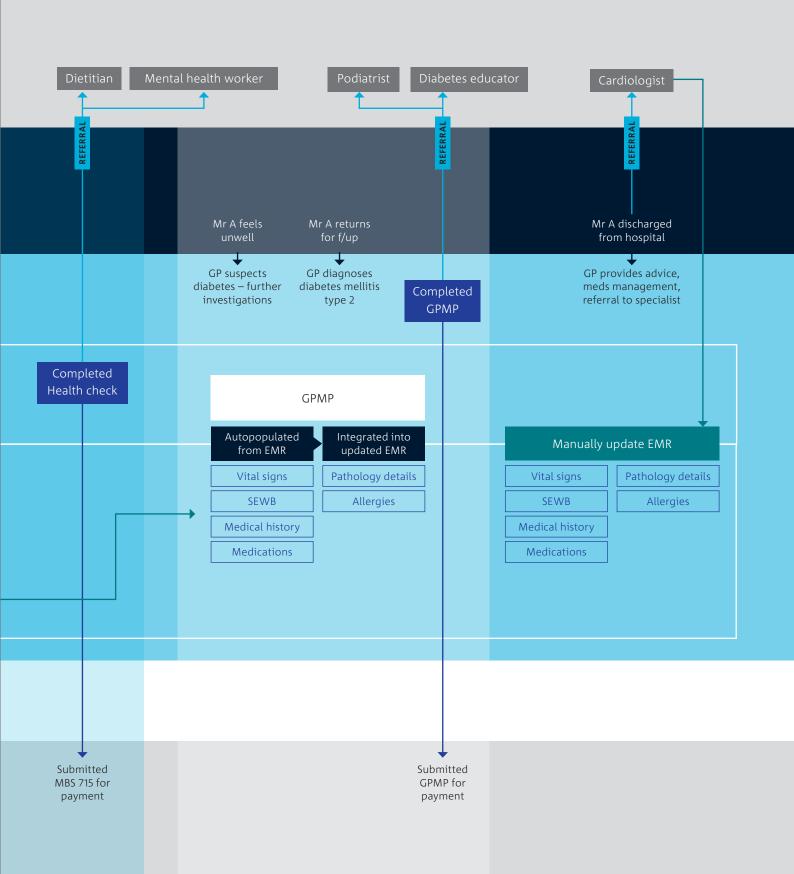


Horizon 2: Reuse SMART for other assessments/health checks e.g. GPMP

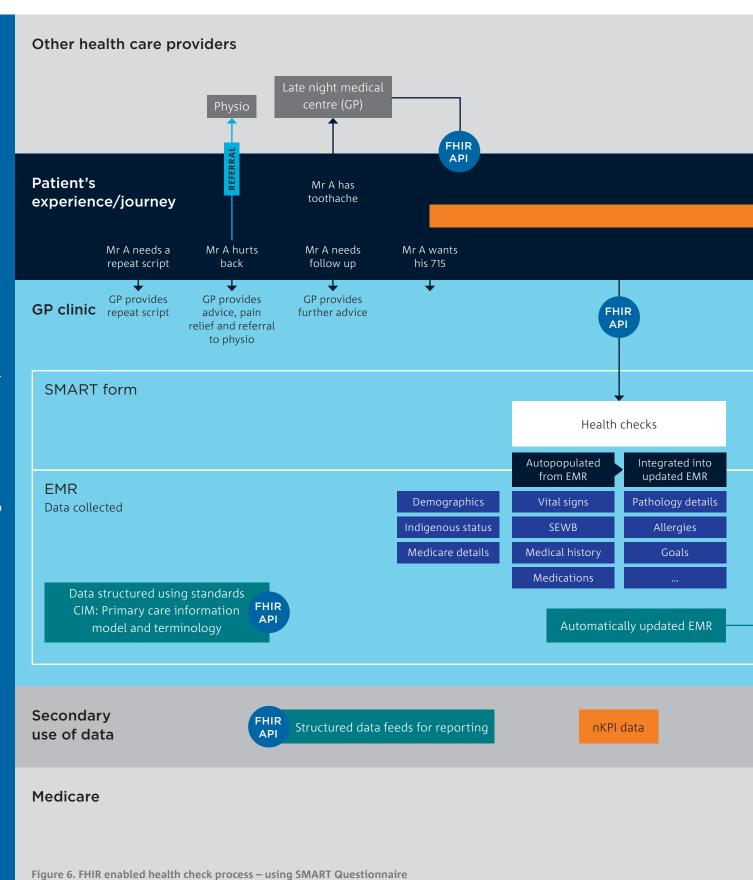


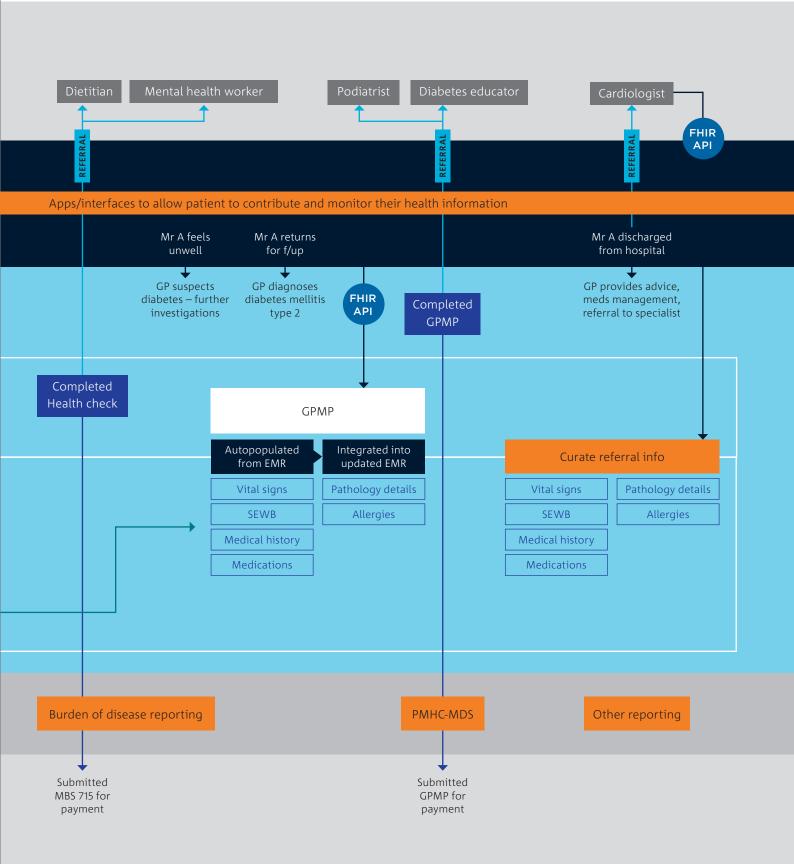
Medicare

Figure 5. Reuse SMART for other assessments/health checks e.g. GPMP



Horizon 3: Standards for interoperability – reuse, reuse everywhere





Interoperability roadmap

Figure 7 summarises the data interoperability roadmap.

There are many advantages of adopting consistent data standards and the proposed approach to utilising SMART (on FHIR) forms technology:

- A SMART on FHIR app can be developed and componentised which can be picked up by the different GP vendors who can each implement it with relatively less effort. As time passes and they build out their product roadmaps, they can start looking at how they may wish to build their own.
- The 'SMART' part sorts the authorisation part so that data can flow in to (and out of) the form directly into the GP system even though it may be a third-party app.
- Once the app is built and implemented, it could used to launch any form or update any of the forms that might sit in the form repository/library – build once (for the health check), reuse many times (for many different forms/use cases incl care plans, screening tools).
