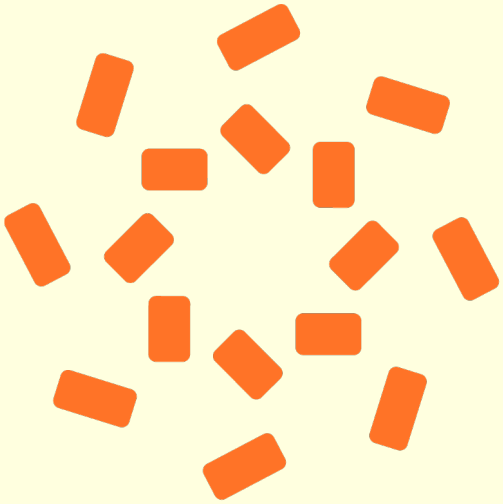

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HL7® FHIR®

Sparked Clinical Data Design Group

Wednesday 17 January 2024 Meeting

Online

Acknowledgement of Country

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

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

For us in Brisbane, it is the Turrbal and Jagera peoples

Agenda

Item	Item	Time	Lead/facilitator
1	Welcome	5 mins	Michael Hosking
2	Update from last meeting/AUCDI Notes from last meeting:	15 mins	Michael Hosking Kylynn Loi Kate Ebrill
3	Clinical modelling discussion • Medication statement • Vital signs and measurements • Encounter – clinical context • Biomarkers • Gender and sex	60 mins	Heather Leslie
4	Wrap up and close	10 mins	Michael Hosking Kylynn Loi

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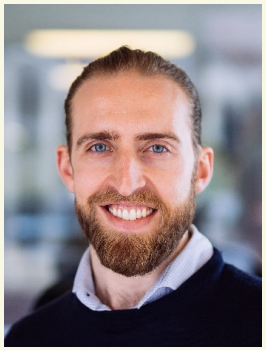
Welcome and intro

FHIR@csiro.au

Kate Ebrill – Sparked Lead



Michael Hosking – Sparked Deputy Lead

Kylynn Loi – Clinical Design Lead

Dr Heather Leslie – Lead Clinical data modeller

Danielle Tavares-Rixon – FHIR technical lead

Dr Chris Moy– Co-Lead Sparked Clinical Design Group

Brett Esler – FHIR expert

Matt Cordell – Clinical Terminology Specialist

Michael Osborne – FHIR Terminologist

Bernadette Cranston – Program Manager

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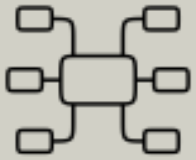
What is AU Core and Australian Core Data set for Interoperability (AUCDI)?

CDG is here

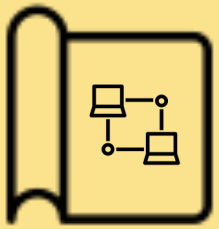
AU CDI



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

TDG is here

AU Core



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

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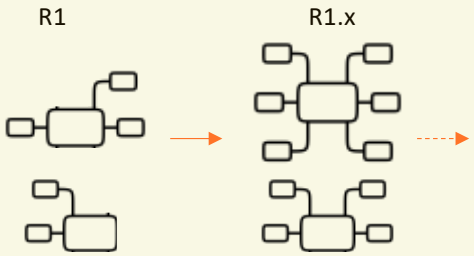
Sparked: AUCDI

Key outcome is “core of the core”

Start small and grow iteratively

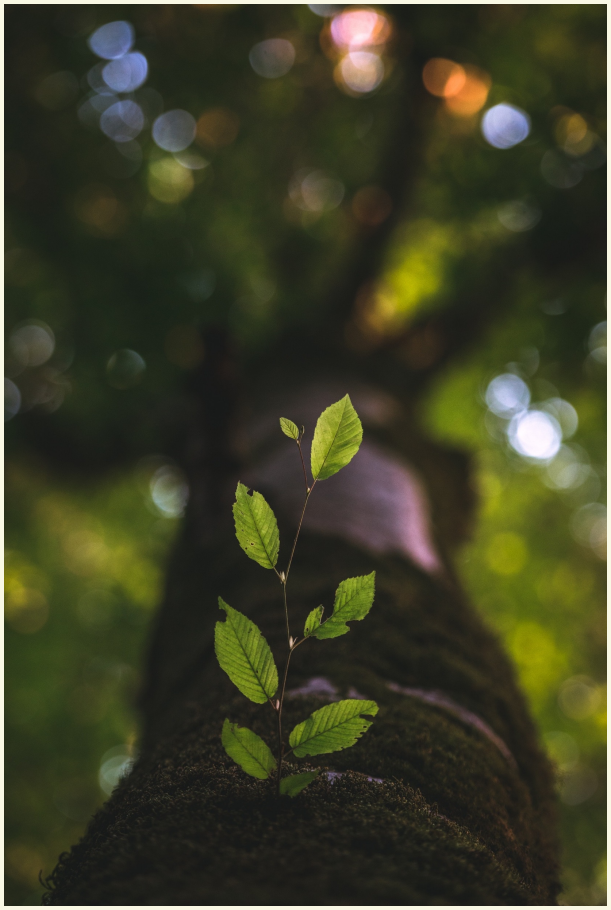
- No simple “undo” – impact of change can be high
- Data elements can be added to over time
  - Work through backlog/to do list
  - Add more use cases
  - More functionality available



Stick with our design principles

Align and leverage work internationally were possible

- Where we differ, need to understand the impact



“From little things, big things grow”

“When in doubt, leave it out”

AUCDI 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 Draft Principles of Data Set 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

