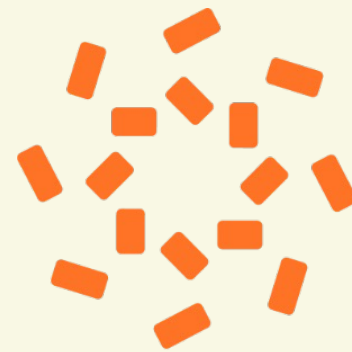


# Rural and Remote Health Equity Roundtable

17 – 18 July 2024



# Sparked





# Acknowledgement of Country

We acknowledge the Traditional Custodians of the land on which we all gather today, the land of the Larrakia people.

We pay our respect to elders past, present, and emerging and extend our respect to all Aboriginal and Torres Strait Islander people. We acknowledge the First Peoples as the first scientists, educators and healers.

# Agenda – Day 2 Thursday



Time	Topic	Facilitator
8:00am	Registration	
8:30am	Overview of the day's objectives and workshop agenda	Kate Ebrill
9:00am	Presentation : NHI project update WORKSHOP 1: Healthcare Identifiers  Objective: to help inform the Agency and Services Australia about IHI data matching challenges, lessons learned and recommended solutions for Aboriginal and Torres Strait Islander peoples and those in rural and remote areas.	NT Health Facilitated by Kieron McGuire and Chris Genc
10:30am	Morning Tea	
11:00am	WORKSHOP 2: Barriers and Opportunities with data standardisation in rural and remote Australia  Objective: to ensure that the data foundations being developed by Sparked reflect the priority use cases and data elements for rural and remote Australia	Introduction by Dr Chris Pearce and Dr Andrew Bell  Facilitated by Kate Ebrill, Kylynn Loi, and Heather Leslie
12:30pm	Lunch	
1:30pm	WORKSHOP 3: Social Determinants of Health (SDOH) and Social and Emotional Wellbeing (SEWB)  Objective: to explore and understand the importance of SDOH and SEWB information, identify key use cases and priority data elements.	Introduction by Jason Agostino and Maia Sauren  Facilitated by Kate Ebrill, Kylynn Loi, and Heather Leslie
3:00pm	Afternoon Tea	
3:30pm	WORKSHOP 4: Population Health  Objective: To explore and identify the key opportunities for AUCDI/SDOH/SEWB to support population health use cases. For example regional and national reporting, quality indicators, etc.	Facilitated by Kate Ebrill, Kylynn Loi, and Heather Leslie
4:15pm	Closing remarks and next steps	Kate Ebrill



# Objectives





# Objectives for the workshop



**Reflect and discuss** barriers and opportunities with data standardisation in rural and remote Australia



**Identify priority use cases** to inform core data for interoperability (AUCDI) development over the next 12 months for rural and remote Australia



**Validate AUCDI R2 backlog** to ensure it reflects needs of rural and remote Australia



**Develop the roadmap** for Social Determinants of Health and Social Emotional Wellbeing data group definition



**Identify opportunities for population health** use of data

# Introductions and Menti





# Getting to know each other

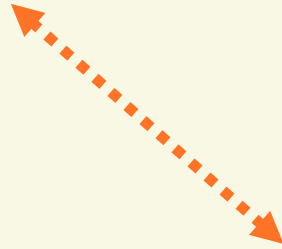
- Introduce yourself at your table
- As a group discuss your key objectives for the day

Why  
standardise?

# Why Standardise?

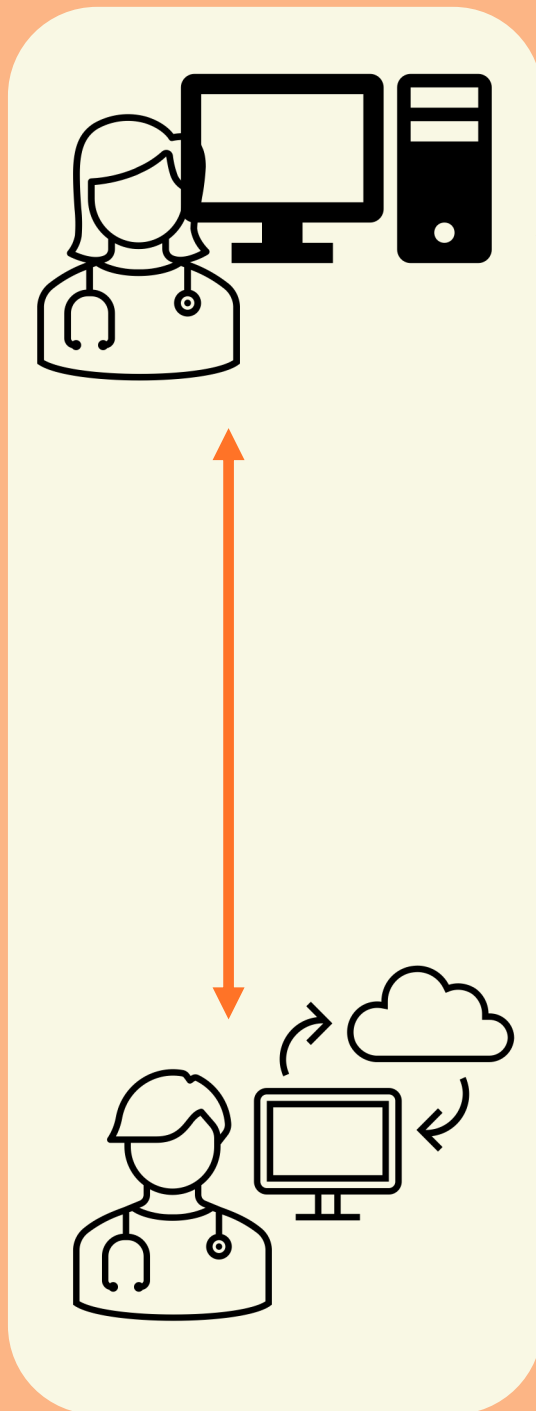


Single Provision Multiple Use/Reuse



# Improves clinician patient experience

- Agreed core data and agreed exchange formats
  - Enter data once, reuse many times across different use cases
  - Use of standardised clinical decisions support, Smart Forms and other knowledge related tools to support person centred care
  - Best of breed user tools made available through agreed interfacing with existing software



Enables exchange of data with meaning  
between clinical systems

- Agreed core data and agreed exchange formats
  - data can be meaningfully exchanged

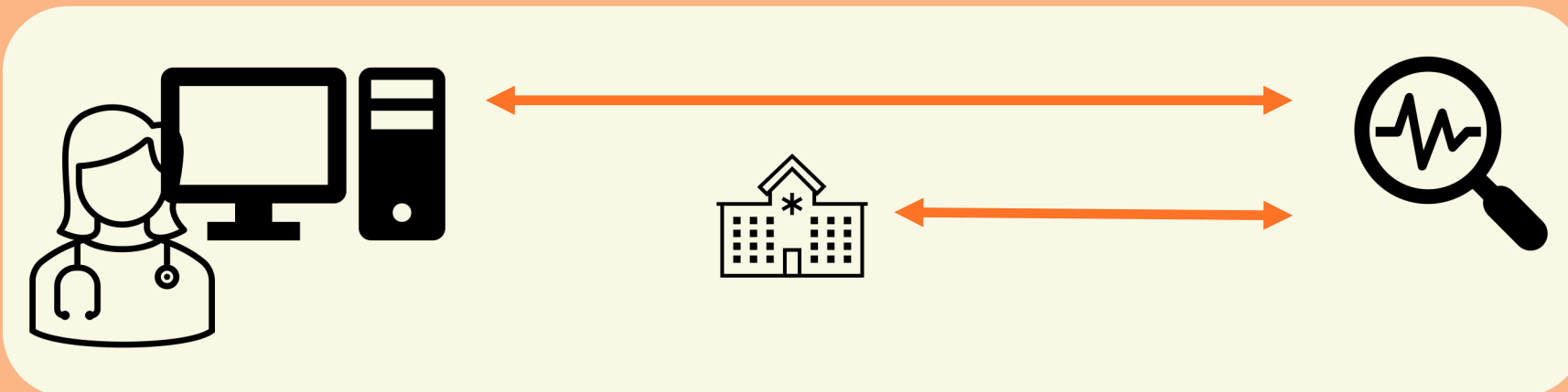


## Supports industry and innovation

- Agreed core data and agreed exchange formats
  - Standardised knowledge related activities such as common decision support tools and Smart Forms that can be used across systems, rather than a unique one per project or implementation
- Provides a ready-made library of information models, questionnaire modules, value sets that can fast-track the development of new clinical systems, forms, applications or projects.
- Allow best of breed, value add software to be built agnostic of existing systems and then used together as “plug and play”

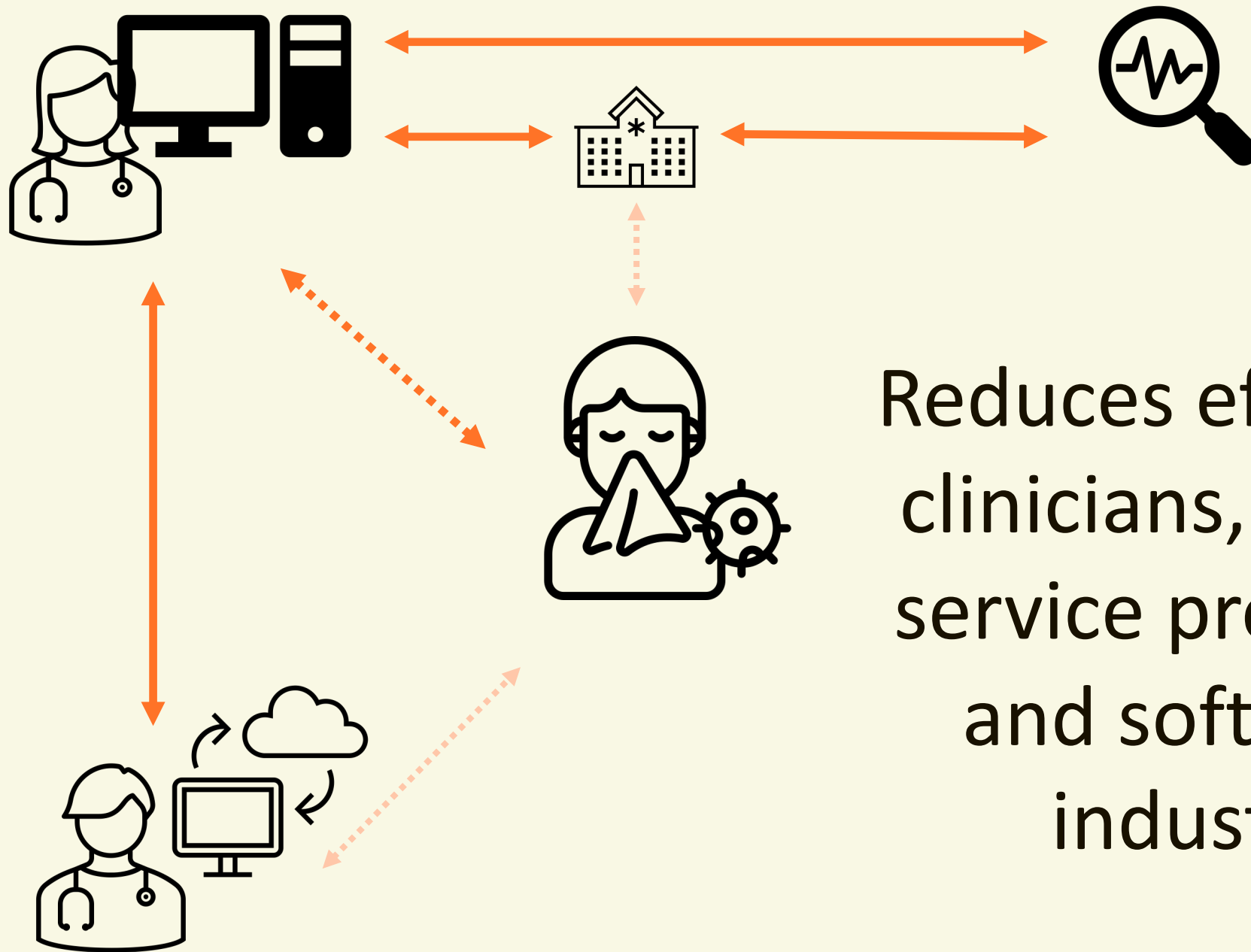




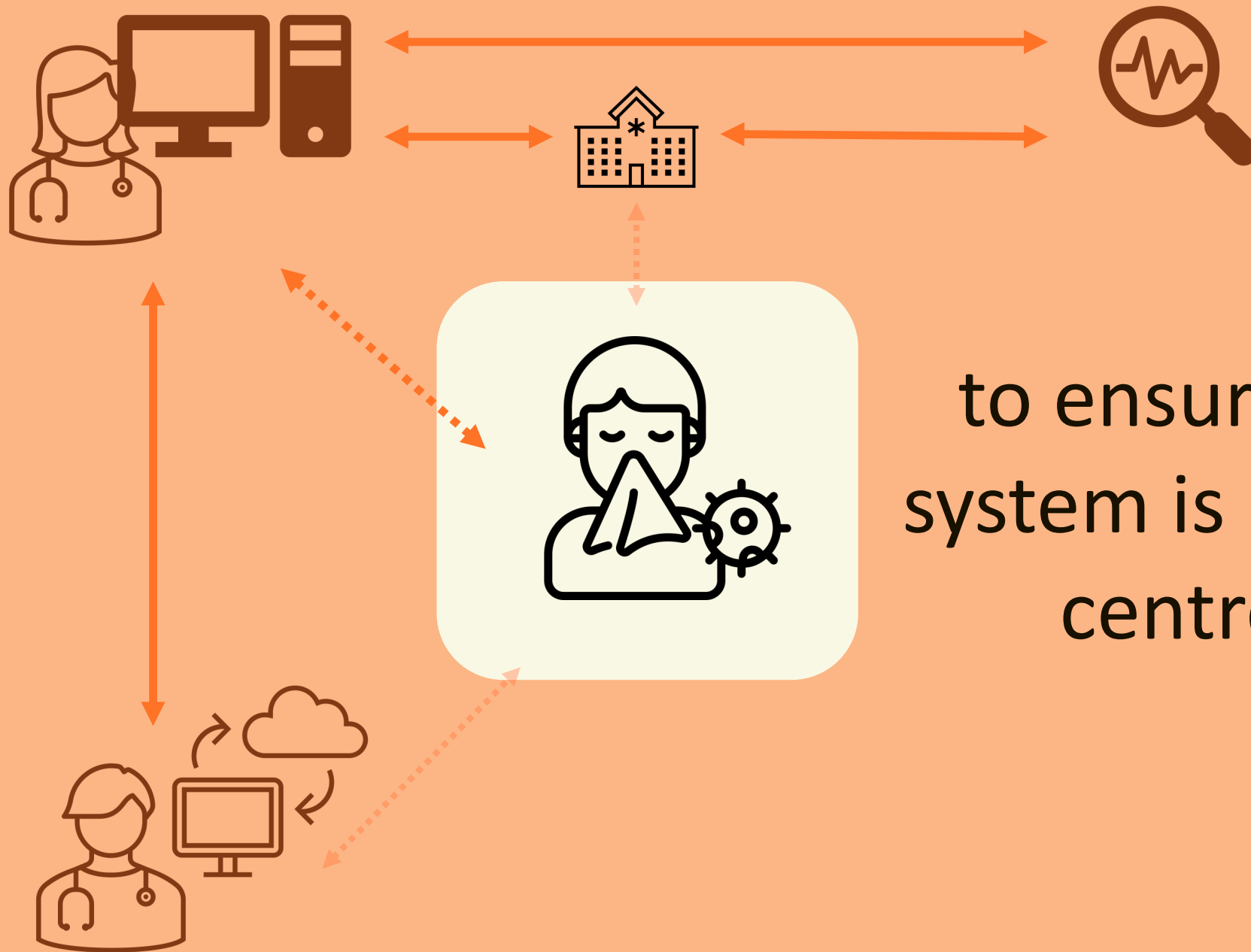


## Supports population health, reporting and analytics

- Agreed core data and agreed exchange formats
  - Supports interrogation of data sets using standardised queries, resulting in consistent data results
  - Supports safer and more accurate extracts, aggregation and analysis of data (assuming appropriate privacy, consent and authorisation)



Reduces effort for  
clinicians, health  
service providers  
and software  
industry



to ensure the  
system is person  
centred

# Workshop 1

# NHI project update

NT Health

NT HEALTH

# Expansion of NHIs within NT Health

# Steve Schatz,

## Clinical Engagement & Design Support Lead

# Office of the CCIO



# NHI Uptake Improvement Project Vision:

To have a compliant & unified healthcare system in the Territory that is empowered by National Health Identifiers (NHIs) to deliver seamless, coordinated care for all, fostering improved patient outcomes and a more efficient healthcare ecosystem.  
(aka “Get healthcare providers and patients to use NHIs more”)

## Key project objectives:

1. Compliance with ACSQHC’s standard (see advisory [AS18/11](#)) & national legislation (negating reliance on exemptions)
2. Improved identification, communication & more seamless patient handovers
3. Better inter-agency, organisation and cross-border information sharing
4. Enhanced data interoperability & analytics
5. Optimised resource allocation & utilisation

# Phased approach:

PHASE	Description
1	Enrich current external messages with NHIs (with National Portals & also intersystem messaging)
2	Embed NHI visibility & use into core EMRs
3	Implement new messages (to NT Health) for specified documents posted to MHR <i>(dependant on capacity/resourcing)</i>
4	Create new MHR documents & functionality with ADHA using NHIs such as <i>(dependant on ADHA)</i>



# Phase 1:

	Description	Details
PHASE 1	Enrich current external messages with NHIs	<ol style="list-style-type: none"><li>1. Immediately <u>enforce HPI-I</u> for all current MHR uploads</li><li>2. Enhance <u>HI connections</u> for Core EMRs to validate/use/store NHIs.</li><li>3. Enrich existing external messages to <u>national repositories</u> letters, summaries, eResults, eReports, etc.</li><li>4. Include NHIs in existing <u>external messages</u> sent on SEMS.</li><li>5. Improve validations with HI service &amp; business partners.</li><li>6. Improve <u>CQI &amp; Supports</u>; Dedicated team, including the development of policies / procedures / dashboards, and other monitoring tools to support NHI adoption &amp; address failures.</li></ol>

# Phase 2:

	Description	Details
PHASE 2	Embed NHI visibility & use into core EMRs	<ol style="list-style-type: none"><li>1. <b><u>Display</u> NHIs appropriately in systems:</b> Acute Care (Acacia/CareSys/etc.) &amp; Primary Care (PCIS/CCIS/etc.)</li><li>2. <b><u>Print</u> NHIs on Paper/PDFs for:</b> Referrals, Letters, Summaries, Path/DI (Request &amp; eResults / eReports)</li><li>3. <b>Enhance onscreen / printed <u>lists</u> to include NHIs:</b> IHI / HPI-I / HPI-O</li><li>4. <b>Improve system <u>search</u> abilities using NHI's:</b> IHI / HPI-I / HPI-O</li><li>5. <b>Enrich Local &amp; National <u>reporting outputs</u>:</b> IHACPA / AIHW / National Data Linkage Programs.</li></ol>

# Phase 3:

	Description	Details
PHASE 3	Implement new messages (to NT Health) for specified documents posted to MHR (include NHIs)	<ol style="list-style-type: none"><li>1. Post NT Health APPs (Advance Personal Plans)</li><li>2. Post NT Health ACTS (Aged Care Transfer Summary)</li><li>3. Modulate integration architecture to support <u>matching</u> of NHIs provided on:<ul style="list-style-type: none"><li>· Incoming referrals</li><li>· Incoming eResults/eReports</li><li>· Incoming Specialist Letters, Discharge Summaries &amp; other hospital communications</li></ul></li></ol>

