Evaluation Plan for 'Important Diabetes Checks' booklets

Background:

The 'Important Diabetes Checks' booklets were created through a project of the 'Ovens Murray-Goulburn Diabetes Service Improvement Collaborative' ('The Collaborative'- previously named the '*Hume* Diabetes Service Improvement Collaborative'). The Collaborative was established to enhance the implementation of the 'Hume Region Chronic Care Strategy (2012-2022)'.

Of the seven priorities for action identified in the 2012-2022 Strategy, the consumer booklet project relates most closely to the following two;

> Priority 3- Embed self-management approaches in all aspects of care
> Priority 4- Provide clear and consistent information for people with a chronic condition and their carers.

The Hume Region Chronic Care Steering Committee ('The Steering Committee') also developed a further, shorter term, strategic plan 2016-17, which identified three strategic focus areas (SFA), one of which is particularly relevant to this project;

- SFA 3: To increase access to high quality diabetes services in the Hume (by continued support of the Hume Diabetes Service Improvement Collaborative projects)
    - 3.3. To strengthen consumer focused care by coordinating a region wide refresh of health literacy and self management resources by 31 Dec 2016.

The tool was developed by 'The Collaborative' and supported by the Department of Health and Human Services (DHHS). The intent of the tool is to enhance self-management of people with Diabetes, by providing a small booklet from a member of their care team, to talk with them about aspects of their care. The booklet is intended to be owned by the person, and notes, questions, dates etc can be written into it as needed. 'The Collaborative' believed that the booklet would enhance health literacy of consumers, if used appropriately to build knowledge and self-management capacity of consumers with Diabetes.

The final version of the tool was printed in January 2018. A distribution plan identified Primary Care Partnership (PCP) coordinators from the four relevant PCP catchments within the Ovens-Murray & Goulburn area, as the most appropriate avenue to promote and deliver the booklet to agencies, consumers, and community, due to their existing connections with applicable stakeholders.

Goals of Evaluation:

Goal 1: Assess whether or not the (booklet) project was successful in meeting its objective (as per the 'Hume Diabetes Service Improvement Collaborative' terms of reference, 2015), which is to "strengthen consumer focused care, by building health literacy among people with a diagnosis of Diabetes across the OM-G region".

The individual health literacy level of those receiving the Diabetes Booklet was not assessed prior to the distribution of the booklets; therefore no baseline was established to enable follow up assessment of health literacy. Some feedback from consumers about their experience of using the booklet, and their opinion of it as a tool has been collected (see below), however a change in individual health literacy was not measured.

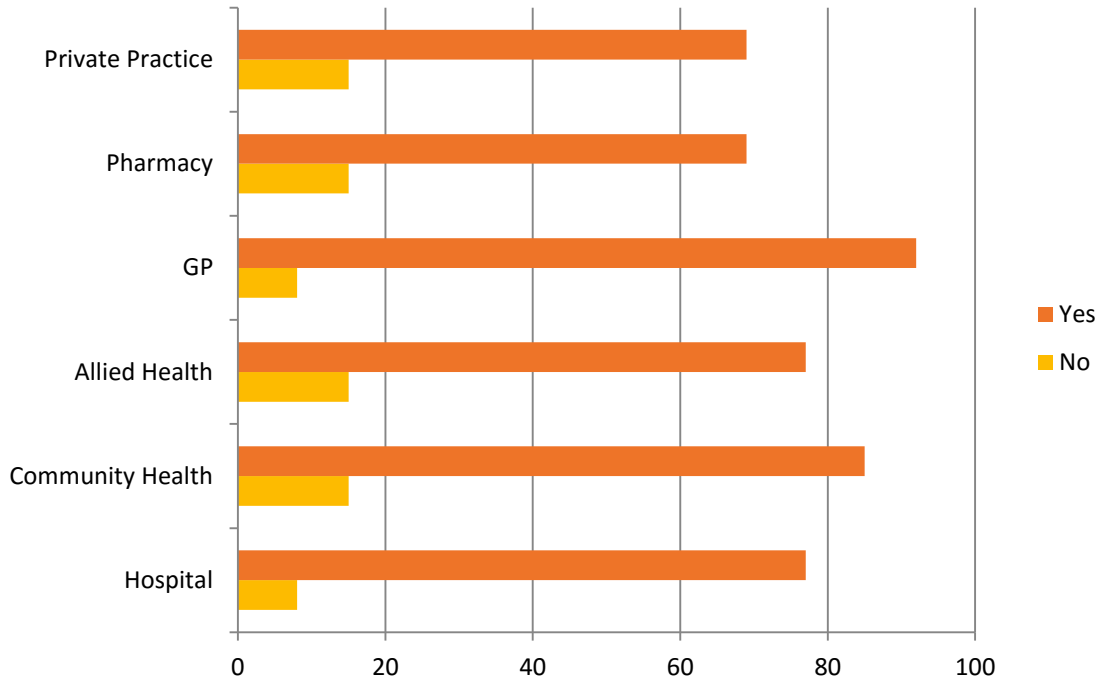
Goal 2: Evaluate the cultural relevance of the booklet when used with people from cultural backgrounds other than mainstream.