- The same standards and APIs could also be used to communicate with the GP system to extract the dataset required for KPI reporting. Using FHIR technologies this can be achieved securely, and the required consent and de-identification processes can be built into the processes using the SMART technology.

This would be one of the first steps towards FHIR-enabled systems in the GP sector. Once achieved the same principles can be extended to other health care providers, enabling the sharing of data from other forms - such as care plans.

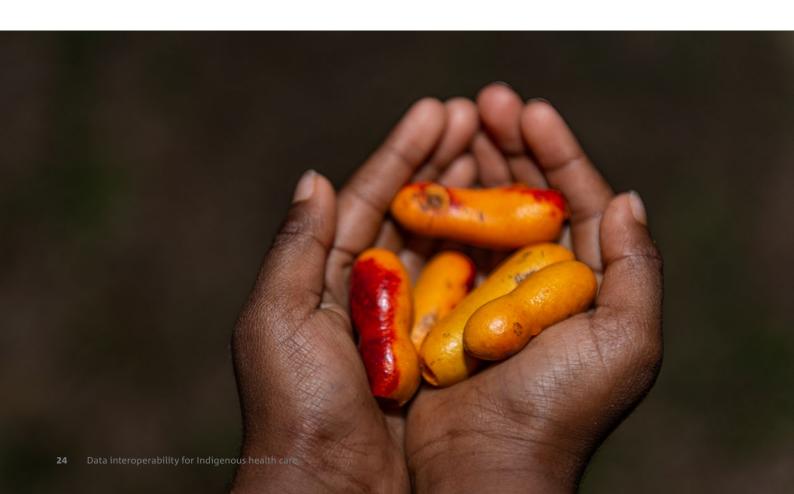
Progressive adoption of these agreed data standards across the health sector is the road to data interoperability.

If these building blocks are in place, data will be able to flow to support a range of existing and future work processes – always consistent, always with known provenance.

And the data will be re-usable. The same data can be used to:

- auto-populate forms and reports (where safe and sensible to do so)
- drive care planning at local, regional and national levels.

The secondary benefit is the increased data quality which then flows through to local practice reporting, regional and national reporting.