# Phase 4:

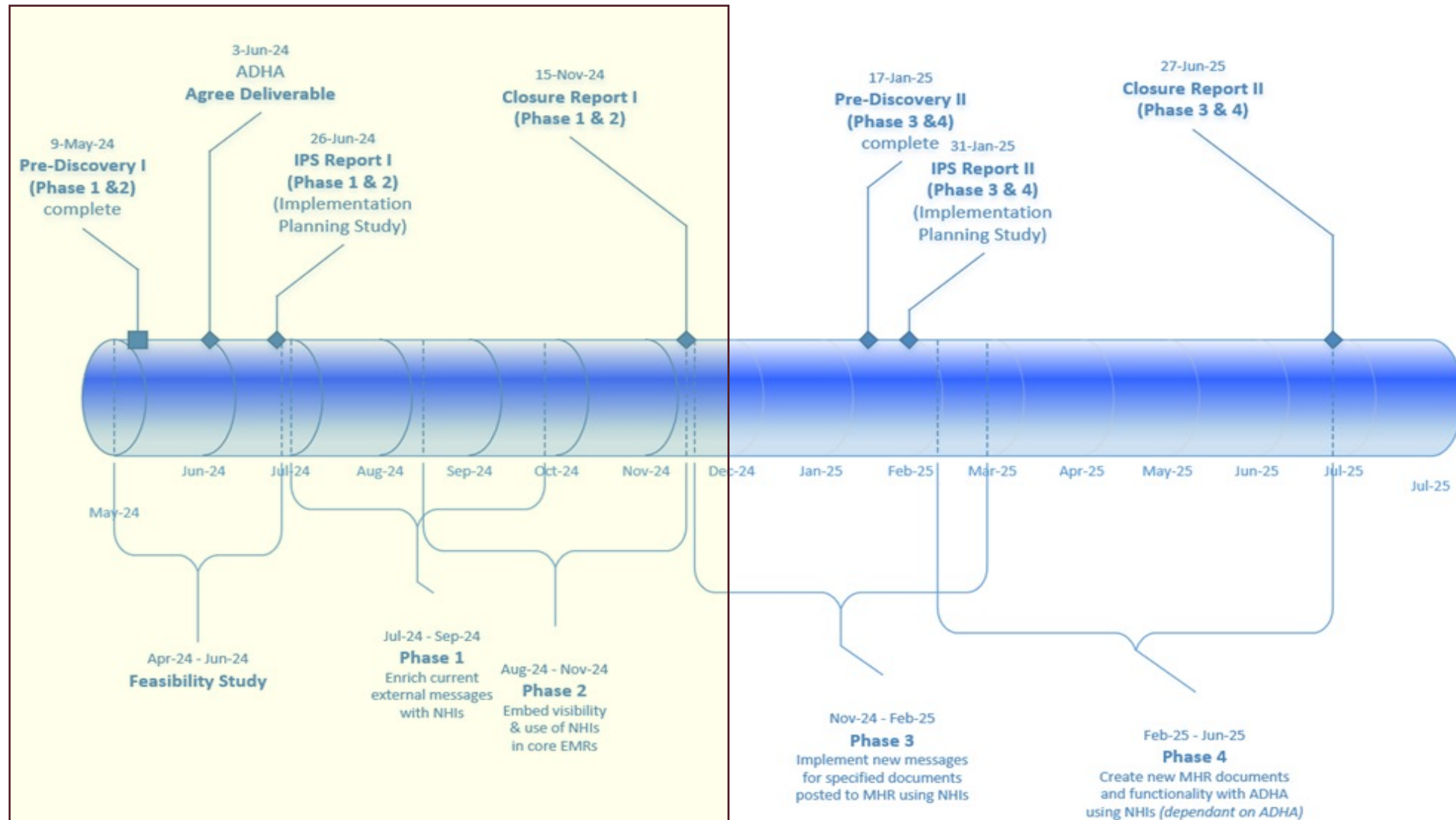
	Description	Details
PHASE 4	Create new MHR documents & functionality with ADHA using NHIs such as <i>(dependant on ADHA)</i>	<ol style="list-style-type: none"><li>1. Post <u>enriched content</u> PHC Medical Event Summaries to MHR. (i.e. consolidated notes)</li><li>2. Post current <u>eReferral's</u> to MHR.</li><li>3. Post current <u>Antenatal Summaries</u> to MHR.</li><li>4. Post all <u>eRequest's</u> to MHR (commencing with Path / DI).</li><li>5. Post "Other" major <u>hospital document</u> types to MHR (e.g., MDCPs, Letters and Summaries currently excluded).</li><li>6. Post current <u>OPD notifications</u> to MHR (SEMS Appts, Waitlist, DNAs, Attendances etc.).</li><li>7. Post &amp; Integrate systems with patient determined <u>Usual GP</u> (inc. concepts for Care Teams, Correspondence Manager, etc) drawn from MyHR (to improve validations, and semi-automatically determine recipients for NTH communications)</li></ol>



# Timelines

3

# NHIs Enhancement Project Timeline





# Workshop 1: Healthcare Identifiers (Australian Digital Health Agency)

- Improvements to healthcare identifier data matching and data quality improvements are key strategic activities outlined in the recently released National Healthcare Identifiers Roadmap 2023-2024.
- Objective: to help inform the Australian Digital Health Agency and Services Australia about IHI data matching challenges, lessons learned and recommended solutions for Aboriginal and Torres Strait Islander peoples and those in rural and remote areas.





Australian Government

Australian Digital Health Agency

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# Sparked rural and remote roundtable Healthcare Identifier Matching

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**Kieron McGuire, Monique Warren, Chris Genc**

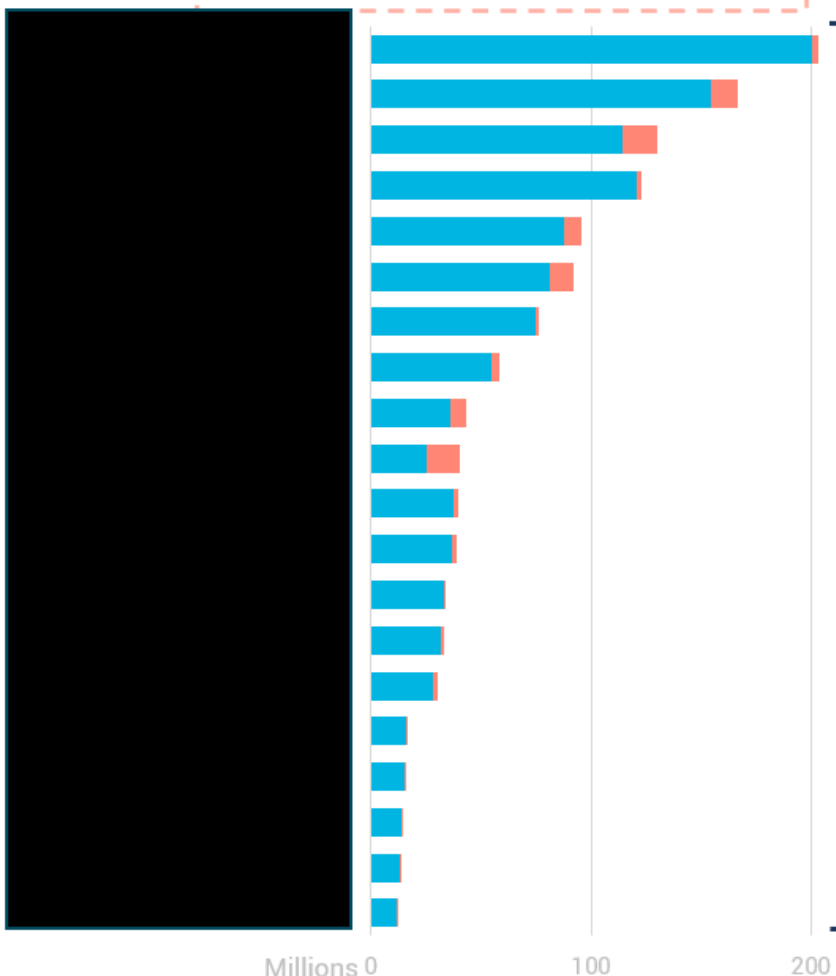


# Match rates by vendor and product.

## Insights

Top 20 Products by search volume

1



Most frequent error messages

3

Error Description	Total	%
Invalid Locality-Postcode-State	1,944,892	27.1%
Invalid Surname	1,911,532	26.7%
Invalid Firstname	1,561,535	21.8%
The IHI search request does not contain the minimum search criteria	558,015	7.8%
Failed Medicare card number check digit routine	253,507	3.5%
Invalid Address Line 1	187,242	2.6%
Invalid DVA file number	171,114	2.4%
Future DOB	156,935	2.2%
Invalid Locality	110,802	1.5%
Birth year less than 1800	96,640	1.3%
Other	220,419	3.1%

2

- 128 Vendor products accessing the HI Service over the reporting period, with the top 20 products representing **89%** of searches made.
- The three most frequent error messages account for **75.5%** of errors returned (**5.4 million**).
- The 10 most frequent error messages returned for these products tracks the most frequent error messages by all vendors (*see page 22*), with only slight changes to the order.
  - 44 different error message types returned across these 20 products (34 bucketed under the 'Other' Category).

Reporting Period: Jan '22 – April '24

\* Does not include "This IHI record has a RETIRED IHI status and cannot be retrieved via this channel message"

Match Found No Match Found

# OFFICIAL: Sensitive HPI-Os with highest search rates across the HI Service.

## Organisations with highest search volume



## Most frequent return messages

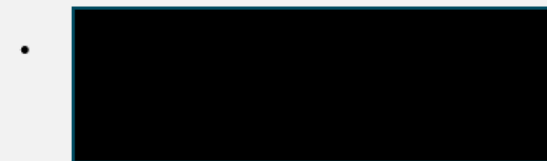
### Error Description

Total %

This IHI record has a RETIRED IHI status and cannot be retrieved via this channel	1,751,981	55.0%
The IHI search request does not contain the minimum search criteria	558,015	17.5%
Invalid Locality-Postcode-State	278,862	8.8%
Invalid Surname	204,063	6.4%
Invalid Firstname	123,156	3.9%
Failed Medicare card number check digit routine	95,696	3.0%
Future DOB	55,454	1.7%
Invalid Address Line 1	38,762	1.2%
Birth year less than 1800	27,731	0.9%
Invalid Locality	17,294	0.5%
Other	32,461	1.0%

## Insights

- **20,296** unique users (organisations) accessed the HI Service over the reporting period.



- Error message 'The IHI search request does not contain the minimum search criteria' is up from **7.5%** when compared to total messages sent by all vendors (see page 22).

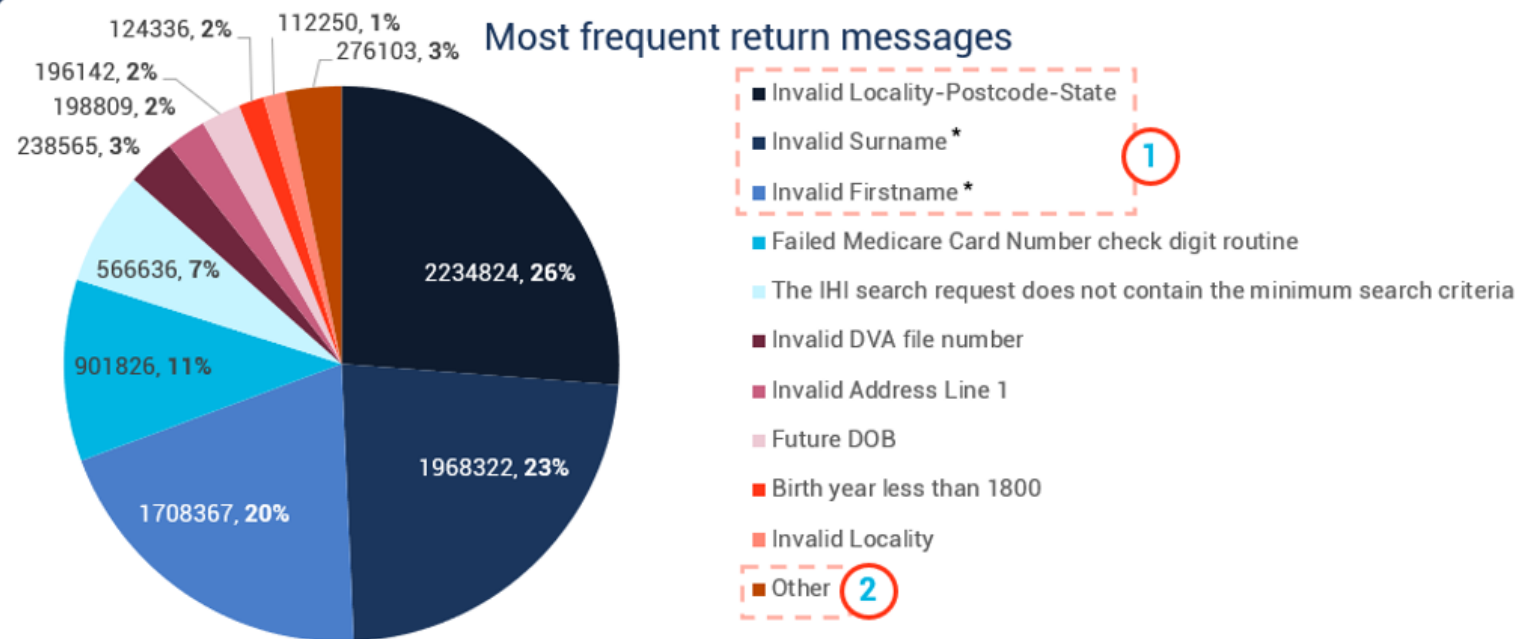
- Top 20 organisations by no match found rate, and utilises software in the top 20 products by no match rate

Reporting Period: Jan '22 – April '24

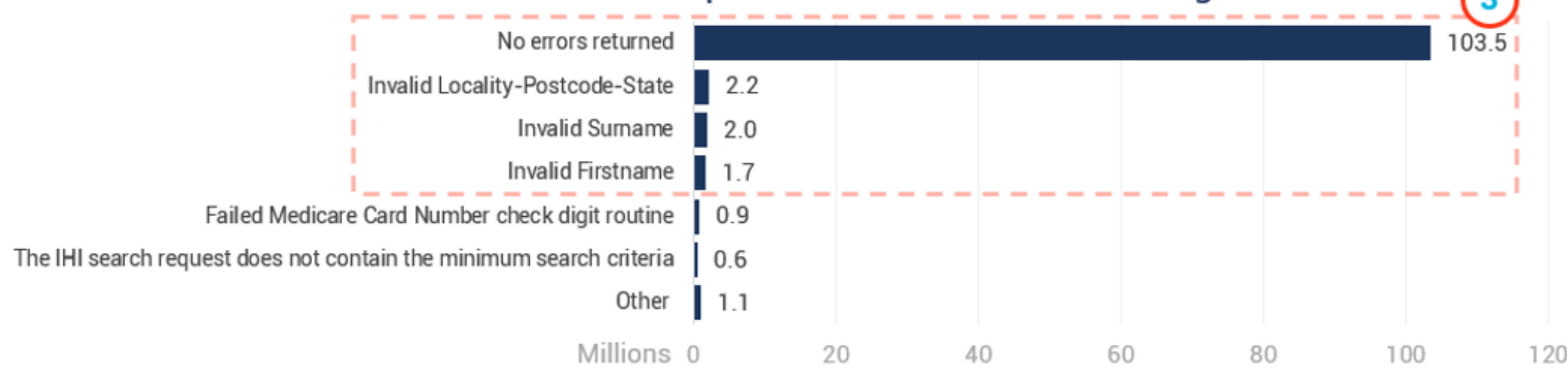
\* Blank Org means there was an issue with the joining table in the data warehouse and the org could not be extracted

Match Found No Match Found

## Most common error messages returned to users.



### Most frequent 'No Match' error messages



\* Note: error returned due to invalid characters being included in the search field  
Reporting Period: Jan '22 – April '24

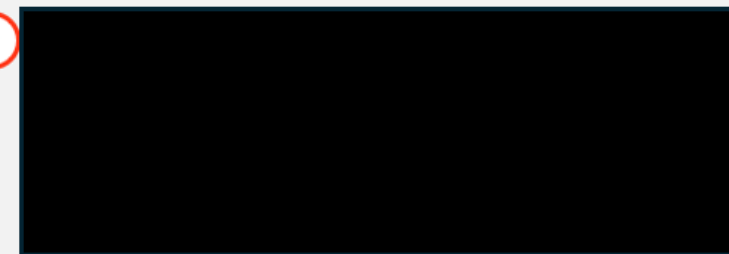
## Insights

- The 'Match Found' return message "This IHI record has a **RETIRED IHI status and cannot be retrieved via this channel**" is not included in the chart but represents **46%** of all messages returned to a user (7,306,556 returned over the reporting period).

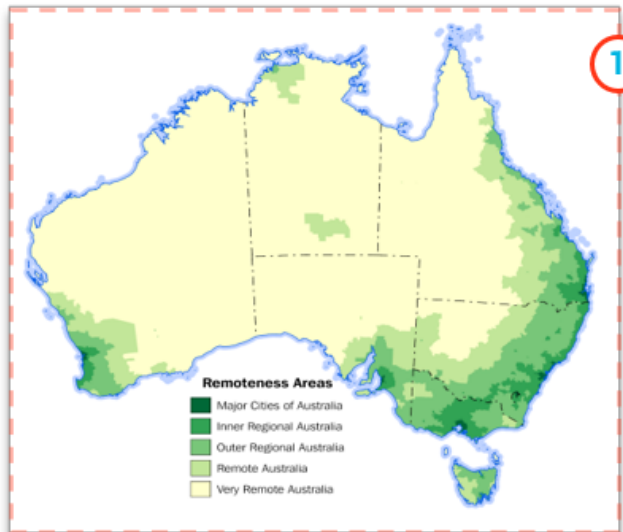
1 Combined, the entering of an **Invalid Postcode, Surname** and **First name** represent **69%** of all errors returned to users.

2 There are **40** distinct return messages grouped into the '**Other**' category, which combined represent **3%** of all messages returned over the reporting period.

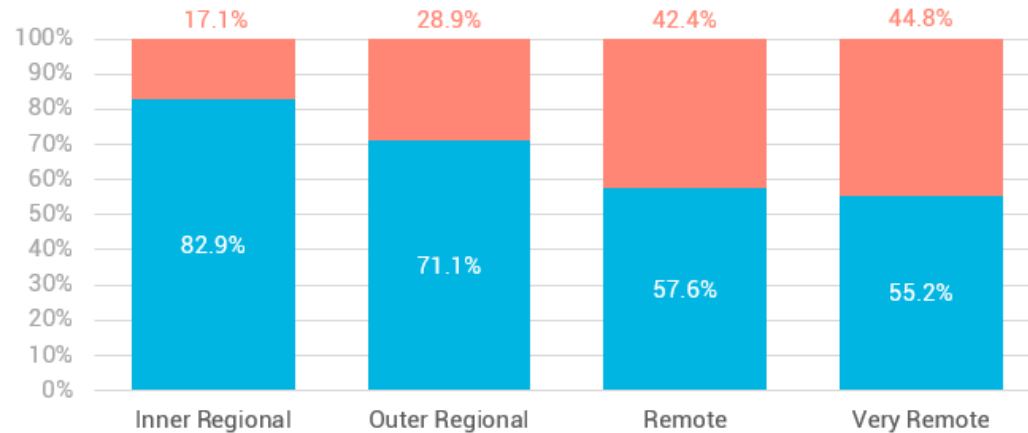
3



# Medicare card number search match rates for organisations in regional, rural and remote areas are significantly lower than the overall match rate average.



Match rates by Remoteness Area (%) - Medicare <sup>2</sup>



## Insights

- Definition of Regional, rural and remote are based off ABS designations, and a sample of **776** organisations were selected from these areas for analysis, based on some assumptions\*.
- When including all search types, match rates for Inner Regional, Outer Regional, Remote and Very Remote are all within the expected range when compared to the overall Australian average; however, when viewing solely Medicare card number searches, the rates are significantly below the average (*Total Medicare average is 20% - see page 20*).
- General trend when looking at all search types is the more remote/less population dense the area a clinic is located, the lower the match rate is. This is especially so for Medicare card number searches.

<sup>3</sup>

Match Found %

No Match Found %

# The challenge

Digital health systems must query the HI Service to find a patient's IHI using the patient's identifying information:

- name;
- date of birth;
- Sex; and
- either Medicare card+IRN or DVA file number\*.

Failures can occur due to:

- Differences in name
- Differences in dates of birth
- Unavailability of Medicare card / DVA file numbers



# The ultimate challenge

How can we find an IHI for someone if:

- We don't know the name on their Medicare/IHI record
- We don't know the date of birth on their Medicare/IHI record
- They don't have their Medicare card with them
- They don't have a personal digital device



# Meeting the challenge

## What we have done

- Soft-matching introduced in 2016

## What we are doing

- Introducing additional search options
- Allowing additional names and an alternate date of birth

## What we are considering

- Commence the evaluation of phonetic matching of names in online searches with a view to potential future use.
- Explore the integration of Healthcare Identifiers into the Australia Government Digital Identity System - so that patients can present a Digital Identity with their IHI attached.



# Enhanced search options

- Ignore sex when searching with Medicare card / DVA file number
- Add additional names on behalf of a known patient
- Add an alternate date of birth on behalf of a known patient
- Search using a mobile phone number or email address in place of a Medicare / DVA file number\*

\*Note that soft-matching rules will apply when a mobile phone number is used, but not when an email address is used





# Enhanced search options - timeline

- June 2024: changes deployed into production
- October 2024: Conformance profile draft for stakeholder consultation
- July 2025: Software developers can declare conformance and apply for Notice of Connection to use the new capabilities



# Discussion topics

- Using the new HI Service features to improve on current state
- Blue sky thinking – beyond current state



# Discussion – new HI Service features

- How might you take advantage of the enhanced search options to improve IHI matching for your patients?
- How can the Agency best support you to do this?
- Can you foresee any unintended consequences of these enhanced search options?
- What else can we do to improve IHI matching in remote and rural communities?



