

## Capturing the User Experience of the Obesity Management Service

"Where do I go from here?"

-Consumer Participant in Co-Design Workshop, 9 June 2016

## Submitted 30 June 2016

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## 1. Executive Summary

#### **1.1 Introduction**

Health services that create opportunities for people to share their experiences, and that value and act on this consumer feedback, are better able to meet consumer and community needs.

In this project, data about consumer and clinician experiences of the Obesity Management Service (OMS) were gathered through qualitative inquiry. This data informed a co-design process in which consumers and clinicians worked together to identify priority service improvements and to identify appropriate ways that these improvements could be implemented.

The project has been a partnership between HCCA and the ACT Health Chronic Disease Management Unit. In the qualitative inquiry component of the project, HCCA's role was to capture the experiences of individuals participating in the OMS (Phase One of the project), while the Chronic Disease Management Unit (CDMU) captured the experiences of OMS clinicians (Phase Two of the project). Each of these processes employed semi-structured interviewing designed to elicit rich data about consumer and clinician experiences of the service and views about the current and potential role of peer support within the service. HCCA employed the Real People, Real Data methodology developed by the Consumers Health Forum of Australia (CHF) in Phase One of the project. Building on Phase One and Two of the project, HCCA with support from the CDMU, facilitated a co-design process (Phase Three of the project) that brought consumers and clinicians together to identify priority service improvements and appropriate ways to implement these changes.

This report details HCCA's role in this project, the methodology and key findings from consumer interviews, and the co-design process. Based on these findings the report makes several key recommendations for service improvements, and for future research into consumer experiences of ACT Health services. The methodology and findings from Phase Two of the project are provided at Appendix A.

# **1.2 Understanding user experiences of the Obesity Management Service and co-designing service improvements**

This project aimed to capture and analyse consumer and clinician experiences of the OMS. HCCA's role in this project was to capture and analyse consumer experiences of the service, and to facilitate a co-design process in order to identify service changes that would improve the consumer experience.

The OMS supports adults with a high level of obesity to improve their health and wellbeing. The service focuses on those who are at high risk of developing complications from their obesity or those who already have additional health problems. The service team includes doctors, nurses, dietitians, psychologists, physiotherapists and exercise physiologists.<sup>1</sup>

To evaluate the impact and outcomes of participating in the OMS, it is important to have an understanding of the user experience of the service. Learning from and acting on people's experiences is a powerful way to work towards person-centred care. Narratives from people who use and work in health services can draw attention to what matters to most people about their experiences of these services, and "contain almost everything that is needed to gain a deep appreciative understanding" of a health service and its impacts on the people who access it.<sup>2</sup>

In collecting and analysing consumer experiences of the OMS, HCCA used the Real People, Real Data (RPRD) applied qualitative research methodology developed by CHF. This methodology provides tools for gathering consumer narratives about experiences of health services, with a focus on inviting detailed and consumer-centred information about "whole of life" and "whole of person" experiences and

<sup>&</sup>lt;sup>1</sup> ACT Health *Obesity Management Service* Accessed 25 June 2016 <http://health.act.gov.au/ourservices/chronic-disease-management/chronic-disease-services/obesity-management-service> <sup>2</sup> Bate, Paul and Glenn Robert (2006) *Experience-based design: from redesigning the system around the patient to co-designing services with the patient,* Quality and Safety in Health Care 15(307-310), p309

outcomes.<sup>3</sup> This made the RPRD methodology a good fit for undertaking an evaluation of user experiences of the OMS.

In this project, the RPRD methodology allowed HCCA to gather detailed information about consumer experiences of the OMS. Based on this information, HCCA with support from the CDMU, facilitated a co-design process. This process also drew on the key findings from semi-structured interviews with OMS clinical staff, which were conducted by the CDMU. Consequently the co-design process built on a strong understanding of consumer and clinician experiences and the views of both groups with regard to the current and potential future delivery of peer support within the OMS.

Modifications were made to the planned co-design process, in order to ensure that this process responded appropriately to the emerging requirements and situation of OMS staff and consumers, and in particular to accommodate demands on staff time. Rather than delivering two 2.5 hour co-design workshops as initially envisaged, HCCA with the support of the CDMU delivered one (2.5 hour) consumer workshop on 26 May 2016, a presentation for OMS staff on the key findings from consumer interviews (2 June 2016) and a one (2.5 hour) co-design workshop (9 June 2016). This final workshop reached consensus on key priorities for service improvement and identified practical ways of achieving these improvements over the short and medium term.

This report describes the methodology and key findings from both the consumer interviews and the modified co-design process.

<sup>&</sup>lt;sup>3</sup> Consumers Health Forum of Australia (2013), Real People Real Data Project - Literature and Practice Review: Capturing, analysing and using consumers' health experience narratives to drive better health outcomes, Consumers Health Forum of Australia, Canberra, Accessed 15/06/2015: <u>https://www.chf.org.au/pdfs/rep/rep-1142-Literature-Review-Using-Consumer-Narrative-to-Inform-Better-Health-Outcomes.pdf</u>

#### 1.3 Themes and Findings from Consumer Interviews

- While consumers identify a variety of changes that would improve their experience of the OMS, it is a highly valued service which consumers regard as offering a valuable and appropriate health intervention.
- OMS participants are hopeful that the OMS can make a positive difference to their health.
- OMS participants seek to achieve diverse health goals through their participation in the service.
- Participants value the personalised and integrated approach that the OMS offers, in which different medical and allied health professionals are available to support consumers to set and work towards their health goals. However, it is the experience of some participants that the OMS does not consistently deliver a personalised approach and that the integrated service model could be strengthened. Consumers perceive that the barriers to integrated and personalised care include limited flexibility in how the service is delivered, difficulties recruiting and retaining staff and in particular difficulty recruiting to key allied health positions, and long wait times both prior to and once having entered the service. Consumers also perceive the service has too few staff to meet very high levels of demand.
- The OMS is seen by participants as an evidence-based and trustworthy service, and distinct from other approaches to obesity management in being firmly based in the latest and most reliable science and evidence.
- In general, OMS staff are highly valued as respectful, professional, helpful, empathetic and committed to assisting consumers to achieve their goals.
- The advice and information that the OMS offers is generally regarded as relevant and valuable, although not all the information or options that the OMS provides will necessarily suit the preferences, situation or existing knowledge base of all participants.

- Consumers value that the service provides up to 12 months of support and assistance, but there is strong consumer feedback that this time is insufficient to achieve or sustain lasting health changes.
- The primary challenges reported by participants have to do with communication about and from the service, including:
  - Lack of clarity about the aims, processes and likely consumer pathways through the service, contributing to unclear expectations of the service and possible outcomes of participating.
  - A lack of clarity about the role of the case manager, when to contact or expect contact from the case manager; and from some consumers a preference for more proactive contact from the case manager or the service.
  - Difficulty contacting the service, including being unable to contact the case manager by email and delays in contacting the service by telephone.
  - Difficulty managing information from the service, for example not receiving handouts with key information discussed at the group education session, or having too many paper handouts that are difficult for participants to manage or refer to.
- The consumer experience of the OMS is often one of waiting, including waiting to enter the service and waiting to access individual appointments with the clinical and allied health staff.
- There is a preference for greater flexibility in the delivery of the OMS, including provision of the service in more than one location, as well as for greater choice of times for both the group education sessions and individual appointments, and for delivery of OMS services outside of Monday-Friday, 9:00am to 5:00pm hours.
- Staff turnover, delayed recruitment processes and high staff workloads relative to demand for the service are perceived by consumers to contribute to delays and wait times. Consumers are strongly of the view that access to

an OMS psychologist (or psychologists) is central to the integrated service and its success. Swifter recruitment to clinical and allied health roles, and an increase in resources to the service to allow it to better respond to demand, were identified by some consumers in interviews as important to ensuring the OMS delivers appropriate and high quality care.

• Many participants value the supportive relationships they develop with others in the group education sessions, and would welcome additional peer support options within the program, including both online and in-person options.

#### 1.4 Recommendations

Analysis of the consumer experiences gathered through interviews, and the key findings from the co-design process, suggest a number of recommendations in the areas of priority service improvements, and recommendations about future consumer experience research and co-design processes.

#### 1.4.1 Priority service improvements

• Develop a clearly articulated OMS program approach.

Many of the challenges that consumers describe in navigating the OMS relate to their perception of having committed to a year-long health intervention, yet lacking information on which to base realistic expectations of their likely consumer journey through the service or the possible outcomes of participating in the service. Where consumer experiences of the service are less positive, this is sometimes because consumers feel the service has failed to consistently deliver or fully embed a personalised, integrated and whole-of-person model of support.

