

Sparked



Clinical Design Group

AUCDI Release 2 Chronic Disease Management

Monday 9th December 2024

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.



Agenda

- Update on AUCDI R2 Patient Summary
 - Out for community comment
- Update on AU Patient Summary Clinical Focus Group
- Chronic Disease Management data modelling discussion



Objectives



Updating the CDG on the AUCD Release 2 Chronic Disease Proposals – and outputs from the CDG Chronic Disease Management Workshops



Propose requirements for the data groups to support real-time shared care planning and chronic disease management



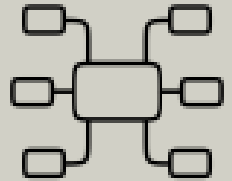
Updates



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

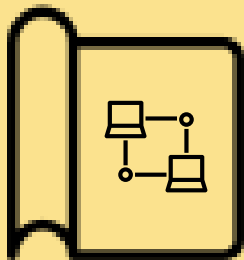
CDG is here

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

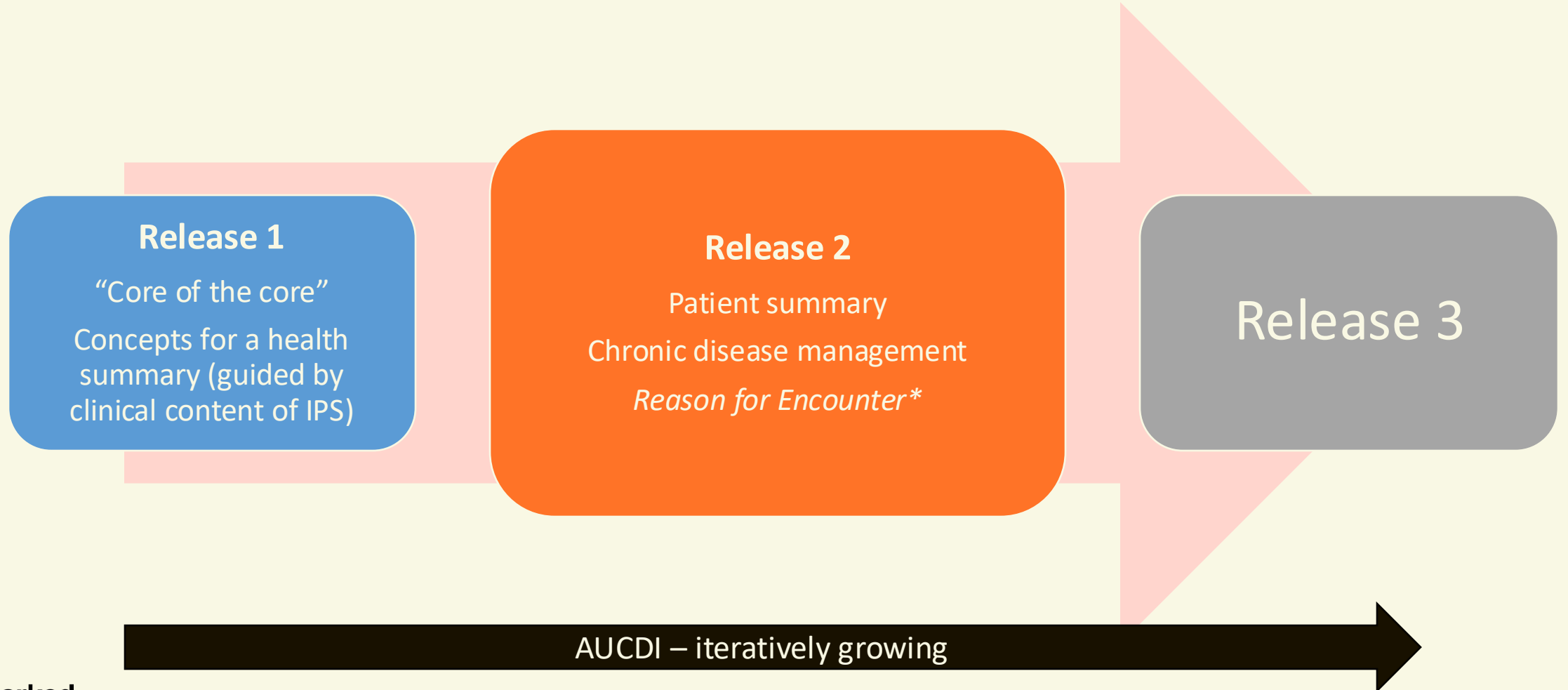


Specifies “*HOW*” the core set of data (above) and information should be structured, accessed and shared between systems

