

## Consumer Directed Integrated Diabetes Care

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### Introduction

Chronic illnesses are responsible for the majority of the burden of ill health, disability and death across Australia.<sup>1</sup> Diabetes is a chronic illness that affects the body's ability to produce and/or use insulin, resulting in the inability to regulate blood glucose levels. There are three types of diabetes, however the work referred to throughout this report primarily relates to type 2 diabetes, as it accounts for approximately 85 per cent of diabetes prevalence. Type 2 diabetes is largely preventable by following a healthy lifestyle.<sup>4</sup>

Diabetes related complications can include heart attacks, strokes, amputation, blindness, kidney failure, depression and nerve disease. "Annual direct costs for people with diabetes complications are more than twice as much as for people without complications".<sup>4</sup>

To prevent complications and effectively self-manage those living with diabetes require care from a variety of health services, especially in the early stages of the condition. Evidence on best practice and quality diabetes care highlights the importance of interdisciplinary team care cross primary, community and specialist services, with direct consumer and carer involvement.<sup>4</sup>

In Victoria, 28 Primary Care Partnerships (PCP) are funded by the Department of Health and Human Services (DHHS) to strengthen collaboration and integration across sectors for the purpose of improving early intervention and integrated care.<sup>3</sup> The Lower Hume PCP works across two regional municipalities north of Melbourne; Mitchell and Murrindindi.

Diabetes is the priority condition as informed by the *Hume Region Chronic Care Strategy*. Lower Hume PCP facilitated interagency planning in February 2015 to identify strategies to improve access, quality and coordination of local services to provide person centred diabetes care. The Lower Hume diabetes working group was formed to lead improvements and consists of representatives from Small Rural Health Services (SRHS), Local Government, the Aboriginal Health and Wellbeing Program, a local Pharmacy, Murray Primary Health Network (PHN) and the National Association of Diabetes Centres (NADC). The working group valued input from consumers as a basis for future reforms.

## Methods

The Lower Hume diabetes working group conducted a research project to examine consumers' lived experience, behaviours, attitudes and beliefs regarding the diagnosis and management of their diabetes. The group considered the benefits and limitations of various research methodologies and agreed to develop a survey, and conduct focus groups.

A survey tool was designed by the working group to meet the distinct purpose of the project. The tool gathers information that depicts the local and personal circumstances and health actions of respondents in terms of: demographics, general health, diabetes self-management, access and continuity of care, and beliefs about diabetes. These key themes informed four broad research questions (Table 1). Survey questions were derived from previous research such as the National Diabetes Services Scheme's (NDSS) Management and Impact for Long-term Empowerment and Success (MILES) study, allowing for comparison against national indicators. The resulting survey, entitled 'Your Diabetes, Your Say' was condensed to 27 questions across 7 pages.

**Table 1: Research Questions**

1. Do people with diabetes understand how to manage their condition and avoid risk factors?
2. Do people with diabetes access recommended health professionals? And if not, why?
3. Is the community satisfied with the support provided by local health services for diabetes care?
4. What recommendations would people with diabetes have to improve access, coordination and quality of care?

Ethics approval was gained from the Goulburn Valley Health Human Research Ethics Committee in September 2015 (Ref: GVH 30/15). Distribution of surveys commenced in October 2015. Participants had the option to complete the survey online or as hard copy. NDSS registration data identified 2,584 people within the catchment had diabetes in 2015. Seventy-seven surveys were completed and returned, of which the majority (92%) were hard copies and entered into Survey Monkey by the PCP for analysis. Five responses from people who lived outside of the catchment were still included in analysis as they accessed services within the study area (Figure 1).

An opportunity presented to have La Trobe University (Wodonga) conduct consumer focus groups and Murray PHN generously funded this additional research. Survey participants that had provided their details to be contacted for further research were invited to attend a focus group.