A focus group was planned to be completed with members of the Aboriginal and Torres Strait Islander community to discuss the appropriateness and usability of the booklet, however, this was unable to be completed because of limited staff capacity. Feedback from a staff member at an Aboriginal Community Controlled Health Organisation (ACCHO), however, provided the following feedback on the tool;

> *'We have asked some patients to use, but have had few engage with the tool. Feedback noted that the first page was confusing; these books last for 3 years (2017-2019) but there wasn't space to put in a date or the name of the person who did a check. Also not enough space to put in results given it was the front page. Overall it was not user friendly and with our community not culturally appropriate, therefore the usage not taken up with our clients'.*

Of those service providers who responded (N=14) to the survey, 8% believed they were able to use the tool with Aboriginal and Torres Strait Islander people; 23% believed they were able to use it with people from culturally and linguistically diverse (CALD) backgrounds; 31% noted they don't have clients from culturally diverse backgrounds; 19% believe that it is only appropriate for mainstream community members (these respondents noted the following reasons for this response, "[the booklet is] *more aimed at community clients, not facility clients with nurses on site 24/24"; "NA"; "Not used the resource*").

The following graph depicts the respondents' thoughts on where they believe the resource could be appropriately used (orange) and where it should not be used (yellow)



Goal 3: Identify recommendations to enhance usability of the tool for consumers.

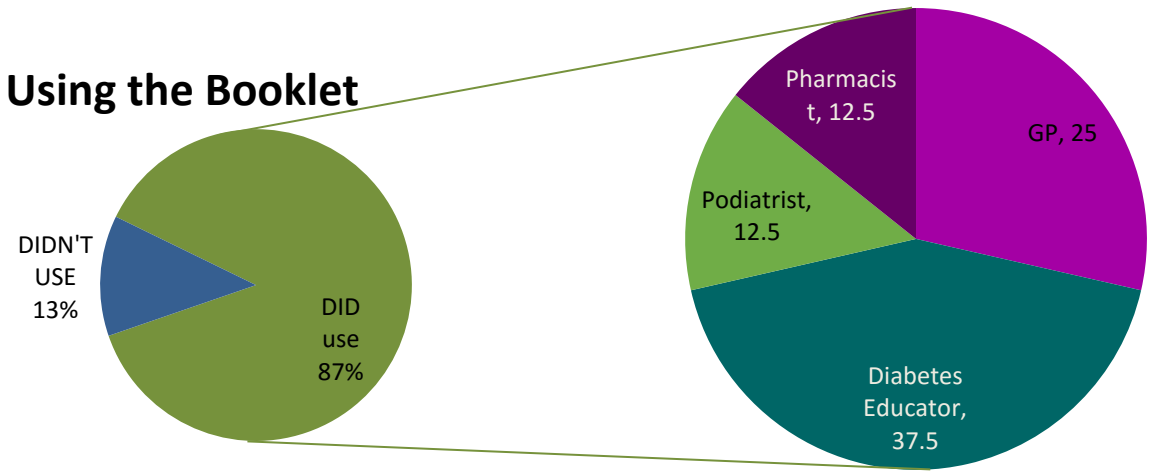
The Suitability Assessment of Material (SAM) Score Sheet[i] was used by two of the PCP coordinators to review the readability of the material, to determine its relevance to the target audience. The assessment looks at readability, content, graphics, layout, learning motivation, as well as the cultural appropriateness of a document, and uses a scoring system to determine a total score, which correlates with a scale of 'Superior', 'Adequate', or 'Not Suitable'. The two assessments scored 72% and 75% respectively, both of these scores indicate the booklet to be in the 'Superior' category. The 'literacy demand' sub category of the assessment requires a sub assessment, called a SMOG (simple measure of gobbledygook) assessment. The two SMOG assessments carried out by the PCP coordinators found scores of '1' (6th to 8th grade level), and '0' (9th grade level and above). The Tasmanian DHHS identify a reading age of Grade 6 (11-12 years old) as being most appropriate for documents intended to be read and utilised by consumers.