# Discussion – blue sky thinking

- Cultural practices
- Patient cohorts with unique challenges
- Duplicate IHIs
- Successful solutions
- HI Service FHIR uplift
- Lessons learned
- Additional barriers to a successful IHI match



## Further feedback and ideas:

Email: [interoperability@digitalhealth.gov.au](mailto:interoperability@digitalhealth.gov.au)



**Australian Government**

**Australian Digital Health Agency**



Australian Digital Health Agency



@AuDigitalHealth



@AuDigitalHealth



# Workshop 2



# Workshop 2: Barriers and Opportunities with data standardisation in rural and remote Australia

## Objectives:

- To ensure that the data foundations being developed by Sparked reflect the priority use cases and data elements for rural and remote Australia
- Understand rural and remote perspectives on connected care use cases
  - Patient summary (portability of record)
  - Chronic disease management
- Identify and prioritise data elements for AUCDI to support rural and remote

# Perspectives

Chris Pearce & Andrew Bell

Australian College of Rural & Remote Medicine

Northern Territory Health

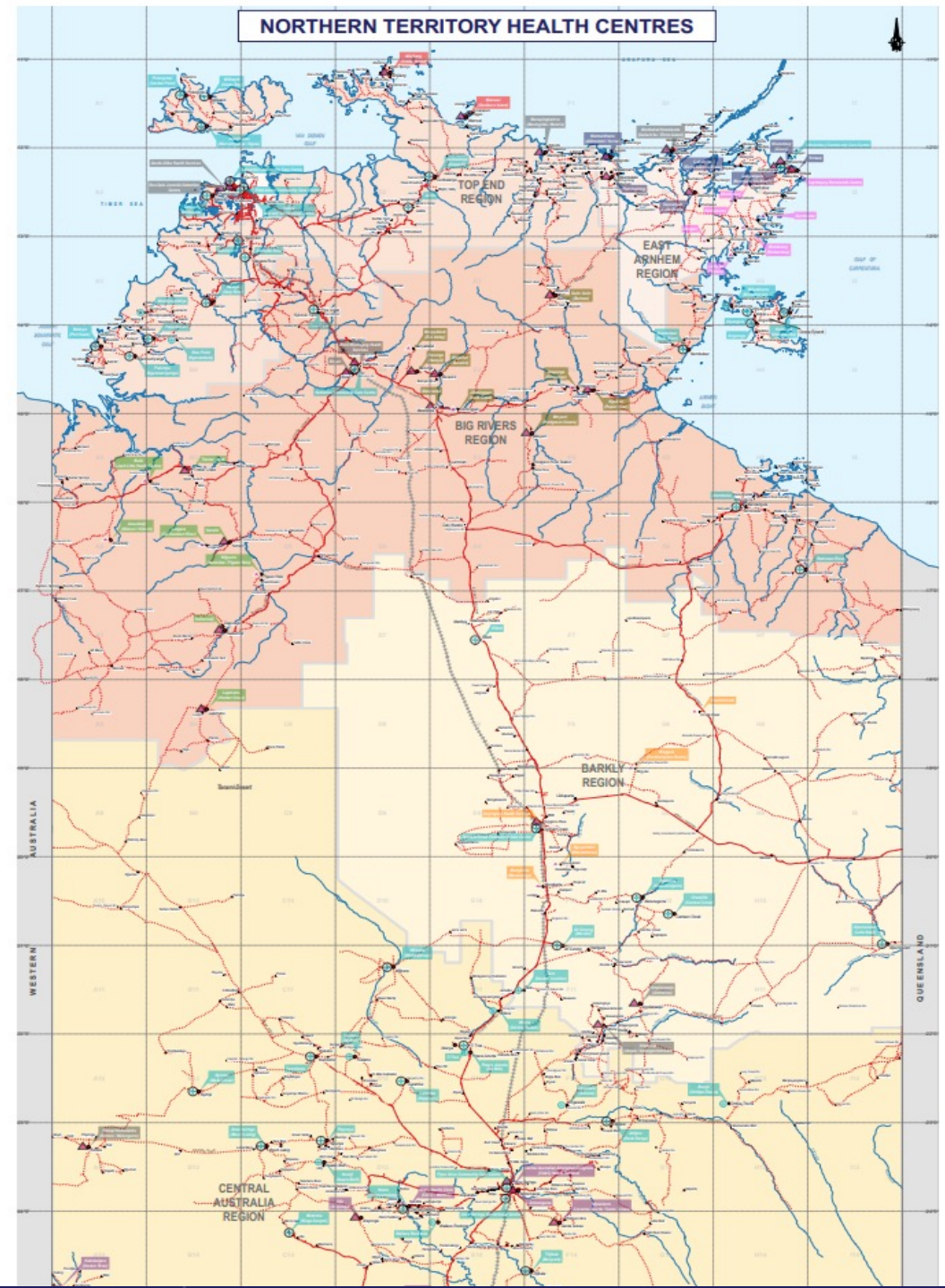


NT HEALTH

How will FHIR make  
clinician's days better?

How will it improve  
patient care?

Dr Andrew Bell / Office of the CCIO







# Remote Health Landscape:

1. Socially and economically disadvantaged population, high burden of chronic illness, requiring complex systematically planned care, often mobile between PHC providers.
2. Large temporary population, “health care home” elsewhere
3. Travelers, often with complex care needs.

# How could FHIR make things better:

Three examples:

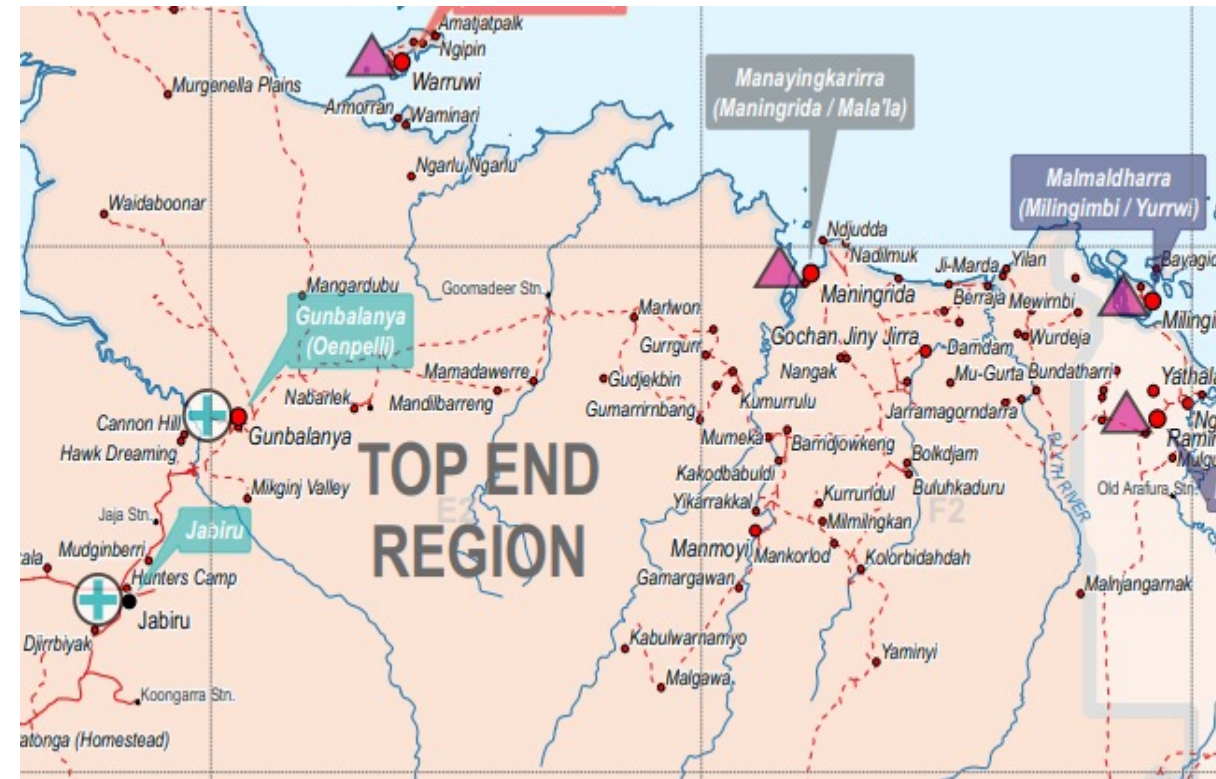
- Two low hanging fruit
  - One great for providers
  - One great for system designers
- One a harder nut to crack but very high value to consumers.

# Example 1: Patient Summary

Patient moves from Maningrida (Mala'la Health Service - *Communicare EHR*) To Gunbalanya (NTG - *PC/SEHR*)

Now:

Faxed summary or emailed PDF  
Manual Transcription





# Example 1: Patient Summary

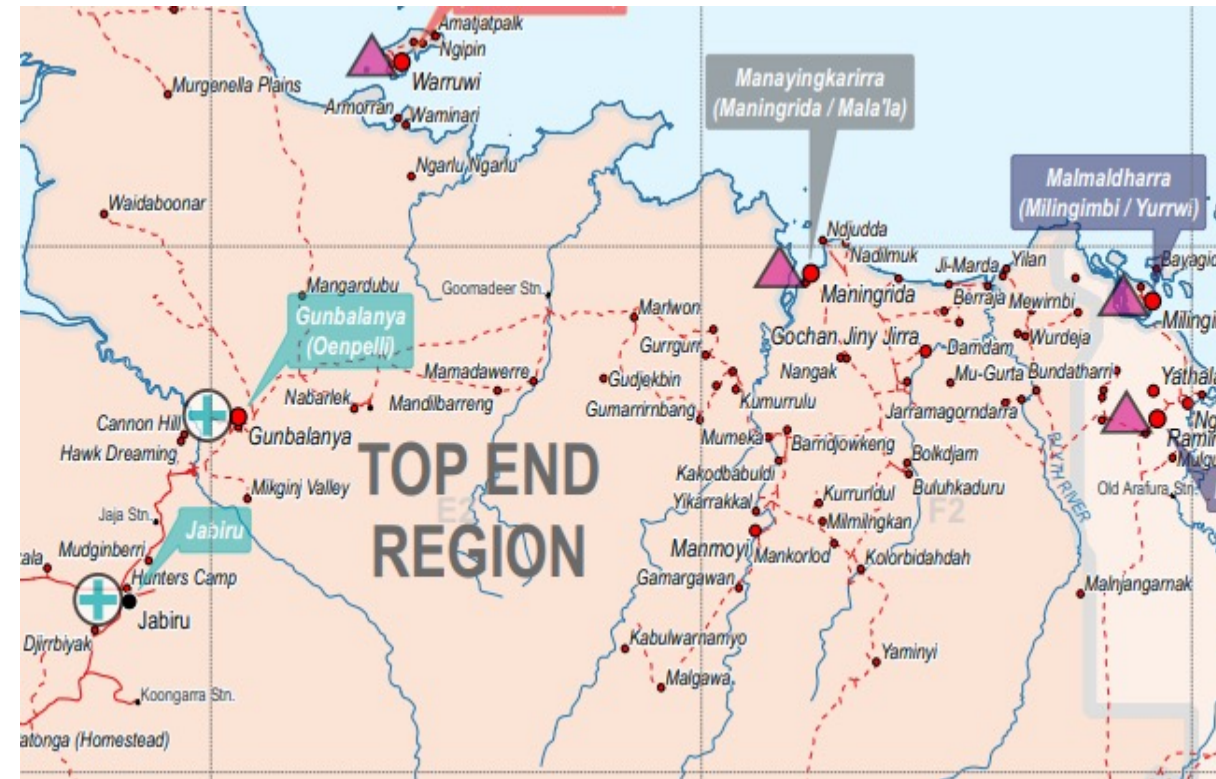
Patient moves from Maningrida (Mala'la Health Service - *Communicare EHR*) To Gunbalanya (NTG – *PCIS EHR*)

Now:

Faxed summary or emailed PDF  
Manual Transcription

FHIR future world:

eRequest standardised summary  
Data ingested into requesting system



# Example 2: Decision Support

## 1. Cardiovascular Risk Calculator

**Australian NT CVR Calculator: ref CARPA**

Name : **Zzzconnectit, My Ehealth Sehr**

HRN: **2042424**

DOB : **5/05/1972**

Gender : **Female**

Age (yrs): **52**

Ethnicity: **either Aboriginal Nor TSI**

TC/HDL: **2.50** No data in PCIS

Smoking Status : **Non-Smoker** 13/04/2016

Blood Pressure : **145**  
**over** 15/08/2017  
**75**

Hx of Angina, Heart Attack,  
Stroke or Bypass Surgery: **No**

Alb/Creat Ratio : **5**

Atrial Fibrillation : **No**

eGFR : **40**

**Calculate**

**Five year CVD Risk : **30.00%****

**High Risk**

**Risk Calculator A**

- Adults without diabetes
- Non-indigenous adults
  - \* 65yrs and under
  - \* Over 65yrs and no AF

≥ 30%

25-29%

20-24%

16-19%

10-15%

5-9%


<5%

High Risk

Moderate

Low Risk

56

 **NORTHERN  
TERRITORY**  
GOVERNMENT

# Example 2: Decision Support

## 1. Cardiovascular Risk Calculator: New NHF guidelines

1 Enter variables

2 Consider reclassification factors

3 Discuss risk result & management

This risk assessment is recommended for the following individuals without known atherosclerotic cardiovascular disease:

- All people aged 45-79 years
- People with diabetes aged 35-79 years
- First Nations people aged 30-79 years (assess individual risk factors 18-29 years).

Clinically determined high risk\*

Clinical conditions that automatically confer high risk. If either of these apply, you will be redirected to management for high risk category

☐ Moderate-severe chronic kidney disease ?

☐ Familial hypercholesterolaemia ?

☐ Neither present

Age\* ?

Enter age 30-79

Years

Sex at birth\* ?

☐ Female

☐ Male

Smoking status\*

☐ Never smoked

☐ Previously smoked

☐ Currently smokes

Systolic blood pressure\* ?

SBP

mmHg

Ratio of total cholesterol to HDL cholesterol\* ?

Ratio of total cholesterol to HDL cholesterol

OR enter mmol/L

Use of CVD medicines within last 6 months\*

☐ Blood pressure-lowering medicines ?

☐ Lipid-modifying medicines ?

☐ Antithrombotic medicines ?

☐ None

History of atrial fibrillation ?

☒ No

☐ Yes

Postcode ?

Enter postcode to generate SEIFA quintile

Diabetes\* ?

☐ No

☐ Yes

Calculate

Please see our privacy statement [here](#)

Risk Calculator A

- Adults without diabetes

- Non-indigenous adults

\* 65yrs and under

\* Over 65yrs and no AF

≥ 30%

25-29%

20-24%

16-19%

10-15%

5-9%

<5%

High Risk

Moderate

Low Risk



# Example 2: Decision Support

## 1. Cardiovascular Risk Calculator: New NHF guidelines

Now:

new builds of complex calculator  
in each product

FHIR future world:

National heart Foundation releases  
FHIR enabled calculator with new  
guidelines

1 Enter variables

2 Consider reclassification factors

3 Discuss risk result & management

This risk assessment is recommended for the following individuals without known atherosclerotic cardiovascular disease:

- All people aged 45-79 years
- People with diabetes aged 35-79 years
- First Nations people aged 30-79 years (assess individual risk factors 18-29 years).

**Clinically determined high risk\***  
Clinical conditions that automatically confer high risk. If either of these apply, you will be redirected to management for high risk category.

☐ Moderate-severe chronic kidney disease ?

☐ Familial hypercholesterolaemia ?

☐ Neither present

Age\* ?  Years

Sex at birth\* ? ☐ Female ☐ Male

Smoking status\* ☐ Never smoked ☐ Previously smoked ☐ Currently smokes

Systolic blood pressure\* ?  mmHg

Ratio of total cholesterol to HDL cholesterol\* ?   
OR enter mmol/L ▾

Use of CVD medicines within last 6 months\* ☐ Blood pressure-lowering medicines ? ☐ Lipid-modifying medicines ? ☐ Antithrombotic medicines ? ☐ None

History of atrial fibrillation ? ☒ No ☐ Yes

Postcode ?

Diabetes\* ? ☐ No ☐ Yes

**Calculate**

Please see our privacy statement [here](#)

### Risk Calculator A

- Adults without diabetes
- Non-indigenous adults
  - 65yrs and under
  - Over 65yrs and no AF

≥ 30%	High Risk
25-29%	
20-24%	
16-19%	
10-15%	Moderate
5-9%	
<5%	Low Risk

# Example 3: Complex Care Plans

Client with complex care needs  
moves from Gunbalanya (NTG) to  
Ngukurr (Sunrise Health Service)

Plan of care is in Gunbalanya, no  
visibility from Ngukurr



# Example 3: Complex Care Plans

Client moves from Gunbalanya to Ngukurr

Now:

The best we can do is an inadequate document  
or start from scratch:

FHIR future world?

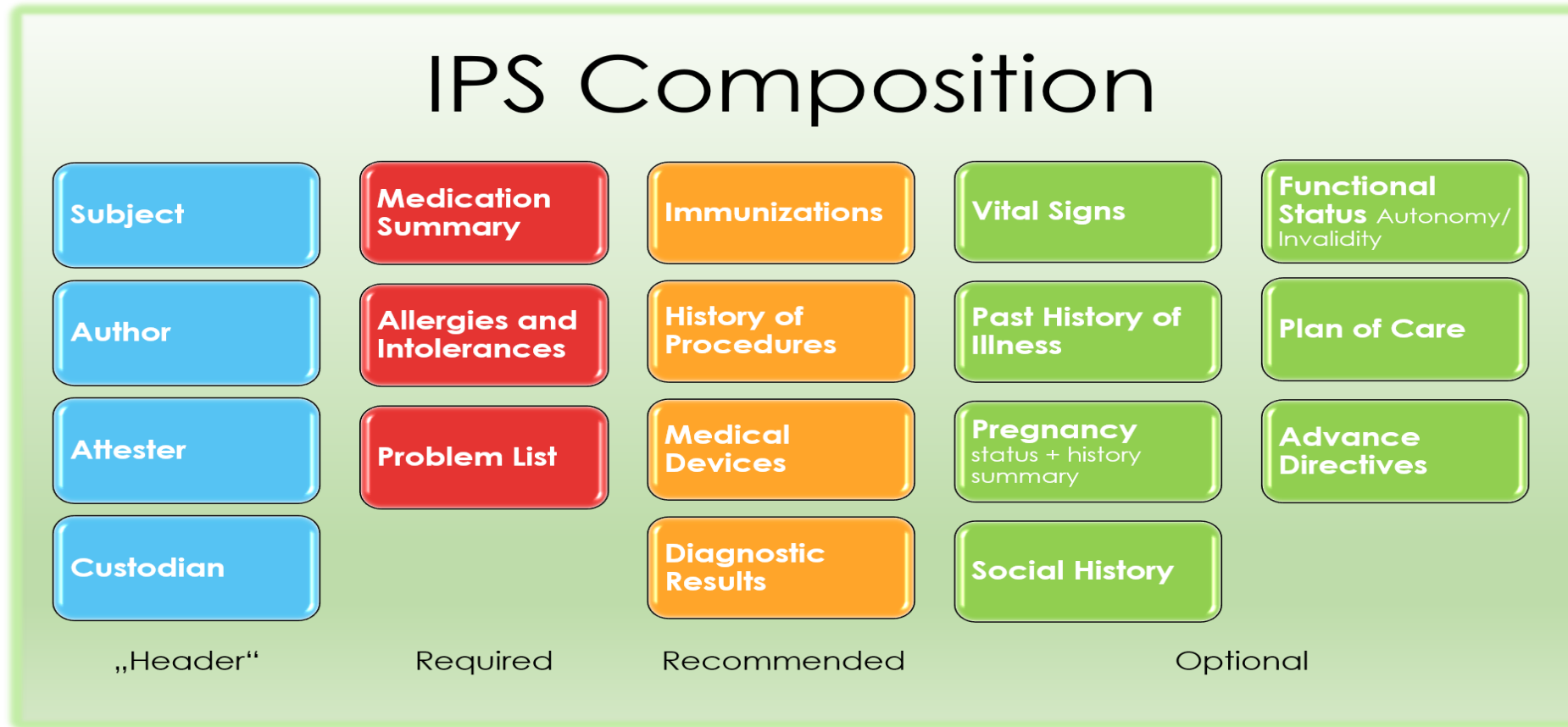
Detailed transfer of past events, planned  
future care, goals, care team members,  
updates...