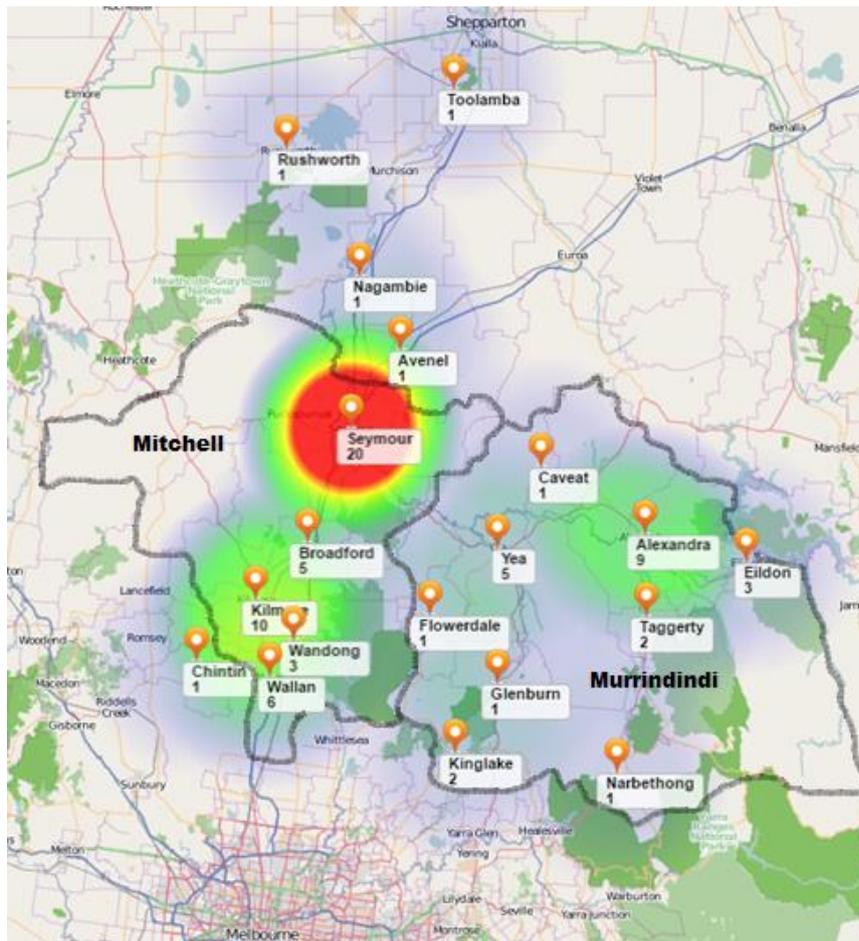
Seven participants contacted (44%) agreed to participate. Due to the limited number, only one focus group went ahead in April 2016. In place of the second consumer focus group, a health care professional's (HCP) focus group was organised, with three participants attending. Of the three participants, two were middle managers of local community based allied health services and the other was a diabetes nurse working in the catchment.

The focus group questions were informed by the survey results to further explore consumers' responses and identify specific local needs and collaborative strategies to maximise the capacity of existing services. Each focus group ran for approximately one and a half hours, and was voice recorded, transcribed and thematically analysed by La Trobe University researchers.

**Table 2: Participant Information**

	<b>Consumer Survey</b>	<b>Consumer Focus Group</b>	<b>Health Professional Focus Group</b>
<b>Number of participants</b>	77	6	3
<b>Aboriginal and/or Torres Strait Islander</b>	2	1	0
<b>First diagnosed</b>			
0-8 years	43%	67%	N/A
8-20 years	37%	33%	
20+ years	17%	-	
<b>Diabetes type</b>			
Type 1	12%	-	N/A
Type 2	86%	100%	
<b>Gender</b>			
Female	52% (n=40)	83% (n=5)	100%
Male	48% (n=37)	17% (n=1)	-
<b>Age</b>			
	13% 35-54	50% 50-60	Unknown
	49% 55-74	17% 60-70	
	38% 75+	33% 70+	
<b>Employment</b>	65% Retired	Unknown	100% Employed

Figure 1: Geographical Spread of Survey Participants



## Findings

Survey and focus group findings are presented together under the four research questions. The words of the consumers (C1-6) and the HCPs (P1-3) are used to emphasise particular points raised.