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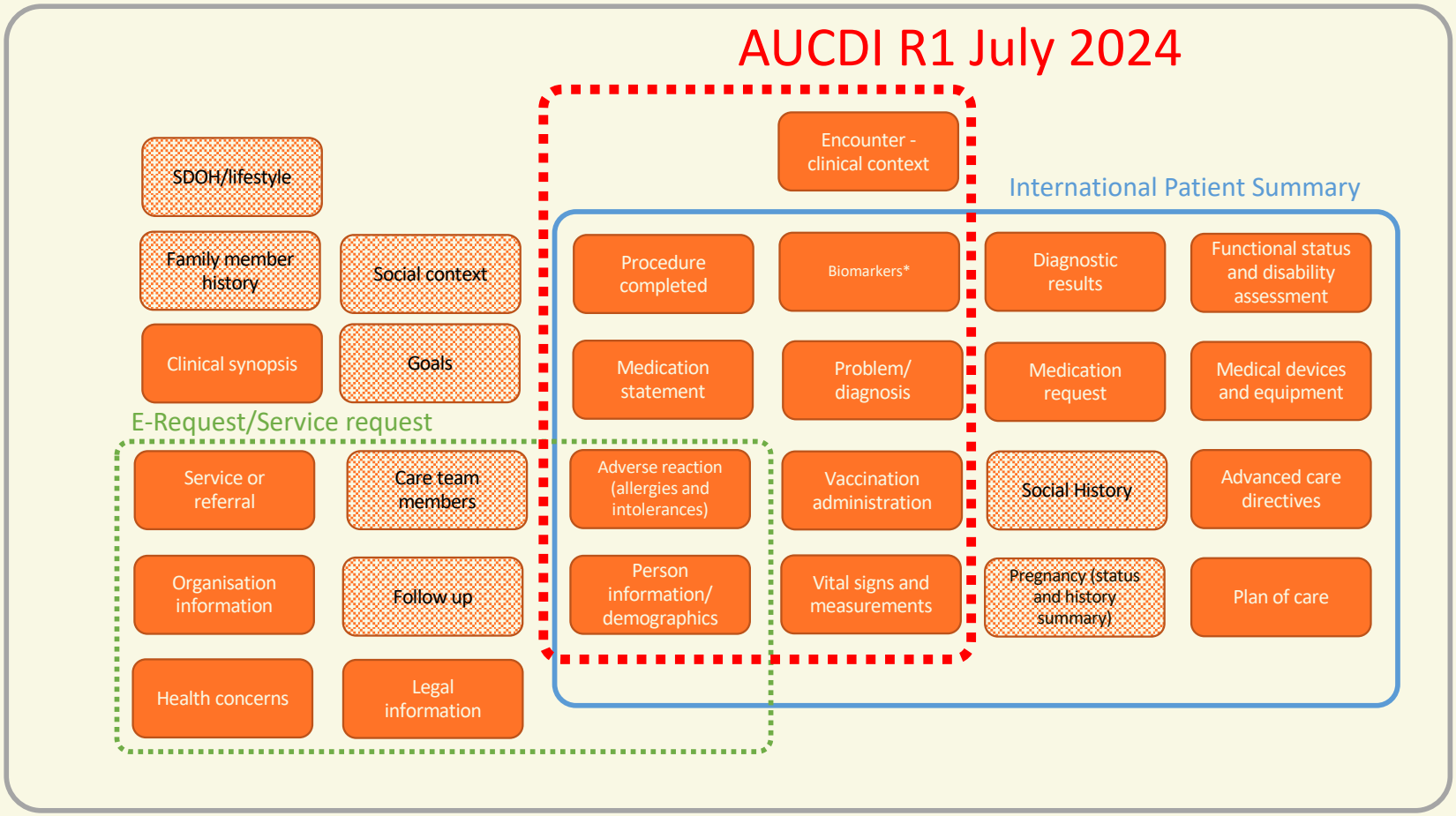
Core principles of data set design

Design Principles	Approach
Reduce duplication - Single entry, single development (multiple use and reuse)	Supporting preventative care/chronic disease management to drive clinical decision support, considering secondary use data sets e.g. AIHW primary care data model, PIP QI
Supports patient centred care - driven by a clinical quality and safety use case	Engaging with clinicians from the beginning across the health ecosystem Looking at agreed national clinical standards and guidelines
Not data for data's sake	Starting with “core of the core” and growing iteratively
Driven by primary clinical data use not secondary data use needs	Considering secondary use data sets e.g. AIHW primary care data model, PIP QI, etc. Looking towards data that can be reused
Supports best practice care, clinical guidelines and clinician workflow	Engaging with clinicians across the health ecosystem from the beginning Looking at agreed national clinical standards and guidelines
Systems can support now or with minimal effort, supporting a strategic roadmap with an agile iterative process	Aligned with AU Core, looking at US core Meetings with vendors and survey to go out to TDG to validate
Leverage agreed national health data standards	Using agreed national clinical and technical standards – FHIR, SNOMED CT, LOINC, clinical standards e.g. RACGP Clinical guidelines
Involve and consider all healthcare domains and care modalities	Engaging with clinicians, jurisdictions and industry from across the health ecosystem

Potential AUCDI R2 candidates

AUCDI –Scope



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* initial scope towards preventative health and chronic disease management

AUCDI Release 1 at a glance

Problem/Diagnosis
- Problem/diagnosis name
- Body site/laterality
- Status
- Comment

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

Vaccination administered event
- Vaccine name
- Sequence number
- Date of Administration
- Batch
- Comment

Adverse reaction risk summary
- Substance name
- Manifestation/s
- Comment

Medication use statement
- Medicine name
- Clinical indication
- Strength
- Form
- Dose
- Route of administration
- Dose frequency
- Duration
- Instructions
- Start date
- Date/time of last administration
- Long term indicator
- Comment