A plan for a patient, not a provider

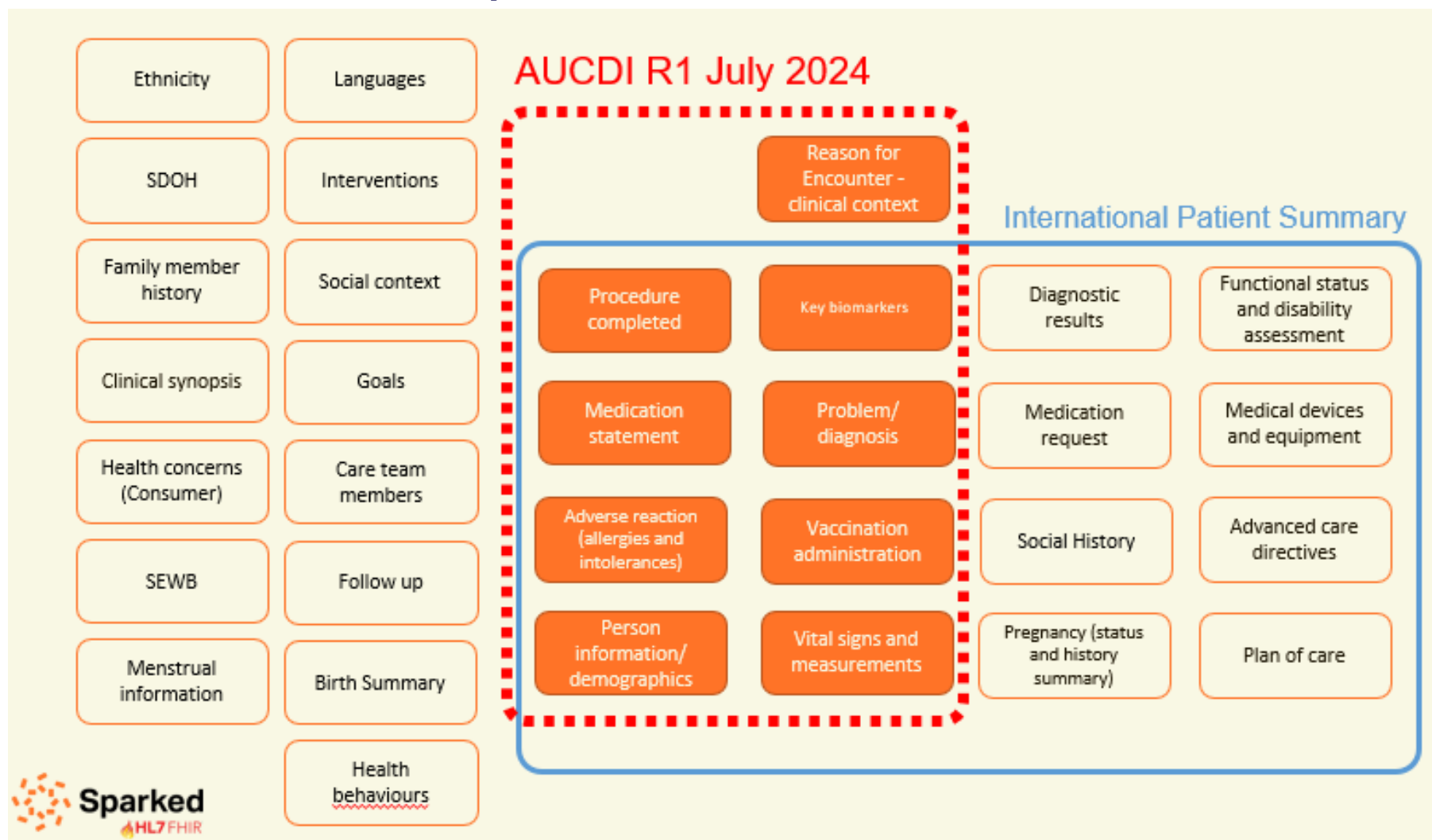
Clinical Management Plan					
AHC (715), GPMP (721), TCA (723) AND TCA/GPMP REVIEW (732)					
<a href="#">Back to Full Summary</a>		HRN: 1234567		DOB: 1/01/1970	
Plan developed for:		*****			
Date of Plan:		2/01/2024		Address: Gunbalanya, 0822	
Date next Review:		2/06/2024			
				Signed by Doctor	
Smoking Nutrition Alcohol Physical Activity					
PHYSICAL EXAM		Result	Date	BLOOD TESTS	
Weight (Kg):		112.6	1/01/2024	HbA1c (long sugar):	
BMI:		41	1/01/2024	Total Cholesterol:	
Waist Circumference:		125	1/01/2024	HDL Cholesterol:	
Blood Pressure:		113/71	1/01/2024	LDL Cholesterol:	
Random Glucose:		8		ACR: (kidney):	
Cardiovascular Risk:		High		eGFR: (kidney):	
Comment:				Uric Acid: (Gout):	
EXAMINATION BY DMO/GP/SPECIALIST					
Action Plan:					
PROGRESS/FEEDBACK					
PERSONAL HEALTH GOALS					
Goal 1: Daily walk to shop or billabong, or hunting					
Goal 2: Decrease weight by 5kg over next 6 months					
Goal 3: Maintain smoking cessation					

# Example 1: Patient Summary

## International Patient Summary



# Patient Summary





# AUCDI R1: CVR calculator?

<b>Problem/Diagnosis</b> <ul style="list-style-type: none"><li>• Problem/diagnosis name</li><li>• Body site/laterality</li><li>• Status</li><li>• Comment</li><li>• Last updated</li></ul>	<b>Adverse reaction risk summary</b> <ul style="list-style-type: none"><li>• Substance name</li><li>• Manifestation/s</li><li>• Comment</li><li>• Last updated</li></ul>	<b>Sex and Gender Summary</b> <ul style="list-style-type: none"><li>• Sex assigned at birth</li><li>• Gender identity</li><li>• Pronouns</li><li>• Last updated</li></ul>	<b>Vital signs*</b> <ul style="list-style-type: none"><li>• Blood pressure<ul style="list-style-type: none"><li>• Systolic</li><li>• Diastolic</li></ul></li><li>• Pulse<ul style="list-style-type: none"><li>• Rate</li></ul></li><li>• Body temperature</li><li>• Respiration<ul style="list-style-type: none"><li>• Rate</li></ul></li></ul> <b>Measurements*</b> <ul style="list-style-type: none"><li>• Height/length</li><li>• Body weight</li><li>• Waist circumference</li></ul>
<b>Procedure completed</b> <ul style="list-style-type: none"><li>• Procedure name</li><li>• Body site/laterality</li><li>• Clinical indication</li><li>• Date performed</li><li>• Comment</li></ul>	<b>Medication use statement</b> <ul style="list-style-type: none"><li>• Medication name</li><li>• Form</li><li>• Strength</li><li>• Route of administration</li><li>• Dose amount and timing</li><li>• Clinical indication</li><li>• Comment</li><li>• Date of assertion</li></ul>	<b>Tobacco smoking summary</b> <ul style="list-style-type: none"><li>• Overall Status</li><li>• Last updated</li></ul>	<b>Encounter – clinical context</b> <ul style="list-style-type: none"><li>• Reason for encounter</li><li>• Modality</li></ul>
<b>Vaccination administered event</b> <ul style="list-style-type: none"><li>• Vaccine name</li><li>• Sequence number</li><li>• Date of Administration</li><li>• Comment</li></ul>		<b>Biomarkers*</b> <ul style="list-style-type: none"><li>• HDL</li><li>• LDL</li><li>• Total Cholesterol</li><li>• Triglycerides</li><li>• HbA1c</li><li>• eGFR</li><li>• uACR</li></ul>	

\*Each Biomarker, Vital sign and Measurement has a date of measurement or date of observation

# Care Planning

Complexity and a lot of work

Whose priorities will rise to the top?

## Backlog - extension to AUCDI R1

- new items

## Backlog – new items



Complexity and a lot of work

Whose priorities will rise to the top?





# Workshop 2: Barriers and Opportunities with data standardisation in rural and remote Australia

## Objectives:

- To ensure that the data foundations being developed by Sparked reflect the priority use cases and data elements for rural and remote Australia
- Understand rural and remote perspectives on connected care use cases
  - Patient summary (portability of record)
  - Chronic disease management
- Identify and prioritise data elements for AUCDI to support rural and remote



# What is the Australian Core Data for Interoperability (AUCDI)?

- Common data foundation for national interoperable health information exchange in Australia
- Incorporates and builds upon existing standards and prior work
- A living artefact that will evolve and grow in future iterations

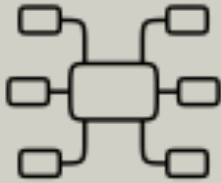
AUCDI provides the common data foundation that can be referenced for specific use cases, with data groups being reused and extended as necessary.



# What is AU Core and Australian Core Data set for Interoperability (AUCDI)?

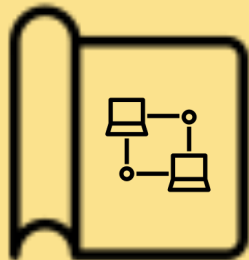
CDG is  
here

AU  
CDI



Specifies “*WHAT*” clinical information  
(and corresponding data elements and terms) should  
be included for data entry, data use and sharing  
information supporting patient care

AU  
Core



Specifies “*HOW*” the core set of data (above) and  
information should be structured, accessed and  
shared between systems

TDG is  
here



# AUCDI Release 1 Scope Drivers

Concepts for a health summary (guided by clinical content of IPS)

- Clinical content to underpin any type of health summary
- Transfer of care summary
- Chronic disease management
- Decision support – e.g. CVD risk
- Referral



# Core Principles of AUCDI Design

- 1 Reduce duplication - Single entry, single development (multiple use and reuse)
- 2 Supports patient centred care - driven by a clinical quality and safety use case
- 3 Not data for data's sake
- 4 Driven by primary clinical data use not secondary data use needs
- 5 Supports best practice care, clinical guidelines and clinician workflow
- 6 Systems can support now or with minimal effort, supporting a strategic roadmap with an agile iterative process
- 7 Leverage agreed national health data standards
- 8 Involve and consider all healthcare domains and care modalities



# “Core of the Core” AUCDI Release 1 at a glance

## Problem/Diagnosis

- Problem/diagnosis name
- Body site/laterality
- Status
- Comment
- Last updated

## Procedure completed

- Procedure name
- Body site/laterality
- Clinical indication
- Date performed
- Comment

## Vaccination administered event

- Vaccine name
- Sequence number
- Date of Administration
- Comment

## Adverse reaction risk summary

- Substance name
- Manifestation/s
- Comment
- Last updated

## Medication use statement

- Medication name
- Form
- Strength
- Route of administration
- Dose amount and timing
- Clinical indication
- Comment
- Date of assertion

## Sex and Gender Summary

- Sex assigned at birth
- Gender identity
- Pronouns
- Last updated

## Tobacco smoking summary

- Overall Status
- Last updated

## Biomarkers\*

- HDL
- LDL
- Total Cholesterol
- Triglycerides
- HbA1c
- eGFR
- uACR

## Vital signs\*

- Blood pressure
  - Systolic
  - Diastolic
- Pulse
  - Rate
- Body temperature
- Respiration
  - Rate

## Measurements\*

- Height/length
- Body weight
- Waist circumference

## Encounter – clinical context

- Reason for encounter
- Modality

# Federal Budget 2024-25

Continue work already underway to improve:

- consumer access to their health information.
- healthcare providers ability to provide safe, high quality care.

- Building on work underway via Australia's FHIR accelerator program - **Sparked** – planning work will be undertaken to establish:
  - a long-term **FHIR standards development roadmap**
  - a digital **Chronic Disease Management Plan**
  - an internationally consistent **patient summary**; and
  - capabilities to enable **reason for a health encounter** to be captured in clinical systems.
- Complete consultation and policy work to inform the business case for a future national **eRequesting** capability for Australia.
- Complete initial policy work to establish a national **electronic Clinical Decision Support** (eCDS) governance framework.







# Workshop 2 - Priorities for use and exchange of core data in Rural and Remote Australia

Activity 1: Refining the workflows and information (data flows)  
20mins, 10 mins report back

- Portability of record
  - Transfer of Care
  - Patient Summary
  - Reason for encounter
- Chronic Disease Management

Activity 2: AUCDI data model gaps  
10 mins

Activity 3: Individual prioritisation of AUCDI backlog  
10 mins

Activity 4: Group prioritisation of AUCDI backlog  
10 mins



# Activity 1: Refining the workflows and information (data flows)

As a group at your table, identify:

- What are the key priorities to support use of core data within your systems and to exchange that information.
  - For example:
    - GP Management plan
    - Health assessments
    - eReferrals
    - Encounter note
    - Clinical decision support
    - GP to Aged Care
    - Aged Care Transfer
    - Patient summary for inclusion in eRequesting, eReferral
    - International patient summary
    - Bulk FHIR for reporting- local , state, national
- Who is this information relevant for?
  - For example: The consumer, the provider, the broader care team...
- How could this information be best used?



As a **group**  
at your table



# Activity 2: AUCDI data model gaps

“Core of the Core” AUCDI Release 1 at a glance

## Problem/Diagnosis

- Problem/diagnosis name
- Body site/laterality
- Status
- Comment
- Last updated

## Adverse reaction risk summary

- Substance name
- Manifestation/s
- Comment
- Last updated

## Sex and Gender Summary

- Sex assigned at birth
- Gender identity
- Pronouns
- Last updated

## Vital signs\*

- Blood pressure
  - Systolic
  - Diastolic
- Pulse
  - Rate
- Body temperature
- Respiration
  - Rate

## Procedure completed

- Procedure name
- Body site/laterality
- Clinical indication
- Date performed
- Comment

## Tobacco smoking summary

- Overall Status
- Last updated

## Measurements\*

- Height/length
- Body weight
- Waist circumference

## Vaccination administered event

- Vaccine name
- Sequence number
- Date of Administration
- Comment

## Medication use statement

- Medication name
- Form
- Strength
- Route of administration
- Dose amount and timing
- Clinical indication
- Comment
- Date of assertion

## Biomarkers\*

- HDL
- LDL
- Total Cholesterol
- Triglycerides
- HbA1c
- eGFR
- uACR

## Encounter – clinical context

- Reason for encounter
- Modality



### Problem/Diagnosis summary

Date/time clinically recognised  
Date/time of onset  
Date/time of resolution  
Diagnostic certainty  
Method of diagnosis/Clinical evidence  
Practitioner role that confirmed the diagnosis  
Qualifiers  
Resolution phase  
Severity  
Staging/grading

### Biomarkers

Creatinine - clearance and serum levels  
ECG  
Full blood examination/count  
Lipids

- LDL formula
- Lipoprotein (a)
- TC:HDL ratio

Liver function tests  
Fasting insulin  
Blood glucose  
Folate/B12  
Iron studies  
Microbiota markers  
Nutrigenomics  
Thyroid function  
Vitamin D

### Encounter

Comment  
Type of encounter/modality  
Location/s  
Outcome

### Adverse reaction risk summary

Adverse reaction status  
Clinical management description  
Clinical status  
Clinical verification  
Criticality  
Date exposed to substance  
Dose/frequency and form  
Initial exposure  
Method of diagnosis/Clinical evidence  
Patient must avoid statement  
Reaction mechanism  
Severity  
Status  
Timing and duration of exposure  
Type/Category  
Type of reaction  
Verification status  
reaction event

- Date of manifestation
- Dosage
- Formulation and strength
- Delabelling
- Time/timing exposure to

Adverse reaction – authoring clinician  
Immunogenic testing

### Procedure completed event

Description  
Intent  
Total duration  
Location performed  
Procedure status

### Tobacco smoking summary\*

Amount  
Cessation  
Cigarette smoking  
Comment  
Daily smoking started  
Frequency  
Overall pack years  
Pattern  
Previous episodes of use  
Quit date  
Regular smoking started  
Years of smoking



### Medication use statement

Administration aid  
Endpoint  
Episode type  
First prescribed date/Medication start date  
Identify medications used in combination  
Infusion - related data  
Last administration  
Medication Details  
Medication details  
Medication History concepts  
Preferred brand  
Regular medication indicator  
Status for changes  
Reason for prescribing  
Regular medication

### Sex and Gender

Sex parameter for clinical use

### Vital signs

Blood pressure

- Location of measurement
- Mean arterial pressure
- Method (of measurement)
- Position
- Ambulatory, acute (exceptional)

Body temperature

- Comment
- Location of measurement

Blood glucose  
Heartbeat  
Oxygen saturation  
Peak expiratory flow rate (PEFR)  
Pulse

- Body site
- Method (of measurement)
- Regularity
- Rhythm

Respiration

- Body position

### Measurements

Calculated body weight  
Body weight

- Device

BMI

### Vaccination administered event

Batch Number  
Body site  
Route of administration  
Target disease  
Vaccine serial ID

**Advanced care directive****Adverse event****Alcohol consumption summary** ★**Birth summary**  
Place of birth**Care pathways****Care plan****Care team members**Name  
Organisation  
Role  
Contact  
CC option**Clinical evidence****Clinical synopsis**Author  
Summary (free text)**Communication capability\***

Languages spoken ★

**Contraindication****Estimated Date of Delivery (EDD)****Diagnostic test results**Arterial blood gases  
Cardiac imagery  
Colonoscopy  
ECG  
Full blood examination  
Gastroscopy  
Genetic/genomic test results  
Imaging results  
Imaging test results – echocardiography  
Path test results  
Path test results – histology  
Spirometry**Diet****Drug interactions****Education summary\***

Education level ★

**Ethnicity\***

Aboriginal and Torres Strait Islander status ★

**Family history****Family member history****Financial summary\***Finance  
Income  
Social economic (?) ★**Food and nutrition summary\***Diet  
Food security ★**Functional status and disability assessment****Genetic/genomic test results**Genetics  
Epigenetics**Goals**Frequency  
Function impact  
Measureable time frame/SMART  
Preventative nutrition goals  
Relevant supports**Health concerns****Health equity summary\***Access of care  
Distance from care  
Health literacy/numeracy ★**Housing summary\***Housing  
Housing status  
Rurality ★**Imaging completed****Imaging results****Informed Consent****Living arrangements\***Household  
Residential setting ★**Medical devices****Medication order****Medication summary**

# Backlog – new items

## Menstrual information

Last menstrual period  
Menstrual status

## Obstetric summary

Gravidity/Parity

## Occupation summary

Occupation

## Pathology results

## Personal safety summary\*

Childhood trauma



## Physical activity summary\*



## Pregnancy

Examinations  
Progress  
Risk (level)  
Start of pregnancy

## Pregnancy summary

## PREMs and PROMS

## Product errors

## Pulse oximetry

FiO2  
SpO2

## Screening activity completed

## Service request

Follow up

## Sexual characteristics

## Shock index

## Side effect register

## Social determinants of health and Social emotional wellbeing

Groups marked with a \*

## Social network\*

Carer  
Next of Kin  
Relationships



## Substance use summary



## Transport summary\*

Transport access



## Vaping summary

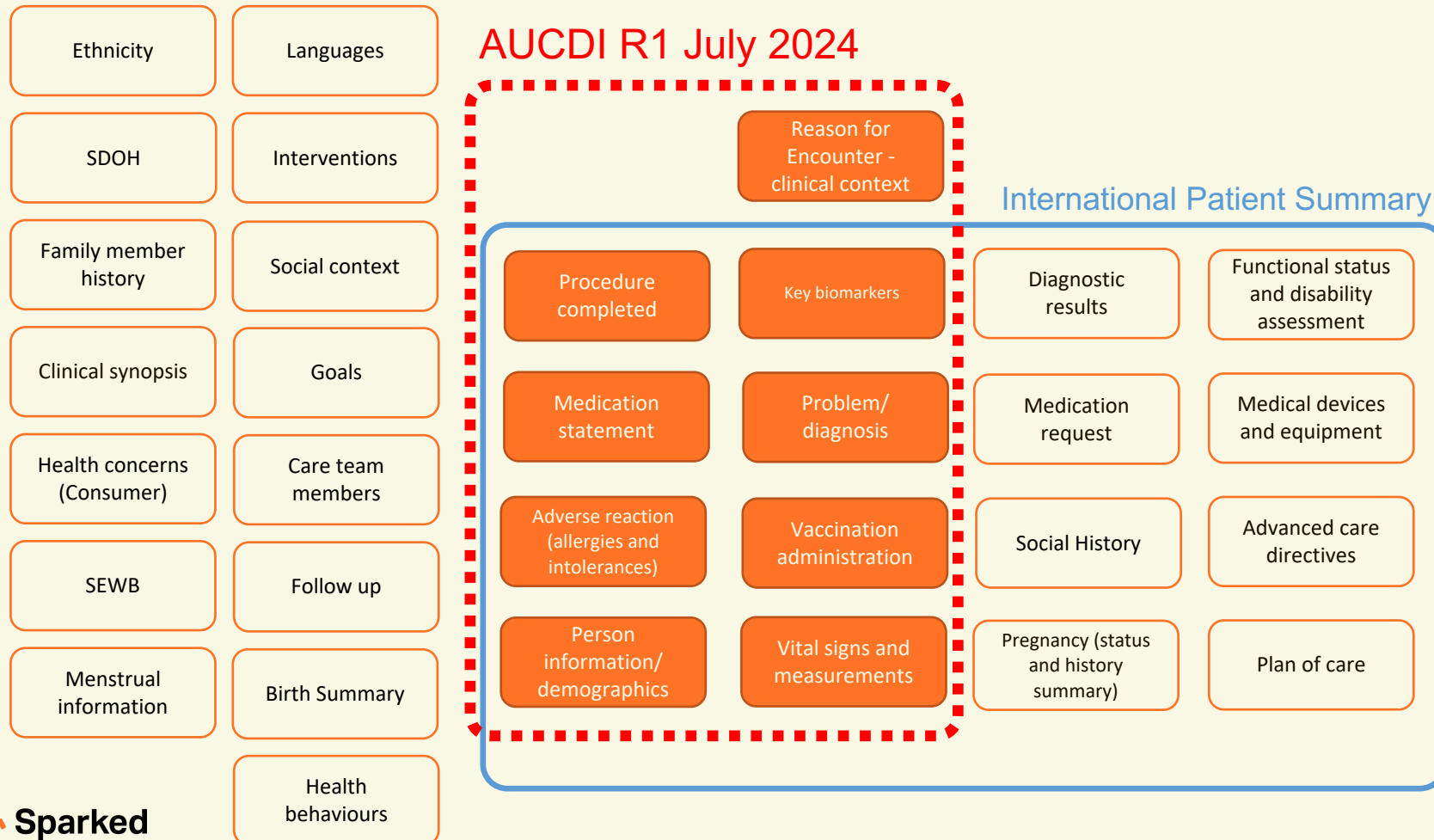


## Vital status

# Activity 2: AUCDI gaps – what's missing?



As a group at your table, identify the high-level data buckets that are missing – write each data group on an individual post it note



As a **group**  
at your table



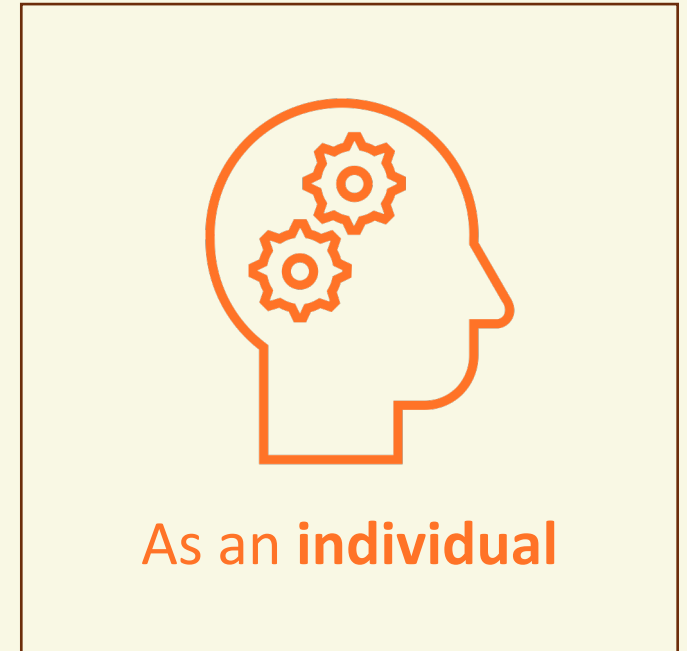
# Activity 3: Individual prioritisation of AUCDI backlog

Each person should have 8x **ORANGE** coloured sticker dots

- Identify priority data groups to be included in next release AUCDI
- Place the dots on the pages on the data groups on the wall

## Optional

If you identify data groups that should not be included in AUCDI, please mark them with a BLACK sticker dot.