### Understanding of how to manage their diabetes

Consumers within the focus group highlighted that understanding of diabetes from diagnosis varied significantly. Some were prepared for the diagnosis having grown up in 'diabetic families', others did not know much about the illness, contributing to a greater concern and poorer management:

*...having so many diabetics in the family – I knew what to expect, I knew all about it (C4).*

*I did not accept the diagnosis and now I have several diabetic complications that I would not have had had I looked after myself when I was first diagnosed...(C3).*

One consumer's grasp of self-management was compromised not only by hospitalisation for acute illness but confusion about the kinds of food served on his meal tray:

*...I was too sick to take in anything... I found that the information I was being given wasn't adding up. The food ... being delivered – your meal (was not right) (C5).*

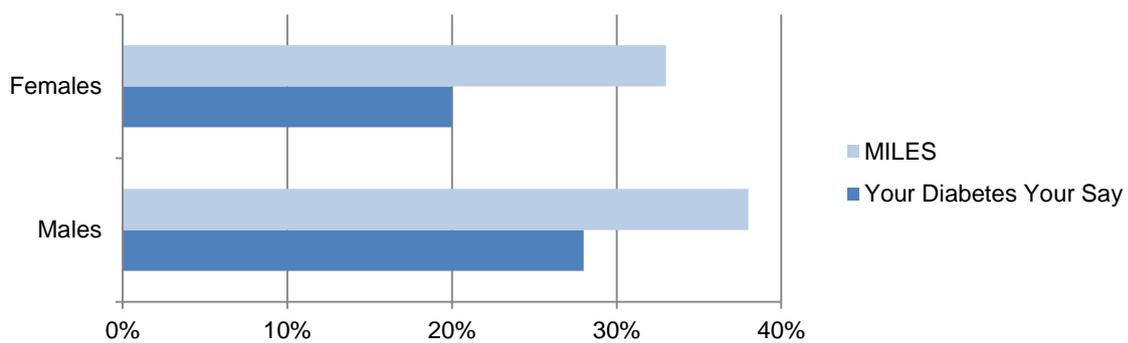
Survey participants were asked to rate their health on a scale from poor to excellent.

Compared to MILES results, participants were:

- Less likely to rate their health as either excellent or very good (25% n=19).
- More likely to rate their health as fair or poor (39% n=30).

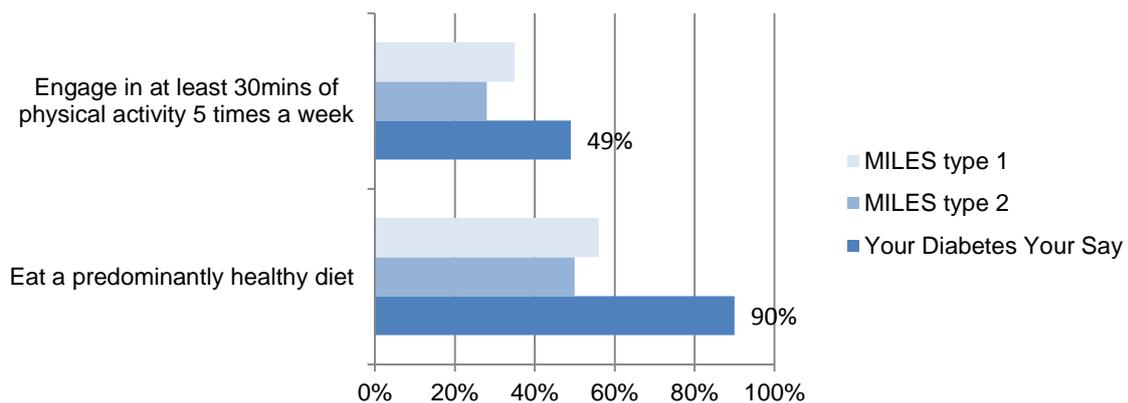
Consistent with national results, males were more likely to report excellent or very good health than females (28%; 20%) (Figure 2).