A program approach would outline the principles of self-management and integrated and personalised care that inform the OMS, as well as the various possible consumer pathways and possible outcomes of participation. Articulating a program approach, and conveying this in written consumer information as well in group education sessions and individual appointments, would assist consumers to understand the service, the possibilities it offers, and what it cannot deliver. This would strengthen the delivery of an integrated and person-centred approach. • Develop and provide of additional consumer information for people waiting to enter the service and using the service.

Participants in interviews and the co-design process drew attention to the importance of written consumer information about the service. This could be provided online, as a service brochure or as an information kit that should include consumer-centred information about the OMS model and its aims, likely wait times, indicative OMS consumer pathways, possible outcomes for consumers, consumer FAQs about the service, and links to further information and resources about nutrition, exercise and other aspects of obesity management that would be of benefit to consumers while they wait to enter the service.

In line with principles of consumer partnership, HCCA suggests that the OMS establish a consumer reference group to advise on the development of this consumer information.

• Establish a peer-led online peer support forum

There is interest from consumers in additional online peer support. This could take the form of inviting members of group education sessions to share email contacts with one another as a standing item during the group education sessions; or establishing a closed Facebook group to allow information sharing by participants. Feedback from the co-design process suggested the OMS explore possibilities for OMS staff to participate in these online forms at regular intervals, for instance by taking part in a Q and A session with consumers.

• Introduce exercise groups (walking and swimming) as a form of peer support

Interviews drew attention the importance that many consumers place on the provision of additional peer support options. In the co-design process it was identified that walking and swimming groups were among the preferred peer support options, with the OMS to provide assistance potentially in the form of practical information about exercising safely, and assistance to establish the groups for example providing initial training to peer organisers of these groups.

• Introduce electronic communication and resources

Interviews and the co-design process found that some consumers have a strong preference for electronic communication with the service, and would welcome the introduction of an OMS email address through which they could contact the service or their case manager. Similarly, some consumers would welcome the option for information and resources from the OMS to be delivered by email (or to be accessible online). This would include information and resources provided in the group education sessions. Consumers would also welcome the introduction of an OMS SMS reminder system, to be used to notify consumers of upcoming appointments, group education sessions and cancellations.

• Extend the program beyond 12 months

Consumer interviews and the co-design process drew attention to the consumer benefits of providing ongoing support after 12 months with the service concludes. This might take the form of 'drop in' access to the service, regular check-ups or monitoring by the OMS clinical staff, an extension of time to participate in the service, and/ or group education refreshers that previous participants can attend.

• Develop and provide refresher group education sessions

The co-design process identified refresher group education sessions as one specific and valuable way that past participants could maintain engagement with, and continue to access support from, the OMS over time.

 Deliver core service components (group education sessions and/or appointments) outside of Monday to Friday 9:00am to 5:00pm hours and in locations other than the Belconnen Community Health Centre.

Consumers experience barriers to access resulting from the delivery of the service in one location, and the limited flexibility in delivery of core service components (group education sessions and individual appointments). Through the co-design process it was identified that the consumer experience of the service would be improved if the service, or aspects of it, were delivered with greater flexibility. In particular, the co-design process identified the value of providing group education sessions on the south side of Canberra and outside of Monday to Friday 9:00am to 5:00pm hours. • Consider how best to integrate the OMS with support provided to consumers by their General Practitioners (GPs) and other treating health professionals.

A longer-term challenge identified by this research is to ensure that the support offered by the OMS is integrated with the support provided to individual consumers by their GPs and other treating health professionals. For example, policies and procedures relating to information sharing with GPs and other treating professionals, and the involvement of GPs in escalating referrals to the OMS, could be introduced.

• Update information provided to GPs about the service

Providing an updated OMS information leaflet or information session for GPs who refer patients to the service, would assist to ensure that up-to-date and appropriate information about the service is provided to consumers by GPs. HCCA recommends that consumers be involved in the design and delivery of information for GPs.

#### 1.4.2 Future research and co-design processes

We believe that this project demonstrates the value of both the Real People Real Data methodology and co-design for future applications in ACT Health services. These methods provide an external, independent way of drawing on consumer experience to evaluate ACT Health services, and to bring together consumers and clinical staff to co-design improvements to consumer experiences of those services.

• Continue to implement co-design approaches to identify service improvements.

Based on learning from this process, HCCA suggests that future co-design processes carefully consider and work with ACT Health staff to identify processes most suited to supporting staff engagement. This may include considering online engagement methods or a series of shorter face-to-face co-design workshops that better account for demands on staff time.

## 2. Introduction

This report outlines the methods, results, and recommendations from this evaluation project capturing the experiences of individuals taking part in the OMS. It details the process and findings from the three Phases of the Project:

- Consumer Interviews and analysis conducted by HCCA employing the Real People, Real Data (RPRD) methodology;
- Staff interviews and analysis conducted by the ACT Health CDMU (the approach taken and findings from this Phase are documented in Appendix A); and
- 3. Co-Design workshops facilitated by HCCA with support from the CDMU.

The report has five main sections; background to the project, consumer interview methodology, consumer interview results and thematic analysis, co-design process and findings, and recommendations. It should be read in conjunction with the Summary Report provided by HCCA to ACT Health on 17 June 2016 (provided at Appendix B). Appendices contain additional information about the project including project information for participants, participant wheels and transcripts and key documents from the co-design process.

### 3. Background

#### 3.1 About the Health Care Consumers' Association

The Health Care Consumers' Association (HCCA) is a health promotion agency and the peak consumer advocacy organisation in the Canberra region. HCCA provides a voice for consumers on local health issues and now provides opportunities for health care consumers to participate in all levels of health service planning, policy development and decision making.

HCCA involves consumers through:

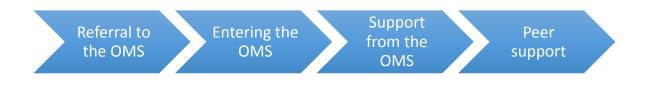
- consumer representation and consumer and community consultations
- training in health rights and navigating the health system
- community forums and information sessions about health services
- research into consumer experience of human services.

In January 2016 HCCA was engaged by ACT Health Policy and Government Relations to capture the user experience of the Obesity Management Service and to facilitate a co-design process bringing together clinicians and consumers to identify priority service improvements and the future role of peer support within the service. HCCA has considerable experience in qualitative research and co-design processes, and was pleased to partner with ACT Health to complete this important work.

#### 3.2 About the Obesity Management Service

The OMS is an ACT Health service that supports adults with a high level of obesity to improve their health and wellbeing. The service focuses on those who are at high risk of developing complications from their obesity or those who already have additional health problems. The service team includes doctors, nurses, dietitians, psychologists, physiotherapists and exercise physiologists.<sup>4</sup>

The consumer narratives gathered through this process reflect a simple ideal journey through the OMS service, which is visually represented below. Peer support is specifically featured because this was an area of particular interest to ACT Health, and had been previously identified by OMS staff and consumers as an area where the service could be strengthened.



#### Figure 1: OMS Service Journey

<sup>&</sup>lt;sup>4</sup> ACT Health *Obesity Management Service* Accessed 25 June 2016 <a href="http://health.act.gov.au/our-services/chronic-disease-management/chronic-disease-services/obesity-management-service">http://health.act.gov.au/our-services/chronic-disease-management/chronic-disease-services/obesity-management-service</a>

## 3.3 The Power of Consumer Experience: Consumer Narratives and Co-Design

Consumer narratives can provide valuable insights into the experiences of service users when navigating different system and service settings. This evaluation sought to capture the consumer experience and voice using the Real People, Real Data (RPRD) methodology developed by CHF. In short the value of a narrative-based approach is that:

"Stories provide rich information about people's experiences of their health, health services and the health system. This is essential information for better decision making, for quality improvement and to guide health reform."<sup>5</sup>

In this evaluation, consumer narratives were gathered by HCCA using the RPRD methodology while clinician experiences of the OMS were gathered by the CDMU. This approach allowed an appreciation of the key issues for clinicians and consumers, and shaped the approach to the co-design phase of the project, in which clinicians and consumers worked together identify priority service improvements.

#### 3.4 Project Key Deliverables

The project involved the following key deliverables by 30 June 2016:

• .....

<sup>&</sup>lt;sup>5</sup> Consumers Health Forum of Australia, *Real People Real Data Toolkit*, Accessed 26 June 2016 <<u>https://ourhealth.org.au/sites/default/files/docs/rprdtoolkit.pdf</u>>, p4

## 4. Consumer Interviews and Analysis Methodology

#### 4.1 Capturing consumer narratives: the Real People Real Data Toolkit

The RPRD toolkit was developed by CHF for capturing and analysing consumer narratives of health, illness and the health system. It can be used to gather and analyse consumer stories and use this evidence base to inform policy development and program evaluation. It presents user experiences in people's own words, and identifies areas that are working well and those that need improvement.

The RPRD methodology is free to use and can be adapted by other organisations. There are no licensing requirements other than attributing CHF with the development of the methodology.