These assessment results therefore indicate that the 'Important Diabetes Checks' booklet is written at an inappropriate level for the majority of the target audience to be able to utilise and understand. Improvements in the language used within the document, however, to create an overall lower reading (<grade 6 level) level may improve its useability for some consumers.

The PCP coordinators collected consumer feedback directly from consumers, as well as via various members of the workforce, who provided the connection between the distribution of booklets from the PCP coordinators, and the consumers who received them. The feedback was collected in various ways, from surveys sent via email or through the post, and through a community forum.
Eight consumer surveys were completed by those who had received and used the booklet, and a further eight provided feedback in a forum setting, facilitated by PCP staff.

Of the survey respondents, 87.5% said that they had used the booklet, with the following members of their care team:

- 25% used the booklet with their GP
- 37.5% used it with their Diabetes Educator
- 12.5% with podiatrist
- 12.5% with pharmacist
- 12.5% with no one



The respondent who didn't use the booklet provided the following explanation as to why:

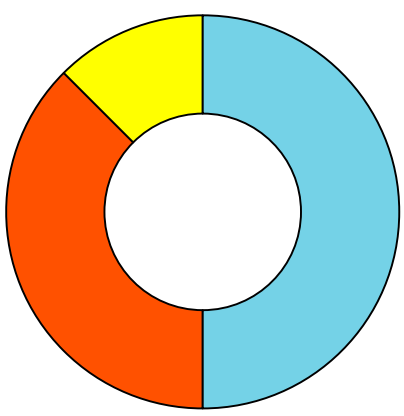
- *I already keep my own blood test records in my insulin pump notebook which I update after appointments with my Melbourne-based endocrinologist & local diabetes educator.*
- *I annually renew my chronic care plan with my GP*
- *I use 'My Health Record' for medication updates*
- *If such a booklet had been available when I was first diagnosed I would have used it - I think it is a great resource for those who are newly diagnosed, guiding them in self-managing their diabetes.*

The majority of respondents noted that they received the booklet from their Diabetes Educator (75%), with the remaining two respondents they got it directly from a PCP Coordinator, and from the Albury-Wodonga Diabetes Support Group.

Three quarters of respondents indicated that they believe that the booklet helped them better self-manage their Diabetes, with only one quarter noting that it did not assist them to self-manage. Three respondents expanded on their answers about how the booklet helped them;

- *Included somethings that weren't being checked e.g. waist measurement*
- *I was able to make the notations for my next doctors visit*
- *It helped me become better organised*

Respondents were asked whether they thought the booklet had too little or too much information included, results are indicated in the following graph. Half of respondents thought the booklet had the right amount of information included. Of those who thought there was too little (37.5%), two responses were provided as to what else they would like included in the booklet, these comments are written below;



- *A hearing check could be added, as apparently nerve damage which is a long term complication of diabetes can affect hearing. (Perhaps just to alert people rather than specify how often it should be checked)*
- *Something about heart health*

A discussion of the booklet was had with consumers as part of a broader forum in the Upper Hume catchment. Eight people with Diabetes, and one carer, contributed to the discussion. Only two out of the eight consumers had seen and used the tool prior to the forum, therefore the discussion began with an overview of the tool, and its projected benefits. A range of questions were then asked and discussed regarding potential use and benefits perceived. The following were noted by the consumers involved;

- The tool was seen as something that could be used with a range of care team members, including;
  - GP
  - Specialists
  - at hospital admission
  - Diabetes educators.