# Activity 4: Group prioritisation of AUCDI backlog



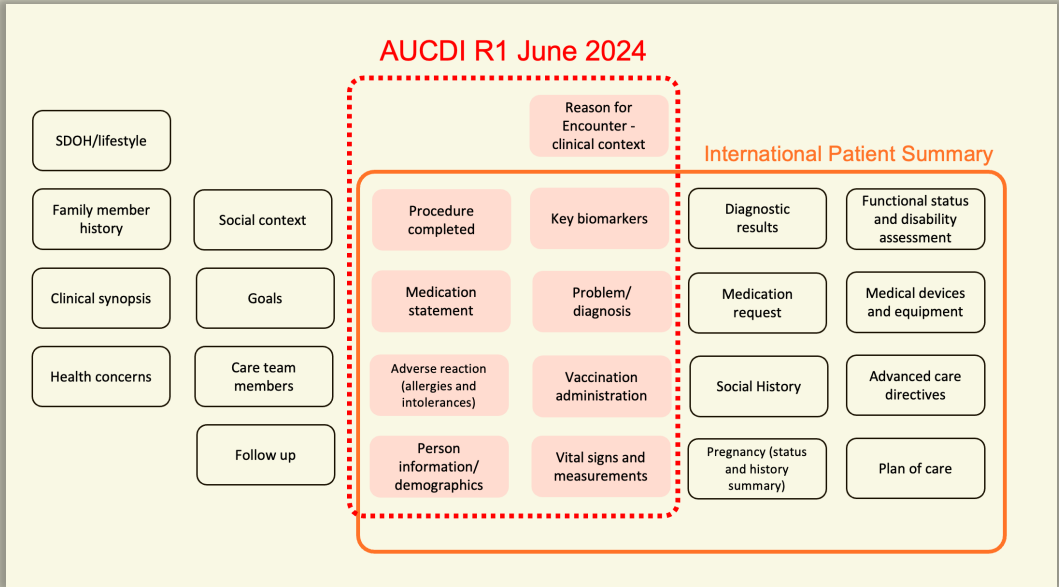


# May Workshop Overview

Stakeholders were asked, as an individual, to identify priority data groups to be expanded/included in the next release of AUCDI.

They were asked to identify 5x high priority (red), 5x medium priority (orange), and 5x low (green) priority use cases.

The following slides detail all responses received from attendees on the day.



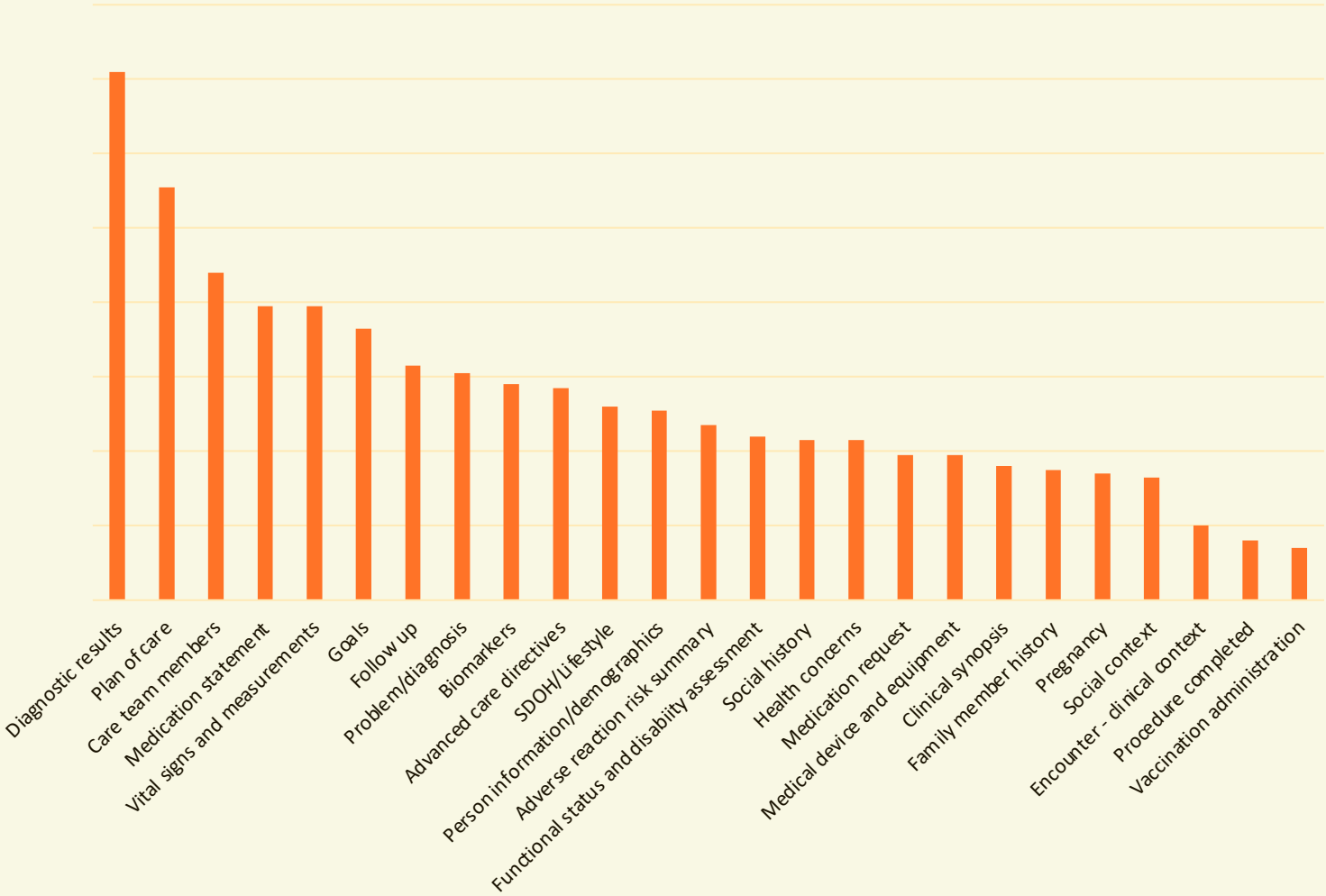


# MAY WORKSHOP RESULTS

For the Chronic Disease Management use case, the following data groups received the highest number of total votes from attendees:

- Diagnostic results,
- Plan of Care,
- Medication statement,
- Care team members, and
- Vital signs and Measurements.

Chronic Disease Management





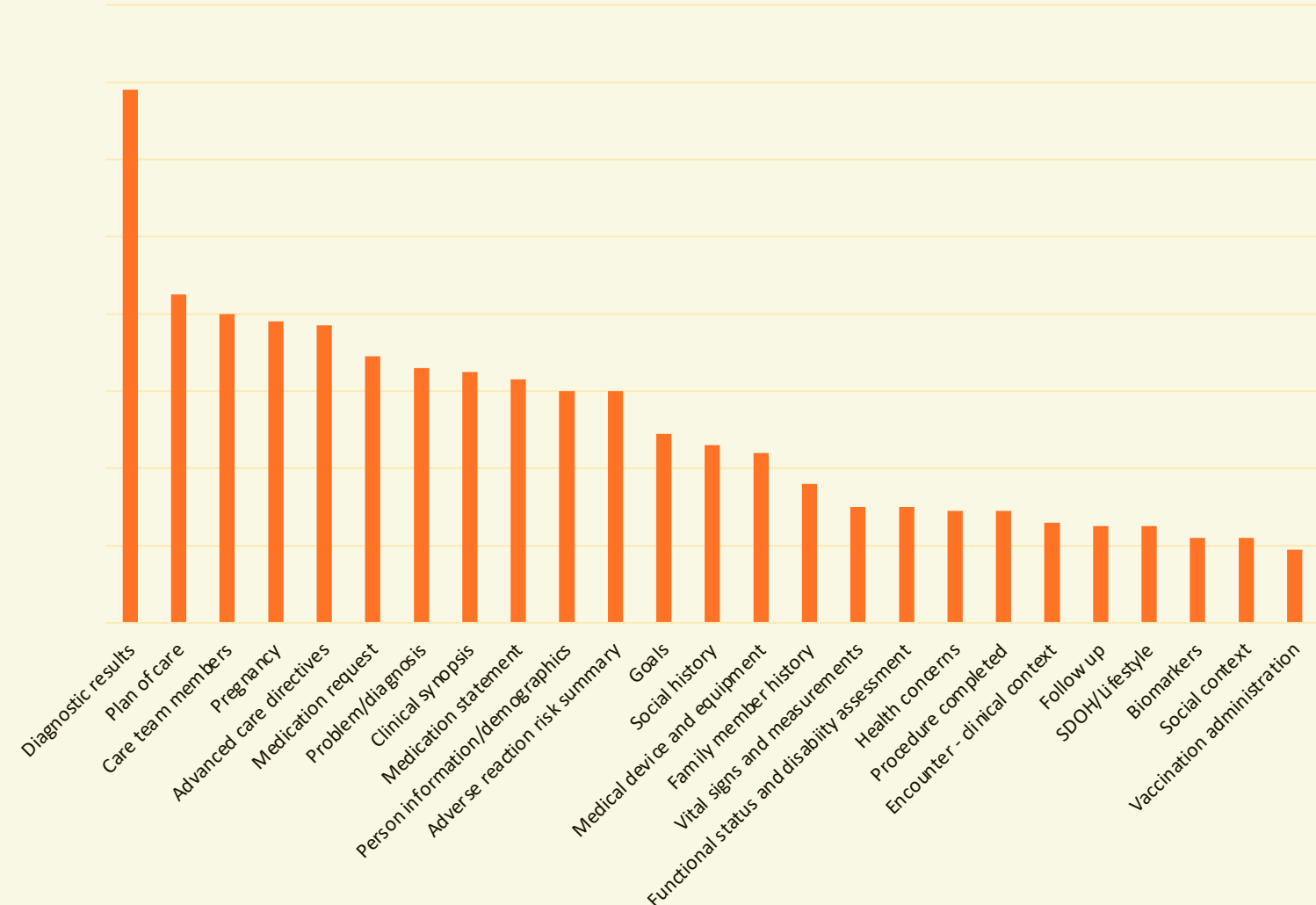
For the Patient summary use case, the following data groups received the highest number of total votes from attendees:

- Diagnostic results
- Plan of care
- Care team members

This was closely followed by:

- Pregnancy,
- Advanced care directives,
- Medication request,
- Problem diagnosis,
- Clinical synopsis,
- Medication statement,
- Person information/demographics, and
- Adverse reaction risk summary

Patient Summary



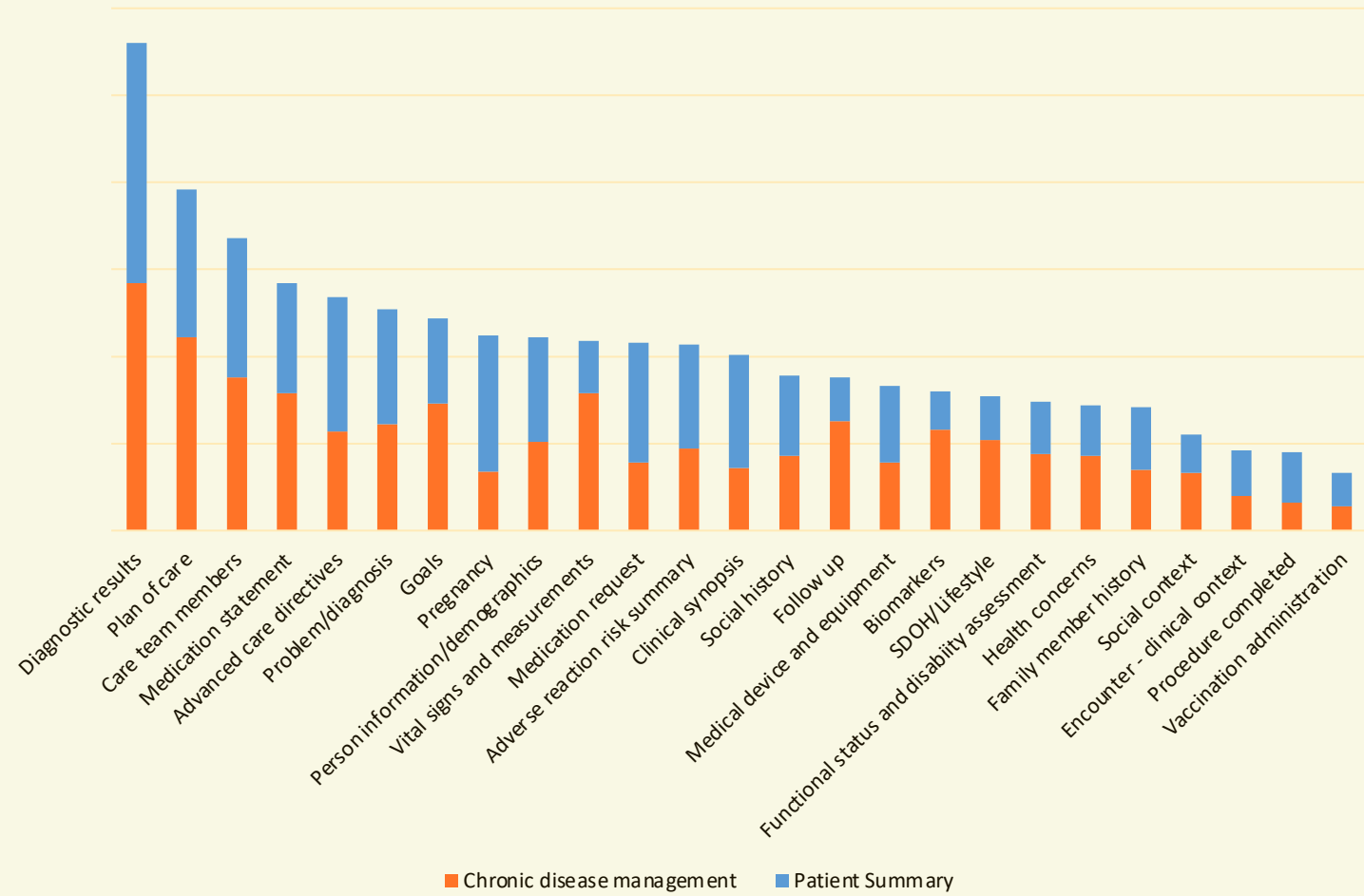
# MAY WORKSHOP RESULTS

When analysing the votes for the data groups across the two use cases, there are clear commonalities; specifically:

- Diagnostic results,
- Plan of care, and
- Care team members

Whilst these three had a higher number of total votes, the remaining data groups were quite closely clustered together.

Chronic Disease Management and Patient Summary



# Workshop 3



# Workshop 3: Social Determinants of Health, Social and Emotional Wellbeing and health behaviours

## Objectives:

- To explore and understand the importance of SDOH, SEWB, and health behaviour information,
- To identify key use cases
- To prioritise data groups.

# Workshop 3 - Social Determinants of Health (SDOH) and Social and Emotional Wellbeing (SEWB)



Activity 1: Identifying important information/data to support workflow and exchange of information  
20 mins, 10 min report back

Activity 2: Data model gaps  
10 mins

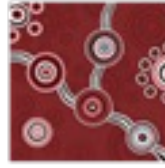
Activity 3: Individual prioritisation of backlog  
10 mins

Activity 4: Group prioritisation of backlog  
10 mins



# Perspectives

Jason Agostino & Maia Sauren  
National Aboriginal Community  
Controlled Health Organisation  
Kimberley Aboriginal Medical Services



Transforming Indigenous  
Mental Health and Wellbeing  
[www.TIMHWB.org.au](http://www.TIMHWB.org.au)



# Social and Emotional Wellbeing: Exploring the foundations for appropriate and usable clinical terminology

Presenter: Dr Maia Sauren (KAMS Manager health informatics)

Contact: Dr Emma Carlin (KAMS/ UWA Senior Research Fellow)

[emma.carlin@rcswa.edu.au](mailto:emma.carlin@rcswa.edu.au) for further information



Transforming Indigenous  
Mental Health and Wellbeing  
[www.TIMHWB.org.au](http://www.TIMHWB.org.au)

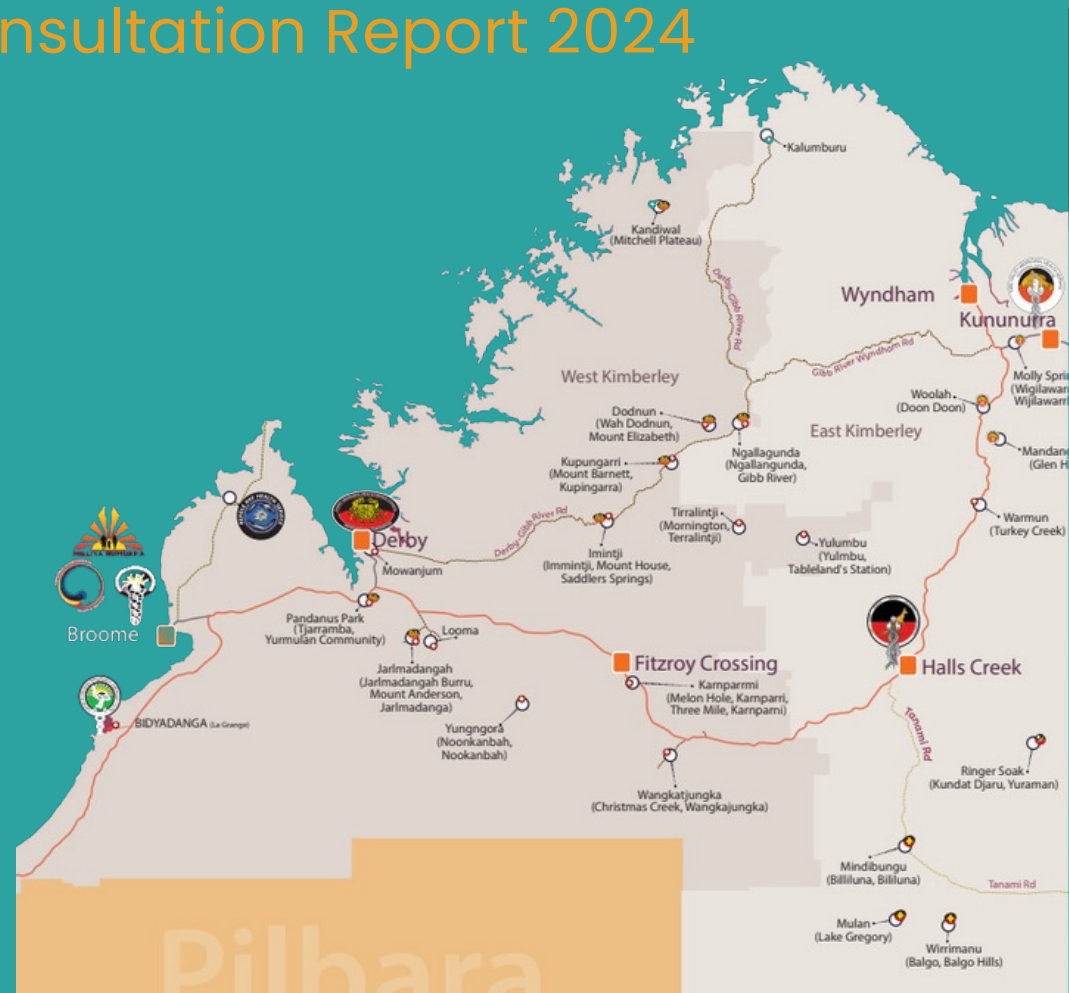


# WELLBEING INFORMED CARE – KIMBERLEY

## Community Consultation Report 2024

We stand on Yawuru Country.

We acknowledge and pay our respects to  
Aboriginal Elders and Leaders, past, present and  
emerging.



