Minutes – Chronic Condition Management Clinical Focus Group
Online Meeting 4

Meeting Details	
Date	3 June 2025
Time	11:00am – 1:00pm AEST
Location	☒ Virtual

Meeting Overview	
Agenda Items	1. Welcome and General Updates 2. Workshop Activity 1: Detailed CCM Journey Timeline 3. Workshop Activity 2: Chronic Condition Management Journey Wheels 4. Future Meetings and Upcoming Events

Discussion Summary	
Welcome and General Updates	*Welcome and Acknowledgement of Country* *General Updates* • This is the final scheduled chronic condition management clinical focus group meeting with any future meetings dependent on upcoming activities *Sparked Symposium* • The Symposium received a lot of positive feedback from the community and the recordings for the sessions are now available on the Sparked Website *CCM CFG Scope* • The focus of the CCM CFG is chronic condition in the context of Sparked and in regard to the user scenarios, data flow challenges and opportunities for interoperable health information exchange *Previous Meeting Recap* • In meeting 2 there were two diagrams discussed, the high-level wheel representation of some of the interactions in the patient journey and the detailed timeline, which then expanded to three diagrams in meeting 3
Workshop Activity 1: Detailed CCM	*Timeline Diagram* • The persona for the patient/consumer has changed from Maria, 58yo to Caterina Foreman, 55yo

Journey Timeline	• It is acknowledged that the diagram is highly detailed and not intended to be looked at in full on a slide. The updated version has been emailed to CFG members and the detailed view exists to be made available to the Sparked community when ready. • The centre of the diagram is the story section, where the timeframe associated with the journey, the stage of the journey, the activity and description, the care team members for each stage and the data and information artefacts for each stage are displayed • The opportunities down the bottom of the diagram are grouped into patient empowerment, and data and systems both immediate (now – 12 months) and future (2-5 years) • The side panel includes a simple case scenario, and the complete list of care team members identified for the patient <u>Question for CDG: Even though they are not referenced in the patient journey – should an endocrinologist be included as a member of Caterina's care team?</u> *Group discussion* • A patient may never have a need to see an endocrinologist however, there is still value in having the capability and it's worthwhile to have the ability to include an endocrinologist, even if it may not always be an essential part of the team for all patients • Could there be the inclusion of a 'future considerations/extended care team' box which includes care team members like endocrinologists or ophthalmologists – people who may be included in the patient journey however, are unlikely to be involved within the first twelve months • There may be other specialists, like a cardiologist or ophthalmologist, who may be more likely to be involved within a type 2 diabetic's patient journey than an endocrinologist due to the potential complications associated with T2D • George, Caterina's husband and Enzo, Caterina's son are listed as part of the care team however, George does not appear anywhere throughout the journey and Enzo only appears at the very end – could this be updated to more consistently show these care team members throughout the journey • Additional health providers in the journey may include: endocrinologist, ophthalmologist, nephrologist, cardiologist, gastroenterologist, wound care specialist service, home-care services – this list is not exhaustive • Discussion regarding if there are other allied health or health care provider roles that may be included, noted that this list is not comprehensive or exhaustive and should be considered representative of potential providers/interactions for this patient journey.

Per Stage Breakdown

- Care team members - The grey care team panels at each journey stage represent the actors at that particular stage, with the full care team found on the side panel of the journey
- Timeframe, stage, activity – shows the details and phases of care as the patient journey continues. The only update to this section is that the 12-month stage is now framed as a wellbeing review rather than the previous 'annual check-in'.
- Data and information – represents the artefacts created, updated, and accessed/viewed at each stage. The order of the artefacts has been updated to be the same throughout, i.e. CCMP, encounter records, patient summaries are grouped together, with only the new/changed artefacts being updated.

CCM Timeline: Stage 1 – see slide pack for full detail and updated diagram

- Previously stage 1 included the dietitian and the exercise physiologist receiving referrals for Maria. The previous feedback from the group included updating the wording and moving the referrals to the dietitian and exercise physiologist to stage 1 from stage 2
- The updated stage 1 diagram shows Caterina's (previously Maria's) journey as follows:
    - Caterina is overwhelmed by the diagnosis but relieved to receive an explanation for recent fatigue
    - Caterina's GP explains her condition, initiates a chronic condition management plan, and coordinates referrals including to a credentialed diabetes educator within the practice
    - The diabetes educator supports Maria in her understanding of the diagnosis and diabetes management
    - Caterina's GP refers her to a dietitian and exercise physiologist
- Updates based on previous feedback on the opportunities section includes wording changes to "updates to My Health Record" and "Updates to patient summary" to instead say that the encounter information is readily available
- Broader 'policy'/'hairy' question recorded: Can a consumer update their own CCMP/PS to correct, add new, to update? If yes, how is this managed, what are the implications and how do we show the provenance of the change?
- The opportunities captured within this stage include:

- Patient empowerment: Caterina accesses her CCMP to record her own goals and nominate members of her personal support network, including her husband and son
- Data and Systems (Immediate): Creation of CCMP FHIR questionnaire, service requests sent to relevant healthcare providers, encounter record information readily accessible and exchangeable to My Health Record
- Data and Systems (Future): All members of Caterina's care team can view and update Caterina's CCMP, CCMP links to relevant clinical guidelines and clinical decision support tools to assist with evidence-based care planning, prompts and recommendations for service requests, care pathways, service providers etc are displayed to CCMP users based on clinical preference or discipline, encounter record information readily accessible and exchangeable to update AU Patient Summary information

Group Feedback

- Some of the care team members are specifically named (e.g. Tim the CDE) at this stage whereas others aren't – this could be updated with their first names (specify this for Dr Jones) for consistency throughout
  - Group suggestions to address Dr Jones as Dr (first name), or trial a first-name only for all involved and gauge feedback on whether the title needs to be returned
- To further condense the description of this stage, the call-out to specify Tim is within the practice could be removed however, if there is a reasonable proportion of general practices that have in-practice CDE's it could be beneficial to keep this language in. Also noted that identifying the CDE being a member of the GPs practice was raised at previous CFGs.

CCM Timeline: Stage 2 – see slide pack for full detail and updated diagram

- The journey has been updated based on previous feedback, including expanding both Dr Jones' and the practice nurse's involvement and responsibilities, removing 'begins to walk daily' to shorten, and moving the dietitian and exercise physiologist referrals to stage 1
- The updated stage 2 diagram shows Caterina's journey as follows:
  - The dietitian works with Caterina to develop a personalised nutrition plan, provides guidance on

tracking her food intake and schedules a follow-up appointment
    - The exercise physiologist designs an individualised physical activity plan with Caterina
    - The practice nurse administers Caterina's yearly influenza vaccination, updates Caterina's care plan and organises a 3-month case conference for all members of Caterina's care team
    - The GP reviews Caterina's care plan and notes her blood glucose levels remain outside target range. The GP adjusts Caterina's current medications, requests updated blood tests and arranges a follow-up visit to monitor progress
- Updates based on previous feedback on the opportunities section includes the addition of 'food and nutrition summary' to the data updated in the CCMP, updated wording to include "Encounter record information readily accessible & exchangeable to My Health Record", the addition of "all members of Caterina's team can view and update Caterina's CCMP" to make data accessible to the care team, updated wording "Clinical decision support recommends best practice medication treatment, **relevant diagnostic tests & timeframe to arrange follow-up**", and updated wording "encounter record information readily accessible and exchangeable to update AU Patient Summary information"
- The opportunities captured within this stage include:
    - Patient empowerment: Caterina tracks her weight and activity in an app, Josh the Exercise Physiologist is able to provide support & encouragement to Caterina via the app
    - Data and opportunities (Immediate): Service request received by dietitian and exercise physiologist; goals, interventions and procedures updated, changes to goals, interventions and procedures and food and nutrition summary updates CCMP, prescribing for medications, encounter record information readily accessible and exchangeable to My Health Record
    - Data and opportunities (Future): All members of Caterina's care team can view and update Caterina's CCMP, clinical decision support recommends best practice medication treatment, relevant diagnostic tests and timeframe to arrange follow-up, changes to CCMP notifies care team members, tailored by clinical preference or discipline, encounter record information readily accessible and exchangeable to update AU Patient Summary information

Group Feedback

- The patient is already on medications however, the pharmacist has not been mentioned in the journey yet – should the pharmacist be included sooner in the journey?
    - To include every activity may become exhaustive, and it can be assumed that some activities are happening behind-the-scenes and are not being referenced within the journey
- Suggested short-hand for care team members – e.g. Kate (Diet), Josh (ExPhys), Tim (DE)
- Whilst prescribing captures the initiation and dispensing of medications there can be a disconnect with what the patient is taking – e.g. titrating up their medication, and what was prescribed 3 months ago may not be what's happening in reality. Is there an opportunity for the patient to input their medication usage into the CCMP/system visible to the care team
- Potential to have a data and systems opportunity to include a check box which can indicate whether the patient is still taking the prescribed medication