- The potential benefits were predicted as;
    - Being able to compare results (biomedical)
    - Easy language used, so could understand
    - Visual cues make it easy to see when and why to do things
    - The front page flagged important aspects of care, which is a good reminder
    - Good for people who don't self-test blood sugar levels and don't have a record book
- The only negative comment stated about the booklet was that;
    - Hearing/ ear health information is not included

Goal 4: Identify recommendations to enhance usability for organisations and services

Feedback from three organisations noted that they did not feel a need to use the booklet with consumers.

Organisation 1;

- *'most clients know what they need to do because they've had Diabetes for over 40 years'*
- *'people in aged care facilities have their plans on file'*
- *'GPs should be the ones using these with consumers'*
- *'there needs to be more room for consumers to write their own notes into the booklets'*
- *'a preamble information sheet is needed to go with the booklets, so that staff don't have to be relied on to pass on this information'*

Organisation 2;

- *'from our clinic's perspective we haven't really found a need for this booklet (…we'd be interested in feedback from other sites and would be happy to be involved in future trials/ innovations from the PCP)'*

Organisation 3;

- *'The Diabetes Educator didn't use the tool with consumers as she felt they were not the right demographic for this tool. The Diabetes Educator goes through everything on the checklist with consumers one on one and gives them a diary which she asks them to monitor BGL's and sometimes other health indicators. The clients often struggle to do this and giving them more brochures would risk overloading them'.*

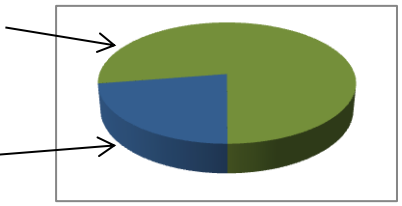
Another organisation that did use the booklet with some consumers had the following feedback;

- *'many consumers didn't utilise the document or bring it back to any session following distribution'*
- *'could the medicine wise app, CGM net, or My Health Record be a better tool to use than this booklet, as people are becoming more technology literate and usually carry their phone with them at all times?'*
- *'double handling; and would be better if could have a modifiable version to change dates or not have dates, just a section to add dates as they are used (limit wastage of outdated booklets).*
- *'pictures aren't consistently linked with the same terminology and could be confusing for people with low health literacy'*
- *Make sure Aboriginal specific appointment timeframes are included and clear throughout the document'*

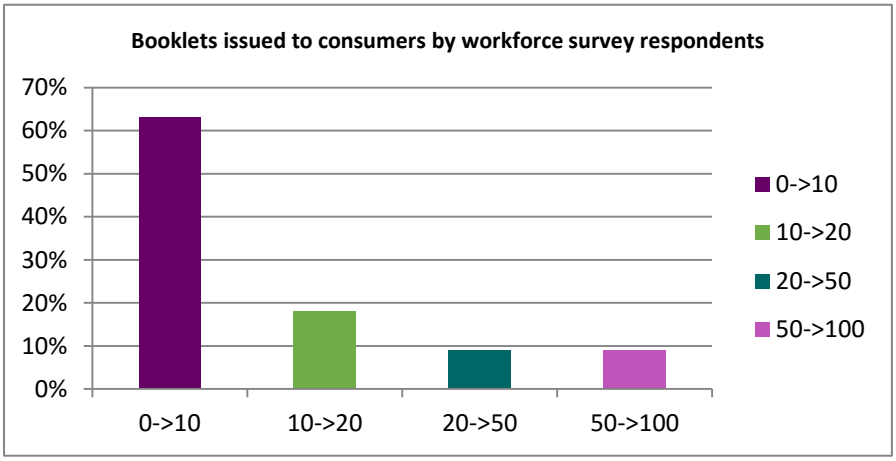
- *'how does this link with patients' NDSS booklets, GP management plans, blood glucose diaries/records, MPS Diabetes health tracker screening, medical test and health check sections?. Are we just adding to patients document load, especially those with multiple chronic conditions?'*
- *'Can they be sent as a modifiable document, as well as printed version so people can enter service details or local area details before printing?'*

Only fourteen workforce respondents completed the staff survey distributed from the four PCP coordinators:

- 79% (N=11) of respondents used the resource with consumers to support self-management
- 23% of respondents note they use a 'different, but similar resource with clients



- 8% said none of their clients wanted to use the resource, after they discussed its role and benefits with them
- 8% of respondents said they didn't have time to discuss these types of resources with clients in a consult
- 58% (of those workforce respondents, who used the tool (N=12) to discuss self-management with consumers, distributed between 0-10 booklets; 17% distributed between 10-20 copies; 8% distributed 20-50; and 8% also distributed between 50-100.