**Figure 2: Percentage of Males and Females Rating their Health as Very Good or Excellent**



Survey participants were more likely to agree that they eat a predominantly healthy diet (90%), and meet the recommended physical activity guidelines (49%) than in MILES (Figure 3). 63% of survey participants described themselves as overweight.

**Figure 3: Percentage of Participants that Eat a Healthy Diet and Meet Physical Activity Guidelines**



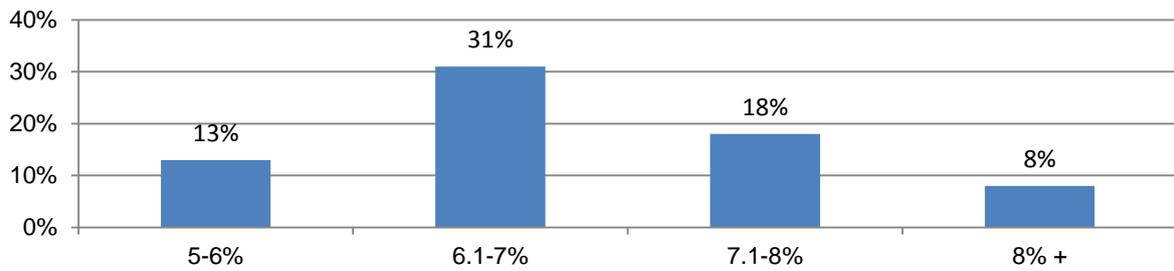
65% (n=49) of survey respondents treated their diabetes with blood glucose lowering medications, 52% (n=39) through diet and exercise, and 37% (n=28) injected insulin.

When asked what their most recent HbA1c result was, 49% (n=38) skipped or answered inadequately (e.g. can't remember, doctor said went ok), which was slightly higher than in MILES (32%).

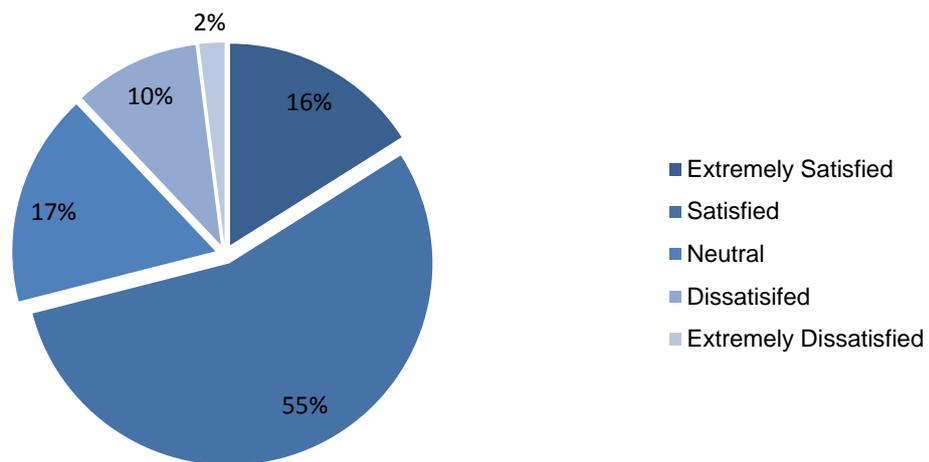
Diabetes Australia recommends that most people with diabetes should aim for an HbA1c between 6.5% and 7%.<sup>5</sup> The average HbA1c was 6.9%; the same as MILES type 2 non-insulin respondents (Figure 5).

12% were either dissatisfied or extremely dissatisfied with their blood glucose control (Figure 6).