TDG is here

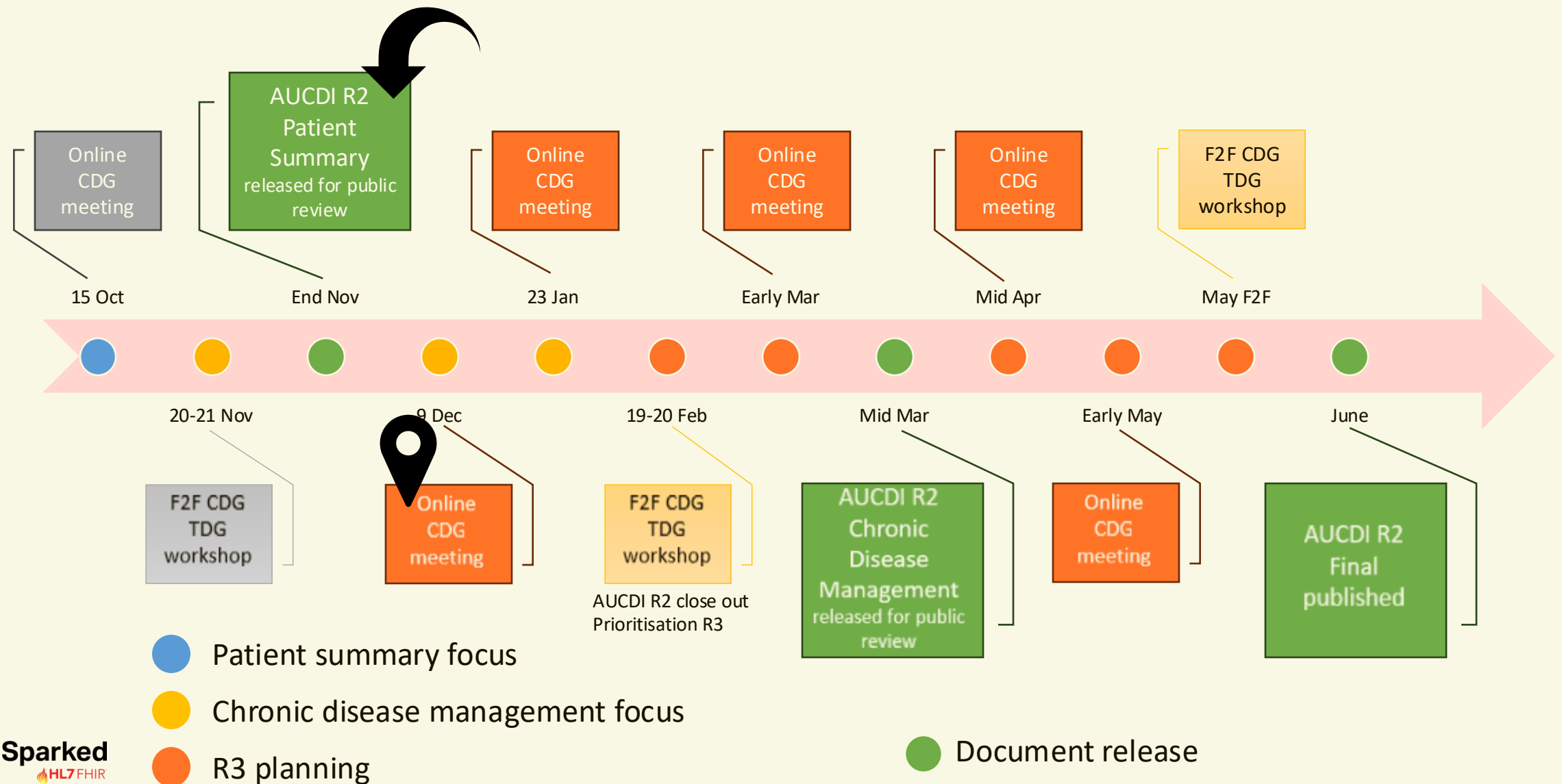


AUCDI Release 2 Chronic Disease Management





AUCDI R2 schedule



AUCDI R2 Patient Summary

Open for community comment

Target Audience:

- all interested stakeholders
- intended to be inclusive of all points of view and not requiring specific skill sets or professional background

Review period:

- Closes Friday 17 January 2024
- Please contact us at sparked@csiro.au if you have any issues



AUCDI R2 Patient Summary Open for community comment

Available on Sparked webpage -
sparked.csiro.au

- AUCDI R2 Patient summary draft for comment PDF
- Feedback form
- Prep sheet





Feedback

1. Suggestions for improvement in the new and updated data groups or elements in the patient summary context
2. Suggestions for additional data elements that are not yet in the backlog and why?
3. Are there significant barriers to development, implementation, or use for any of these data elements in Draft AUCDI R2 Patient summary that warrant a change in definition, or removal?
4. Suggestions around additional use cases and data groups/elements to support those use cases to go on our roadmap
5. General feedback on the document

Review is not expected for content that has not changed from AUCDI Release 1

Feedback

- Through the Microsoft form
 - General feedback
 - Specific feedback about each data group and each data element
 - Overall recommendation for each data group
 - Accept
 - Minor revisions
 - Major revisions
 - Reject
 - Abstain
- Due 17 January 2025
- Please share with your networks!
- Please contact us at sparked@csiro.au if you have any questions



AUCDI Release 2 – Patient Summary

Problem/Diagnosis

- Problem/diagnosis name
- Body site/laterality
- Date/time of onset
- Date/time of resolution
- Status
- Comment
- Last updated

Adverse reaction risk summary

- Substance name
- Date/time of onset of first reaction
- Manifestation/s
- Severity of reaction
- Comment
- Last updated

Sex and Gender Summary

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

Pregnancy assertion

- Pregnancy assertion
- Justification
- Date of assertion

Procedure completed

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

Medication use statement

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

Last Menstrual Period assertion

- Date of onset
- Certainty
- Date of assertion

Estimated date of delivery summary

- EDD by cycle
- EDD by ultrasound
 - Date of ultrasound
 - Gestation by scan
- Last update

Vaccination administered event

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

Patient Summary Clinical Focus Group update

- 5 Patient Summary Consumer Journey maps developed
 - Interstate GP Visit
 - Emergency Hospital Attendance
 - Referral to Specialist & Allied Health
 - Hospital to Aged Care Interstate Transfer
 - Pre-operative Surgical Journey
- at the face-to-face Sparked CDG in November
- AU Patient Summary FHIR IG Project have nominated 3 reference Consumer Journeys
 - Interstate GP Visit
 - Emergency Hospital Attendance
 - Referral to Specialist & Allied Health



Patient Summary Clinical Focus Group update

- Aim to have Patient Summary Consumer Journeys published by end on Jan 2025
- To be published via the Sparked Website & shared via the Sparked CDG once available
- Working on a mechanism to provide feedback prior to publishing
 - Email with details on the feedback window and how to submit to be sent out prior to Christmas closures

Patient Summary Clinical Focus Group update

- Aim to have Patient Summary Consumer Journeys published early Feb 2025
- To be published via the Sparked Website
- Working on a mechanism to provide feedback prior to publishing
 - Email with details on the feedback to be sent out prior to Christmas closures – **register with Sparked to get on the mailing list**