- 66% of workforce respondents answered NA to the question 'why did you choose not to use the tool'
- 100% of respondents believe that the booklet provides appropriate information on all aspects of the annual cycle of care recommended for people with Diabetes.
- Workforce respondents believed that the following should be included in the booklet;
    - *Explanation of pathology*
    - *A place for the care team (eg so the CDE, Dietitian, Podiatrist can write their name and contact); x2 respondents suggested this.*
    - *Goal setting page (rather than 'my targets')*
    - *Information re endocrinologist and Insulin*
    - *Information relating to equipment maintenance and expiry dates*
    - *A message to alert the person when a cost might be required when visiting a care team member, and advise to find out more before visiting*

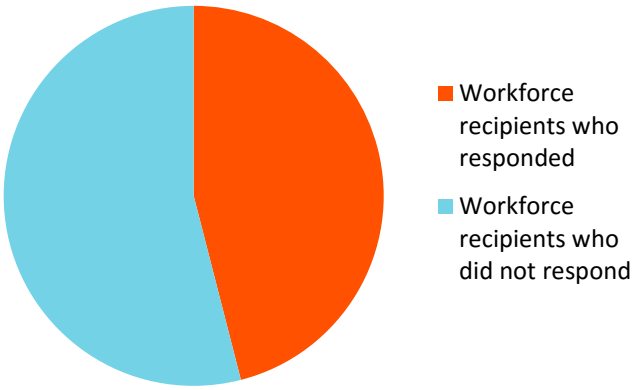
- *A recommendation to see a Credentialed Diabetes Educator every year, not just saying diabetes education.*

- Workforce respondents believed the following should NOT be included in the booklet;
  - *Printed dates*
  - *My goals (pg 12&13)*
  - *Front Page (not clear what it is for (date of appointment/ Level/ result?- two respondents queried this)*
  - *Use of Diabetes Nurse and Diabetes Educator is confusing*
  - *Remove space on front page, except for space for name*
  - *Term GP nurse used where nurse practitioner or Diabetes Resource nurse could be used*
  - *The 3 monthly visits to the GP, or GP nurse, for emotional support, this should be looked at by all health professionals and added to the 3-6 month reviews.*

Discussion of Findings

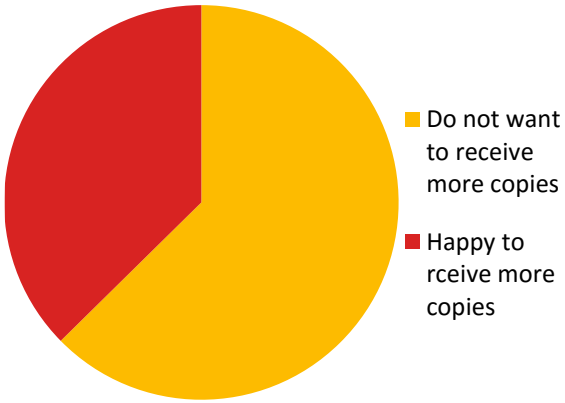
There seems to be a discrepancy of the perceived merits and usability of the tool between service providers and service users.

Approximately 1750 'Important Diabetes Checks' booklets were distributed to health professionals from within 28 organisations across the OM-G area via the four PCP coordinators. A further 150 booklets were provided to a consumer based group (after an initial 50 were provided and a request for more was later made). The responses to the workforce survey represents a maximum of only 250 booklets were distributed, it is unknown how many other booklets were distributed across the region.



All organisations that were provided with the booklets were sent survey monkey links to provide feedback regarding their perceptions about booklet as a tool to utilise to support self-management with consumers. Unfortunately, less than half (46%) of the organisations who received booklets to distribute are represented in the feedback received.

The feedback was received via survey responses (36%), email responses (7%), or verbal communication to PCP coordinators (3.5%).