**Figure 4: Most Recent HbA1c Result**



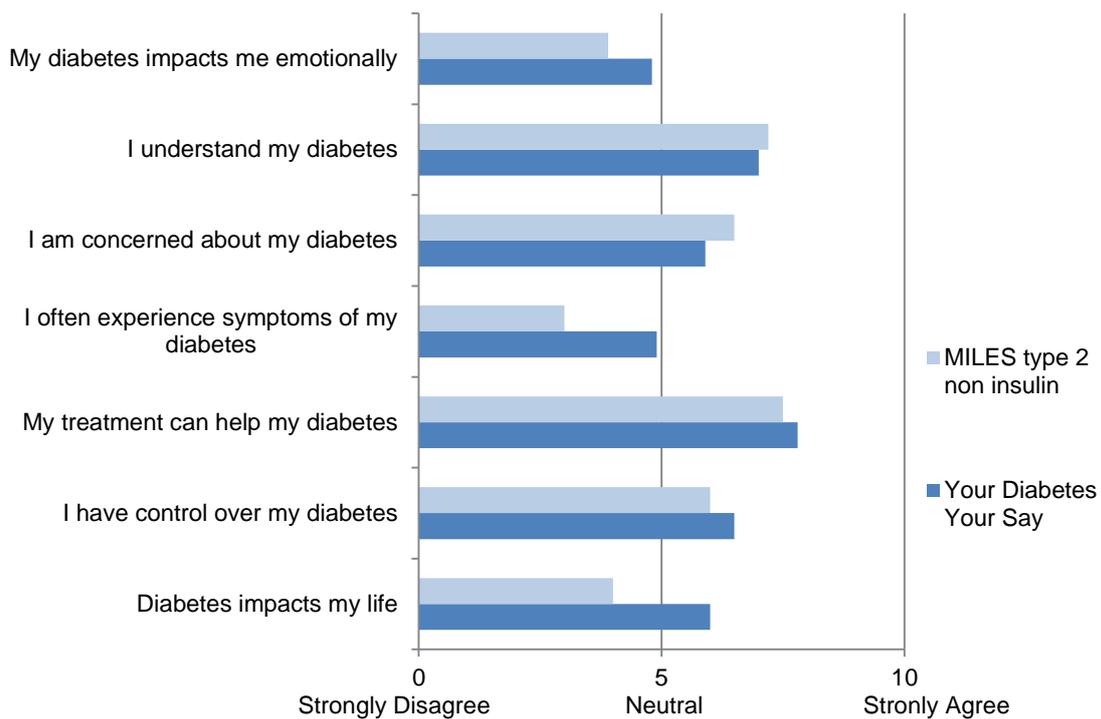
**Figure 5: Satisfaction with Blood Glucose Control**



Compared to MILES, people with diabetes in Lower Hume were more likely to:

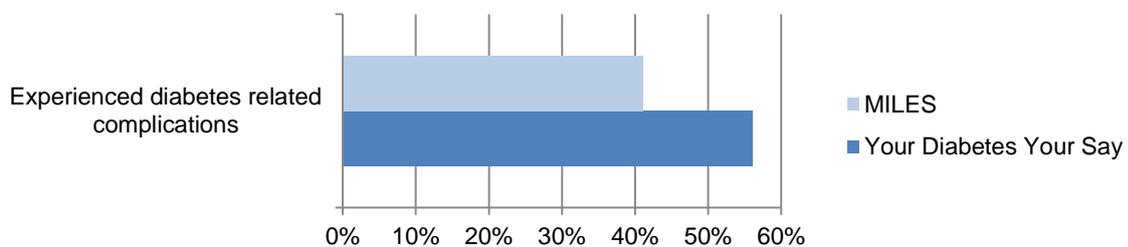
- agree that diabetes impacts their life,
- experience symptoms of their diabetes,
- be impacted emotionally by their diabetes (Figure 6).