# Clinical coding within ACCHS

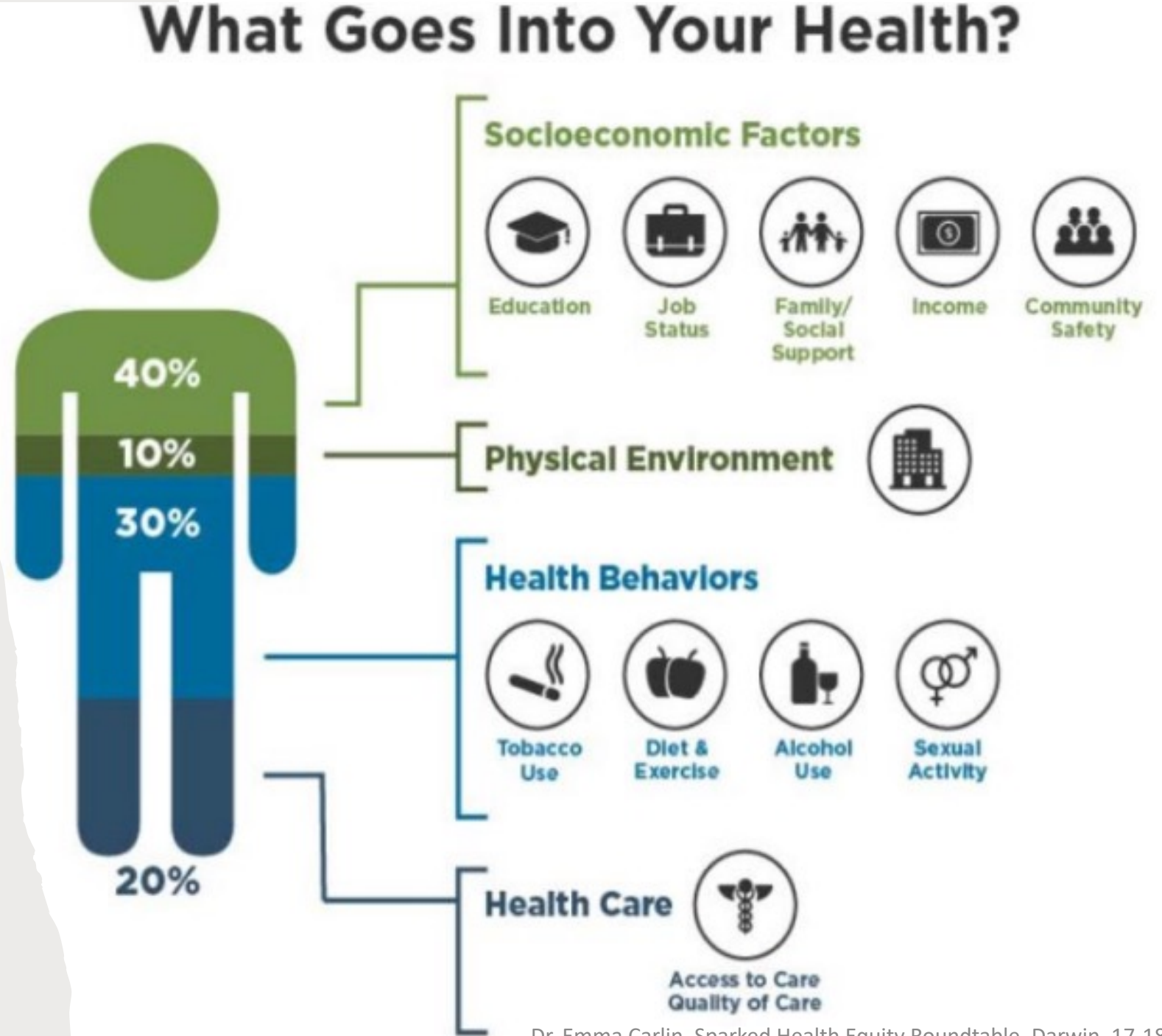
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(ACCHS = Aboriginal Community Controlled Health Services)

- Gradual adoption of standardised codes
- Diverse information entered by healthcare professionals
  - Different EMRs
  - Different customisation
  - Free text entry

## Towards holistic health

- Super important
- Could be coded better



# Social Determinants of Health

Economic Stability	Neighbourhood & Physical Environment	Education	Food	Community & Social context	Health Care System
Employment	Housing	Literacy	Hunger	Social integration	Health coverage
Income	Transportation	Early childhood education	Access to healthy options	Support systems	Provider availability
Expenses	Safety	Vocational training		Community engagement	Provider linguistic & cultural competency
Debt	Parks	Higher education		Discrimination	Quality of care
Medical bills	Playgrounds			Stress	
Support	Walkability				
	Geography				
<b>Health Outcomes</b> Mortality, Morbidity, Life Expectancy, Healthcare Expenditures, Health Status, Functional Limitations					

# Social Determinants of Health

- Responsible for health inequalities
- Unfair, avoidable differences in health status
- Conditions in which people
  - Born
  - Grow
  - Live
  - Work
  - Age
- Circumstances shaped by
  - Money
  - Power
  - Resources – global, national, local

# Social determinants of health coding

A review of four clinical terminology vocabularies identified over 1000 clinical terms relating to the SDoH.

**Despite** the volume of clinical terminology, the terms did not consistently match practice needs and were conceptually ambiguous.

***Recommendation:***

*...bring together **clinical content experts** (patients and providers), policy makers, and informaticists to achieve consensus on what is **useful** for SDoH codes to document, what level of granularity, and for what purposes.*



# SEWB Wheel



SEWB Diagram adapted from Gee et al., (2014)



Because...

*“Since the current SDOH framework fails to acknowledge that structural racism is the root cause of racial health disparities, it is inadequate as a means to achieve racial health equity.*

*Hence, the SDOH framework must be revised.”*

*Rugaiijah Yearby, Structural Racism and Health Disparities: Reconfiguring the Social Determinants of Health Framework to Include the Root Cause, 48, Law, Med. & Ethics 518-526 (September 2020).*

# Relationship between social determinants of health and SEWB

---

Social Determinant of Health Domain	Social and Emotional Wellbeing domain
Economic Stability	Body: Influences access to healthcare, nutrition, and living conditions. Mind and Emotions: Affects stress levels and mental wellbeing. Family and Kinship: Provides resources for family wellbeing. Community: Contributes to community resilience. Culture, Land, and Spirituality: Supports cultural and spiritual practices
Education	Body: Enhances health literacy and informed healthcare choices. Mind and Emotions: Develops critical thinking and emotional resilience. Family and Kinship: Empowers families through education opportunities. Community: Promotes civic engagement and collective wellbeing. Culture, Land, and Spirituality: Preserves cultural heritage and knowledge
Neighborhood Environment	Body: Provides safe and supportive environments for physical health. Mind and Emotions: Reduces stress and promotes mental wellbeing. Family and Kinship: Impacts family dynamics and cohesion. Community: Fosters social interaction and a sense of belonging. Culture, Land, and Spirituality: Reflects and supports cultural practices and spiritual connections
Social Support Networks	Body: Offers emotional support and reduces stress-related health issues. Mind and Emotions: Enhances emotional resilience and wellbeing. Family and Kinship: Promotes supportive family and community relationships. Community: Builds cohesive and resilient communities. Culture, Land, and Spirituality: Maintains cultural practices and social connections
Access to Healthcare	Body: Directly impacts physical health outcomes and disease prevention. Mind and Emotions: Supports mental health and reduces stigma. Family and Kinship: Affects family health and caregiving dynamics. Community: Contributes to community health and emergency preparedness. Culture, Land, and Spirituality: Integrates cultural and spiritual support in healthcare
Food Access	Body: Essential for nutrition, physical health, and disease prevention. Mind and Emotions: Reduces stress related to food insecurity. Family and Kinship: Supports family nutrition and wellbeing. Community: Impacts community health, equity, and resilience. Culture, Land, and Spirituality: Reflects cultural food practices and beliefs

- Mental health terminology coding:
  - diagnosis of a mental health condition
  - management of the diagnosed mental health condition
- Terminology (SNOMED, ICPC-2+) is highly stigmatising
- Mental health as a *diagnosis and condition* are not what we want to focus on

SEWB is not mental health  
clinical terminology

**Instead:** focus on  
broader holistic health  
profile

# Benefits of implementing SEWB clinical terminology



Consistent coding



Generate localised aggregated data pertaining to nature & prevalence of adverse SEWB and the impacts on health



Inform evidence-based health priority setting



Drive advocacy efforts



Catalyse development of data-driven health promotion strategies & population health interventions



Aboriginal owned data



Measure health outcomes associated with adversity

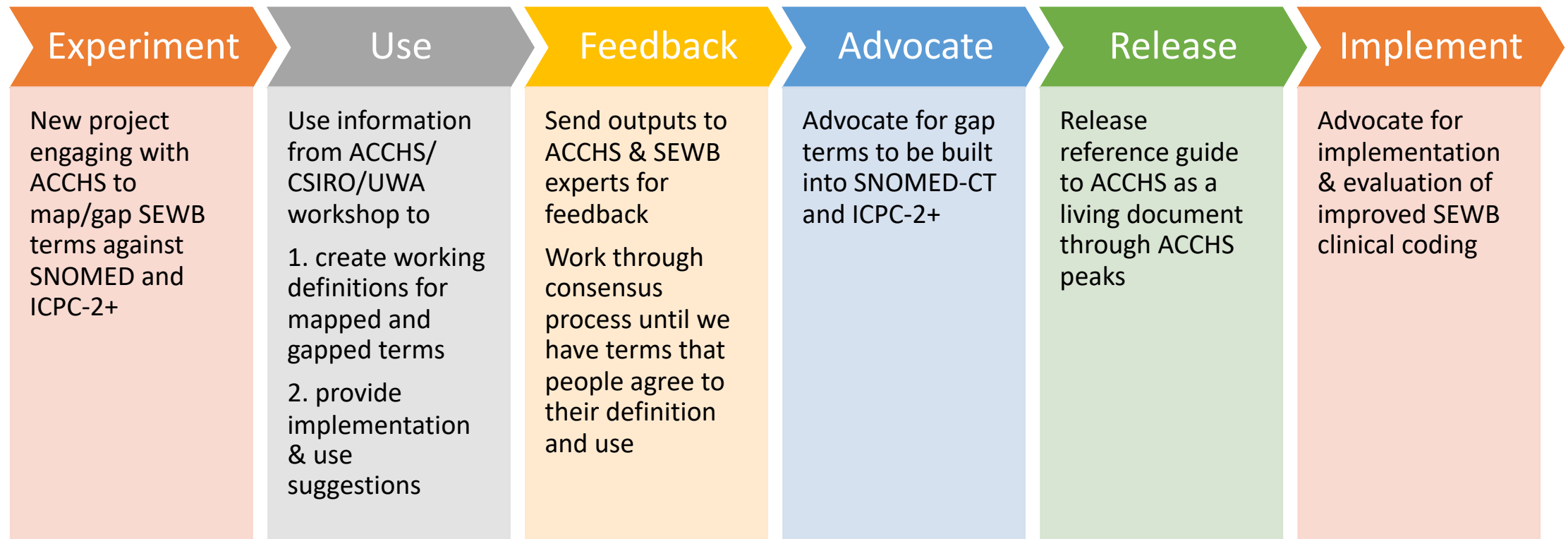


Improve care

# What are the barriers?

- Lack of understanding of the value of SEWB data
  - how it can be used at the patient and population health level
- New and emerging space
  - ACCHS working out systems and approaches to coding
  - No standards of health KPIs related to mental health/SEWB that promote good data standards, information collection
- Unclear what terminology to use and when
  - Gaps and overlap in existing terminology

# Towards a reference guide





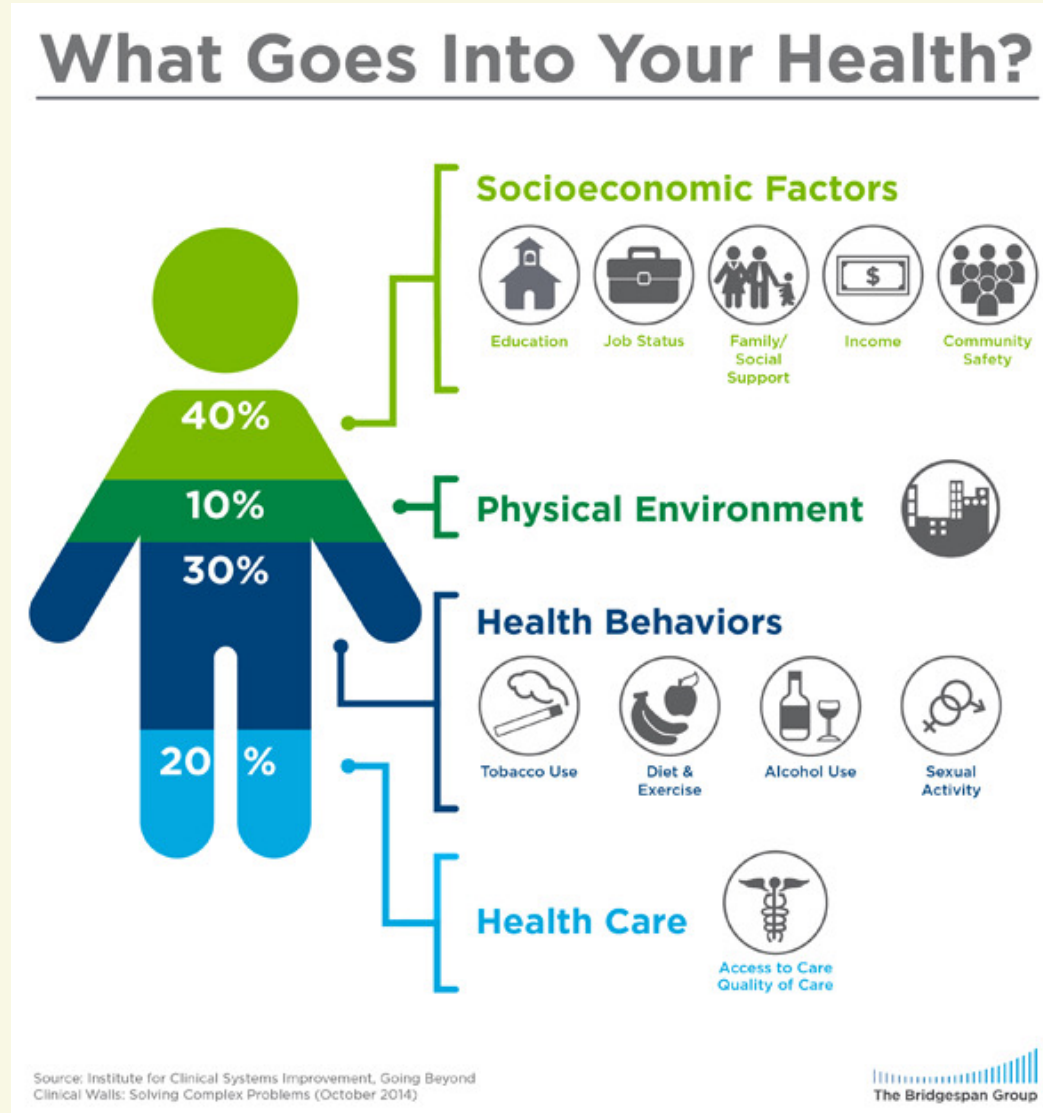
# Workshop 3: Social Determinants of Health, Social and Emotional Wellbeing and health behaviours

## Objectives:

- To explore and understand the importance of SDOH, SEWB, and health behaviour information,
- To identify key use cases
- To prioritise data groups.



# Determinants of Health



# Social and emotional wellbeing

Diagram 1: A Model of Social and Emotional Wellbeing<sup>16</sup>



© Gee, Dudgeon, Schultz, Hart and Kelly, 2013

# Print outs on your table for reference

## Defining Social Determinants

The social determinants of health are the conditions in which people are born, grow, live, work and age. These circumstances are shaped by the distribution of money, power and resources at global, national and local levels. The social determinants of health are mostly responsible for health inequities - the unfair and avoidable differences in health status seen within and between countries.

Economic Stability	Neighborhood and Physical Environment	Education	Food	Community and Social Context	Health Care System
Employment	Housing	Literacy	Hunger	Social integration	Health coverage
Income	Transportation	Language	Access to healthy options	Support systems	Provider availability
Expenses	Safety	Early childhood education		Community engagement	Provider linguistic and cultural competency
Debt	Parks	Vocational training		Discrimination	Quality of care
Medical bills	Playgrounds	Higher education		Stress	
Support	Walkability				
	Zip code / geography				
Health Outcomes Mortality, Morbidity, Life Expectancy, Health Care Expenditures, Health Status, Functional Limitations					

## Relationship between social determinants of health and SEWB



Social Determinant of Health Domain	Social and Emotional Wellbeing domain
Economic Stability	Body: Influences access to healthcare, nutrition, and living conditions. Mind and Emotions: Affects stress levels and mental wellbeing. Family and Kinship: Provides resources for family wellbeing. Community: Contributes to community resilience. Culture, Land, and Spirituality: Supports cultural and spiritual practices
Education	Body: Enhances health literacy and informed healthcare choices. Mind and Emotions: Develops critical thinking and emotional resilience. Family and Kinship: Empowers families through education opportunities. Community: Promotes civic engagement and collective wellbeing. Culture, Land, and Spirituality: Supports the preservation of cultural heritage and the transfer of cultural knowledge.
Neighborhood Environment	Body: Provides safe and supportive environments for physical health. Mind and Emotions: Reduces stress and promotes mental wellbeing. Family and Kinship: Impacts family dynamics and cohesion. Community: Fosters social interaction and a sense of belonging. Culture, Land, and Spirituality: Reflects and supports cultural practices and spiritual connections
Social Support Networks	Body: Offers emotional support and reduces stress-related health issues. Mind and Emotions: Enhances emotional resilience and wellbeing. Family and Kinship: Promotes supportive family and community relationships. Community: Builds cohesive and resilient communities. Culture, Land, and Spirituality: Maintains cultural practices and social connections
Access to Healthcare	Body: Directly impacts physical health outcomes and disease prevention. Mind and Emotions: Supports mental health and reduces stigma. Family and Kinship: Affects family health and caregiving dynamics. Community: Contributes to community health and emergency preparedness. Culture, Land, and Spirituality: Integrates cultural and spiritual support in healthcare
Food Access	Body: Essential for nutrition, physical health, and disease prevention. Mind and Emotions: Reduces stress related to food insecurity. Family and Kinship: Supports family nutrition and wellbeing. Community: Impacts community health, equity, and resilience. Culture, Land, and Spirituality: Reflects cultural food practices and beliefs



# The Gravity Project...

**Goal-** Develop consensus-driven data standards to support use and exchange of social determinants of health (SDOH) data within the health care sectors and between the health care sector and other sectors.





# Canada - SPARK tool

# SPARK Tool

Screening for Poverty And Related Social determinants to improve Knowledge of and links to resources (SPARK)

## Demographics

### 1 Language

- If available, would you prefer your healthcare appointments offered in another language?
- If yes, which language?

### 2 Born in Canada

- Were you born in Canada?
- If no, when did you arrive?

### 3 Indigenous Identity

- Do you identify as an Indigenous person?\*
- If yes, are you Status (Registered or Treaty Indian as defined by the Indian Act of Canada)?\*
- If yes, Inuk/Inuit, are you a member of an Inuit land claims agreement?\*

\*This data must be collected with engagement with local First Nations, Métis, and Inuit governance bodies in accordance with the First Nations OCAP, Métis OCAS, and Inuit Qaujimajatuqangit data governance and sovereignty principles.

### 4 Race

In our society, people are often described by their race or racial background. Our race may influence the way we are treated by individuals and institutions, and this may affect our health. Which category(ies) best describes you? Select all that apply.

### 5 People with Disabilities

Do you currently experience any of the following due to a severe and persistent physical or mental condition? Select all that apply.

### 6 Sex at Birth

What was your sex at birth?

### 7 Gender Identity

What is your gender identity?

### 8 Sexual Orientation

Which category(ies) best describe your sexual orientation? Select all that apply.

### ? Descriptors

Patients can click on a hyperlinked "?" beside each question to learn about each question's purpose, a definition of terms, and why it is being asked.



## Optional Questions

### 1 Ethnicity

What is your ethnic or cultural background? e.g., Chinese, Filipino, Guyanese, Scottish, Somali, Korean

### 2 Religion

What is your religious or spiritual affiliation? Select all that apply.

## Social needs

### 9 Education

What is your current level of education?

### 10 Income/Finances

Do you currently have difficulty paying for basic needs?

### 11 Food Security

Please respond to the following statements:

- "Within the past 12 months, we worried whether our food would run out before we could buy or get more."
- "Within the past 12 months, the food we bought just didn't last and we could not buy or get more."

### 12 Medication Access

In the past 12 months, were you unable to get medicine or medical supplies, or did you do anything to make them last longer *because of the cost*?

### 13 Housing

- What is your current housing situation?
- Who do you live with? Select all that apply.
- In the past 12 months, was there a time when you were not able to pay the mortgage or rent on time?

### 14 Transportation

In the past 12 months, has lack of transportation kept you from medical appointments, meetings, work, or from getting things needed for daily living? Select all that apply.

### 15 Phone and Internet Access

Do you currently have consistent access to a phone or the internet?

### 16 Utilities

In the past 12 months, did you miss making a payment on any utility bills (e.g., electric, gas/oil, water) *because of cost*?

### 17 Social Supports

- Do you feel you have people who you can open up to or confide in?
- Do you have people to rely on if you needed help?

### 18 Employment

a) Are you currently employed (this includes self-employed, full-time, part-time or other)?

If no:  
b) Are you currently looking for work?

If yes:  
c) Is your main job temporary or part-time (e.g., casual, contract, freelance, short-term, seasonal)?

d) Do you feel that your current employment could be negatively affected if you raised concerns about your work (e.g., health, safety, rights)?

e) In the past 12 months, did your income change a lot from month to month?



# Pan-Canadian Health Data Content Framework

## Data Content Standard: Open Review

March 2024



Data element name	Data element definition	Data element maturity	Value set (Code System)	Value set examples	Value set maturity
Sociodemographic Information and Equity Stratifiers (continued)					
Indigenous Self-Identification	The person's self-identification as either First Nations, Métis and/or Inuk/Inuit	0: In development	<a href="#">IndigenousIdentityCode</a> (SNOMED CT CA, HL7)	<ul style="list-style-type: none"><li>• First Nations</li><li>• Inuk/Inuit</li><li>• Métis</li><li>• Do not know</li><li>• Not applicable</li><li>• Asked but declined</li></ul>	1: Draft
Ethnicity	The person's ethnic or cultural background	0: In development	To be confirmed	n/a	n/a
Religious or Spiritual Affiliations	The person's religious or spiritual affiliations	0: In development	To be confirmed	n/a	n/a

Data element name	Data element definition	Data element maturity	Value set (Code System)	Value set examples	Value set maturity
Employment and Finance Information					
Employment Status	The person's current job status	0: In development	To be confirmed	n/a	n/a
Household Income	The sum of the total incomes of all members of a household	0: In development	To be confirmed	n/a	n/a
Financial Stability	Information about a person's ability to pay for their household's basic needs, including food, water, housing and clothing	0: In development	To be confirmed	n/a	n/a
Housing Information					
Housing Stability	The person's current housing situation, including whether they are housed or unhoused	0: In development	To be confirmed	n/a	n/a
Housing Condition	The physical infrastructure of the residence, including overcrowding, a leaking roof, no bath/shower and no flushing toilet, or a dwelling considered too dark	0: In development	To be confirmed	n/a	n/a
Household Composition	Information about who the person lives with, such as parents, children, spouse or roommates	0: In development	To be confirmed	n/a	n/a

### Accessibility Information

Access to Food	The person's ability or inability to access food over the past 12 months	0: In development	To be confirmed	n/a	n/a
Access to Medication	The person's ability to access or afford medicine	0: In development	To be confirmed	n/a	n/a
Access to Internet	The person's ability to access or afford internet over the past 12 months	0: In development	To be confirmed	n/a	n/a
Access to a Phone	The person's ability to access or afford a telephone over the past 12 months	0: In development	To be confirmed	n/a	n/a

## Assessments and screening

### Social history

The following data elements pertain to information about health behaviours that influence the risk of developing chronic disease (e.g., smoking, alcohol consumption).