Sixty two percent of workforce survey respondents noted they do not want to receive more copies of the booklet, and 43% (6 respondents) noted they would be happy to receive more copies of the booklet. The limited number of responses to survey or other requests for feedback from the

workforce, as well as the number of those responses that noted they did not want to receive further copies of the booklet (57%) indicates a poor engagement of the workforce to utilise this resource to support self-management. Many respondents did indicate that they already utilise other similar resources for this work.

Analysis:

It would appear that the value of the 'Important Diabetes Check' booklet cannot be clearly defined because of the limited feedback from the audience utilising the booklet (the workforce, and consumers). The following analysis will attempt to explore where the strategy and processes may have affected the intended change, which was in utilisation of the resource.

It is acknowledged that there are various resources available to consumers and the workforce that includes the same or similar information about Diabetes care as the 'O-M&G Collaborative's' booklet. However, the underlying purpose and objective of creating a tool for use across the region is embedded in the principles of health literacy. To enable promotion of a standardised resource with consistent language, imagery, and messages to be provided and promoted at all points of care has been identified as a key recommendation to enhance health literacy from a system level[ii]. The booklet's intent was not to provide new information, but rather to present it in a consistent form, to become recognisable across the O-M&G catchment. The diversity in how information is presented (even though, to a health professional, it may appear to be the same information) can be confusing and overwhelming for consumers. Consistent language and imagery in information delivery is advised as a key way to improve organisational health literacy (OHL); which is the capacity of an organisation to communicate effectively with individuals and consumers, to improve their ability to access appropriate services and support. The initial purpose of the booklet development also supports this principle; a key priority area of the Chronic Care Strategy (2012-2022) was to provide clear and consistent information.

Although feedback from both cohorts is limited, the consumers who provided feedback on the use of the tool identified positive aspects of using the tool, in regard to their own knowledge and potential to improve self-management. The reluctance of workforce and organisations to engage in the use of the tool with clients may be more indicative of the meso and macro systems in place to address and enhance Organisational Health Literacy of the O-M&G area, rather than the individual health literacy level of consumers, who, in the majority of cases, were selected to utilise the tool based on the clinician's opinion of the potential impact.

The group who requested the most copies of the booklet was a consumer led Diabetes Support Group. This could indicate that the consumers' appetite for additional supported self-management strategies is potentially higher than the health workforce's recognition of what it is needed, or wanted.

When analysing the processes used to create and utilise the booklets a systems approach has been used to identify where the challenges may have been, to indicate why this project was not effective in the ways that it was intended to be, and provide learnings to enhance success of future initiatives and processes.

The six conditions of systems change, as described by Kania, Kramer, & Senge (2018)[iii] are all important components of a system, which need to be actioned against, in order to create a change

to a system. It is these conditions which are believed to play the most significant role in holding a system or process in place. Image 1 provides a summary of the strategy and processes relating to this Diabetes booklets project, with the 'Six Conditions of Systems Change' framework overlaid to identify potential gaps in the implementation process.