**Figure 6: Beliefs about Diabetes**



56% (n=43) had experienced at least 1 diabetes-related complication, compared to 41% of MILES participants. Eye complications were the most common.

**Figure 7: Percentage of Respondents who Have Experienced Diabetes Related Complications**



Accessing health professionals

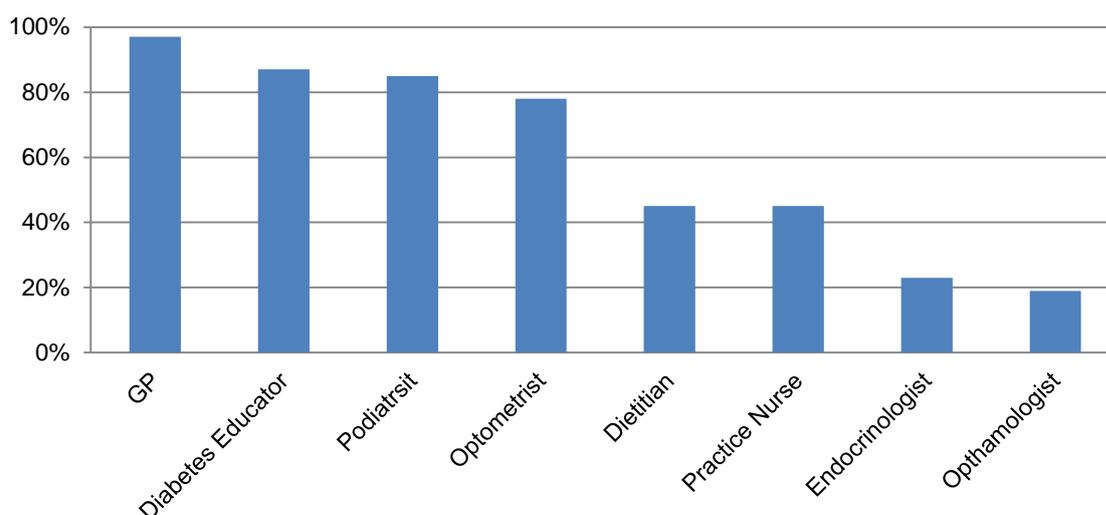
The majority of survey participants had accessed their local SRHS for health care services in the past twelve months (82%).

When asked who they considered to be their main HCP for their diabetes, 51% of respondents selected two or more. The combination most commonly reported was General Practitioner (GP) and diabetes educator.

Survey participants were asked which HCPs they had seen within the past twelve months. The majority had seen a GP, diabetes educator, podiatrist and optometrist (Figure 9).

6% of survey participants had not seen a diabetes educator since first diagnosed and one respondent had never been offered or informed.

**Figure 8: Health Care Professionals Seen within Last Twelve Months**



HCPs noted that demands on services are increasing with the growing incidence of diabetes and the need to adapt to changes to service structures, guidelines and funding:

*The volume and the continuity of clients...there is an increasing number of working, younger 40-50 year olds with type 2 referred to us now, and lots of elderly. The challenge now with working adults is their access to service. Can they get time off for appointments with us – from work or caring for children? We run some of our education groups in the evening so we try to build a flexible workforce so we can offer appointments at 5 or 6 to fit in with these clients (P2).*

But current funding and staffing limits make it is difficult to achieve service flexibility to meet the needs of this growing group of clients:

*Not every staff member can be flexible because they have family commitments.... If we can't offer flexibility, some clients just won't come. Budgets are the key things here. We can't afford to run an after-hours service... (P3).*

Survey respondents were asked to identify barriers to accessing health care. 61% did not face any barriers, whilst the others noted:

- distance (21%)
- time (9%)
- cost (8%)

Overall, the HCPs and consumers did not consider that they were significantly disadvantaged by their rural location. Both groups saw that local services offered a substantial and accessible range of expertise. When specialist input, such as endocrinology, is deemed necessary, consumers must travel to Melbourne for appointments.