The RPRD method involves:

- **1.** Identification of key stages of the consumer experience, prior to data collection.
- **2.** Semi-structured qualitative interviewing with individuals about their experience of these stages in the context of their life journey.
- **3.** A three-step analysis process that involves:
  - a. Creation of a Health Experience Wheel, which concisely presents primary coding of transcripts selected by the participant as key experiences in a person's narrative of their life journey, presenting the emotional high and low points in this journey. The Health Experience Wheel tool produces a one-page experience summary that is participant-controlled and relevant to policy, decision-makers and service providers.
  - b. Coding of the Health Experience Wheel and experience narrative against relevant indicators. In this case, 12 indicators were identified jointly with the CDMU. Eleven of these indicators are aspects of person-centred care suggested by CHF for use in the RPRD Toolkit.

Indicator 12 is *Peer Support*, which was identified by ACT Health as a priority area for inquiry in this project.

c. Thematic analysis of indicators and evidence of these indicators across all wheels and interviews.

#### 4.2 Qualitative Research, Sample Size and Data Saturation

HCCA was engaged to deliver 15 qualitative interviews with OMS participants. Fourteen interviews were completed. One consumer withdrew from the project after completing an interview. Information from this interview was not used in further stages of the project, and is not reflected in the analysis of interviews presented in this report. This participant's consent to participate forms will be held by ACT Health in line with the Human Research Ethics protocol that governs this project, and HCCA has shared this information with the participant.

The research findings discussed in this report thus reflect the data gathered in 13 interviews conducted by HCCA during April and May 2016. Of the 13 interviews, 4 were conducted with men and 9 with women. HCCA understands that this gender balance is broadly representative of the overall OMS cohort. While this method does not aim to provide a demographically accurate sample of the OMS cohort it does aim to reflect the diversity of this cohort. Thus HCCA is pleased that the research participants include both men and women, people of different ages, and people with diverse lengths of engagement with the OMS including people who had recently entered the service, others who had been with the service for some months, and others who had exited the service after 12 months or longer.

Clear themes in consumer experiences emerged early in the interview process, and saturation in themes was reached at eight interviews. As a result the methodology was slightly altered in negotiation with the CDMU and with the approval of ACT Health Policy and Government Relations, such that the final planned interview did not take place. It was agreed that completing one additional interview would not have generated additional information.

A smaller sample size such as that represented in this study can raise concerns around representativeness, objectivity, validity, reliability and the subjective nature of the research. The intent of this research was to support the 13 participants to tell the story of their experience of the OMS, to understand their experiences and to accurately reflect their views, experience and expectations in relation to the OMS. This research does not intend to present a basis for making broader claims about the experience of all participants in the OMS. However the qualitative data captured does provide valuable insights into the user experience of service participants.

The quality of the data collected and saturation of data is central to qualitative sampling.<sup>6.</sup> Theoretical saturation is a process in which the researcher continues to sample relevant cases until no new theoretical insights are being collected from the data<sup>7</sup>. This was the case with this evaluation after eight interviews. These interviews are a rich source of information about user experiences of the OMS.

#### 4.3 Development of discussion guides and coding criteria

Discussion guides for the identified consumer interviews were developed initially by HCCA and then finalised in consultation with ACT Health Chronic Disease Management Unit staff (see Appendix C). Open-ended questions and prompts were developed with the aim of inviting participants to reflect on their experiences with the OMS. Each question aimed to assess the OMS against the twelve criteria selected for the evaluation. Analysis criteria One to 11 are those suggested by CHF in the RPRD Toolkit as central aspects of consumer-centred care. Analysis criteria 12, *Peer Support*, was selected because this was an identified by ACT Health as a priority for investigation.

#### Consumer-centred care criteria:

- 1. Access, equity and affordability
- 2. Information and understanding

<sup>&</sup>lt;sup>6</sup> Glaser, B. G., and Strauss, A. L. (1967). *The Discovery of Grounded Theory: Strategies for Qualitative Research*. Chicago: Aldine.

<sup>&</sup>lt;sup>7</sup> Flick, U. (2008). *Designing Qualitative Research Book 1 of The SAGE Qualitative Research Kit.* London/ Thousand Oaks, CA/ Delhi: Sage.

- 3. Informed Consent (including informed financial consent)
- 4. Appropriate Care
- 5. Respectful Care
- 6. Whole of person care
- 7. Coordinated care and supported transitions
- 8. Safety and quality
- 9. Control and choice
- 10. Social, economic and community participation
- 11. Carers and support

Criteria specific to this project:

12. Peer support

HCCA appreciates the timely feedback that the CDMU provided about the interview discussion guide and analysis criteria. The interview questions and coding criteria were developed by HCCA in consultation with the CDMU.

#### 4.4 Selection of participants

ACT Health undertook recruitment for this phase of the project. At OMS education and gym sessions, and individual appointments, ACT Health staff informed consumers about the project and provided them with a participant information sheet and consent form (see Appendix C). OMS staff had also been keeping a list of consumers who would like to be kept informed about developments related to peer support and ACT Health staff provided these consumers with information about the project. The contact details of consenting participants were provided to HCCA to schedule and conduct the interviews.

Consumers were offered a \$30 travel reimbursement to support their participation in the interview and were provided with taxi vouchers to enable them to attend the co-design workshops.

#### 4.5 Data collection

#### 4.5.1 Interviews

HCCA is very appreciative of the time that participants volunteered to take part in interviews. There was a very low rate of interview postponement. No interviews were cancelled. HCCA considers that this may reflect the high level of participant engagement and investment in the OMS and in this evaluation process. In addition, a number of interviews took place at the Belconnen Community Health Centre or other ACT Health facilities in south Canberra, and holding the interviews at these locations may have contributed to ease of participation for interviewees who were attending interviews before or after scheduled appointments at these locations.

Interviews lasted between 30 minutes and 75 minutes. Most of the interviews were close to one hour in duration. Interviews were audio-recorded and transcribed. Transcription allowed a precisely accurate record of the interview, and ensures that the consumer experience is described in the consumer's own voice.

#### 4.5.2 Reviewing transcripts

The RPRD method invites consumers who take part in interviews to be actively involved in reflecting on and analysing their interview transcript. Participants are invited to read through their transcript and then to identify their key positive and negative experiences, as these are represented in the transcript. Participants in this research were advised that they could do this in a conversation with a HCCA researcher, or by "marking up" their transcript using highlighters or pens, or, if working at a computer, using the highlighter tool in Word. Participants were invited to identify key positive and negative experiences and a single "take home" message that captured what matters most to them about their experience. This consumer-led transcript review process ensures that the experiences represented in Health Experience Wheels accurately reflect what was most significant to consumers (see Appendix E).

## 4.5.3 Modifications to the RPRD methodology to ensure person-centred and supported participation

Participants in this research were highly engaged. A consideration when using the RPRD method is that the process of transcript review can be time-consuming for

participants,<sup>8</sup> yet of the thirteen participants who remained in this study to completion, eleven reviewed their transcripts to identify their key experiences of the service. HCCA considers that the high level of engagement by consumers in this process reflects the high value that participants place on the OMS, and their strong interest in sharing their experiences to improve the service for future users.

HCCA made minor modifications to the RPRD process in order to support consumer participation. In this and other uses of the RPRD tool, HCCA has observed that transcript review can be difficult or inappropriate for people with limited English language proficiency. In this and previous applications of this method HCCA has also observed that the transcript review process can create moderate emotional discomfort for participants, who can find it discomforting to reflect on their experiences as represented in their transcripts. In this project, HCCA made minor modifications to the RPRD process, in consultation with the CDMU, in order to support two participants. In one case, the participant had discussed in interview an experience of significant distress in which symptoms of post-traumatic stress disorder were triggered by participation in an OMS food diary exercise. Although this participant advised HCCA that they would like to continue in the project, they asked the HCCA lead researcher to identify key experiences to appear on the Health Experience Wheel. It is relevant to note that this participant had advised the OMS of her experience at the time it had occurred and reported in interview with HCCA that the OMS had provided her with appropriate support at that time. HCCA provided support to this participant in line with the Human Research Ethics protocol that governs this project, with the HCCA lead researcher confirming with the participant that she felt emotionally safe during the process, and verbally reiterating the availability of telephone counselling services for anyone experiencing discomfort or distress after participating in interview. A second participant advised that she had limited literacy and would prefer HCCA to identify experience points to appear on the Health Experience Wheel. In both cases HCCA liaised with the participants to check that they were comfortable that the Health Experience Wheels present an accurate summary of their experiences of the service. In both of these instances, minor

<sup>&</sup>lt;sup>8</sup> Tong, Alison, 18 June 2014, *CHF Real People Real Data Pilot Phase Evaluation* p9-13 Accessed 20 June 2016 <a href="https://ourhealth.org.au/sites/default/files/docs/chf\_rprd\_external\_evaluation.pdf">https://ourhealth.org.au/sites/default/files/docs/chf\_rprd\_external\_evaluation.pdf</a>

modifications were made to the methodology in order to best meet the needs and preferences of participants.