Chronic Disease Management

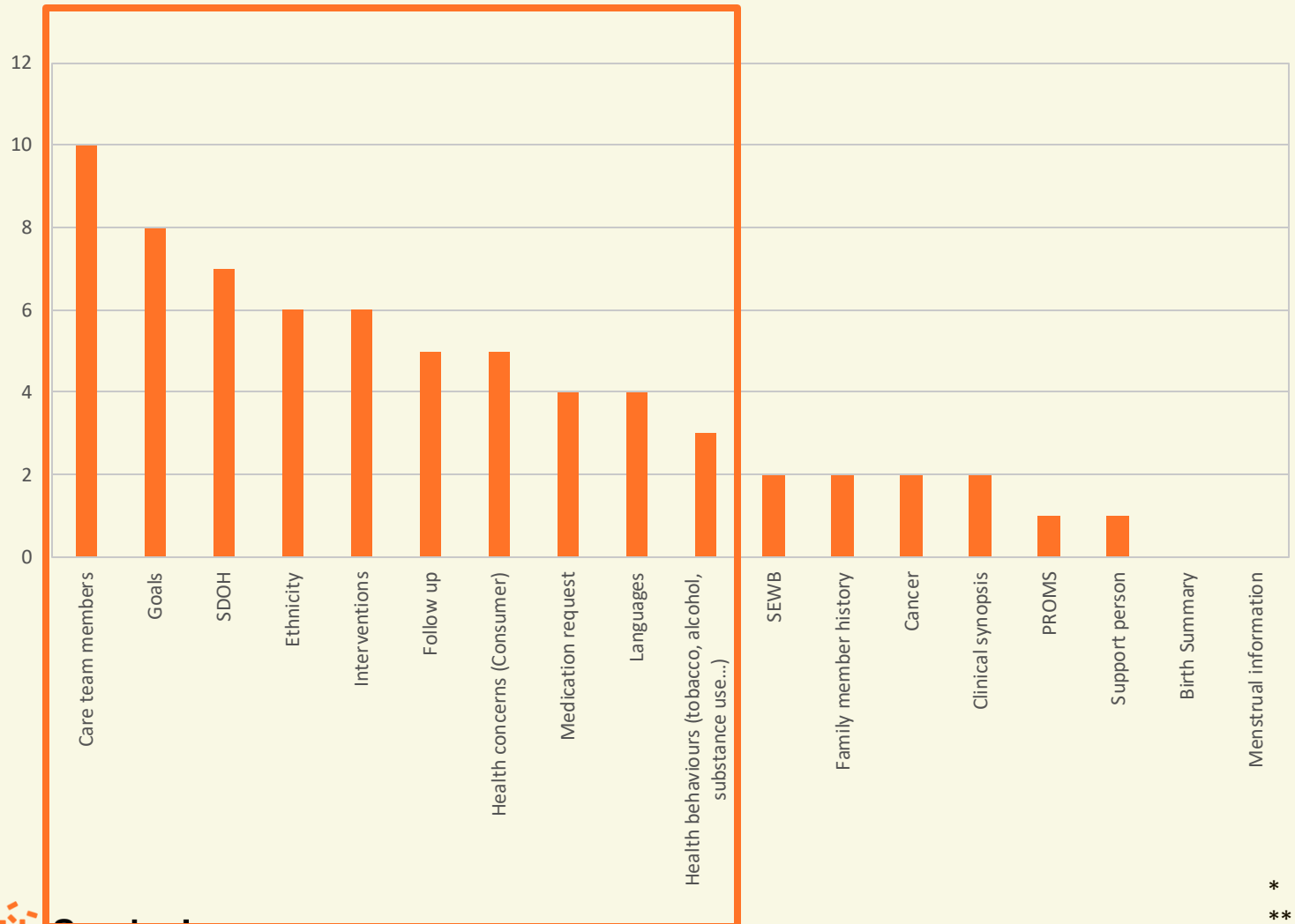
September & November 2024 CDG workshops

- Series of workshop activities focused around
 - AUCDI R2
 - Patient summary
 - Chronic disease management
 - Reason for Encounter





Chronic Disease Management Data Group Prioritisation



1	Care team members*
2	Goals
3	SDOH
4	Ethnicity**
5	Interventions
6	Follow up
7	Health concerns (Consumer)
8	Medication request*
9	Languages***
10	Health behaviours (tobacco, alcohol, substance use...)
11	SEWB
12	Family member history
13	Cancer
14	Clinical synopsis
15	PROMS
16	Support person
17	Birth Summary
18	Menstrual information

*
**

To be deferred to TDG

Needs to be aligned to national standards

Part of a wider "Communication" topic that should be considered



Proposed AUCDI Release 2

☆ Updates to existing AUCDI R1 content

★ New data groups for Patient Summary

⊛ New data groups for Chronic Disease Management

Ethnicity	Languages
SDOH ⊛	Interventions ⊛
Family member history	Medication request
Clinical synopsis	Goals ⊛
Health concerns (Consumer) ⊛	Care team members
SEWB	Follow up ⊛
Menstrual information	Birth Summary

AUCDI R1 July 2024

Reason for Encounter - clinical context		International Patient Summary	
Procedure completed	Key biomarkers	Diagnostic results	Functional status and disability assessment
Medication statement	Problem/diagnosis ☆	Social History (health behaviours) ⊛	Medical devices and equipment
Adverse reaction (allergies and intolerances) ☆	Vaccination administration	Pregnancy (status and history summary) ★	Advance care directives
Person information/demographics	Vital signs and measurements	Plan of care	Past history of illness



Health Behaviours

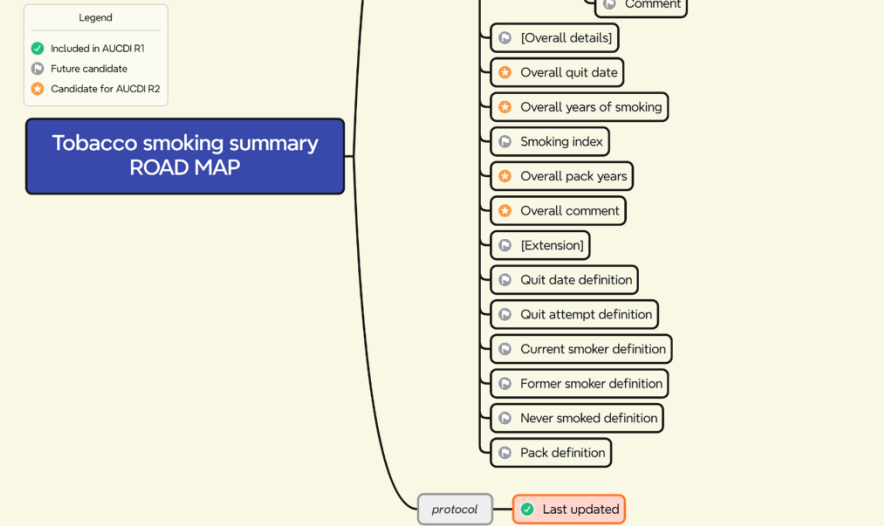
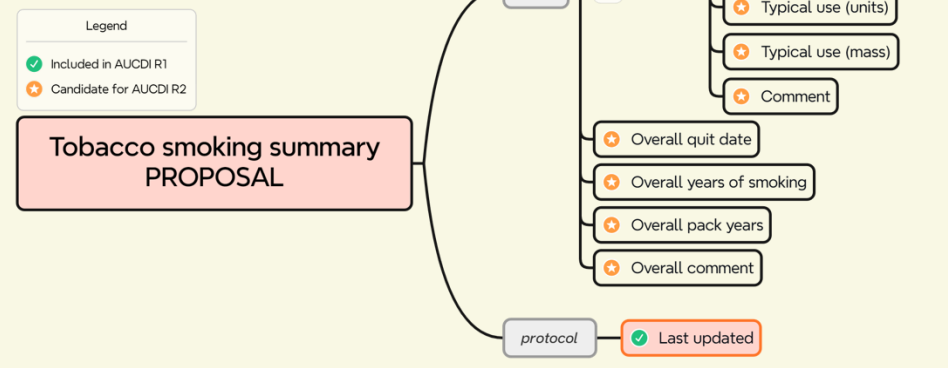
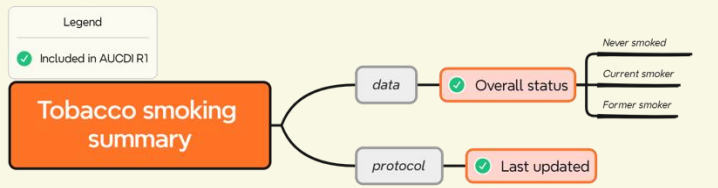
Tobacco smoking summary

AUCDI R1

- **Concept description** - summary information about an individual's pattern of smoking tobacco and tobacco-containing products.