Sex and Gender
- Sex assigned at birth
- Gender identity
- Pronouns

Tobacco smoking summary
- Overall Status

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
- Type of encounter

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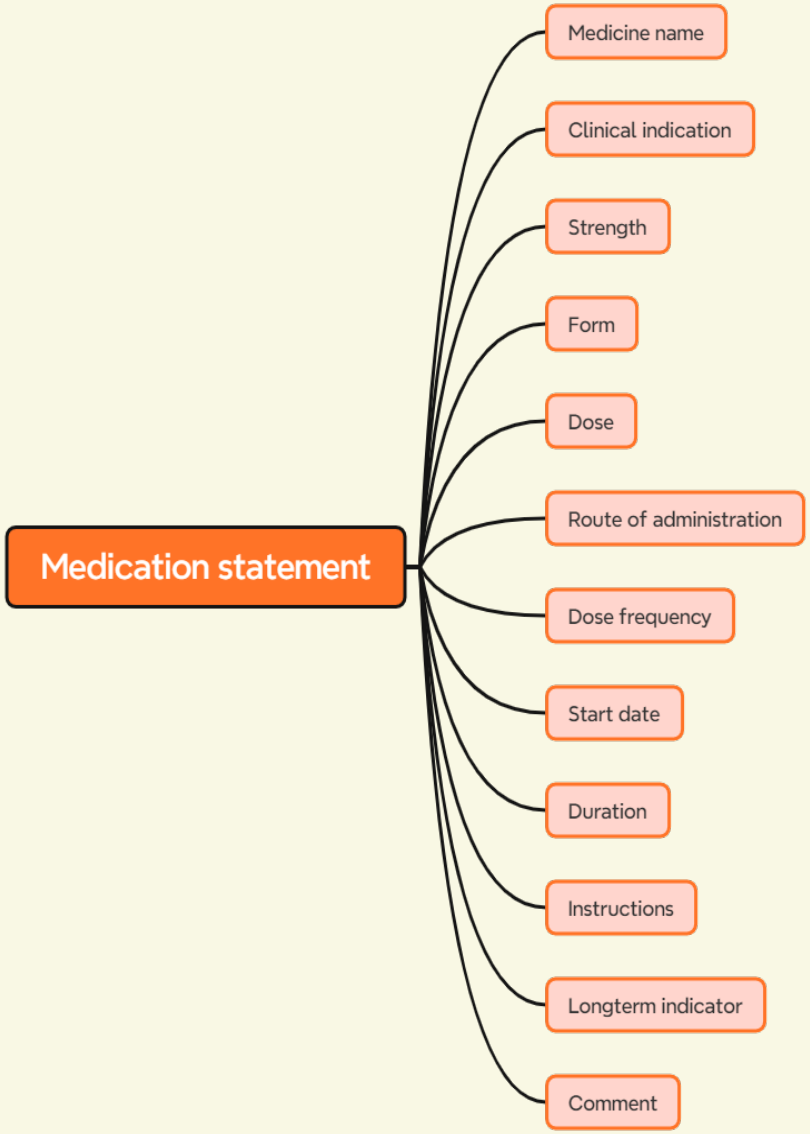
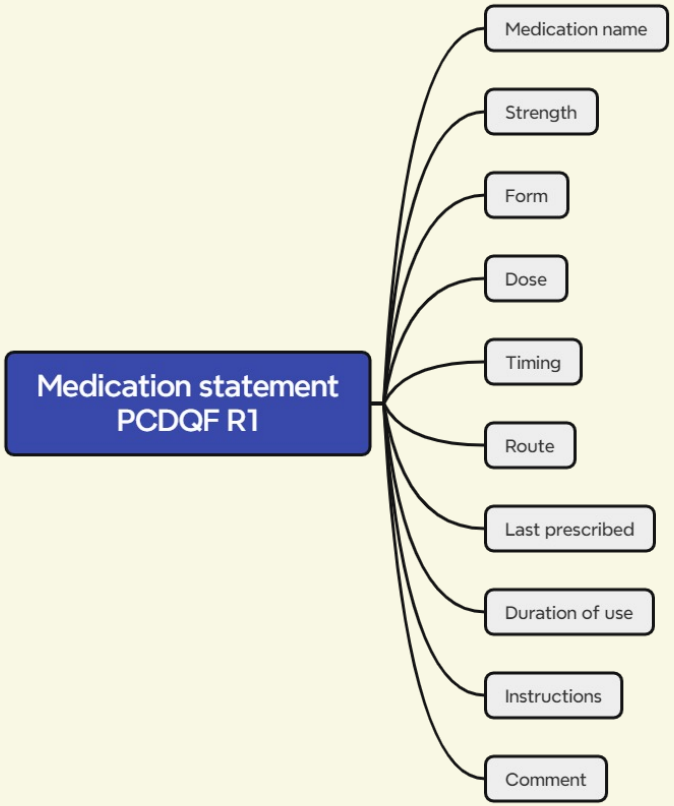
Into the data model…