Note: there are a number of quotes included in this report from participant Experience Wheels and transcripts. These have been recorded verbatim from audio recordings and may contain syntax or grammatical errors. We have chosen not to edit this to ensure that the consumer voice as is, is heard.

#### 4.6 Data storage

HCCA took audio-recordings of the interviews and stored these on a secure computer server, with one back up recording stored on an external hard drive which was stored in a locked filing cabinet for the length of the project. The audiorecordings were destroyed after they were transcribed. HCCA transcribed the audiorecordings, removing any identifiable text, and stored a copy of these on a secure computer server, separately from participant details so participants cannot be identified from their story. Quotes selected from the transcript were uploaded to a secure online software program to develop the wheel graphic. These documents were deleted from the online software as soon as the graphic was generated. The online server is located in Australia. Participant details were stored on a secure computer server, separately from transcripts, and audio files so participants cannot be identified from their story. Consent forms will be stored securely in line with the ACT Government Records Disposal Schedule and the Human Research Ethics Protocol that governs this project.

#### 4.7 Analysis

#### 4.7.1 Process

As discussed above at 5.4.2, consumer participants in interview took part in a process of review and reflection on their interview transcripts. In this process they identified what was most significant to them in their experience of the OMS. This consumer-led process was central to the analysis of the interview data. The Health Experience Wheels provided at Appendix E present a consumer-led analysis of what was key in each individual's experience of the OMS. These consumer-identified key experiences also underpinned the analysis of consumer experience undertaken by the HCCA research team. The HCCA researchers reviewed the key

experiences identified by consumers, and applied one or more of the consumercentred care criteria and project-specific analysis criteria used in this project to each of these key experiences. The discussion of findings at Section 5 below presents a thematic analysis of these criteria as they relate to key consumer experiences of the OMS (5.1), and a qualitative analysis of themes that recurred in the 13 interviews, as participants described each stage of the OMS consumer journey (5.2).

#### 4.7.2 Researcher/Coding Bias

Coding bias is a possible limitation with qualitative analysis of interviews and transcripts against particular criteria. When reading this report, it is important to be aware that analysis and interpretation of the transcripts and wheels was undertaken by the researchers, who aimed to minimise the potential for bias.

Primary coding and selection of data (positive, negative and take home message) was selected by participants with support from HCCA (and in two instances by HCCA in discussion with participants as discussed at 4.5.3). However coding against the criteria was completed by the HCCA researchers. Whilst all coding is subjective and results are easily influenced by the researchers' personal biases and idiosyncrasies all coding decisions used a framework that attempted to be transparent, communicable and coherent. This framework is outlined by Auerbach & Silverstein (2003):<sup>9</sup>

'The purpose here is not to actually replicate the study but to be at that level of understanding of the original researcher's findings. Although the reader may not agree with the interpretation, he or she will have a clear understanding of how the researcher arrived at the interpretation'<sup>10</sup>

The subjective nature of qualitative coding also means it is inappropriate to make strong quantitative predictions. However, the coding and measures of the number of

<sup>&</sup>lt;sup>9</sup> Auerbach, C. F., & Silverstein, L. B. (2003). (P. 82-85) *Qualitative data: An introduction to coding and analysis*. New York: New York University Press

<sup>&</sup>lt;sup>10</sup> *Ibid p.84* 

times each criterion appears in each participant's wheel and across the nine wheels does provide insight into the key aspects of the user experience of the Obesity Management Service.

The feedback contained in this report should be considered in light of these limitations.

## 5. Results: Thematic Analysis of Consumer Experiences

The wheels and coding sheets for each participant can be seen in Appendix E. The wheels are organised into sections which reflect both the Service Journey through the OMS (*See Figure 1, Section 3.2*) and the stages in experience around which the interview discussion guides were organised. These stages are shown below at *Figure 2*.



Figure 2: Stages in experience around which interview guides were based

The Health Experience Wheels have been coded according to the following criteria. Criteria One to 11 are drawn from the RPRD Toolkit and are widely recognised as central aspects of consumer-centred care. Criteria 12, *Peer Support*, is a project-specific criteria, identified by ACT Health as an important area for potential service improvement.

#### Consumer-centred care criteria:

- 1. Access, equity and affordability
- 2. Information and understanding
- 3. Informed Consent (including informed financial consent)
- 4. Appropriate Care
- 5. Respectful Care
- 6. Whole of person care
- 7. Coordinated care and supported transitions
- 8. Safety and quality
- 9. Control and choice
- 10. Social, economic and community participation
- 11. Carers and support

#### Criteria specific to this project:

12.Peer support

Thematic analysis of the wheels is discussed under each of these key areas below.

#### 5.1 Trend analysis of consumer-centred care criteria

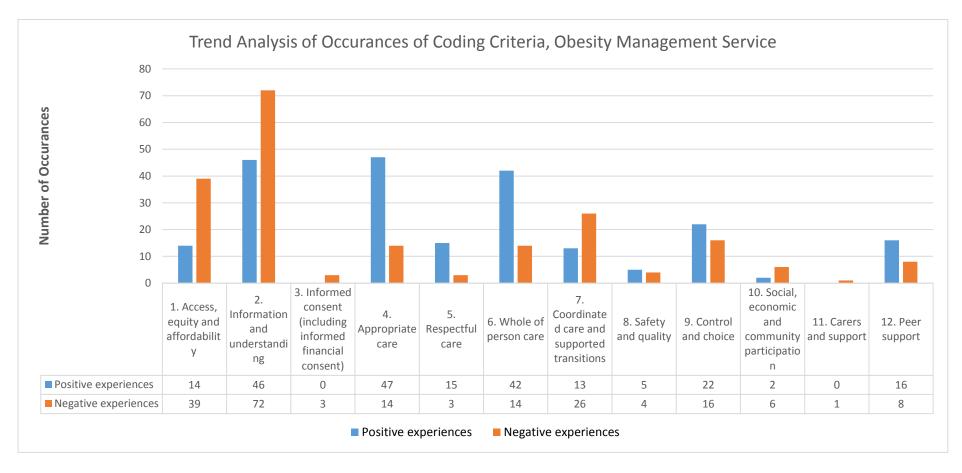


Figure 3: Consumer-centred care criteria in OMS Health Experience Wheels

#### 5.1.1 Overall trend analysis

The overall trend analysis demonstrates that issues relating to *Information and Analysis* were the single most commonly appearing analysis criteria. These issues were the most frequently identified analysis criteria related to negative consumer experiences, and also the second most frequently appearing analysis criteria relating to positive consumer experiences. This suggests the very high value that consumers place on the delivery of high quality consumer information about obesity management, and about the OMS. It also suggests the high value consumers place on ease of communication with the service and ready access to information resources provided by the OMS.

The analysis criteria most frequently identified as relating to key positive consumer experiences was *Appropriate Care*. This reflects a key finding of this research, namely that while consumers identify many changes that would improve their experience of the OMS, it is regarded as a very valuable service. Interview participants unequivocally perceived the service to be of benefit to consumers and the community. The OMS is regarded as distinct from other approaches to obesity management that consumers may have tried in the past, because it is evidence-based, and aims to provide an integrated, personalised model of care. Where experiences of *Appropriate Care* were negative, this sometimes reflected consumers' perception that the service had yet to fully embed a personalised, integrated approach. From the consumer vantage point it was perceived that this could be due to factors including limited resources relative to high demand for the service, limited flexibility in service delivery, and difficulties in recruiting and retaining staff and in particular an OMS specialist psychologist.

As Figure 3 (above) demonstrates, other frequently appearing analysis criteria include Respectful Care, Whole of Person Care, Control and Choice, Access Equity and Affordability, Coordinated Care and Supported Transitions and Peer Support. This suggests the importance to consumers of experiences that relate to these areas. Less frequently identified analysis criteria included Safety and Quality; Informed Consent; Social, Economic and Community Participation and Carers and *Support.* While this should not be understood as suggesting that these issues are unimportant to consumers, it is notable that these were not identified as recurrent issues for consumers in the context of their experience of the OMS. As is discussed below, there is some overlap in the criteria, meaning that some issues relating to less commonly selected analysis criteria are also addressed in the discussion of more frequently identified criteria.

#### 5.1.2 Information and Understanding

As identified in the summary above, issues relating to *Information and Understanding* are central to the overall consumer experience of the OMS. *Information and Understanding* was the single most frequently identified analysis criteria that related to key consumer experiences. In turn, this reflects the importance to consumers of timely and appropriate information about the OMS, consumer-centred delivery of information about obesity and obesity management by the OMS, and ease of communication with the OMS and its staff. Fourty-six instances of positive experiences in this area were identified, making *Information and Understanding* the second most frequently identified analysis criteria relating to positive consumer experiences of the OMS, just slightly behind *Appropriate Care* (with 47 instances of key positive experiences). However, issues relating to Information and Understanding were also the single largest area of negative consumer experiences of the service (see *Figure 3*).