Potential related future data groups:

- Smokeless tobacco summary
- Exposure summary
- Readiness for change
- Smoking diary

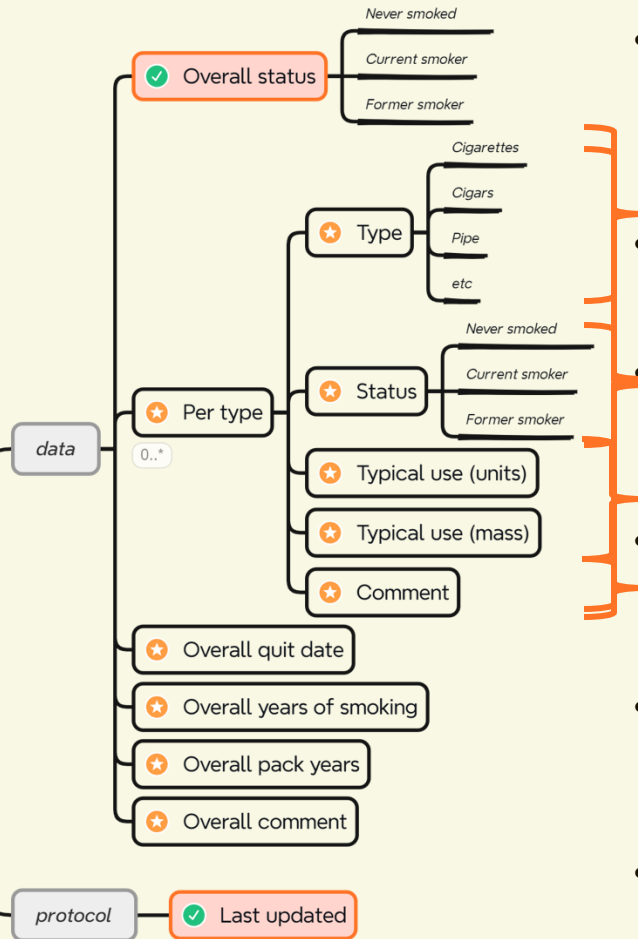


Tobacco smoking summary

Legend

- ✓ Included in AUCDI R1
- ★ Candidate for AUCDI R2

Tobacco smoking summary PROPOSAL



Per type group

- **Description:** Details about smoking activity for a specified type of tobacco.
- *Allows for a repeating set of data elements for each type of tobacco smoked*

Type

- **Description** - The type of tobacco smoked.
- **Value set** – *to be determined eg Cigarette, Cigar, Pipe etc*

Status

- **Description:** Statement about smoking habits for the specified type of tobacco.
- **Value set** – *Current smoker/Former smoker/Never smoked*

Typical use (units)

- **Description** - Estimate of the typical amount smoked over a lifetime by 'sticks' or units.
- *For example: 10-20/day or 15/week*

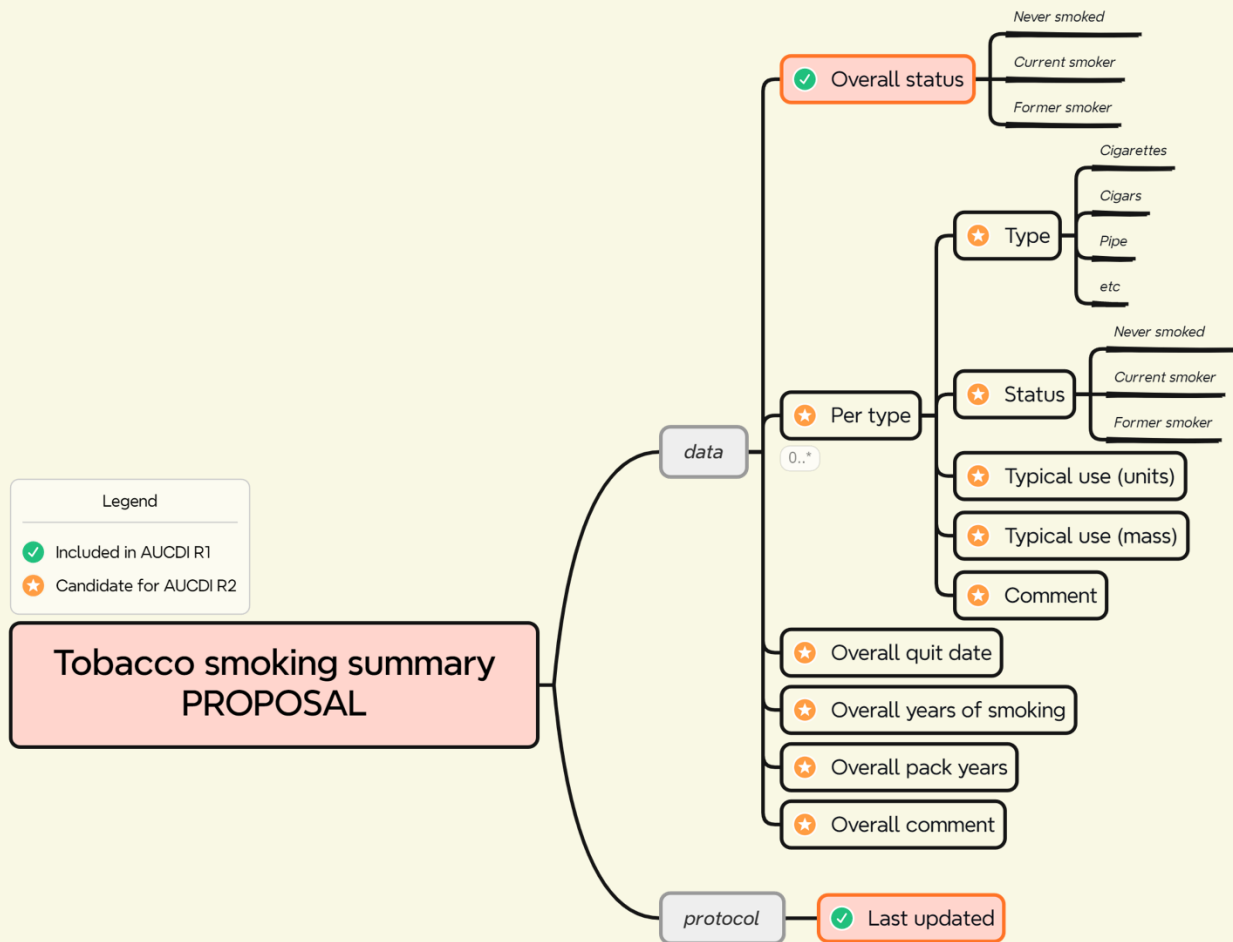
Typical use (mass)

- **Description** - Estimate of the typical amount of loose-leaf tobacco smoked over a lifetime by weight.
- *For example: 10-15g/day or 50g/week*

Comment

- **Description** - Additional narrative about smoking of the specified type of tobacco, not captured in other fields.