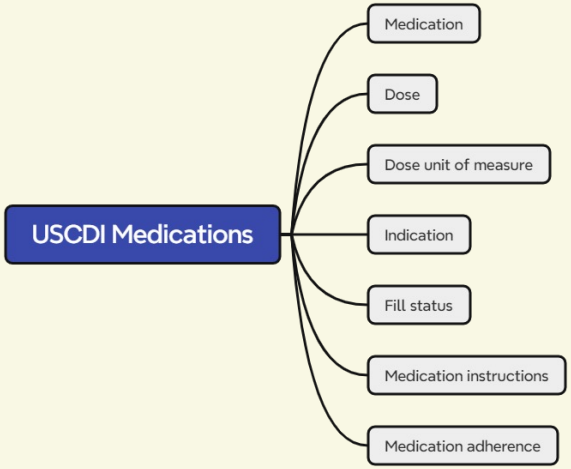
Medication statement

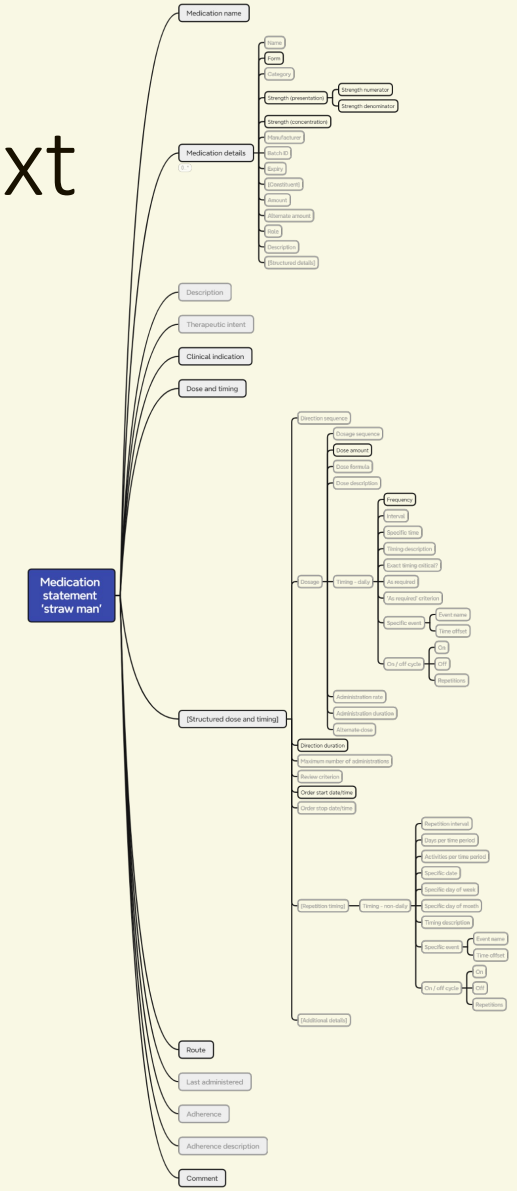
Details about a medicine, nutritional product or other therapeutic item that is currently being taken or used by the individual, including items that are prescribed or obtained over the counter.



Vital signs & measurements context







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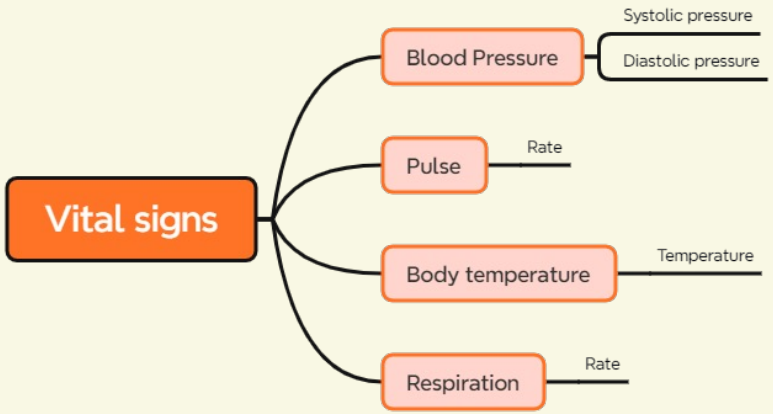
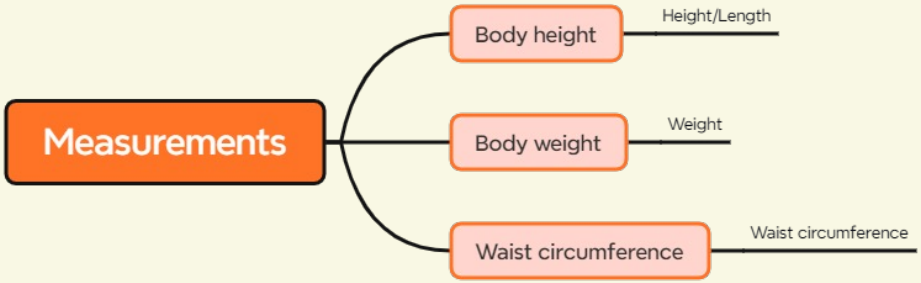
Vital signs and Measurements