Positive experiences of *Information and Understanding* reflect the very high value that consumers place on the information about obesity and obesity management that the OMS provides. The information that the service provides is seen by participants to be based in the latest evidence and scientific understanding of obesity and obesity management, and therefore trustworthy and reliable. From a consumer perspective this is one the qualities that sets the OMS apart from other approaches to obesity management that OMS participants may have tried in the past. For example, consumers identified in their interviews that:

*Um, it's all based on what lots of studies have shown, not, "hey here's a new thing". Participant Two* 

The doctors were talking through research, the latest research, and they explained about bodyweight set points in that you can actually take them down and hold them down to 2 years before they reset, and things like that. And I was like, 'Right, yes!' Participant Three

...That's why it's so empowering, because you know it's right and you can trust it and just get on it with it. You just get on with it. Participant Four

In general, consumers regarded the OMS as a service that provides them with information that is relevant and appropriate to their situation. While not all the information that the service provides was thought to be appropriate to the preferences or situation or existing level of knowledge of every participating person, most interviewees were of the view that the OMS had provided them with at least some new information that they could feasibly act on and incorporate into their own lives in ways that would be of benefit to them. For example, this consumer explained that:

Every week if you really look for it, you will find a gem. They won't provide all your answers, but they will give you some things to live with. Participant Eleven

Consumers regarded the group education sessions as a key vehicle through which the OMS provides information about obesity management. Consumers recognised the challenge of providing information to groups in which members often had varied levels of pre-existing knowledge and awareness of the diet, lifestyle, cognitive, exercise and movement and medical aspects of obesity and obesity management. While some consumers regarded much of the information provided in the group education sessions as new and valuable, others found the group education sessions provided them with little information of which they were not already aware. With this caveat, almost all the consumers who took part in interviews felt that the group education sessions had provided some information that was of value to them. Often, it was the practical and up-to-date qualities of the information delivered that made it particularly valued: Little things, at the last session, the dietician gave us this little card and it said how much fat we should be looking... It's practical, I take it out when I go shopping.... We did talk about things like coconut oil, and someone asked the question, should we be eating coconut oil because it's the latest fad at the moment, and it is confusing, because you get so much information, and you know, what do you eat, what should you eat? So this is really helpful. Participant Thirteen

I love the exercise physiology and the dietician, those sessions where awesome, I liked the fact that they had the slide shows, they had hand-outs, they actually got us to introduce ourselves, it was more of a happier, fun, upbeat kind of woohoo, kind of thing, feeling... I left those sessions feeling a sense of achievement, which was great, a real understanding of like, the dietician lady she gave us like a business card with the calories. Participant Five

As these consumer narratives demonstrate, practical resources and information that people are able to apply in their daily lives are valued by participants.

Negative experiences that have been coded as relating to *Information and Understanding* relate to three distinct but inter-related sets of communication issues. One set of issues relate to consumers' perception that they lack the information they require in order to form reasonable expectations of the OMS, including an understanding of their likely pathway through the service and possible outcomes of their participation. The second set of issues relates specifically to the delivery of information in the group education sessions, and highlights the importance of the first group education session as an opportunity to provide information and opportunities for discussion in order to assist consumers to set reasonable expectations of the service as well as to establish rapport as a group. The third set of issues in this area relate to practical challenges of communicating with the OMS and its staff, for example difficulties contacting the service and its staff and difficulties managing the information the service provides.

Information about the OMS consumer journey

A recurring theme in the consumer interviews was consumers' perception that they lack the information they require in order to form reasonable expectations of their likely consumer journey through the service. In interviews, consumers drew attention to their uncertainty about what the service aims to achieve, and what they were likely to achieve themselves as a result of their participation in the service. This lack of clarity about the aims and process of the service characterises the period between referral to the service and entering the service, as this consumer reflected on the waiting period:

Really I didn't have any idea what the service, only I had a letter from them saying there was an appointment and all that? Participant Thirteen.

For some consumers this uncertainty about what they can expect from the service, and can themselves reasonably expect to achieve as a result of taking part, continues into later stages of their OMS journey:

But then I really don't know because I really just don't know what the next steps are in the program anymore... Participant One

One of the recurring negative experiences for consumes was their lack of clarity about the OMS process, or their consumer journey through the service. For example, interviewees described feeling uncertain what the role of the case manager was, not knowing how to arrange individual appointments with the OMS clinicians after completing their group education sessions, and a general sense of not knowing what the "next steps" were likely to be at any point in their participation with the service or following discharge from the service.

But I don't know, do you call your case manager and then they book you for the dietician? None of the process stuff was ever explained... I think they've mentioned the services that are available, but not how you can access them. Participant Seven.

It's not very clear what the process is. Do we talk to our case manager and she will line up what we need based on what we need, or do we arrange it with the

different areas? Just knowing... I don't actually know what the case manager's role is. Participant Nine.

This is related to a general lack of consumer information about the OMS. As this consumer observed:

There's not really a lot of information out there about it either, because I did try googling it and there was not a lot there. Participant Eight.

#### The first group education session

The first group education session was a specific negative experience for a number of consumers. Consumers highlighted that they did not have an opportunity to introduce themselves to one another in the group, felt that there was not sufficient time to ask questions about the service, and left feeling uncertain what the OMS could offer to them or what their participation in the service was likely to involve.

That the first week, it would have been great to have an icebreaker, have a cup of coffee, because the session was quite short, we actually got out an hour early, it could've been that we had a cup of coffee together, and had a chat, whether it was just a fun thing or whatever, maybe some of those guys would've been a bit more comfortable. Participant Four

The first thing that you notice in the first meeting is that no one is introduced to each other. It's a basic thing, every meeting that I've ever gone to you introduce everybody to everyone else. It may take a bit of time, but it's important. Or you give people nametags at least... I went in there with a lot of hope, with an idea that someone was going to help, but I left there totally deflated thinking what is the point of this. So that first meeting really was a shocker. Participant One

These consumer experiences highlight the importance of the first group education session as an opportunity to begin the process of building trust and rapport within the group of participants, as well as to allow consumers to ask questions and discuss the service, its aims and their likely progression through the various forms of support that it offers.

#### Communicating with the OMS

The third area of challenges for consumers in the area of *Information and Understanding* relates to practical difficulties contacting the OMS and its staff. One of the challenges in this area was that contact with the case manager and the service could only be made by telephone, and the OMS telephone number was frequently unattended. These consumers describe the experience:

I think the only bad thing I have to say about is the fact that they only have someone manning their phones one day a week is a bit annoying, specially because it seems to be a Wednesday and everyone when they call you they always seem to call you on a Monday or a Friday so it takes two days to get through. You can leave a message, I could leave a message I suppose but... Participant Eight

That's another issue there's no one there much to answer the phones... You ring the obesity management service and you just have to leave a message because is only one person there and they only work one day a week or something like that. Participant Two

A number of consumers highlighted that they would prefer to be able to email the OMS rather than telephone, while others felt that their experience of the service would have been improved if the OMS telephone number had been more regularly attended.

#### Managing information provided by the OMS

The preference by some consumers for contacting the service by email is related to a more general preference from some consumers for greater access to electronic communication with the service. Some consumers would highly value access to electronic copies of handouts and resources provided in the group education sessions, and/or emails of individual plans or other documents provided by the OMS clinicians and allied health staff. Some consumers reported that they found it difficult to store, manage and access the various paper documents provided by the OMS over their 12 months or longer with the service. For some, electronic information would assist them to store and access this information over time.

if you missed a session or whatever, they couldn't send you the slides or whatever, because one thing in this program is they don't use email. They refuse to use email. So everything is mailed to you, photocopied and sent to you in the mail. Participant Ten

That would be good if we could get a copy of the presentation, or the notes emailed around so that I can go back over the information. Participant Two

## 5.1.3 Appropriate Care

The single most frequently appearing positive experiences related to the appropriateness of the care provided by the OMS. This reflects the high value that participants place on the service. It is seen as valuable, necessary and appropriate. Participants appreciate its integrated model of care, which brings together allied health and clinical staff, and the effort that the service makes to provide care that responds to the situation, preferences and needs of individuals. These consumer quotes illustrate the high value that participants place on the integrated assistance provided by the OMS allied health and clinical staff:

I think the doctor that's involved, she [name removed] is fantastic. The psychologist, what's her name, [name removed] she was fabulous, and a real shame that she wasn't replaced while she's away, because I think those two parts of it were really good, and the V.L.E.D. I think is really great.<sup>11</sup> Participant Ten

The session with the doctor, I was amazed that the doctor spent so long with me, that was excellent, because I don't get that when I go to my own doctor. Participant Thirteen

<sup>&</sup>lt;sup>11</sup> V.L.E.D, Very Low Energy Diet.