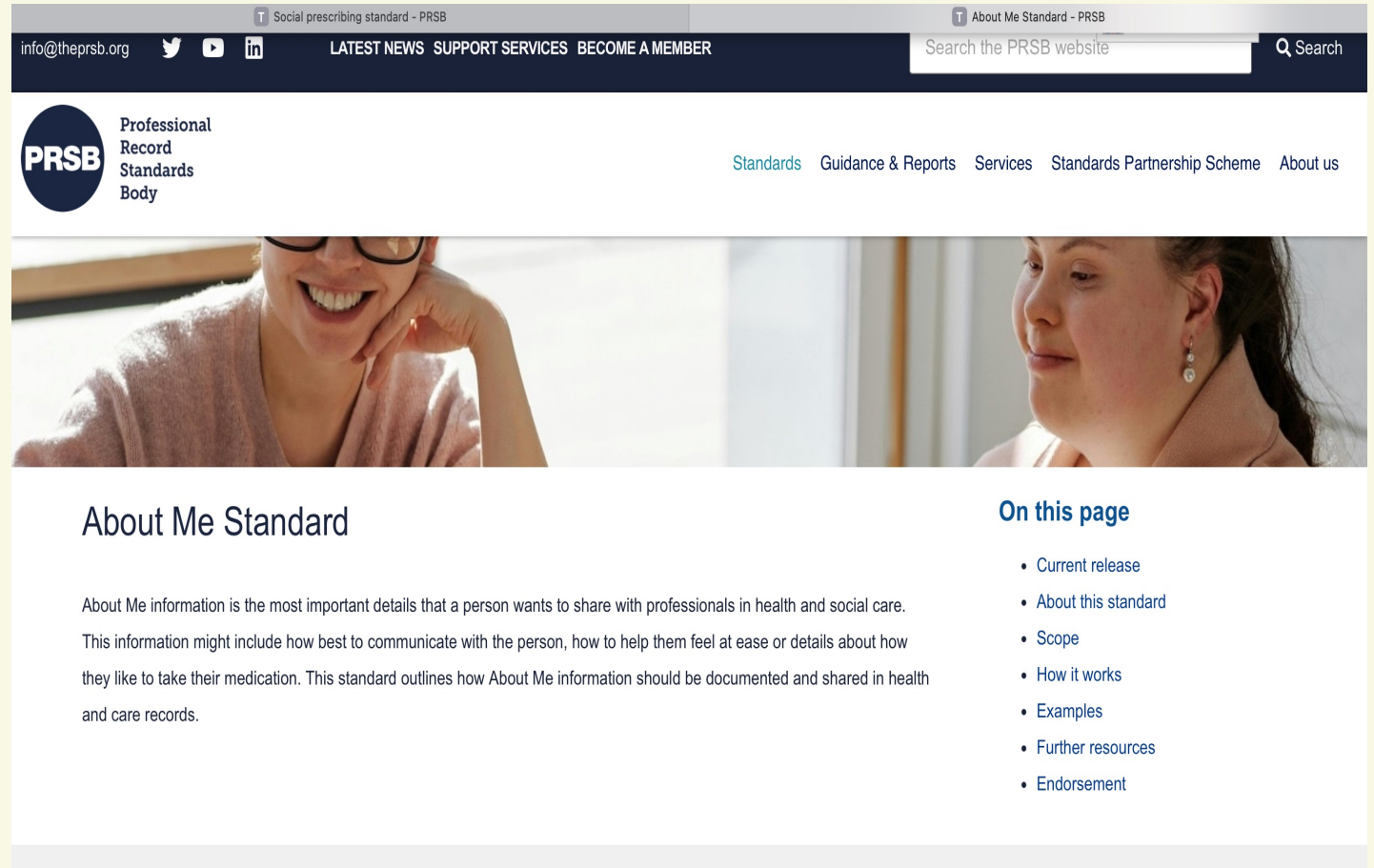
Data element name	Data element definition
Type of Social Behaviour	The type of social behaviour that the person is engaging in that increases the possibility of disease or injury, including risk factors such as tobacco use, alcohol use and problematic use of illicit or prescription drugs
Social Behaviour Observation Date	The date that the social behaviour was recorded
Social Behaviour Value	The measured number of times a person engages in a social behavioural activity (e.g., number of alcoholic beverages consumed per week)
Number of Sexual Partners	The number of sexual partners in the last year
Gender of Sexual Partners	The genders of the person's sexual partner(s)
Safer Sex Practices	The method(s) the person uses to prevent the transmission of sexually transmitted and blood borne infections
Type of Sexual Contact	The type of sexual contact (e.g., oral, vaginal, anal)

Data element name	Data element definition	Data element maturity	Value set (Code System)	Value set examples	Value set maturity
Accessibility Information (continued)					
Access to Transportation	The person's access to public or private transportation over the past 12 months	0: In development	To be confirmed	n/a	n/a
Access to Utilities	The person's ability to access and afford utilities, such as heat, electricity, water, sewage and waste services over the past 12 months	0: In development	To be confirmed	n/a	n/a
Access to Child Care	The person's ability to access or afford child care in the past year over the past 12 months	0: In development	To be confirmed	n/a	n/a
Social Needs					
Social Supports	The actual or perceived availability of family, friends, neighbours and/or community that a person can confide in or rely on to feel more socially connected and secure	0: In development	To be confirmed	n/a	n/a
Incarceration History	The person's experiences with the judicial system such as spending time in a jail, prison, detention centre or juvenile correctional facility	0: In development	To be confirmed	n/a	n/a



# NHS PRSB – About Me

- What is most important to me
- Who is most important to me
- How I communicate
- How to communicate with me
- My wellness
- Please do
- Please don't
- How to support me
- When to support me







# NHS PRSB – Social Prescribing Standard

## PRSB's Social Prescribing Information Standard & How Specialised Tools Can Help

The Professional Record Standards Body (PRSB) has recently published a social prescribing information standard which aims to ensure a standardised approach to collecting, recording and sharing information about social prescribing referrals.

Social prescribing is a non-medical approach to healthcare that aims to address the social, emotional and practical needs of a person. It involves referring people to community-based services or resources that can help to improve their health and wellbeing, such as support groups, social activities or volunteering opportunities.

The information standard was commissioned by NHS England in order to support people providing social prescribing services, individuals referred into social prescribing, and the information needed for secondary purposes such as reporting. The standard has received an Information Standards Notice, making its use a requirement by all models of social prescribing. The image below shows the types of information that services will need to collect and record at different stages of a person's social prescribing referral.

CONTACT	CONVERSATION	INTERVENTIONS	FOLLOW-UP	OUTCOMES
Referral to link worker	Link Worker record	Link Worker record	Link Worker record	Message back to referrer & GP
<ul style="list-style-type: none"><li>Person demographics</li><li>GP details</li><li>Referral details (to/from)</li><li>Presenting needs</li><li>Risks &amp; Safeguarding</li></ul>	<ul style="list-style-type: none"><li>Meetings details</li><li>Care &amp; support plan incl:<ul style="list-style-type: none"><li>Needs</li><li>Strengths</li><li>Goals</li><li>Actions and activities</li></ul></li><li>Updates to person details</li><li>Meetings summary</li></ul>	<ul style="list-style-type: none"><li>Referrals</li><li>Signposting</li><li>Attendance</li></ul>	<ul style="list-style-type: none"><li>Meetings details</li><li>Progress notes</li><li>Outcome assessments</li></ul>	<ul style="list-style-type: none"><li>Consent to share</li><li>Summary</li><li>Actual Needs</li><li>Actions &amp; activities</li><li>Assessments</li><li>Updated person details</li><li>Plan and requested actions for GP/ professionals &amp; person</li></ul>
Plus supporting information via referral or via shared care record				
<ul style="list-style-type: none"><li>About me</li><li>Individual requirements</li><li>Care &amp; support plan</li><li>Relevant problems</li><li>Social context</li></ul>				

- Non-medical approach to address the social, emotional and practical needs of a person
- Referrals to community-based services or resources

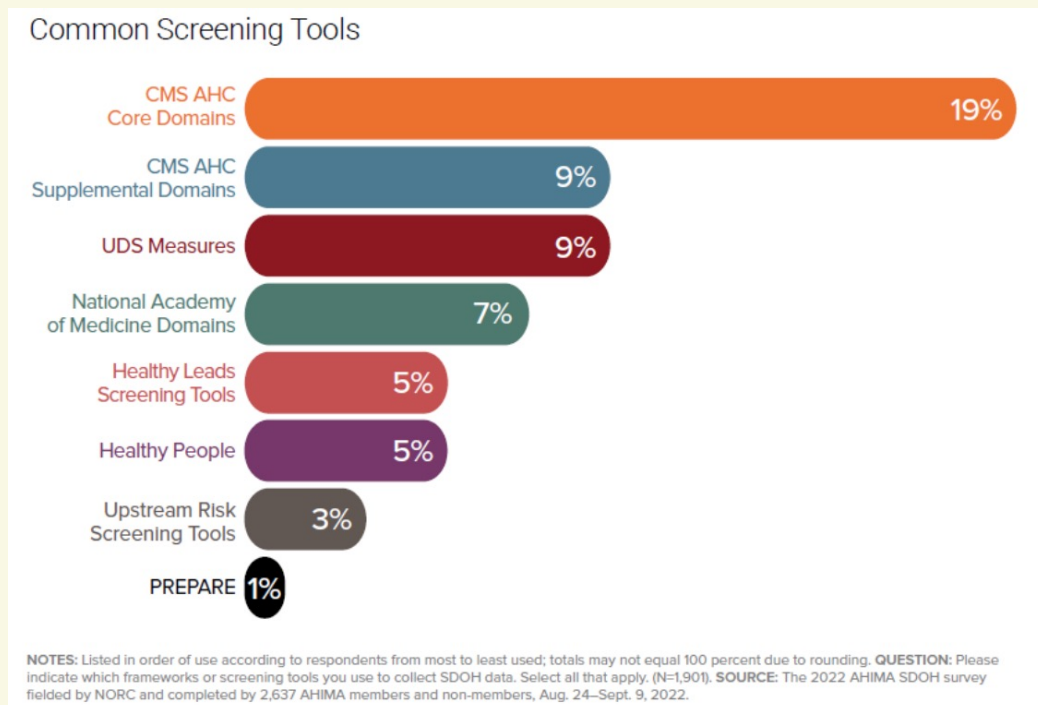
151	Problem	H	1...1	A condition which needs addressing and so is important for every professional to know about when seeing the person. Problems may include diagnosis, symptoms, and social or behavioural issues	group			
152	Coded value	R	0...1	The coded value for the problem list.	SHOWNED CT : - *1227581000000103   Health issues simple reference set	item		
153	Free text	R	0...1	Free text field to be used if no code is available	Free text	item		
154	Onset date	R	0...1	A date or estimated date that the problem began	Date and time	item		
155	End Date	R	0...1	The date or estimated date the problem was resolved.	Date and time	item		
156	Stage of disease	R	0...1	The stage of the disease where relevant.	Free text	item		
157	Comment	R	0...*	Supporting text may be given covering the problem.	Free text	item		
158	Social context	O	0...1	The social setting in which the person lives, such as their household, occupational history, and lifestyle factors.		section	This section includes information about the social setting in which the person lives, such as their household, occupational, and lifestyle factors. Social circumstances includes the person's social background, network and personal circumstances, e.g. housing, and should also include if the person is a carer.	
159	Household composition	O	0...1	Details of the person's household composition.		group		Event Record
160	Household composition	R	0...1	Description of the household composition e.g. lives alone, lives with family, lives with partner, shared accommodation etc.		group		
161	Coded value	R	0...1	The coded value of household composition	SHOWNED CT : - *1027991000000108   Household composition findings simple reference set (foundation metadata concept)	item		
171	Free text	R	0...1	Free text field to be used if no code is available	Free text	item		
172	Occupational history	O	0...1	The current and/or previous occupation(s) of the person.		group		Event Record
173	Occupational history	R	0...1	The current and/or previous occupation(s) of the person.	SHOWNED CT : - *999001571000000109   Occupation simple reference set (foundation metadata concept)	group		
174	Coded value	R	0...1	The coded value for occupational history	Free text	item		
175	Free text	R	0...1	Free text field to be used if no code is available	Free text	item		
176	Educational history	O	0...1	Details of the person's educational history.		group		Event Record
177	Educational history	R	0...1	The current and/or previous relevant educational history of the person.	Free text	item		
178	Lifestyle choices	O	0...1	The lifestyle choices made by the person which are pertinent to his or her health and well-being, e.g. physical activity level, pets, hobbies and sexual habits		group		Event Record
179	Lifestyle choices	R	0...1	The lifestyle choices made by the person which are pertinent to his or her health and well-being, e.g. physical activity level, pets, hobbies and sexual preferences.	Free text	item		
180	Smoking status	O	0...1	Details of the person's smoking status		group		Event Record
181	Smoking status	R	0...1	Record of any smoking use by the person.	SHOWNED CT : - *999000891000000102   Smoking simple reference set (foundation metadata	group		
182	Coded value	R	0...1	The smoking status of the person.	Free text	item		
183	Free text	R	0...1	Free text field to be used if no code is available	Free text	item		
184	Smoking status - details	O	0...1	Further details recorded about the smoking status of the person		group		
185	Date stopped smoking	O	0...1	The date the person stopped smoking (if known)	SHOWNED CT : - 16082504   Date ceased smoking (observable entry)	item		
186	Coded value	R	0...1	The coded value for date stopped smoking.	Date and time	item		
187	Date	R	0...1	The date the person stopped smoking.		group		Event Record
188	Alcohol intake	O	0...1	Details of the person's alcohol intake		group		
189	Alcohol intake	R	0...1	Latest or current alcohol consumption	SHOWNED CT : - <<219006   Current drinker of alcohol (Finding)   OR <<105453008   Current non-drinker of alcohol (Finding)   OR 782051004   Lifetime non-drinker of alcohol (Finding)   OR 1104551000000109   Declined to provide information about alcohol use (situation)   OR 371434005   History of alcohol abuse (situation)	group		
190	Coded value	R	0...1	The coded value of the person alcohol intake	Free text	item		
191	Free text	R	0...1	Free text field to be used if no code is available	Free text	item		
192	Drug/substance use	O	0...1	Details of the person's drug and substance use		group		Event Record
193	Drug/substance use	R	0...1	Latest or current drug/substance use.	SHOWNED CT : - <<361055000   Houses drugs (Finding)   OR <<371422002   History of substance abuse (situation)   OR <<220560007   Has never misused drugs (situation)   OR 78241000000102   Declined to give substance misuse history	group		
194	Coded value	R	0...1	The coded value for drug and substance misuse.	Free text	item		
195	Free text	R	0...1	Free text field to be used if no code is available	Free text	item		
196	Social circumstances	O	0...1	Details of the person's social circumstances		group		Event Record
197	Social circumstances	R	0...1	A person's social background, network and personal circumstances, e.g. housing. This should include whether the person is a carer.	Free text	item		
198	Access	O	0...1	Details of access for the person.		group		Event Record
199	Access	R	0...1	Special access requirements e.g. key safe, coded lock, which door to use, stretcher access, etc.	Free text	item		
200	Dependants	O	0...1	Details of any responsibility the person has for dependants.		group		Event Record
201	Dependants	R	0...1	Provide details of any responsibility the person has for dependants. In the case of children provide date of birth of the child.	Free text	item		
202	Accommodation status	O	0...1	Details of the type of accommodation where the person lives.		group		Event Record
203	Accommodation status	R	0...1	An indication of the type of accommodation where the person lives. This should be based on the main or permanent residence.	NHS data dictionary : Accommodation status	group		
204	Coded value	R	0...1	The coded value for accommodation status	Free text	item		
205	Free text	R	0...1	Free text field to be used if no code is available		group		Event Record
206	Household environment	O	0...1	Details of the person's household environment.		group	This section includes information about the social setting in which the person lives, such as their household, occupational, and lifestyle factors. Social circumstances includes the person's social background, network and personal circumstances, e.g. housing, and should also include if the person is a carer. 'Smoking status' should be shared using SHOWNED CT rather than	
207	Household environment	R	0...1	Factors in the household which impact the person's health and wellbeing, to include	Free text	item		



# AHIMA: Social Determinants of Health Data:

Survey Results on the Collection, Integration, and Use (Feb 2023)

- Lack of standardization and integration of the data into an individual's medical record
- No consensus on which key SDOH domains need to be collected
- No consensus on which screening tools to be used

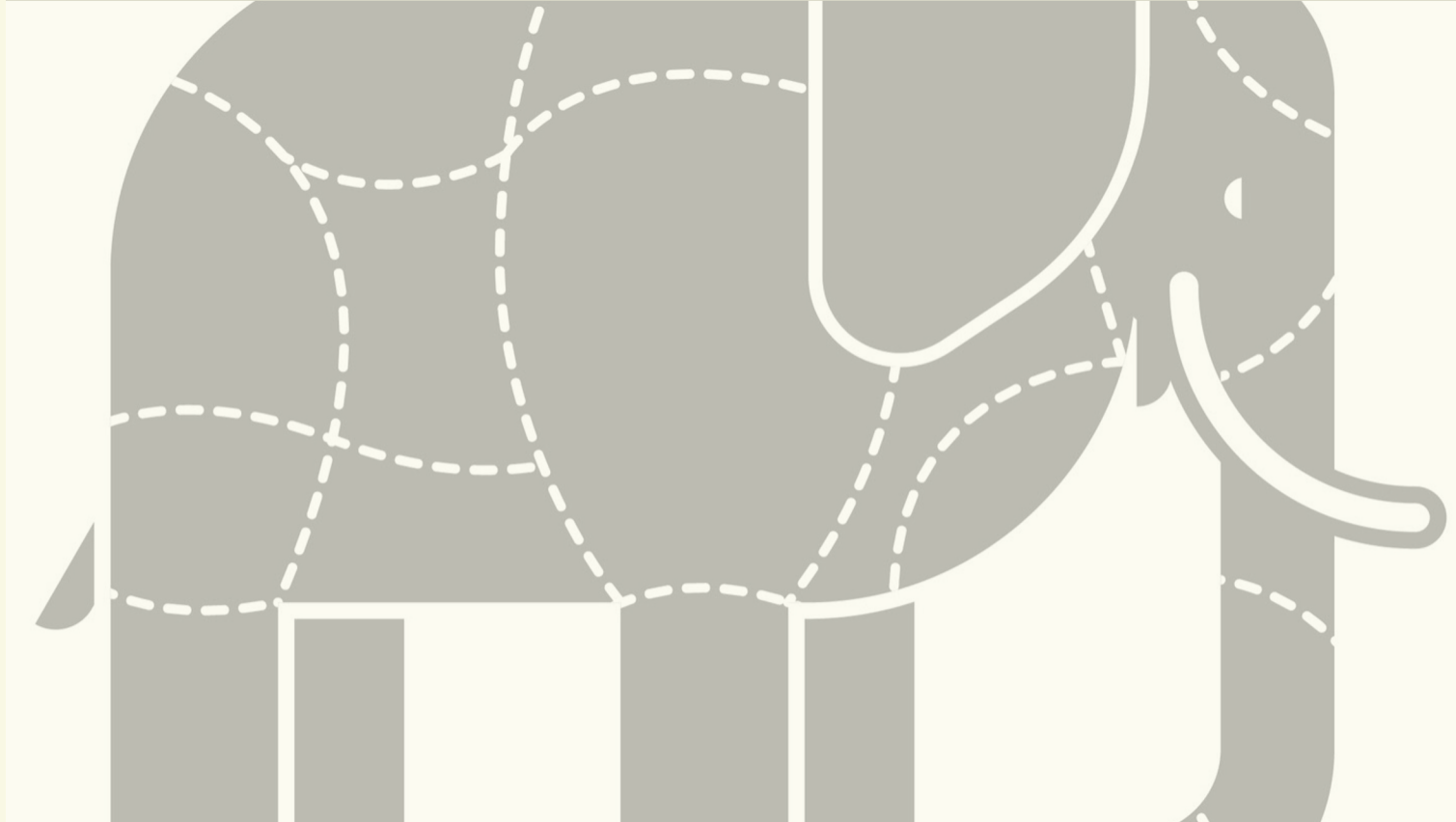


[https://ahima.org/media/03dbonub/ahima\\_sdoH-data-report.pdf](https://ahima.org/media/03dbonub/ahima_sdoH-data-report.pdf)

[illegible]



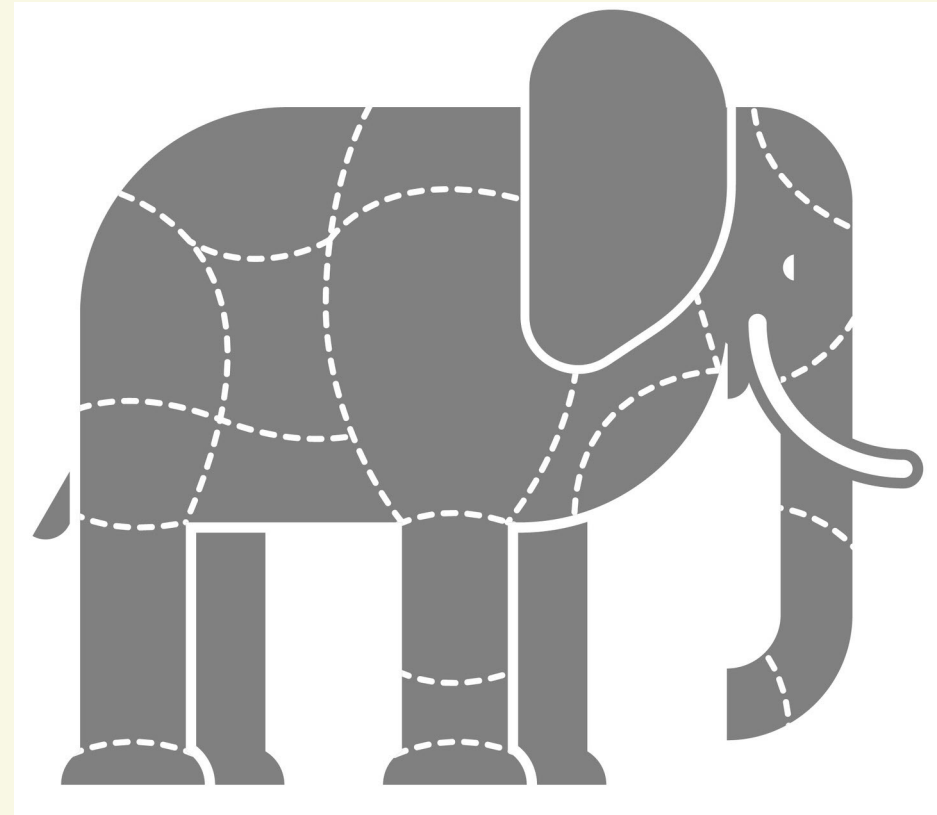
# What do we need in Australia?