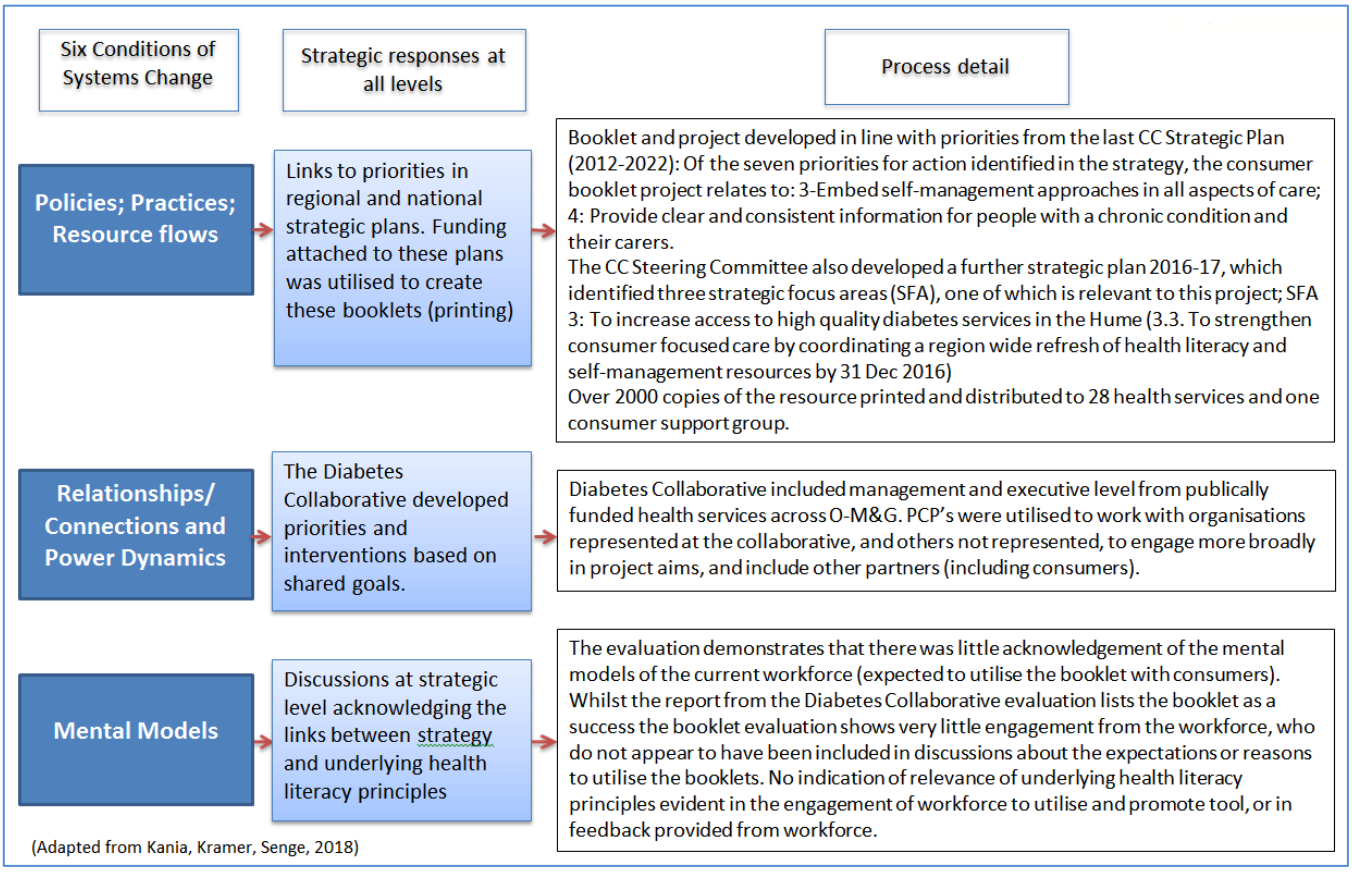


Image 1: Booklet project's Strategy responses to 6 Conditions of Systems Change

The most explicit components of the system are considered in the process of implementing the strategy around utilising the booklets. The principles behind the booklets development link to appropriate national and local strategies and policies; there is a workforce, with appropriate clinical skills, as well as skills in supporting self-management recognised; and there is appropriate resources to fund the project (booklet printing costs) as well as to distribute the booklets (PCP networks).

At the semi-explicit levels of the system the strategy included a focus on relationships, by developing the Diabetes Collaborative, which linked different organisations across the catchment to discuss and develop a plan of implementation. Power dynamics appear to have been of little impact to the process, however this evaluation did not consider or explore the real and perceived power dynamics which may have contributed to the development of the plan and associated processes. Exploration of these may indicate if power at the strategic level influenced the uptake or prioritising of the strategy and its processes within represented organisations.

The 'mental models' are the most implicit component of a system, and it is recognised that this component is often not recognised, or addressed as a component of systems change. It would appear that the value of the booklet itself cannot be measured because this critical condition failed to be addressed adequately as a component of the strategy implementation. Responses from and

discussions with the workforce provided no evidence of insight with the broader strategic goal of the implementation process. There is no indication that those members of the system who were expected to implement the change, had any knowledge or understanding of the strategic reasons and decisions for the change, such as those that link to health literacy principles, and therefore no incentive or motivation to act on the intended change process. Knoster, Villa, and Thousand's (2000) 'Framework for thinking about System's Change'[iv] (Image 2) also provides some insight into potential resistance of the workforce in the implementation of the process. The framework also indicates that a contributor to this resistance could be due to confusion because of the absence of an understanding of the strategic goals or vision.