Consumers also value the OMS is not a short-term intervention. Unlike many diet and lifestyle approaches that consumers may have tried in the past, the OMS offers 12 months of support and follow up:

I think it's the support and the follow up and if you've got someone, if you need to, if you can get hold of them, someone to talk to and everything, and they do check up on you, and make sure you get your blood tested every couple of weeks and that you're on track and all the staff look after you and everything and they keep you updated on if there is changes happening with the service and that sort of thing. Participant Eight

When the OMS is working at its best, it is also flexible and able to tailor the support provided to the needs and situations of individuals. For example, this consumer described the flexible approach that the OMS exercise physiologist took to developing her individual exercise and movement plan:

But I didn't want to wait till then so she said "I think you would be good if you could come to the gym once a week, because I can see that I could sit here and write up plan for you and you could take it away and you would ignore it." And you know she was quite right about that. Participant Two

Overall, consumer experiences of *Appropriate Care* were far more often positive than negative (47 positive to 14 negative). In those instances when consumer experiences of *Appropriate Care* were coded as negative, this sometimes reflected consumers' perception that the OMS had yet to fully embed a personalised, integrated and coordinated model of care. Consumer accounts suggest that this integrated model of care, which they valued highly, was in their experience compromised by challenges including understaffing relative to high demand for the service, difficulty recruiting and retaining staff and in particular difficulty recruiting key allied health staff, long wait times to progress through the service, irregular contact with the service and limited flexibility in how the service is delivered. The following consumer quote illustrates the challenge that perceived understaffing, irregular contact and time spent waiting for appointments can present for consumers' sense of taking part in a smoothly integrated and personalised service:

But then again it needs to be staffed and it needs to be, I feel, more regular because you know the initial meeting then there was the group session then there's nothing really to follow on from the group session, the appointments have been cancelled, and then I've got my review in June and what are they expecting from me in June? Participant Five

Similarly, while consumers value that the OMS is not a short-term intervention, it was a recurring theme in the interviews that consumers perceive the service would provide more appropriate care if it could be extended beyond 12 months. This is discussed further below at *Access, Equity and Affordability*.

I'm wondering if there's a possibility to extend? If your doctor re-refers you. Participant Three

Other issues that recurred in negative experiences of *Appropriate Care* relate to difficulty accessing appropriate facilities and supports in the community after discharge from the service, and the long wait times to progress from group education sessions to individual appointments with the OMS clinical and allied health staff. These issues are discussed in more detail under *Access, Equity and Affordability* and *Coordinated Care and Supported Transitions*.

#### 5.1.4 Whole of Person Care

The high value that participants place on the OMS is reflected in the frequency with which *Whole of Person Care* appears as a positive experience for participants (42 instances). In this area positive experiences related to participants' experiences of the service understanding and responding in an integrated way to the physical, mental, emotional and social aspects of obesity and obesity management. The provision of appropriate advice and support around exercise and physical movement, psychological support and nutritional advice were seen as significant positives of the OMS.

It's the holistic solution. When I came into this program I said to the doctor, this is really important to me. You have to treat me as a whole person, it's not just one thing. Participant Eleven

I came out of that session thinking, "Wow! My goodness me, they are pretty thorough because there is a nurse and a doctor and a case manager sort of thing. And they will certainly knew about being careful with treating people respectfully. Participant Two

## 5.1.5 Respectful Care

Related to this, consumers value the OMS staff team. In general, OMS staff are seen not only as professional but as also able to provide advice and support with respect, empathy, kindness, understanding of the issues affecting people who are obese, and commitment to providing support and care that will make a positive difference to the lives of OMS participants. This is reflected in the high incidence of *Respectful Care* as a code relating to key positive consumer experiences (15 positive incidences).

But the staff are all really positive, and friendly and respectful and knowledgeable some of the questions the doctor asked I thought, 'wow they really know their stuff! Participant Two

I was terrified. I was terrified going, I was feeling sick, I was very weepy, just feeling a bit overwhelmed. Then I went in there, the Belconnen building is new and it's nice, and they directed me, and every single member of staff that I dealt with was so friendly, so helpful, so respectful, like I've never experienced before in my life, it was such a positive thing, and I felt like here's some people who genuinely want to help me, who aren't seeing 'lazy, greedy', who are looking at me seeing, 'medical problem, needs help'. I left feeling on top of the world, like I could do something, like there was hope. Participant Four

Oh Yes. And you don't feel judged, it's a very good interaction you don't feel judged or like you're being told, 'Oh don't eat so much' and stuff like that. Participant One

The staff are really good, they'll help you'll strive for what you want to achieve. I respect that they're trying to help obesity people try to get back on track with their life. Participant Thirteen

When they're actually taking your measurements it is quite confronting. They do it the best they can, and they treat us with respect and kindness and I think that's awesome and it was a positive experience, even with the embarrassment. Participant Twelve

I felt heard, one doctor in particular heard me, and repeated back what he'd heard, and that to me was a really significant thing. I actually had never experienced that before. I knew when he spoke... that he heard me. Participant Eleven

# 5.1.6 Control and Choice

The code criteria *Control and Choice* was identified as relating to 22 key positive consumer experiences. This frequently related to the practicality and relevance of the advice and support offered by the OMS. Many participants regarded the OMS as providing a variety of approaches, possibilities and assistance with obesity management. As discussed above at 5.1.2, *Information and Understanding*, most people who took part in this study felt that at least some of the assistance offered by the OMS was appropriate to their situations and that they could incorporate it into their daily lives. The following consumer quote illustrates this in relation to one of the group education sessions:

I found the session to be quite engaging because the dietician wasn't there to dictate, and because it was a smaller group it meant that there was a lot more interaction between people, so there was little bits and pieces where I could ask questions, where some of the things I do in my food prep it helped me to know where a dietician would stand on it which was useful. Participant Seven

The following consumer quote illustrates the sense of control and choice that the information and support provided by the OMS can engender in participants:

Usually when you talk to your doctor they say I want you to eat so many calories, but they're just saying, small changes. We're not asking you to lose weight, we're asking you to do these things. We're going to support you, you're going to have these things coming up. And they've given us great information, and suddenly these huge obstacles in front of me, comfort eating, chronic pain, all of these things I've had in front of me, it's like oh we can deal with this, it's going to be fine. So I'm not saying I'm never going to comfort eat again, or whatever, but I have so much hope now. Participant Four

Negative experiences of *Control and Choice* (16 instances) often related to the *Information and Communication* issues discussed above, and to *Access, Equity and Affordability* issues which are detailed below. These experiences illustrate the disempowering impact of having a limited understanding of what to expect from the service, difficulty contacting the service, and the frustration that can be caused by long waiting times to access OMS clinical and allied health staff. These long waiting times can contribute to a sense for some consumers that they do not know what they should be doing to manage their situation, or what they can expect to achieve by the time they are discharged.

I asked to see a dietician in October and I got an appointment in February which kind of wasn't... I mean the conversation was initially meant to be about how I was going to manage Christmas... But then it became, 'Well this is how I managed Christmas. Participant Three

For some consumers, what they understand to be the 12 month time limit on the service can also contribute to a sense of uncertainty and lack of control over their health and wellbeing. This relates both to the difficulty of accessing appropriate, long-term facilities and support in the community, and a strong sense for some consumers that longer-term support from the OMS would assist them to maintain momentum or goals achieved during their time with the OMS. The following consumer quote illustrates this second point:

I think there should probably be an option to come back maybe every year for three or four or five years because just feeling that you are going to be... You haven't been thrown to the wolves, someone is still interested in what's going to happen to you later on. Participant Three

#### 5.1.7 Access, Equity and Affordability

Issues coded as related to *Access, Equity and Affordability* were the second most frequently identified area of key negative consumer experiences (39 negative experiences to 14 positive experiences). In this area positive consumer experiences reflect the value that consumers place on the provision of the OMS as a unique and valued approach to obesity management. Negative experiences in this area included long wait times, both to access the service and to access particular clinical and allied health staff for individual appointments that were important to consumers. In particular, consumers identified that in their view a psychologist is an essential member of the clinical and allied health professional team. Those consumers who were not able to access the support of a psychologist due to an extended recruitment process identified that this significantly detracted from the quality of their experience. More generally, consumers observed that staff turnover and what appeared to consumers to be low staffing levels relative to demand for the service, as well as the absence of key professional staff (in particular a psychologist), had led to cancellation of appointments and delays in their progress through the service:

From me getting the letter to actually starting with the service it was about 12 months. Participant Eight

Like the group sessions and a psychologist, but in saying that, they've had to be cancelled because two of the people have left. Participant Five

The prevalence of this criteria also reflects a consumer preference for greater flexibility in the service delivery model. For example, some consumers expressed frustration that the service is offered in only location (Belconnen), while others described difficulty arranging considerable amounts of time away from work or caring commitments to attend multiple OMS appointments, and having limited choice of times to attend group education sessions and individual appointments. Some consumers identified that access to appointments and/or the OMS gymnasium facilities outside of Monday to Friday, 9:00am to 5:00pm would be

easier for them to access. Others identified that they would find it easier to access the OMS if it was also provided in Canberra's South.