The personal and financial costs of travel can be high for some consumers:

*... I've got a spinal injury and it's too far to sit for three hours and then travel home or could we afford to stay in a hotel in Melbourne overnight just for one appointment? I'm not allowed to drive a car anymore so I always have to find a driver... (C6).*

The HCPs suggested several information technology strategies to overcome gaps in service and enhance consumers' capacity for self-management. These included telehealth to connect consumers and their doctors with city-based specialists, use of My Health Record, communication to consumers from HCPs via text messaging, and apps to assist consumers to self-monitor blood glucose trends.

23% of survey respondents agreed or strongly agreed that they would like to receive information regarding diabetes electronically. 9% wanted to try new technologies such as video consultations. Results did not vary significantly by age.

#### Satisfaction with support provided

49% (n=36) of survey respondents were extremely satisfied with the local services they have accessed within the past twelve months, and 48% (n=35) were satisfied.

All consumers in the focus group recalled being referred to a specialist professional such as a diabetes educator and spoke positively about support received.

Only one consumer described difficulty in making an appointment with her doctor in her regional town:

*Because I've got complex issues (the doctor) will see me if I can get through and talk to him but if it's the ladies on the desk they just say the next available appointment is in four weeks time...(C6).*

Emotional health and depression were discussed in the focus groups as all consumers spoke of experiencing low mood states or depression. They linked depression to the disease and indicated that their initial education had not prepared them for this kind of dysphoria:

*You get a sadness that washes over you... people mightn't be aware that depression can be a part of it (C6).*

When discussed at the HCP focus group it became clear that psychological problems draw on limited resources:

*We need expertise to deal with this. Our practitioners have some skills in this area but are not trained to handle problems and we can't tie up their time this way. We could do it a bit better but it's a huge impact on our time (P2).*

#### Improving access, coordination and integration

Both consumers and HCPs acknowledged the role of peer support groups. In addition to the personal and professional support they received, the consumers highlighted the motivating effect of low cost or free services and equipment.

Both consumers and HCPs referred to the difficulty of sourcing accurate, up-to-date information. The HCPs noted that they frequently have to correct the effects of 'misinformation'. One HCP described how she vetted and suggested reliable YouTube clips for consumers.

Consumers noted confusing and misleading food labelling and were concerned for the younger generation who grow up with processed foods and may not have as much knowledge of cooking 'from scratch'. Consumers mentioned the use of natural remedies and had not received information or cautions about the possible impact on their diabetes.

For the HCPs, opportunities to attend conferences and network are central to staying up-to-date in an isolated practice and transferring their learning to consumers and peers. Costs associated with conference attendance are often prohibitive, but at times material can be accessed online. The HCPs needs for current knowledge extended to their role in ensuring that local, referring health care professionals are equally updated:

*We need to do more work with the GP practices around - try to upskill them where possible...make sure that they know we are here as a resource. They may not need us for every client. We can better use our diabetes educator – she shouldn't be seeing as many clients individually as she does – better to be educating whole community – and be a resource for the practices. We have done some practice nurse forums this year... (P2).*

It was suggested that initiatives such as the development and standardisation of referral pathways by the Murray PHN further aims for best use of resources. Yet, the goal of inter-service and professional collaboration is hindered by the distinct record, database requirements and privacy regulations of each service:

*We need one program that talks to us and to the GPs... Now if the client sees practitioners in several settings/agencies they have to repeat their story over and over... frustrating and makes them angry and disengage (P3).*

From their perspectives, consumers agreed that this duplication of assessment and records is a 'nightmare'.

## **Discussion**

Overall survey and focus groups highlighted that the effects of living with diabetes are widely variable depending on individual circumstances. It appears that some individuals are well educated on diabetes and are committed to effectively managing their health, whilst others appear to 'slip through the gaps' and not understand and/or be supported to prevent or effectively manage the condition. The consumer focus group identified factors such as general health, age, emotional response and cognitive capacity impact on how information is received by consumers and subsequently for the way they manage their own care. Consistent, clear and accurate health information appears to be an enabler for behaviour change, with peer support and group services being valuable learning and sharing experiences.