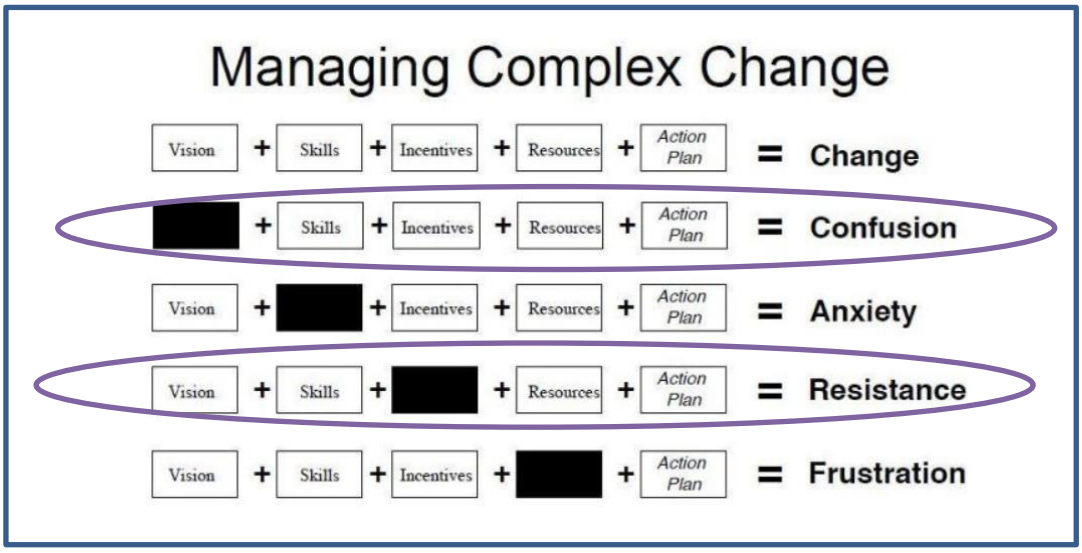


Image 2

The lack of successful integration of the booklet into service provision across the O-M&G area appears to be related to an absence of strategies to explore and impact upon the mental models of those positions which were expected to implement the strategy. 'Mental Models' refers to the habits and thoughts about how and why we do things the way we do. In future change processes it is important to consider Mental Models to enhance the potential for strategy effect, and change at the coalface.

Timeline:

The following timeline was used by the four PCPs to complete the evaluation.

Not started Being completed Done

- Feb-April 2018:
  Distribution and promotion of booklets via PCP coordinators
- April-May 2018:
  Evaluation plan to be completed by PCP coordinators, and distributed to Diabetes Collaborative members.
- June- Oct 2018:
  PCP coordinators to complete SAM score sheet on tool, and compile assessments into one internal report, with recommendations.
- Oct 2018- Mar 2019:
  Consumer focus groups (at least 1x LH PCP, at least 1x UH PCP).

Oct-Dec 18- Survey distribution and completion with/ by clinical staff across OM-G catchment.
Jan-Mar 19- Survey distribution and completion with/ by consumers across OM-G catchment.

- April- May 2019:
  Collation of all components of evaluation.
  Final report due.

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[i] Doak, Doak, & Root (1993) *Suitability Assessment of Materials Score Sheet*, accessed via Department of Health and Human Services, Population Health Services; Tasmanian Government, July 2014

[ii] Hill, S. (2014). *Report of the Victorian 2014 Consultation on Health Literacy*. Melbourne: Centre for Health Communication and Participation, La Trobe University.

[iii] Kania, J., Kramer, M., and Senge, P. (2018) *The Water of Systems Change*. FSG: Reimagining Social Change.

[iv] Knoster, T., Villa, R. & Thousand, J. (2000) *A Framework for Thinking about Systems Change*. In, R. Villa & J. Thousand (Eds) *Restructuring for Caring and Effective Education: Piecing the puzzle together* (pp 93-128). Paul H. Brooks Publishing Co. Baltimore.