So it's like taking away from one thing to give to something else. I know that my health is damn important, but so are my kids. So it needs to be in Woden, or in Tuggeranong as well, not just the one location. Participant Five

They could have put that meeting at any time, they could have put it on a Saturday morning and done the first two classes on a Saturday morning to get them out of the way and not bother anyone, but instead they say "you come on a weekday for two hours", and it ended up being a bad 45 minutes. Participant One

#### 5.1.8 Coordinated Care and Supported Transitions

While consumers value the integrated and coordinated model that the OMS aims to provide, negative experiences in the area of *Coordinated Care and Supported Transitions* outweighed the positive (with 26 incidence of negative experiences and 13 positive incidences).

Waiting times, staff turnover and delays in staff appointments detracted from consumers' experience in this area. The following consumer quote identifies how staff turnover impacted negatively on this participant's experience of continuity in case management:

My case manager left in December, and I got another case manager think it might be [name redacted] for me right now but I'm not 100% sure if she is my case manager. When I rang up and asked they said, 'Just wait a minute' and then they said, 'we can't find it written down anywhere but it's probably one of the nurses' and I was like, 'okay then...' So I'm not 100%... I mean I'm not relying on them to manage me because it's not happening. Participant Three

A number of consumers drew attention to how important they regard psychological support to be to the integrated and coordinated model of care that the OMS provides.

Consumers who were unable to access the OMS psychologist provided clear feedback in interviews that this detracted from their experience.

So the reason I was quite disappointed was she kept reiterating that the psychologist was on maternity leave and they don't know when they're going to get the next time and it could take forever, and that's very discouraging. What's the point of joining this program if you don't even have the services that are integral to this journey? Participant Seven

I think they should have either a couple of psychologists or counsellors on board, that should support people as they go through the program. Participant Ten

Negative experiences in this area also related to difficulties accessing appropriate community facilities after discharge from the OMS. Access to appropriate hydrotherapy facilities was identified as a particular issue for some consumers, as the following consumer quote illustrates:

And of course they really tried the same thing as the exercise physiologists at the hospital when I finished my session of hydrotherapy, to find me somewhere to go when my sessions had finished. Problem is there's only so many places you can go. Participant Eleven

Affordability of access to long-term community facilities was also an issue in this area for some consumers.

Consumer interviews also drew attention to the challenge of liaising and coordinating the care of OMS participants with their other treating health professionals. Consumers recounted being uncertain whether or when health information collected by the OMS would be shared with their GP or other treating health professionals:

I'm not sure where all that information that they collected went. Where it goes to in a way... because they suggested a couple of things to my doctor. Participant Two One consumer reported that they would like information from the OMS to be shared more readily and proactively with their specialists and GP:

With the health issues that I have there's this specialist, this specialist, this specialist and this specialist, and my GP, and the obesity management service. You know, most of the forms don't have at list five doctors to get copies of this! So I have to carry them around and say, 'are you interested in this one? Or that one?' Participant Three

One consumer was diagnosed with Type 2 Diabetes while on the waiting list to enter the OMS. Her GP advised her to call the OMS and see if she could be prioritised for entry, but she was not aware that this altered the service's assessment of her priority for intake:

I was diagnosed with the Type 2 diabetes, and the doctor said, ring up and just let them know that you've got Type 2 diabetes and you need to see the dietician, and I did that and it was like, oh OK.. Participant Nine

These experiences highlight that OMS participants may welcome greater clarity about the ways in which the OMS interacts and coordinates their care with their GP and other treating clinicians.

Extending the program beyond 12 months was also seen by some consumers as important to improving the continuity of care that the OMS provides.

I would want to remain in the program, because I don't really think it's something you can benefit from in a 12 month, 6 month, 12 month program. It really needs to be, something that you've developed over 30 years, isn't going to be fixed in 6 months. Especially if you're only seen every 6 months. So an ongoing relationship with the program in some form. But I think it needs to be better resourced. Participant Ten I don't know, maybe a follow up phone call or appointments, at 6 and 12 months after I've left, I don't know, might be good. Participant Eight

## 5.1.9 Safety and Quality and Informed Consent

Very few of the key experiences identified by consumers relate to *Informed Consent*, or to *Safety and Quality*. Those issues coded as relating to *Informed Consent* reflect the challenges of having limited information about the service and what it offers. These issues are discussed above under 5.1.2, *Information and Understanding*. As also discussed above at 5.1.3, *Appropriate Care* was the single most commonly selected positive code, and this can be understood as reflecting generally positive consumer experiences of the OMS as a safe and high quality obesity management service.

Where key consumer experiences were coded as directly relating to safety and quality issues, this was because consumers identified an OMS response to situations in which they felt unsafe or in which OMS staff felt they may be unsafe. This included an OMS response to symptoms of post-traumatic stress disorder triggered by participating in a food diary exercise, in which the consumer reported that the OMS psychologist provided appropriate support.

Otherwise it was the psychologist and I found her [name removed] fabulous... I know she did all the right things. Participant Eleven

Additionally, one participant recounted his experience that the OMS provided limited and in his view necessary psychological support and follow-up while he undertook an OMS-supported Very Low Energy Diet.

Now, this is a 600- 800 calorie diet, really extreme, to put you into ketosis, so your body's eating its own body fat, and you have no contact with anyone for weeks....Prior to the V.L.E.D. And then she went on maternity leave, and they didn't replace her. They didn't replace her, or have any alternative. I kept saying, are you going to replace her? Yes. Well then I need some support to keep me on the V.L.E.D. And then nothing. Oh, you can go and see a psychologist outside the service. Yes, but I'm actually part of the service. Participant Ten

Another issue raised by one consumer is that OMS participants face the risk that they may not achieve lasting improvements to their health and wellbeing as a result of participating. In particular, this participant expressed the view that if participants lose weight with the support of the OMS, but regain this weight over time, it may become harder for them to achieve weight loss goals or self-manage their health effectively over time.

How many people, and you should be asking this too, statistically, for how many people has this worked? My guess is less than five per cent. Obesity is very specific, it's a major problem for society. And it if works in fits and starts, then you're complicating it for people. And then you've got one of those dips [n weight] and then you've made it harder next time around. Participant Eleven

5.1.10 Social, Economic and Community participation; Carers and Support These criteria were not identified as frequently relating to the key consumer experiences. Those issues that were coded against these criteria often intersected with issues discussed above under Access, Equity and Affordability, and Continuity of Care and Supported Transitions. For example issues in the areas of Social, Economic and Community Participation included the challenges of accessing appropriate community facilities, such as hydrotherapy facilities. Negative experiences in this area also reflected consumer experiences of the negative impacts of obesity on their social, economic and community participation, for example experiences of stigma, discrimination and inability to participate in social and community activities as a result of obesity or related health issues. Carers and Support was rarely identified as relating to key consumer experiences, however those experiences that were selected as relevant to this criteria draw attention to the important role that family members and friends can play in supporting OMS participants to take part in the program and to achieve health goals they set themselves.

## 5.1.11 Peer Support

Experiences of Peer Support were more often positive (16 instances) than negative (8 instances). Some consumers highly value the opportunity to develop relationships of support, information sharing and encouragement with others in the group education sessions. For some consumers, negative experiences in this area reflected their view that they would benefit from the provision of additional peer support options provided by the OMS. As discussed at 5.1.2, *Information and Understanding*, some participants felt that the group education sessions, and the first group education session in particular, were a missed opportunity to provide additional peer support:

We go in there and we didn't say hi to each other. Because basically it feels we are being told from day one that this is our journey only, don't look outwards, you're blinkered. They didn't introduce us. Participant One

Other participants felt that additional peer support options would not be of benefit to them. These participants regard the OMS as an opportunity to pursue individual health goals with support from a team of clinical and allied health professionals, and have limited interest in peer support. This consumer quotes illustrate this view:

We don't need to be supported by each other, we are here to be supported by the service. Participant Ten

Consumers with a positive orientation toward additional peer support saw this as one way to sustain momentum and maintain any changes in health achieved during the 12 months of the OMS:

In the 12 months they give you certain tools, but come back, give us your feedback, what's worked for you, what hasn't worked for you, share with other people who are at the start of their journey. Participant Seven

Consumers suggested a variety of ways that additional peer support options could be provided within the service, including both online and in-person.