# SDOH, SEWB, health behaviours data for interoperability

- Develop the roadmap
  - Identify priority use cases and data groups
  - Consider if/when/how to leverage Gravity and other international work
  - Identify and prioritise (information currently poorly reported)
    - Social well-being
    - Emotional well-being
    - Gaps in Physical well-being
      - Exercise/Physical activity
      - Food & nutrition
      - Sexual health
      - Sleep
      - Health risks – exposure, risky behaviour, alcohol and substance use etc



# Activity 1: Most important information/data to support workflow and exchange of information

As a group at your table, fill in the worksheet at your table.



As a **group**  
at your table

What is the most important SDOH, SEWB and health behaviours information to be defined?

Who does that information need to be shared with?

How will this information be used? (e.g., decision support, reporting assessment information)

What are the policies/inputs that will help scope/should be considered? (e.g. screening tools, assessments)

Which stakeholders should be involved?



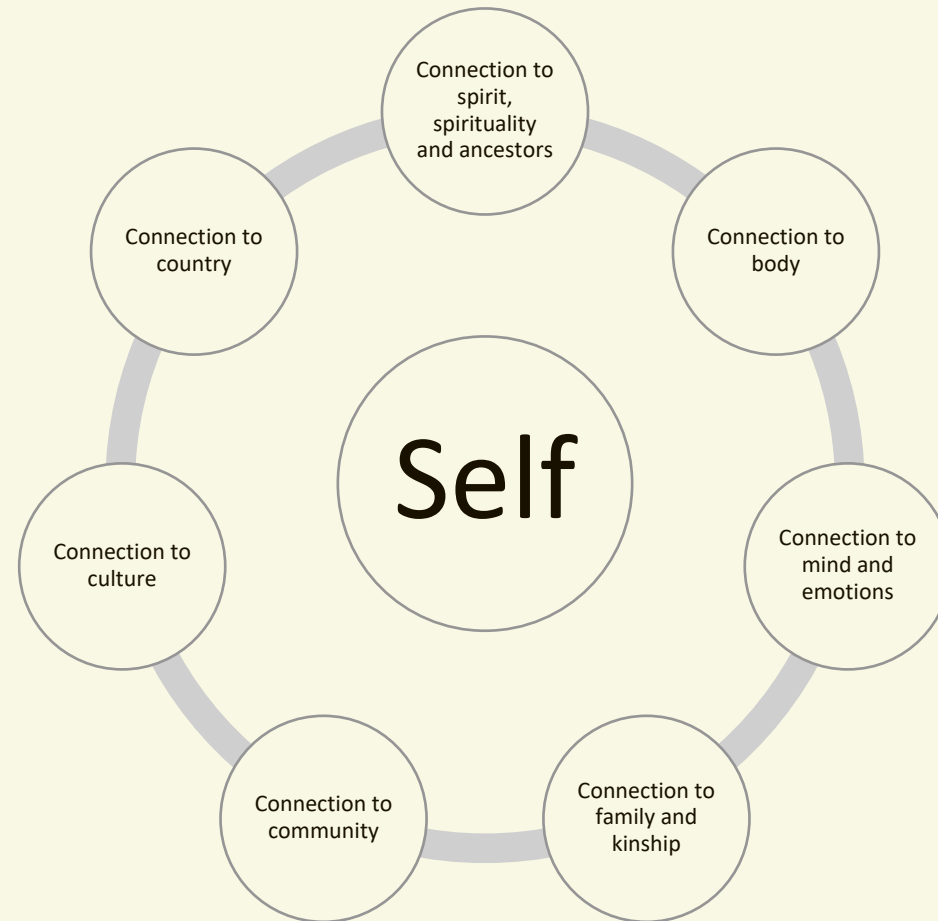
# Activity 2: Data model gaps – current backlog

SDOH topics in the backlog			Health Behaviour topics in the backlog	
<b>Communication capability</b> Languages spoken	<b>Housing summary</b> Housing Housing status Rurality	<b>Transport summary</b> Transport access	<b>Food and nutrition summary</b> Diet Food security	<b>Alcohol consumption summary</b>
<b>Education summary</b> Education level	<b>Living arrangements</b> Household Residential setting		<b>Physical activity summary</b>	<b>Substance use summary</b>
<b>Financial summary</b> Finance Income Social economic	<b>Personal safety summary</b> Childhood trauma Domestic violence			<b>Tobacco smoking summary</b> Amount Cessation Cigarette smoking Comment Daily smoking started Frequency Overall pack years Pattern Previous episodes of use Quit date Regular smoking started Years of smoking
<b>Health access summary</b> Access of care Distance from care Health literacy/numeracy	<b>Social network</b> Carer Next of Kin Relationships			<b>Vaping summary</b>

Tobacco smoking summary has been included in AUCDI R1, however is limited to **Overall tobacco smoking status**. All other elements are in the backlog



# Activity 2: Data model gaps – SEWB wheel



New concept to AUCDI

How can we include this in data to support interoperability?





# Activity 2: Data model gaps – what's missing?

Looking at the SDOH and health behaviours backlog and the SEWB wheel

- As a group
  - Identify **new data points for existing data groups**
    - Record the name of the data group on a post-it note
    - Add names of the data point/s
  - Identify **new data groups that are missing**
    - Record each new data group on a separate post it note.
    - Add names of supporting data point/s, if relevant



As a **group**  
at your table

## HOUSING SUMMARY

- Housing status
- Rural status

Post-it note example:  
High level data group = Housing summary  
Relevant data points = Housing status, rural status



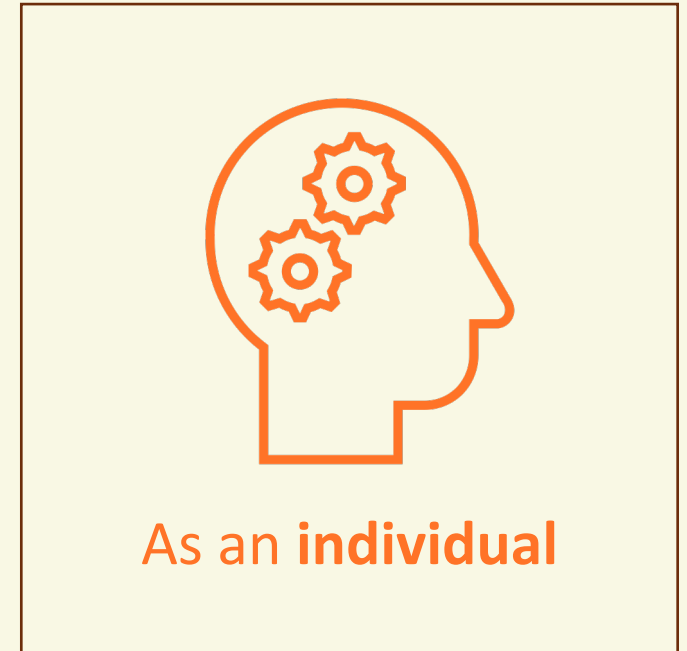
# Activity 3: Individual prioritisation of SDOH, SEWB, health behaviours

Each person should have 8x **ORANGE** coloured sticker dots

- Identify data groups to be prioritised for SDOH, SEWB, health behaviours data for interoperability
- Place dots on the pages on the data groups on the wall

## Optional

If you identify data groups that should **not** be included, please mark them with a BLACK sticker dot.



# Activity 4: Group prioritisation





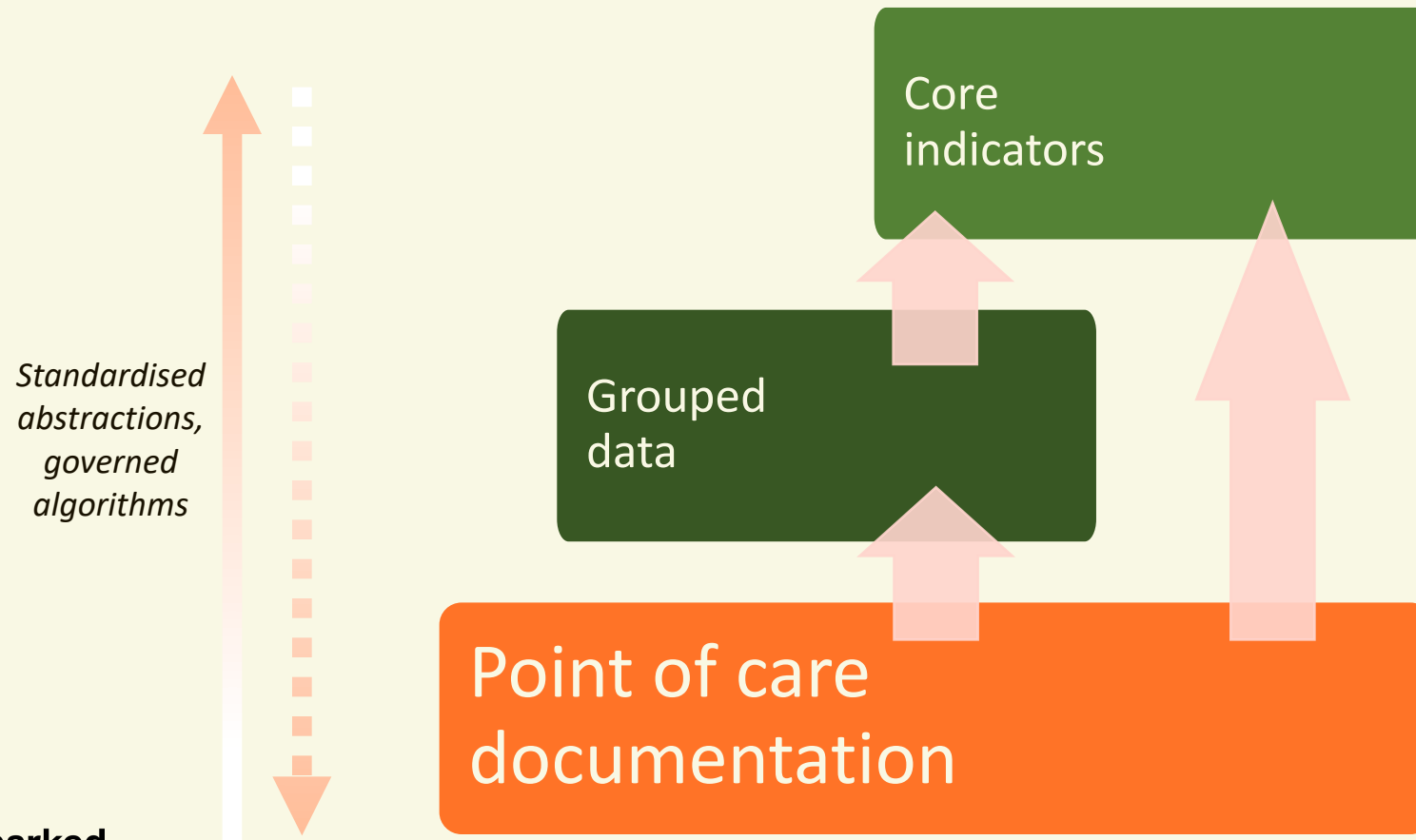
# Workshop 4: From little data to big data

- Objective: To explore and identify the key opportunities for AUCDI/SDOH/SEWB to support population health use cases. For example regional and national reporting, quality indicators, etc.

# Perspectives

Michael Frost & Stephen Hall  
Australian Institute of Health & Welfare  
Department of Health & Aged Care

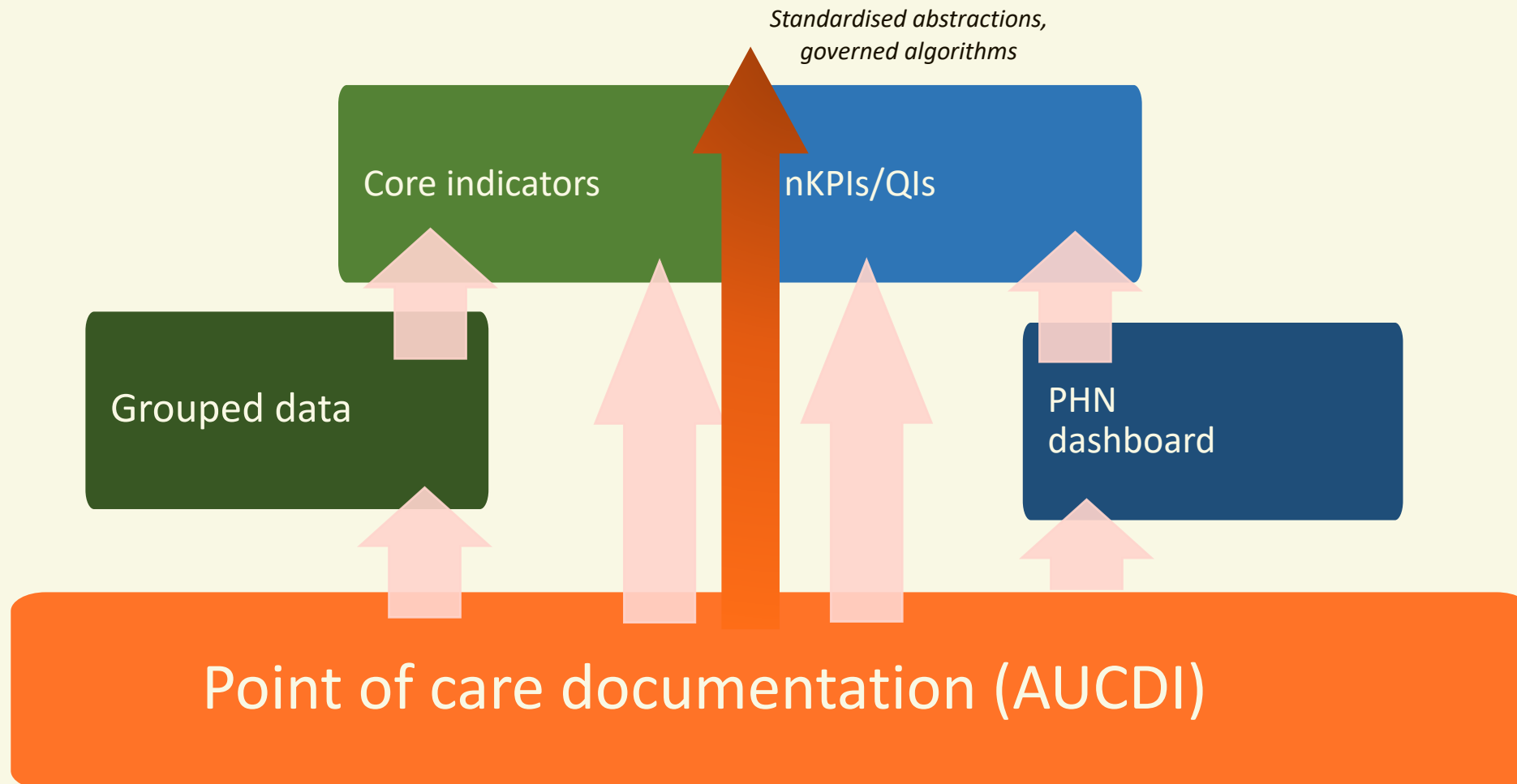
# Primary to population use of data



Continuum of data rather than separation by purpose

- Point of care documentation – most granular
- Abstracted, categorised, grouped to coarser grain data

# Primary to population use of data





# Primary to population use of data - AUCDI







# Activity 1: Imagine a future...

- We are now in a world where core clinical, SDOH, SEWB, health behaviours structured data is available.
- As a group, identify opportunities for improved local, regional and/or national reporting?
  - What data would you use?
  - What indicators would you want to measure?



As a **group**  
at your table

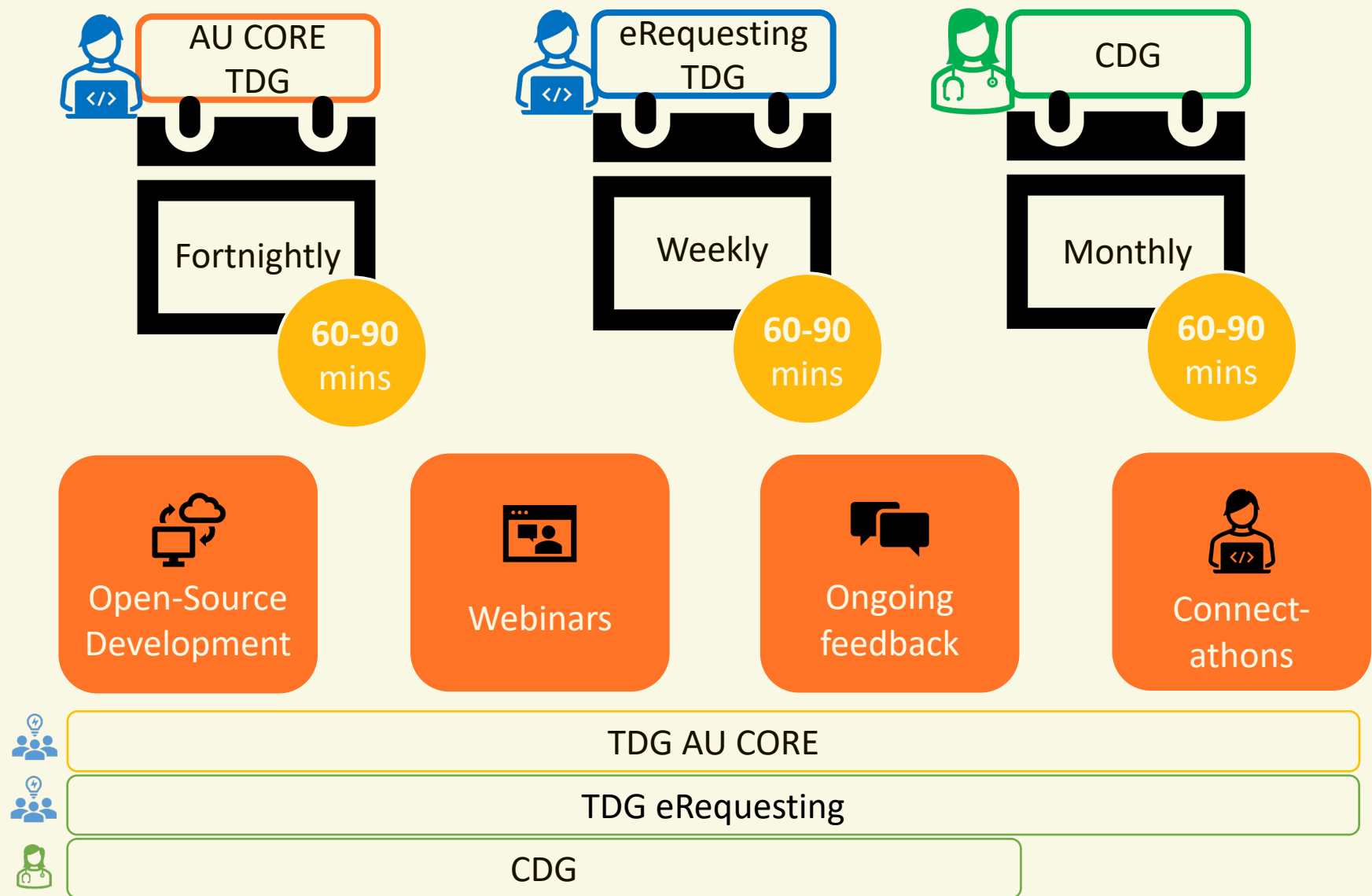


How to get  
involved?

# Sparked Participation



# Sparked Design Groups



# Upcoming Events 2024

## July



AU Core Testing  
Event F2F  
Sydney

## August



AU Core  
Testing Event  
Melbourne



HIC Sparked  
Workshop  
Brisbane



CDG  
Online

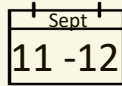


HL7 Au   
Connectathon  
Brisbane



Sparked  
Webinar  
Updates on Sparked Program

## September



Sparked CDG F2F  
CDG & Terminology Workshop  
Brisbane

## October



Sparked  
Webinar



Sparked CDG  
Online

## November



Digital Health  
Summit  
Perth



Sparked Leadership  
evening  
Melbourne



Sparked CDG F2F  
Melbourne



Sparked TDG F2F  
Melbourne

## December



Sparked  
Webinar  
Updates on Sparked Program



HL7 Au   
Connectathon  
Melbourne



# Where Next?

- AUCDI R1 – “Core of the Core” Published!
  - On our website
    - AUCDI R1
    - AUCDI Backlog
    - Feedback and Sparked responses
- AUCDI R2 – Scoping (now!) and development
- AUeReq DI- public comment complete, due to be published in October.

# Closing Menti





# Thank you!



Register for Sparked