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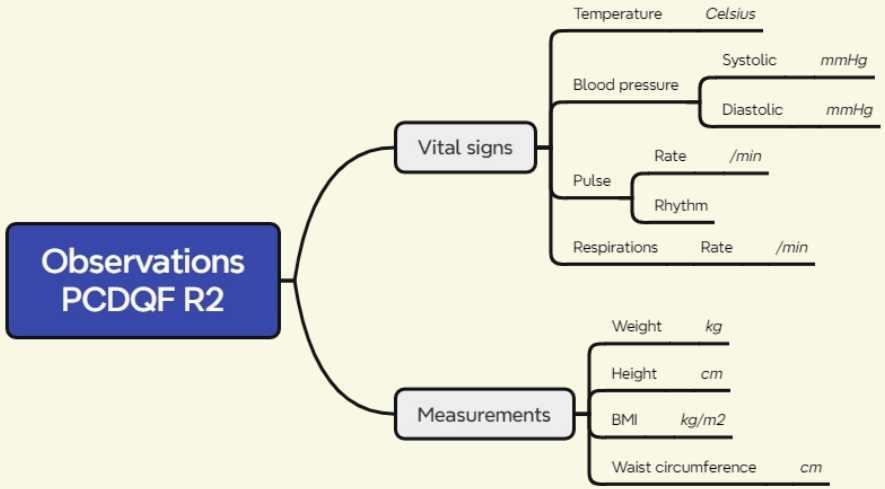
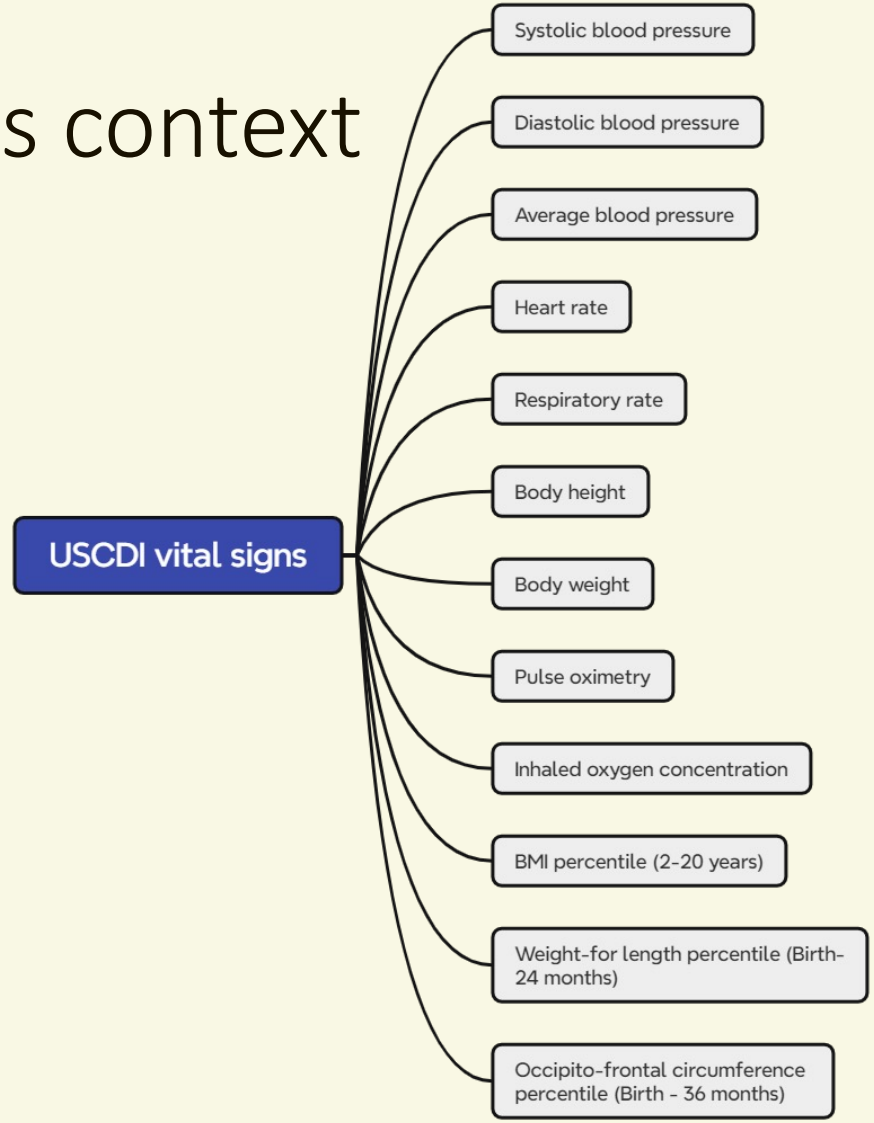
Vital signs & measurements context





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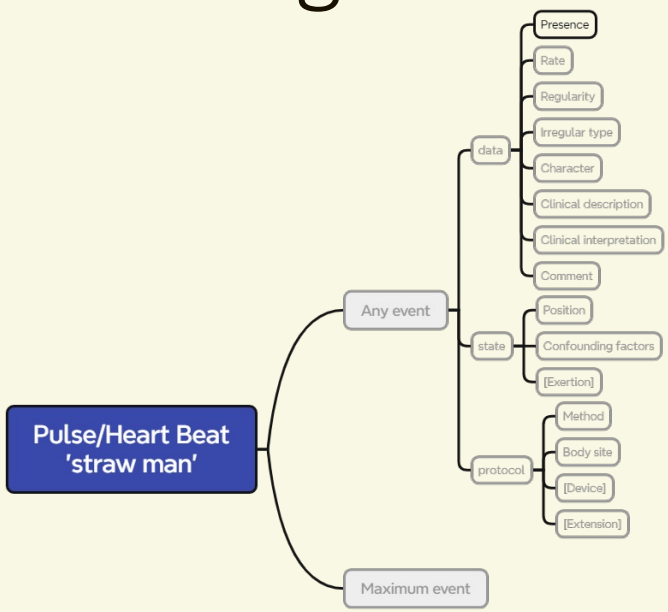
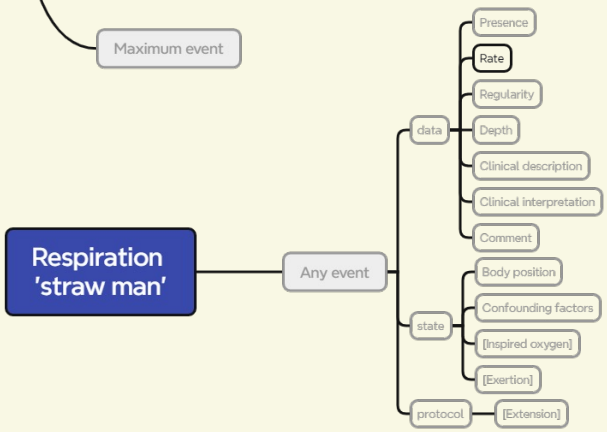
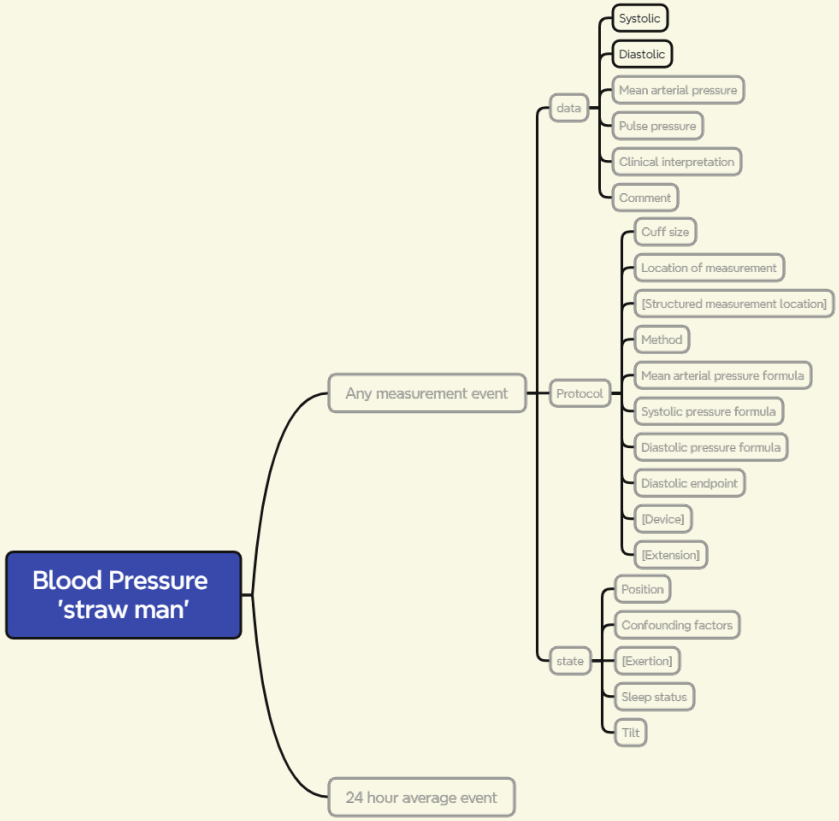
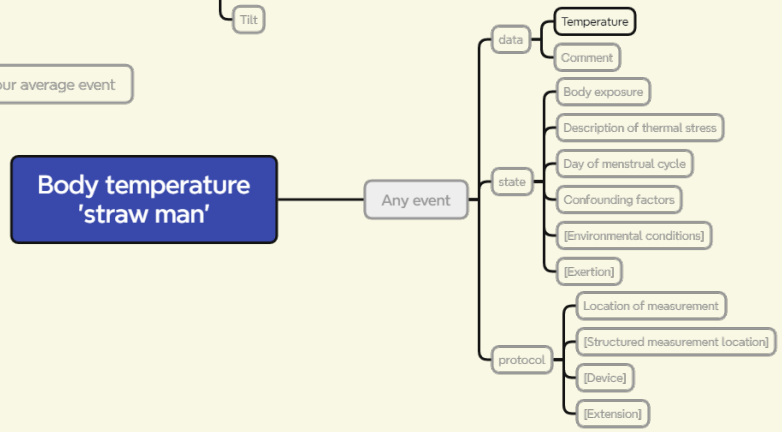
Vital signs context