CCM Timeline: Stage 3 – see slide pack for full detail and updated diagram

- This journey has been updated based on previous feedback, including changing from the patient experiencing fatigue to instead experiencing medication side effects; namely diarrhoea from the use of metformin, changing the language to 'questions regarding' instead of 'confusion', making Dr Jones' activities more comprehensive/holistic, moving reference to the dietitian to stage 4 and instead including the CDE, and making the pharmacist's activities more comprehensive
- The updated stage 3 diagram shows Caterina's journey as follows:
    - Caterina presents to the GP with some questions regarding her medications and reports that she has been experiencing diarrhoea when taking metformin and has stopped taking it
    - The GP assesses Caterina, checks her recent lab results and reviews her current list of medications. The GP agrees with ceasing Caterina's Metformin, and liaises with the CDE to provide additional support and education to Caterina
    - Caterina's pharmacist undertakes a Home Medicines Review, provides additional education to Caterina regarding her current medications

- Updates based on previous feedback on the opportunities is the removal of the PREM as this doesn't measure fatigue, adding 'food and nutrition summary' to data being updated in the CCMP, updated wording to 'encounter record information readily accessible & exchangeable to My Health Record', making data accessible to the care team with the addition of the wording 'all members of Caterina's team can view and update Caterina's CCMP', and updated wording 'encounter record information readily accessible and exchangeable to update AU Patient Summary information'
- The opportunities captured within this stage include:
    - Patient Empowerment: Use of PROMS for monitoring of Caterina's health status and wellbeing
    - Data and Systems (Immediate): Recent diagnostic results promptly available, follow-up scheduled, changes to Problem/diagnosis and Medication statement updates CCMP, encounter record information readily accessible & exchangeable to My Health Record
    - Data and Systems (Future): All members of Caterina's care team can view and update Caterina's CCMP, When Caterina's symptoms are recorded in CCMP, clinical decision support recommends medication review, relevant diagnostic tests and timeframe to arrange follow-up, data linkage to pharmacist's system and dispensing history for Caterina, changes to CCMP notifies care team members, tailored by clinical preference or discipline, encounter record information readily accessible and exchangeable to update AU Patient Summary information

Group Discussion

- Some patients experiencing side effects will adjust themselves and wait until their next review and others will come in early because of them
- Medications with potential side effects (like metformin) may require earlier or more frequent check-ins
- Update wording to say that Caterina has been experiencing mild diarrhoea but has recently stopped using the metformin…
    - Potential wording suggestion around the financial implication of needing gastro-stop to counteract the side effects
- Unless the CDE is in the same practice, 'liaise' may be the wrong wording, as updates would be emailed or faxed to the CDE however, it is unlikely that the CDE would be involved at this step

- Include that Caterina visits the CDE during step 3 rather than the original wording that the CDE is liaised with by the GP
- Metformin should be lowercase in the wording
- Previously clinicians received dispense notifications to alert them to when the patient received their medication however, the RACGP at the time had it stopped.
- We should avoid pushing all responsibilities to clinicians just because data exists in shared systems.
- Hairy question – if the data is available in the system, where/who does the responsibility of that data lie with?
- If a patient opts out of My Health Record or a care plan, they then hold more responsibility for their own health
- In the future, a pathology lab may suggest testing based on the patient information – e.g. Vitamin B12 testing for a patient on metformin with side effects of diarrhoea

CCM Timeline: Stage 4 – see slide pack for full detail and updated diagram

- This journey has been updated based on previous feedback, including the resolution of the diarrhoea side effect; including a worsening HbA1c as a result of the cessation of metformin, with a focus on non-pharmacological management first; including a dietitian review in stage 4 and updating stage 3 to include a referral to the CDE; expansion on activities undertaken by podiatrist and optometrist
- Question for CFG: Does Caterina's appointment with Jessica the podiatrist require a referral earlier in the journey/stages?
- The updated stage 4 diagram shows Caterina's journey as follows:
    - The GP follows up with Caterina regarding her previously reported diarrhoea. Caterina confirms her diarrhoea has resolved. During the visit, the GP also identifies Caterina's recent blood glucose levels are above target range
    - The GP liaises with the Dietitian to review Caterina's current dietary intake and provide guidance to support glycaemic control. The GP also sends a referral to Caterina's optometrist to check her eye health
    - The dietitian works with Caterina to adjust her nutritional plan. The optometrist undertakes a comprehensive eye exam and no issues are identified.
    - Caterina also attends a routine foot check-up with the Podiatrist. Minor neuropathy detected during foot exam. The podiatrist documents her findings and liaises with the GP regarding ongoing monitoring and follow-up