Tobacco smoking summary



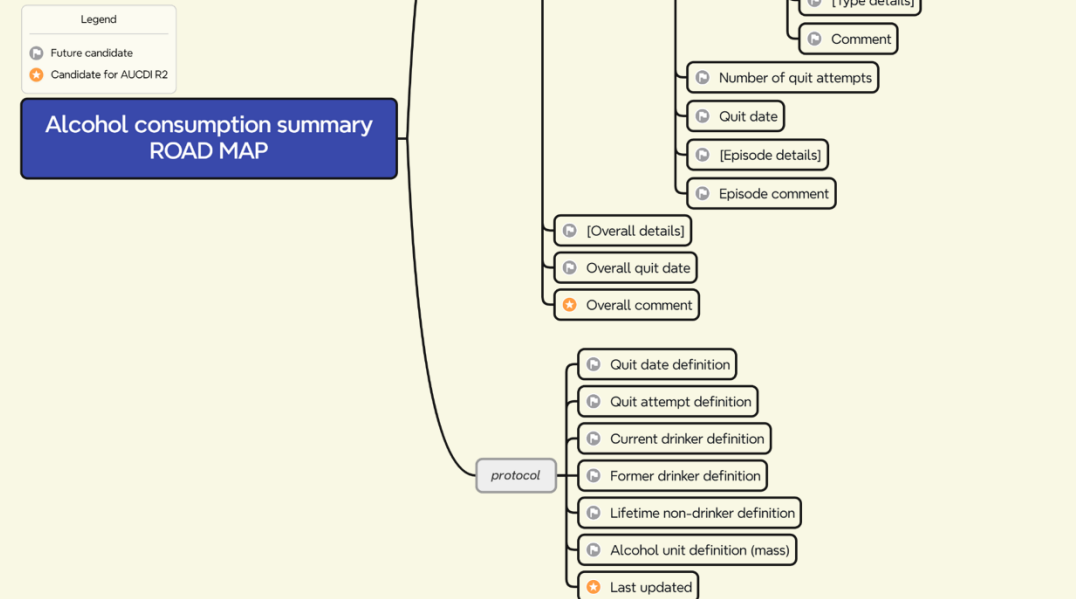
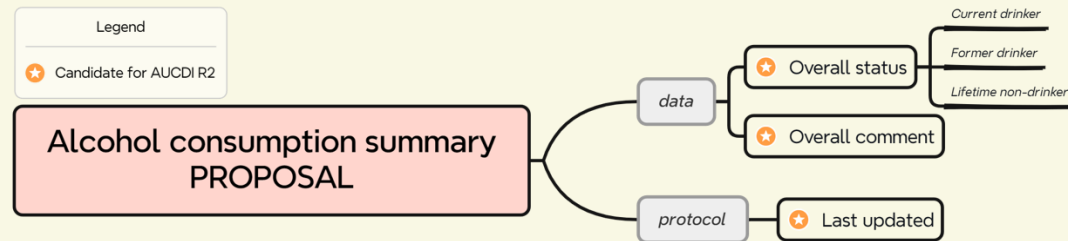
- **Overall quit date**
 - **Description:** The date when the individual last ceased using tobacco of any type.
- **Overall years of smoking**
 - **Description:** Estimate of the total number of years that the individual has smoked any tobacco.
- **Overall pack years**
 - **Description:** Estimate of the cumulative amount of tobacco smoked for all types.
- **Overall comment**
 - **Description:** Additional narrative about all tobacco smoking that has not been captured in other fields.

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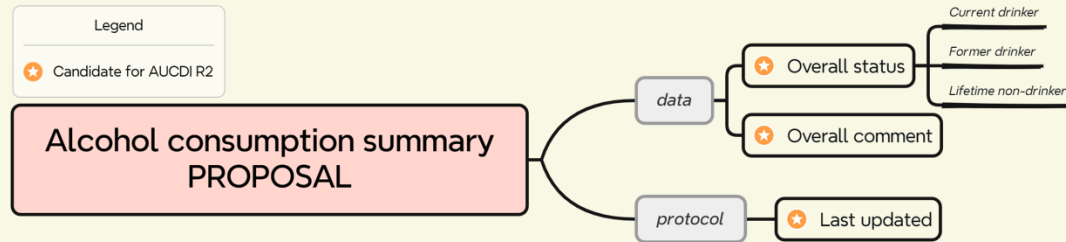


Alcohol consumption summary

- **Concept description** - summary information about an individual's pattern of consuming alcohol and alcohol-containing products.