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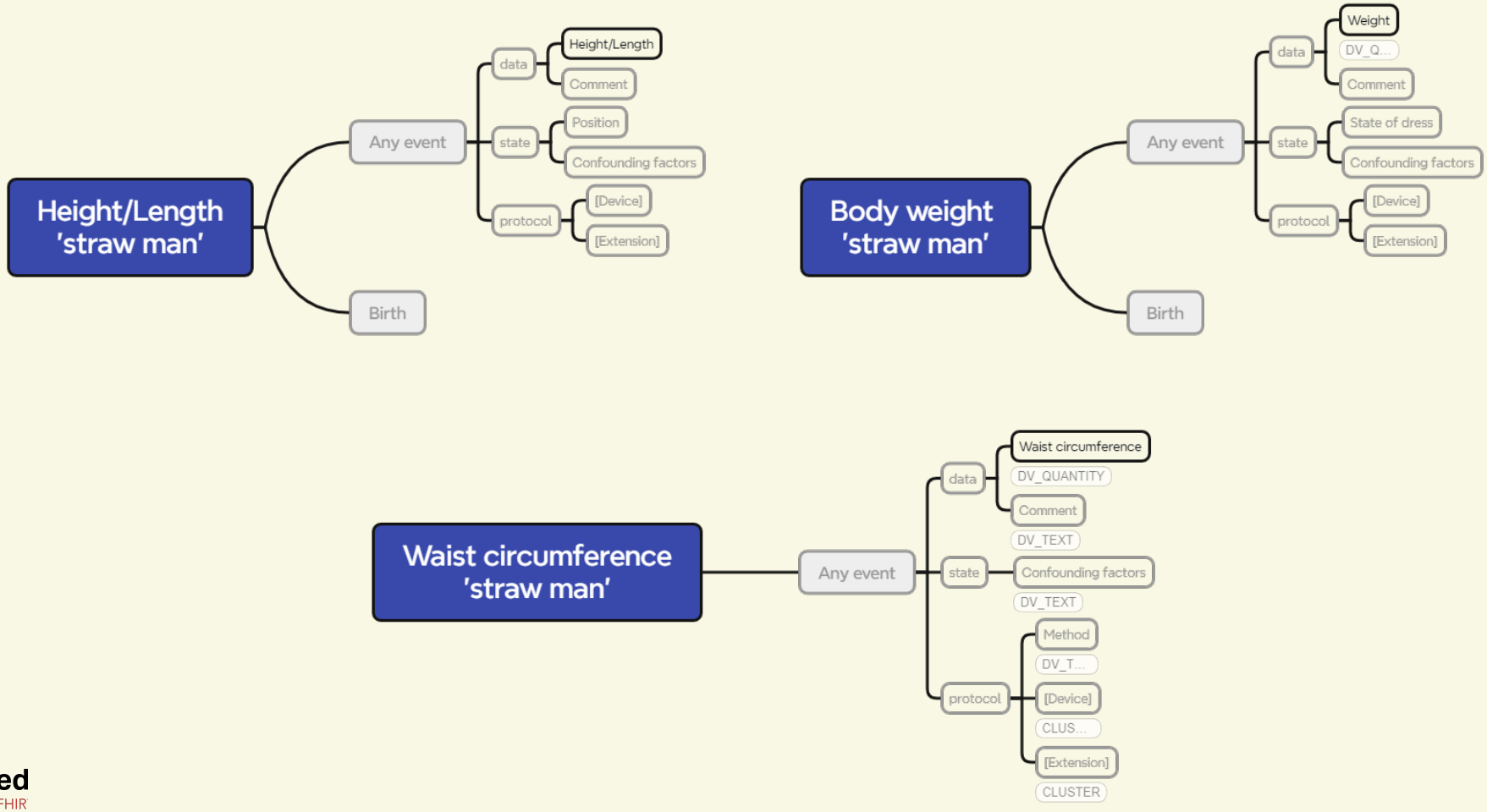
Measurements context