Roadmap Data interoperability Data building blocks re-used for quality reporting National Continue to expand – aligning with mental health/community and including HealthCheck in MyHR infrastructure -Work with industry to leverage re-usable building blocks. Review and streamline mandatory FHIR conformance, reporting requirements leveraging the agreed building blocks. Design will be guided by the terminology and principle of 'collect once, use many' 'build once, use many'. authentication services Work with industry to implement across the sector National library of Aboriginal and Community controlled sector use data for local reporting reusable models -Work collaboratively with all stakeholders to educate and motivate broader CIM, terminology, implementation across primary care. FHIR IGs Develop and pilot FHIR SMART HealthCheck App Ensure app is fit-for-purpose Develop an app that implements the data standards and launches the FHIR SMART Healthcheck. Pilot with early adopter GP systems and GP/ACCHO clinics. Monitor my DATA COVERNANCE AND DATA STANDARDS DEVELOPMENT Co-design data building blocks and exchange standards progress and wellbeing Smart Health Checks Project Work with ACCHO, RACGP and GP system vendors to develop, agree and publish clinical information models (CIM) and FHIR SMART Healthcheck, with agreed terminology/value sets. Record the data Establish data governance that supports Indigenous data governance and sovereignty framework my care Strong data governance that respects Indigenous data sovereignty principles and supports collaborative data standards development will provide a strong foundation for adoption.

Figure 7. Data interoperability roadmap for Indigenous data

What else will be required?

Although data standards are in important foundation for the future, they are only part of the story. In addition, further work and investment will be required to support:

- Culture change to think about data flows from the perspective of the person first and those that directly care for them.
- Industry collaboration to continue to identify, develop and endorse data standards.
- Education of the workforce including clinical, Indigenous health workers and related ICT/ vendor capability.
- Software development and new capabilities of systems in order to drive adoption of standards and testing to confirm compliance with standards and the ability to interoperate.

We perpetually recommend the same approach: to involve us, to listen, to reform and invest.

Closing the Gap Report 2021

- National Infrastructure investment:
 - support for data standards development (Clinical Models, terminology and FHIR IGs)
 - a national data standards library like the ONC data dictionary (https://www.healthit.gov/isa/ united-states-core-data-interoperability-uscdi) or the one CSIRO is building.
 - national distribution services (FHIR, terminology and authentication servers) - API Gateway
 - extension of MyHR to include health checks, and Care plans.
- Incentives:
 - government can help drive uptake by ensuring reporting aligns to the data standards developed for use at point of care
 - government also has a role to play in supporting adoption – potential through payment of incentives, provision of software (e.g. the app described above), requirement for standards conformance in procurement and potential regulatory or legislative requirements.



Outcomes

The proposed approach will deliver an ecosystem of connected open platforms that are scalable and secure. It will also:

- improve the quality of data, ensuring it is available as atomic data, appropriately structured and standardised
- promote contemporary platforms that deliver system efficiency and data reuse
- enable secure access to data, within agreed data governance and sovereignty frameworks
- enhance decision support.

Benefits

Getting the data right – from the beginning – should improve data quality across the care continuum and make high quality data more available for sharing and re-use. If we can agree the core data building blocks, then we can standardise abstraction for reporting purposes – and changes to reporting can be more rapidly implemented, without the need for major software change.

The proposed approach has many advantages:

- The same information can be viewed through different lenses and perspectives
 more efficient, less bureaucracy.
- Information can be collected as a by-product of care delivery.
- Enables interoperability:
 - developers have clear standards for sharing data
 - apps can be developed in the knowledge that they can interconnect with other systems.
- Fosters innovation:
 - for example, sophisticated decision support software can be developed independently (using CDS hooks)
 - adoption of global standards allows competition in the global market-place.
- Enables choice, and promotes flexibility
 - systems become more 'plug and play'
 - new data collections, based on standard data building blocks, can be quickly configured without the need for software changes.

Benefits will be spread across the sector and include:

 Benefits to the consumer – no need to repeat the same information multiple times. Creates capability for their story to be accurately documented to form a coherent story that follows them and their care journey.

- Benefits to the clinician data collection is more worthwhile – providing data that is useful at the point of care, can be recorded once, in one place and used many times.
- Benefits to health managers less duplication and waste, more accurate data that can be drawn as a by-product of data collected along the patient journey.
- Benefits to industry include greater consistency and native data interoperability (built into our Health IT systems), coupled with greater agility and flexibility to innovate.
- Affordability, sustainability and fostering innovation

 re-use of data components and technologies
 (such as Smart Forms and SMART Forms launch)
 will streamline data collection and make it far more affordable. The use of predictive tools and artificial intelligence promise huge and rapid innovation in healthcare but such tools are expensive to develop. Adoption of emerging standards can drive further innovation and development in this area by providing a standardised way to interact and communicate with many different systems.

Clinical decision support

CDS Hooks

Helping clinicians and carers to make more informed decisions by alerting them to drug or food interactions, changes in a patient's condition or prompting them for action at a particular point in the patient's journey is one of the key benefits of introducing electronic systems.

But without common data standards, these intelligence clinical decision support systems cannot interpret data coming from other systems.

CDS Hooks are an open-source specification that builds on FHIR, providing a connection point (or 'hook') for decision support technologies to interact in real-time with any EMR system – or to process data from multiple organsisations, that may be using different platforms – provided they adhere to this standard.

CDS hooks enable federated decision support.

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