Alcohol consumption summary



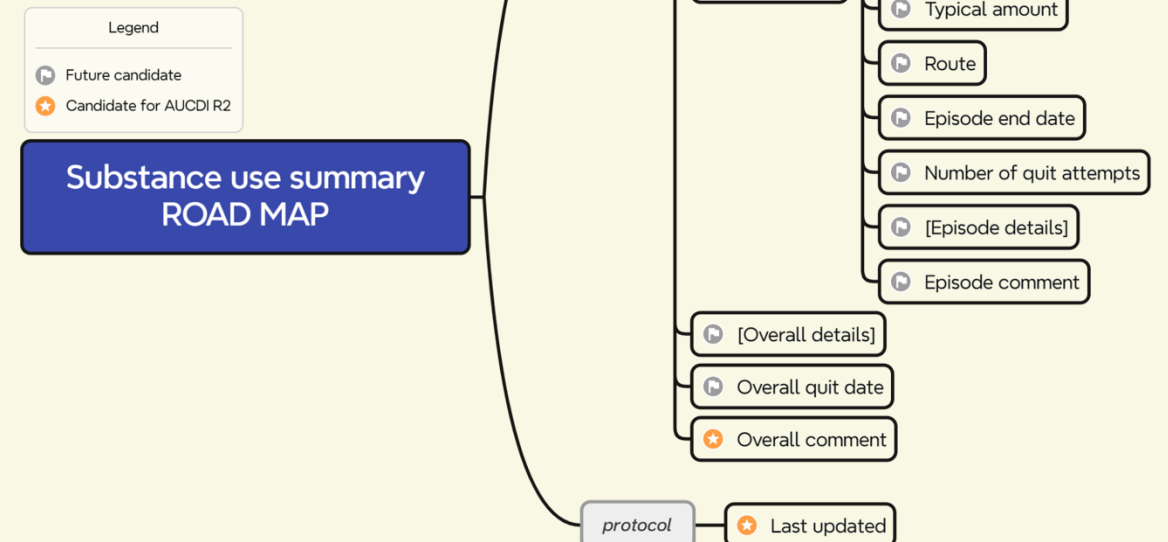
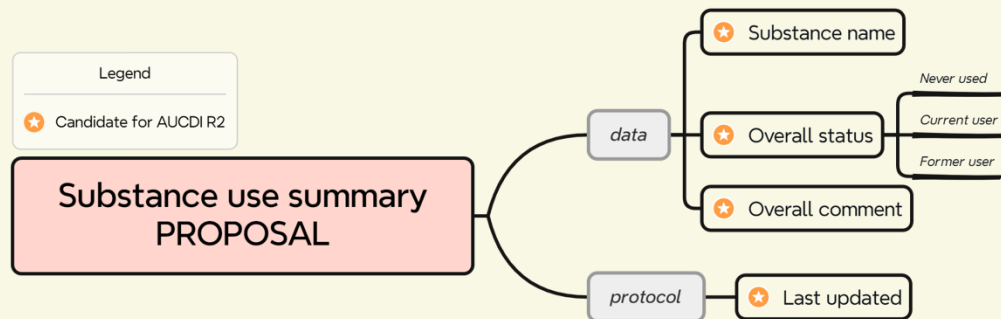
- **Overall Status**
 - **Description:** Statement about current consumption habits for all types of alcohol
 - **Value set** – *Current drinker/Former drinker/Lifetime non-drinker*
- **Overall comment**
 - **Description** - Additional narrative about all alcohol consumption, not been captured in other fields.
 - *Free text*
- **Last updated**
 - **Description:** The date when this 'Alcohol consumption summary' data group was last updated.

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Substance use summary

- Concept description** - summary information about an individual's typical pattern of use of a specified substance or class of substances that may harm an individual's health or social well-being.





“Substance use” scope

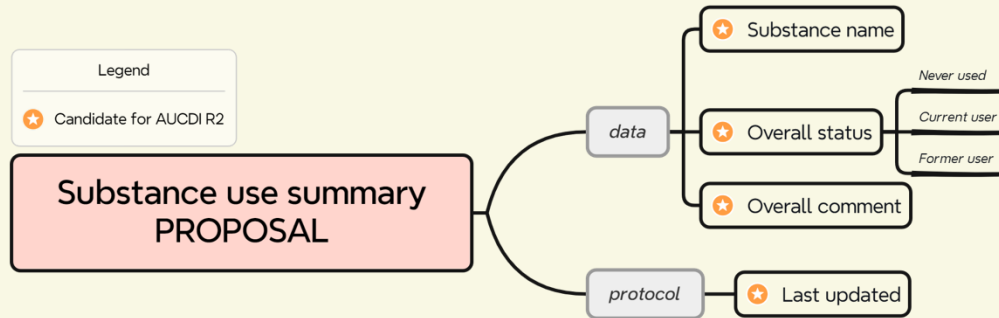
Inclusion:

- Substances that fall within the scope of this data group include harmful or potentially addictive substances as well as medications that are misused. Medication misuse may involve administration without clinical supervision, use for non-recommended purposes, or consumption in quantities or frequencies that exceed safe dosages.
- Examples of substances that may be recorded using this data group include but are not limited to:
 - caffeine;
 - nicotine and other clinically significant components of vaping liquid;
 - Psychostimulants, barbiturates, cannabis, hallucinogens, opioids, GHB, MDMA;
 - sniffing of hydrocarbons or other solvents;
 - "bath salts"; and
 - medication 'misuse', such as
 - a laxative for purposes other than relief of constipation,
 - beta blockers to reduce the heart rate in elite athletes, and
 - anabolic steroids in weightlifters.

Exclusion:

- On the other hand, substances that are commonly recorded in health records and are (or will be) recorded using existing purpose-specific data groups, are excluded from the scope of this data group, including:
 - tobacco smoking;
 - smokeless tobacco use;
 - alcohol consumption;
 - vaping; and
 - medication administration according to established medical guidelines and standards, including the correct dosage and appropriate indication, timing and route of administration.

Substance use summary



- **Substance name**
 - **Description:** The name of the substance or class of substance.
 - **Value set** – Coding with an external terminology is preferred, where possible.
- **Overall Status**
 - **Description:** Statement about current substance use, for all forms and all routes of administration.
 - **Value set** – Current user/Former user/Never used
- **Overall comment**
 - **Description** - Additional narrative about overall use of the substance, not been captured in other fields.
 - Free text
- **Last updated**
 - **Description:** The date when this 'Substance use summary' data group was last updated.