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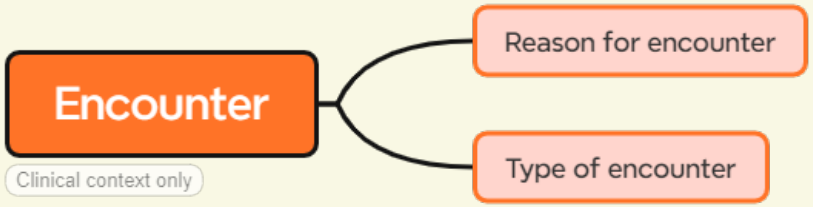
Encounter – clinical context

- Reason for encounter
  - The reason for initiation of any healthcare encounter or contact by the individual.
  - Proposed value set combines:
    - Clinical terms representing ‘Presenting problem’ (or similar)
      - symptoms and signs eg ‘shortness of breath’; ‘vomiting’
    - Administrative terms representing ‘Reason for attendance’ (or similar)
      - eg ‘pre-employment medical’; ‘routine immunisation’.
- Type of encounter
  - The modality through which the encounter occurred or was conducted
  - Proposed value set includes:
    - Clinic visit
    - Home visit
    - Emergency department
    - Telehealth



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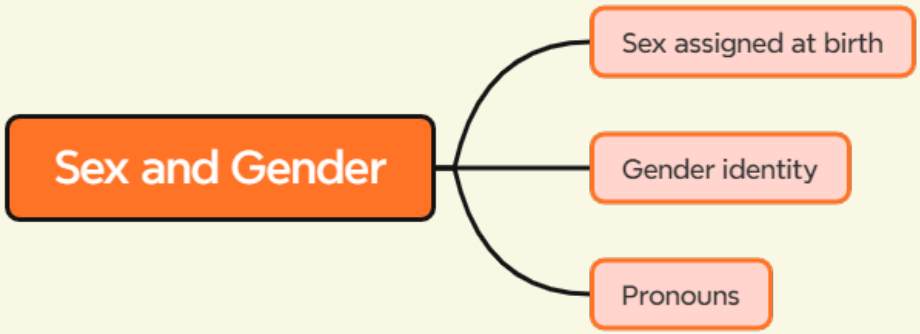
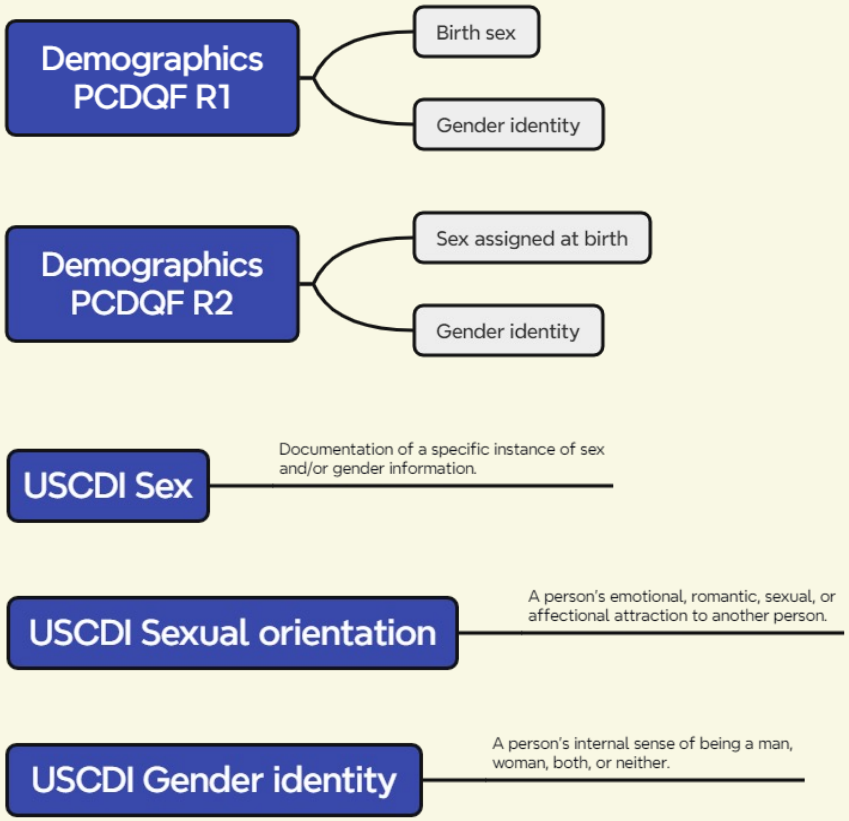
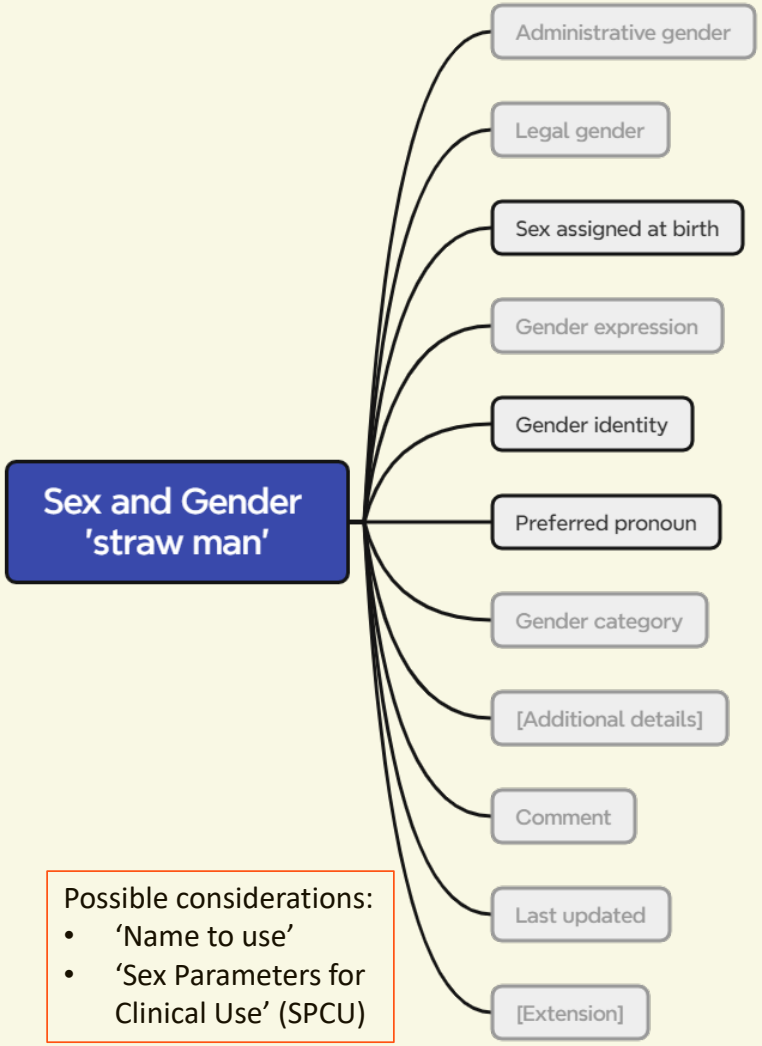
Sex and Gender