The mental health effects of living with a chronic illness became apparent throughout the research, although they can often be a less visible comorbidity. Discussion of mental health throughout routine diabetes care and integrating support services from the early stages is an opportunity for improvement.

The increasing demand on local health services became evident throughout the HCP focus group, specifically their need to be flexible to individual needs. The capacity to offer flexibility

to consumers allows for a level of personalised care designed to engage them in the ongoing management of their health. There are emerging opportunities to improve access and engagement through new information and communication technologies, and many consumers are keen to receive information and services in alternative ways.

It is clear that people with diabetes rely on multiple HCPs to assist them with ongoing management. It follows that enhanced coordination between services will improve consumer experience and outcomes. Technology plays a large role in facilitating that sharing of information, as does having a shared understanding of roles and responsibilities of each provider. Shared professional development opportunities and peer to peer education could be a first step towards a more integrated local service system.

Limitations to the data collected include the relatively small size of the sample and the low participation by younger age groups. The sample largely reflects older consumers who access services; thus cannot provide insights into the experiences of those who do not or cannot access services. The survey tool did not include questions about consumers' comorbidities, an omission that impedes the ability to identify opportunities for improvements in care for people living with multiple illnesses.

To some extent, these limitations are offset by the breadth of survey data gathered about local services and consumer experiences. Equally, data from the focus groups contributes richly to an understanding of the diversity of responses and experiences of diabetes and to the complexity of service provision across regional and rural settings.

## **Recommendations**

The local consumer research highlighted a number of implications for practical changes on the ground. The research provides an opportunity to further explore and design prevention strategies in partnership with consumers. The focus group participants demonstrated an ability to think innovatively about ways so support others based on their own experiences. One such example is suggesting hands on food preparation education be added to food knowledge support. These consumers also valued group education programs such as Life and peer support groups, thus promoting the need for these to be consistently available across the catchment. Lifestyle education plays a critical role for people at risk of developing diabetes as well as those newly diagnosed. The integration of lifestyle education programs and groups into the service spectrum is a priority and should be supported by a consistent screening program to identify and refer people at risk of developing diabetes to such a program. Information and communication technologies can be used to enhance the capacity of education endeavours.

In response to the increasing demand for services, as well as the increasing incidence of co-morbidities, there needs to be increased flexibility in funding and service design to support equitable access and collaboration across the local service system (including pharmacies). Mental health care should be a central component in this coordinated and holistic chronic illness care model. The Health Care Home trials should provide increased evidence for the provision of packaged chronic illness care, and the local system should integrate emerging evidence into service models in preparation for national roll out. To assist with translating best practice integrated diabetes care into practice and establishing a model of integrated

care locally it is recommended that all local service providers become accredited members of NADC. Working together to establish a best practice model of care will ensure consistent quality and access across the catchment. This would include defining roles and responsibilities of clinicians in line with the Murray PHN Health Pathways, establishing agreed referral and triage processes, and implementing new technology to increase access to information and services. The Victorian *Care for People with Chronic Conditions Guide for the Community Health Program* should inform future work to improve chronic illness care.

## **Conclusion**

The research described above provides impetus to review and plan services to further support the needs of regional and rural consumers. Importantly, it elevates the need to consider strategies for ongoing better care in the context of the complexity of local service relationships and delivery as well as the challenges imposed by political, program and practice changes. These challenges are intensified by the growing incidence of type 2 diabetes and by the local demographic circumstances including distance, isolation and the relatively high proportions of ageing residents that characterise rural areas.

While the consumer research methods employed in this study have yielded considerable information and motivation for service integration and improvement, further, complementary work could be undertaken to learn more about the specific education needs of health care professionals and service providers. This work should inform strategies that support aims for maintaining uniform, high quality care across the spectrum of providers into the future.

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