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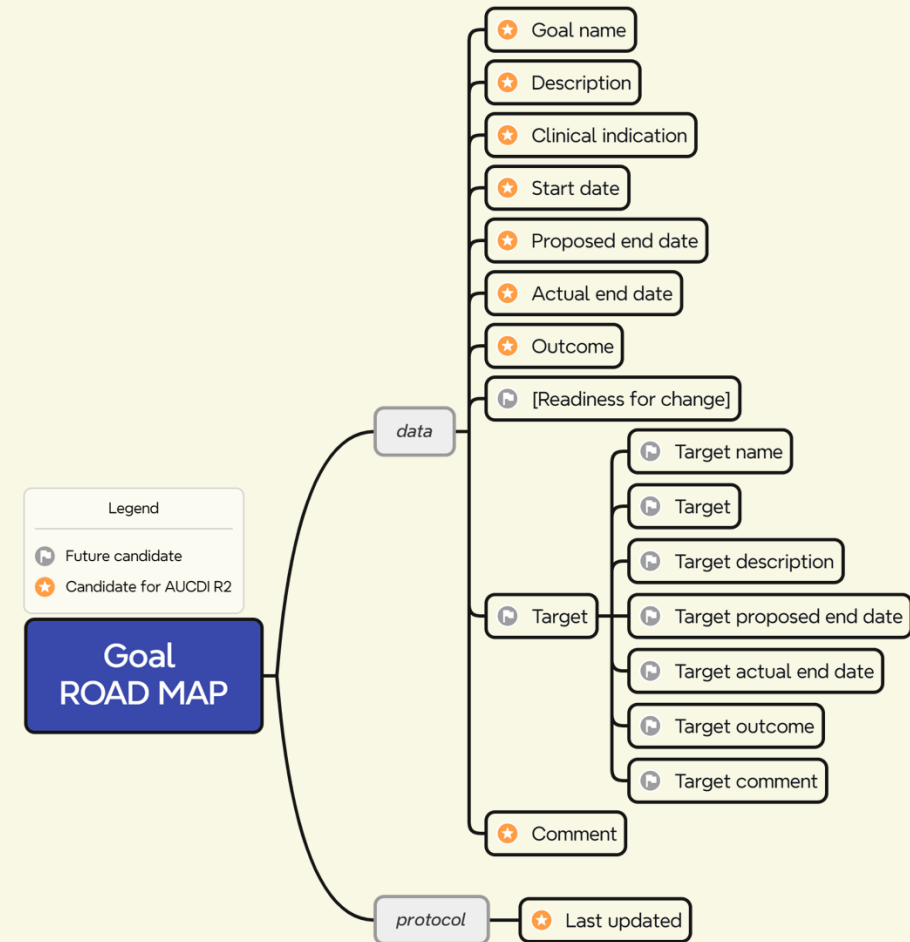
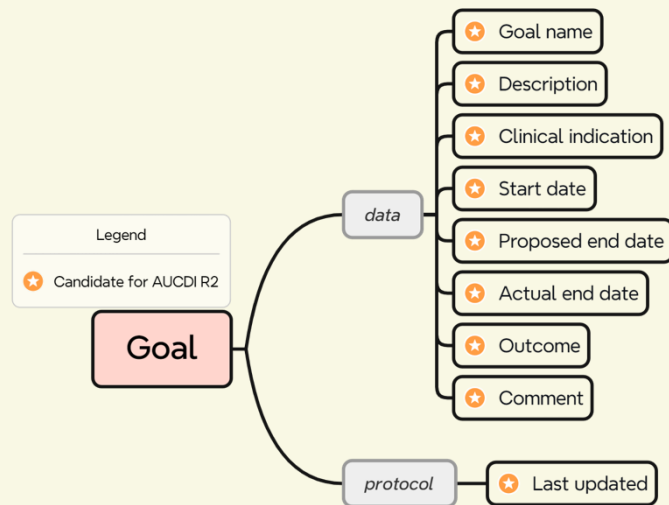




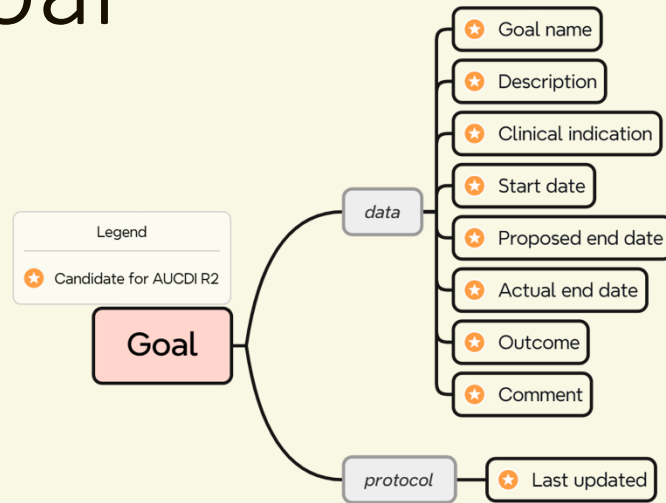
Goals and Health issues

Goal

- **Concept description** - A specific future objective intended to improve or maintain an individual's physical, mental, emotional or social well-being.
- Can be initiated by a clinician or the individual



Goal



Potential related future data groups:

- Goals of care

- **Goal name**
 - **Description:** The name or focus of the well-being objective.
 - *For example: reduced blood pressure; achieved weight loss; or diabetes control.*
- **Goal description**
 - **Description:** A narrative description of the goal, including target/s to be achieved if relevant.
- **Clinical indication**
 - **Description:** The health issue, symptom, sign, problem or diagnosis intended to be impacted by achieving the goal.
- **Start date**
 - **Description:** The date when the activities designed to achieve the goal were initiated.
- **Proposed end date**
 - **Description:** The desired or proposed date for achieving the goal.
- **Actual end date**
 - **Description:** The actual date when the goal was achieved or abandoned.
- **Outcome**
 - **Description:** Single word, phrase or brief description which represents the outcome achieved.
 - *Coding with a terminology is preferred, where possible.*
 - *For example: target weight achieved; poor diabetes control; or successful completion.*
- **Comment**
 - **Description:** Additional narrative about the goal, not captured in other fields.
- **Last updated**
 - **Description:** The date when this 'Goal' data group was last updated.

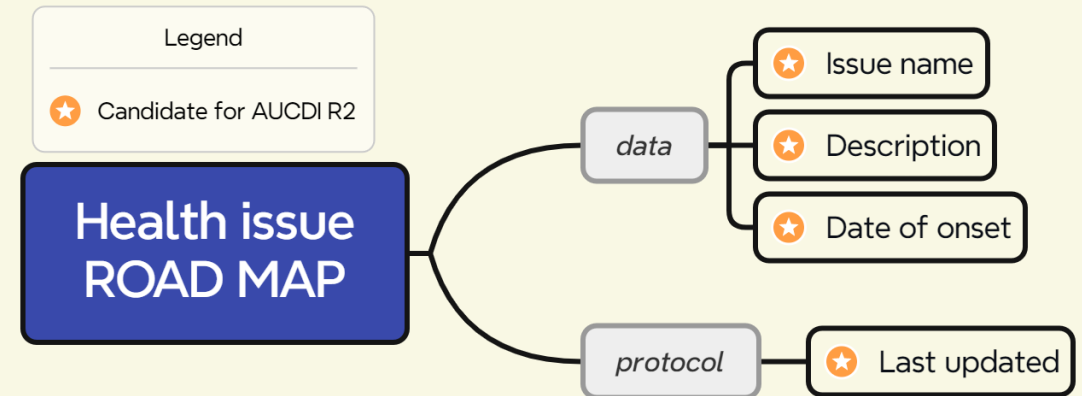
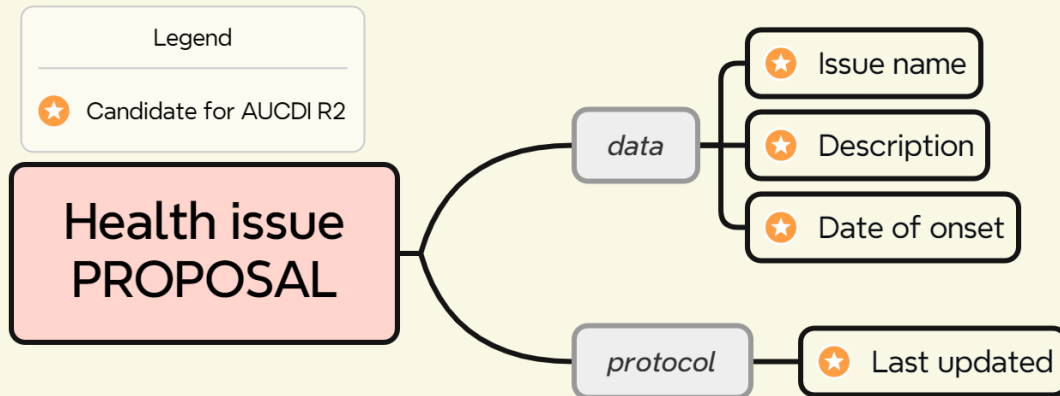
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Health Issue