- Updates based on previous feedback on the opportunities include the alignment of the journey activities in this stage with previous stages
- The opportunities captured within this stage include:
    - Patient empowerment: Caterina updates her goals of care and accesses a current care summary
    - Data and systems (Immediate): Changes to Food and nutrition summary and Follow-up updates CCMP, observations (foot risk, visual status) recorded, foot and eye screening data captured and shared promptly, encounter record information readily accessible & exchangeable to My Health Record
    - Data and systems (Future): All members of Caterina's care team can view and update Caterina's CCMP, changes to CCMP notifies care team members; tailored by clinical preference or discipline, encounter record information readily accessible and exchangeable to update AU Patient Summary information

Group Feedback

- Based on previous discussion in this meeting, the language may need to be updated from liaise to be more explicit
- Include that both the HbA1c and blood glucose levels are elevated
- Can potentially remove the follow-up of diarrhoea symptoms 3 months following the cessation of the metformin, as the elevated blood glucose is the more pertinent thing to follow-up
- Update the wording to “Dr Jones follows up with Caterina regarding her diabetes control and confirms that the diarrhoea has ceased”
- Some diabetics are experiencing diabetic retinopathy at the time of diagnosis and will be referred to an optometrist/ophthalmologist then – this could be included in the patient journey as there is mention that Caterina is referred to multiple healthcare providers
- Mention that Caterina has been referred to a podiatrist for a routine foot check up
- Key allied health that will benefit from Medicare funding as part of a chronic condition management plan, such as podiatry, CDE, exercise physiology, tend to get referred at the beginning
- At this stage of the patient journey, patients are accepting of their diagnosis and willing to talk about other things – this could be an opportunity to ensure their vaccines are up-to-date, discuss screenings (e.g. mammograms, cervical screening) and do a baseline ECG

CCM Timeline: Stage 5 – see slide pack for full detail and updated diagram

- This journey has been updated based on previous feedback, including making the patient's distress more acute, incorporating the use of PROMs information, including the patient's family/support network into the journey, and noting that it is unlikely to do an annual case conference unless a specific issue requires it
- The updated stage 5 diagram shows Caterina's journey as follows:
    - At Caterina's next appointment, the GP observes a shift in her emotional state and reviews Caterina's recent PROMs results. Caterina's son also expresses concern about recent changes in her behaviour
    - Caterina shares that she has been feeling overwhelmed, stressed, and is finding it difficult to cope with the demands of managing her condition
    - The practice Nurse and the GP work closely together to arrange regular check-ins that include Caterina's son and husband, to monitor Caterina's emotional wellbeing and ensure her support network remains actively involved in her care
    - The GP also refers Caterina to a Psychologist. Together, the psychologist and Caterina explore her current emotional state, to develop coping strategies and manage the impact of her chronic condition
    - Caterina reflects on her progress and experience over the past year
- Updates based on previous feedback on the opportunities include the using/actioning the PROMs information review, aligning the journey activities with previous stages, and an added opportunity for PROMs information to be used to enable clinical decision support
- The opportunities captured within this stage include:
    - Patient empowerment: Ongoing use of PROMs monitors Caterina's wellbeing over time, and enables Caterina's care team to tailor their approaches to her specific needs and preferences.
    - Data and systems (Immediate): Structured, multi-disciplinary care contributes to quality improvement datasets, encounter record information readily accessible & exchangeable to My Health Record
    - Data and systems (Future): All members of Caterina's care team can view and update Caterina's CCMP, system trends PROMs data over time and Clinical Decision Support recommends best practice interventions or

	follow-up to relevant care team members) as required, changes to CCMP notifies care team members, tailored by clinical preference or discipline, encounter record information readily accessible & exchangeable to update AU Patient Summary information *Group Feedback* • Include only one family member to condense the description, as having both doesn't considerably add to the clinical care at this stage • The psychologist referral is most likely to be done through a mental health care plan – there is potential to reference the commencement of a mental healthcare plan as one of the opportunities which also highlights the interaction between both the mental health care plan and the chronic condition management care plan • Include whether Caterina is working – e.g. in paid employment or volunteering roles