- Sex assigned at birth
  - The sex of the individual determined by anatomical characteristics observed and registered at birth.
- Gender identity
  - The individual's internal perception of their own gender.
- Pronouns
  - Pronouns specified by the individual.



Sex and Gender context





Possible considerations:
- 'Name to use'
- 'Sex Parameters for Clinical Use' (SPCU)

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Proposal R1: Sex and Gender data elements

Data element	Description	Use
Sex assigned at birth	The sex of an individual determined by anatomical characteristics observed and registered at birth.	Facilitate effective patient care Generate automated recalls for health screens (e.g. pap smears, prostate exams) Clinical decision support for calculation of medications, pathology result thresholds, etc.
Gender identity	The individual's internal perception of their own gender.	Gender identity and sex assigned at birth may differ, having separate data elements allows individuals to be respected and for care providers to deliver personalized care
Pronouns	Pronouns specified by the individual.	To be used when speaking directly to the individual, or when referring to the individual in written documentation.

It is anticipated that this data group will be expanded over time to incorporate additional detail about the aspects of sex and gender – this could include sexual orientation, anatomical inventory, etc.

Australia

Reference	Organisation	Data elements
Collecting and recording information about patient sex, gender, variations of sex characteristics and sexual orientation - RACGP Standards for general practices (5th edition) fact sheet https://www.racgp.org.au/FSDEDEV/media/documents/Running%20a%20practice/Practice%20standards/5th%20edition/Collecting-and-recording-information-about-patient-sex-gender.pdf	RACGP	Gender Sex Sex characteristics Sexual orientation
Guidance note: Inclusive collection and reporting of sex and gender data www.health.vic.gov.au/populations/understanding-lgbtiq-health The Department of Health has approved changes to **two** data elements within its hospital (public and private and day procedure centres) data collections: Victorian hospitals are to report data on patients' '**sex at birth**' rather than 'sex' (effective 1 July 2024) Victorian hospitals are to report on patients' '**gender**' (optional from 1 July 2023, mandatory from 1 July 2024)	Victorian Department of Health	Sex at birth Gender
Standard for Sex, Gender, Variations of Sex Characteristics and Sexual Orientation Variables (2021)	Australian Bureau of Statistics	Sex Gender Variations of sex characteristics Sexual orientation.

International

Reference	Organisation	Data elements
Provider Fact Sheet on Birth Sex and Gender Identity – Jan 2022 https://www.patientcare.va.gov/LGBT/docs/2022/Birth-Sex-Gender-Identity-FactSheet-for-Providers-2022.pdf	Department of Veterans Affairs (VA) – USA Veterans Health Administration (VHA)	Birth sex Self-identified Gender Identity Sexual Orientation
Collecting Sexual Orientation and Gender Identity Data in Electronic Health Records https://www.lgbtqiahealtheducation.org/wp-content/uploads/Collecting-Sexual-Orientation-and-Gender-Identity-Data-in-EHRs-2016.pdf	The National LGBTQIA+ Health Education Center	Gender Identity Sexual orientation

Next steps

- Slides and minutes of this meeting will be posted on Sparked CDG confluence page
  - Please provide feedback by commenting on confluence (you will need a PUMA account) or by emailing fhir@csiro.au

Upcoming items

- First week of February 2024 – AUCDI R1 Draft for comment to be published for review

Next face to face – 13 February

- 13 February 2024 – all day workshop – in person – Melbourne!
  - Agenda – eRequesting
  - Please make travel arrangements early if you are planning to attend – Same week as Taylor Swift concerts!
  - TDG 14 February (also eRequesting)
  - Get tickets here https://www.eventbrite.com.au/e/sparked-erequesting-feb-2024-fhir-accelerator-design-group-meetings-tickets-757555517947?aff=oddtdtcreator

Thank you
See you next time!