- **Concept description** - Any concern or worry that can negatively affect an individual's physical, mental, or emotional well-being or quality of life.
- Can be identified by a clinician or the individual.



- “**Health concern**” – not proposed as a name to avoid confusion:
- Used differently in different standards contexts, for example
 - HL7 – US Core Condition Problems and Health concerns profile
 - inherits from the Condition resource (= Problem/Diagnosis data group)
 - CONTSYS – Health condition is a type of health record extract

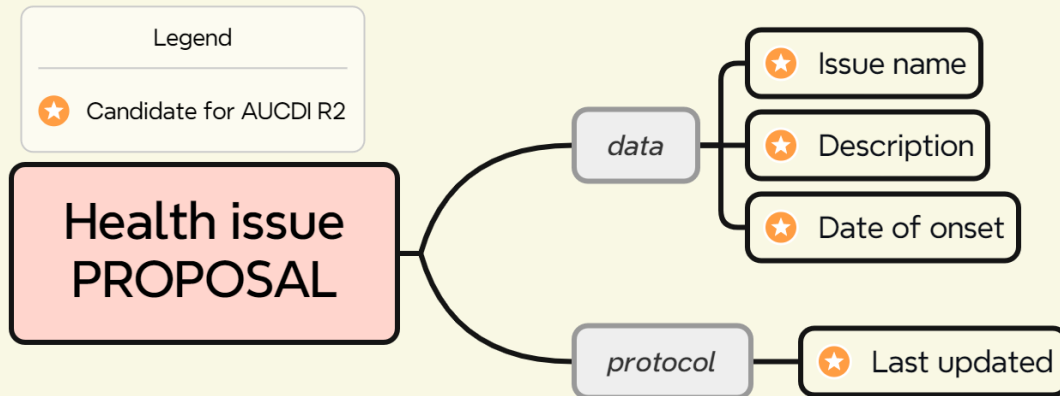
Potential related future data groups:

- Symptom
- Recommendation

NOTE: If a concern or worry needs to be recorded within a Problem list, it should be recorded using a more specific Problem/Diagnosis data group



Health Issue



- **Issue name**
 - **Description:** The name of the health concern or worry.
- **Description**
 - **Description:** A narrative description about the health issue.
- **Date of onset**
 - **Description:** The date when the health issue began.
- **Last updated**
 - **Description:** The date when this 'Health issue' data group was last updated.

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Interventions

Intervention feedback

- 'Get what we can'
- 'Anything that changes the patient care journey'
- Professions:
 - Allied health
 - Physiotherapy
 - Chiropractor
 - Speech pathology
 - Podiatry
 - Psychologist
 - Medical
 - Nursing
 - Diabetes nurse educator
- Types of care
 - Home
 - Patient initiated
 - Medical
- Plans
 - Nutrition
 - Physical activity
- Progress
 - Evaluation
 - Outcome
- Groups of activities
 - Care
 - Social
 - Social supports
 - Carer supports
 - Nursing
- Links to:
 - Procedure
 - Goal
 - Goals of care
 - Problem/Diagnosis
- Specific activities
 - Counselling/advice
 - Home assessment/modification
 - Food bank
 - Education/Patient education
 - Provision of:
 - Equipment
 - Medical devices
 - Transport
 - Exercise prescriptions
 - Social prescriptions
 - Assistive technology
 - Alexa, Google
 - Meals on wheels



Definition - proposal

Intervention

A single therapeutic activity, or a series of activities, intended to prevent, diagnose, treat, or manage health conditions, support mental or physical well-being, or address social and environmental factors that influence health outcomes.

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Follow-up

Definitions - proposal

Follow-up

The process of delivering ongoing, intentional care by a healthcare provider, beyond the initial appointment or intervention.

Follow-up is typically used to track progress, manage ongoing treatment, and assess the outcomes of previous interventions. This process commonly involves scheduling one or more follow-up activities at intervals recommended by the healthcare provider, each tailored to the condition and specific needs of the individual.

For example: a single six-week post-surgery check-up to assess healing and recovery; 6 monthly liver function tests after commencing a hepatotoxic medication; regular 3 monthly visits with a podiatrist to manage long-term foot care; or a palliative care nurse making twice-daily home visits until the end of an individual's life.

Recall

A clinician-initiated action to proactively address an emerging health concern, in a known individual.

A recall is typically associated with the detection of a potential health need or risk since the last appointment or contact, and the recall advice is sent or given to the individual with the intent they receive the necessary follow-up care to effectively and safely manage or monitor their health.

For example: if an abnormality is found in test results, the individual may be recalled for additional testing or treatment.

Reminder

A clinical notification sent to an individual regarding their scheduled, routine, and preventive health and care activities.

A reminder is typically an automated or system-generated message, such as email or text, that proactively help individuals, carers, and families stay up-to-date with regular preventive health activities and appointments.

For example: reminding the individual about routine vaccinations; or regular cancer screenings that are due or scheduled.

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Happy Holidays!

Wishing you all a safe and happy festive season

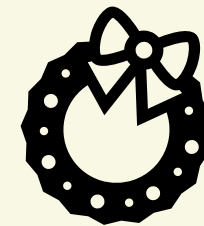
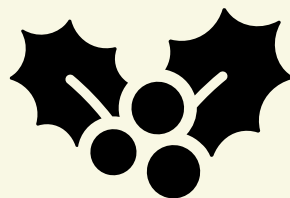
Thank you for this year – it's been a productive one =)

See you in the new year!

Next CDG 23 January 2025 (online)

Next F2F Adelaide 19 February 2025





Thank you!!