Workshop Activity 2: Chronic Condition Management Journey Wheels	*Chronic Condition Management Journey Wheels*
	• Previous feedback:
	  ○ Include dentists – included under other providers
	  ○ Change specialists to 'medical specialists'
	  ○ Lift care team to be more generic
	  ○ Make individual wheel bigger
	  ○ Outer wheel updates – remains as is currently
	  ○ Remove words 'data and information exchange'
	
	Diagram 1
	• The diagram has been titled 'Ongoing Care Coordination and Management'
	  ○ The outer ring highlights the phases of the ongoing care coordination and management, the inner ring includes the core care team around the individual, and interactions with service providers external to the ring
	
	Group Feedback
	• Increase the font size of the core care team, have a single double ended arrow directing out to the service providers and update the outer circles to not include process hatches
	
	Diagram 2
	• Previously in this diagram, the patient is at the centre, followed by their care team, the healthcare services they're interacting with, the phases of the care coordination, the ongoing care

	coordination and management, and finally encompassed by the population health
	• Previous feedback:
	  ○ Remove 'ongoing care coordination and management' ring
	  ○ Focus on population health and simply the internal rings
	  ○ Clarify purpose of diagram
	• The current updated diagram includes the individual at the centre; followed by person care which is broken into family and carers, health professionals and care providers; the phases of the care coordination; the care organisations; and the population and public health. It also includes a written description of the purpose of the diagram
	
	Group Feedback
	• Is there a need to note on the diagram that any population or public health information is de-identified – this could be included in a smaller font underneath the population health heading
	  ○ There are instances in which this information may not be deidentified – e.g. screening registries
	• Potentially remove the orange phases of care coordination ring – it was originally included to highlight the stages at which a patient's information is collected however, this may be adequately represented by the care organisations and care team.
	  ○ This ring however represents shared information between the care team and care organisations – further determine whether to leave this in or represent in a different way
	• Keep the inner wheel colour theme the same as the rest
	• Utilise the care organisations wheel from diagram 1 for diagram 2
	• There is some overlap and lack of clarity between the person care and care organisations wheels and how they differ from one another
	• Consider having the light blue population health background as a square to represent a population data lake
	• Potential to include a map of Australia as the background
	
	Population Health Diagram
	• Designed to represent the amalgamation of each individual person's data and how it feeds into sharing and reusing population and public health data

Future Meetings and	<u>If you have any further thoughts on additional artefacts/materials required for CCM please reach out to the team sparked@csiro.au</u>

Upcoming Events	*Future Meetings*
	• Future meetings to be determined based on July CDG and F2F workshop outcomes
	
	Upcoming Events
	• 29 and 30 July F2F Workshop
	  ○ Tickets released 4pm 3 June 2025
	  ○ Focusing on AUCDI R3 health assessment data and backlog prioritisation, and the processes and workflows associated with chronic condition management and AU Patient Summary
	• 27 August 2025 - Online CDG Meeting
	• 1 and 2 September 2025 – HL7 AU Connectathon
	• 17 September 2025 – Online CDG Meeting
	• 8 October 2025 – Online CDG Meeting

Decisions

ID	Description	Status	Comments
03062025-1D	Trial including Dr Jones in the patient journey with their first name and gauging feedback	Agreed	
03062025-2D	Include that Caterina visits the CDE during step 3 rather than the original wording that the CDE is liaised with by the GP	Agreed	

Actions

ID	Description	Responsible	Due	Status

Attendees

1. Kylynn Loi	2. Tor Bendle
3. Madison Black	4. Shelley Behen
5. Olivia Carter	6. Nyree Taylor
7. Averil Tam	8. Cath Koetz
9. Fabrina Hossain	10. Josielli Comachio
11. Liz Keen	12. Nicola Mountford
13. Oliver Frank	14. Sarah Pearson
15. Ken Sikaris	16. Melanie Smith
17. Troy Burgess	18. Jodie Sheraton
19. Kath Feely	20. Sophie Tran

Apologies

1. Adrian Gilliland	2. Antony David Sangster
3. Charlotte Hespe	4. Chris Boyd-Skinner
5. Eric Au	6. Harry Iles-Mann
7. Janney Wale	8. Kim Drever
9. Shannon Wallis	10. Stephanie Davis