I think that if ACT Health sort of set up a Facebook page and said 'everybody gets to join this Facebook page', then they can put on different programs and they can keep the information up-to-date. Participant One

I think it would be great if they did the old fashioned chat room, or Facebook page, because even if people want to stay anonymous... it's not everybody's cup of tea but sometimes it's enough of their cup of tea just to watch it, and some people will take part and some people will lead it, but I think it's better to have it than to not have it. Participant Four

Having a face to face session that is one hour or two hours once a week or every second week would be amazing. Participant Seven

The variety of peer support options suggested by consumers is considered in more detail below at Section 6.

#### 5.2 Understanding the OMS consumer journey

This section provides an overview of key themes that recurred in consumer interviews, as these relate to the stages in the consumer journey of the OMS and the stages in experience around which the interview guide was based.

#### 5.2.1 Your health

Consumer interviews demonstrate that the OMS cohort is diverse, not only in terms of general health, health issues and health goals, but also in terms of aims, expectations and motivations for participating in the OMS.

Interviews highlighted the varied impacts of obesity on the lives of OMS participants. While some participants felt that obesity had minimal impacts on their life or quality of life, others recounted negative impacts including experiences of stigma, discrimination and negative social judgements. Others spoke about the limitations that obesity places on their daily lives and activities, and the whole of person impacts of obesity including on confidence and mental health.

My overall health is incredibly poor. I've been obese since I was a teenager, and morbidly obese since I hit my 20s so um... And I've had a lot of negative mindsets to everything about whether I could overcome it. And it's affecting every part of my parenting, my confidence... Participant Four

It has a big impact on self-esteem. It has a big impact on your ability to participate in what people are doing. Participant Three

You know I'm not actually sick now but... you know... I find it difficult to do stuff, and I realise that I'm not very healthy and that I have high blood pressure and things like that. But you know high blood pressure is just a number that the doctor tells you about, it doesn't really impact me right now. I mean I wouldn't know what that means.....But you know I find it harder to move about and that sort of stuff. Participant Two

Some consumers also identified positive impacts of obesity, for example they had gained through experience considerable knowledge about nutrition, diet and

exercise. One positive aspect of her experience of obesity for this consumer is that this has had filtered judgemental people from her circle of friends:

It limits your circle of friends to people who were prepared to be nonjudgemental. Participant Three

Many of the interviewees had tried multiple approaches to weight loss or obesity management in the past. A number of interviewees identified that these approaches were initially successful but it was difficult to sustain the goals achieved over time and without ongoing support. For some, the cost of participating in obesity management or weight loss programs was prohibitive.

Tried the shakes, tried the diet, tried the gym. Dietician, been to the doctors. The doctor prescribed me pills. And it hasn't worked. Participant Twelve

Yes well, I used to see a dietician for a number of sessions, I paid money to see her. And that was sort of hopeful, and I've seen doctors and stuff to try and get help but it never came to anything. I would sort of try something and then... It drops off. Participant Two

Most of the programs you go to are only six weeks, or eight weeks, there's just not enough time to set you in a good program, a good eating program or a good exercise program, there's not enough time to progress from that. I've been to a private dietician where I had to pay, and then I went two times and went, I just cannot possibly afford this, you're great but I cannot afford this. Participant Five

For some participants, the OMS is a 'high stakes' intervention in the sense that participants perceive that they have tried multiple approaches in the past with limited success, and look to the OMS to assist them to achieve their health goals in this context.

#### 5.2.2 Diverse motivations and expectations

OMS participants look to the service to assist them to achieve diverse health goals. These include wanting to better manage, or to reduce the impact on their lives of, chronic conditions such as Type 2 Diabetes, high blood pressure, atrial fibrillation and chronic pain. Other participants reported feeling hopeful that the OMS could assist them to achieve lifestyle changes that would improve their general health, for example by exercising more or becoming more physically active, or making changes to their diet or nutrition. Others specifically sought to increase their physical mobility, which was limited for example by pre-existing conditions such as arthritis or chronic pain. Some participants spoke about wanting to participate in physical activities they value, such as gardening, or wanting to be able to be more active with their children.

I've come to the OMS to try and help me get my weight down, having three young kids it's very tiring running around all the time and not having the energy to do what they want, and that's really why I got into the program. Participant Twelve

Still other participants reported joining the OMS because they wanted to learn more about, or gain new insight into, obesity and obesity management. In short, motivations for participating in the service are both diverse, and often highly personal.

Consumers also have diverse preferences for and perceptions of the different obesity management options that the OMS can offer. Consumer orientations toward gastric band surgery are an example. Some consumers recounted that they participate in the OMS in the hope that this will lead to their assessment by the service as a suitable candidate for the waiting list for publicly funded gastric band surgery in the ACT:

Now surgery, to me, is what I'm aiming for. I know it's not a quick fix, I know it's a lifestyle change, but that whole psychological thing. Participant Five

Others described feeling that for them gastric band surgery would constitute an option of last resort or even, in the words of one participant, a "failure" (Participant Four). There was also some confusion among participants about how participation in the OMS related to the provision of gastric band surgery by ACT Health.

Participants also had varied understandings of what the aims of the OMS were, or should be. For example, some participants were strongly in support of the framing of the OMS as an obesity management service, as distinct from a service supporting a weight loss or dieting approach:

It really began with the doctor, I can't remember his name, the one who does the book, "if not diet, then what", it was the first time I came across that, that was a significant change in thinking for me, and I was grateful that this came through. Because if they weren't willing to looking at it from that direction, I wasn't willing to [take part]. Participant Eleven

Other participants felt that weight loss should be prioritised as a service aim.

Initially the thing that was reinforced was, this is not a weight loss program, it's not a weight loss program, and it's not about dieting. You're telling this to a group of people who are morbidly obese, morbidly obese, it's a very serious condition, you could die. And you're told initially that it's not about dieting and it's not about losing weight, it's about lifestyle change. ...So I just thought that was crazy, just crazy.... To say that you're going to have better health outcomes but you're not going to lose some weight, is nuts. The reality is that everyone who is in the program is obese. They know they are. They want to lose some weight. And reduce blood pressure and all the other stuff. Be fitter. But you know. Don't beat around the bush. Participant Ten

One participant identified that there may be a tension in how the service presents weight loss and weight loss diets, particularly in relation to the option of undertaking a Very Low Energy Diet with OMS support: Because the first session I had with the doctor she mentioned that going on a low energy diet would be good for me, but I don't want to do that, so I have no idea why she was saying that. And even the dietician.... was also mentioning it, that it can be part of your program.... On the other hand, she was saying, don't do diets, because most people gain more weight later on. So it's just a contradiction, little things like that throughout my engagement with program, what they're trying to do is a great thing, but the messaging is getting a bit mixed up. Participant Seven

A number of interviewees described having few expectations of the service. For some this was a deliberate strategy, reflecting openness to the advice and options presented by the service. For others, having few expectations of the service reflected unfamiliarity with the OMS model of care, which they had not previously encountered. However for several participants, having minimal expectations of the service reflected their experience of having little information about the service on which to base their expectations of what assistance the OMS could provide, or what they would be expected to do while taking part in the service.

I decided not to have any expectations, just to be completely open-minded, because my first acknowledgement was, I do need to do something about my situation, and if I do have preconceived ideas, given the fact that I do have food issues, would not be the right way to go. So I thought I'd come in, find out everything I need to know to get help. Participant Nine

I think it was the great unknown more than anything else, because I've never used a service or known of one, I didn't know what they could do for us. Participant Four

Honestly I didn't know what to expect. Because a lot of what the service was, wasn't explained. So I went straight in to see the doctor here and she sort of asked, well the nurse first, and she asked me heaps of questions, the doctor did the same, then the case manager. None of the process was explained. I get it from their perspective, because they do this every day, but for someone who has no idea, quite, OK, that contextual knowledge wasn't there. Participant Seven

I didn't really know what to expect. I was hoping I would learn something, and get some clarification around dietary things, and have someone that I could talk to about you know, where I should be going, what I should be doing. Because not all exercise and dietary programs fit everyone, and I wanted something for me. I tried the group education sessions, and I did find them useful. Participant Thirteen

## 5.2.3 Referral to the OMS

Referral to the OMS was generally a smooth process for participants. Consumers were often surprised and pleased to learn that a service like the OMS was available in the ACT.

He said would you be offended if I refer you, and I said not at all. So thankfully it was my doctor who was kind enough and also honest enough to support me... I didn't know there were any obesity related services anywhere. Participant Four

One exception to the generally positive experience of being referred to the OMS occurred when a consumer attempted to personally deliver her referral from her GP to the Belconnen Community Health Centre:

So to be quite honest with you getting the referral to here was a nightmare... I said to... [my GP] it's just as easy for me, not knowing any better, for me to drop the referral in here and make an appointment on the way home. That didn't work. I went to reception. No, I'm sorry, we can't make appointments for you here. OK, well what do I do? You can fax it in. I don't have a fax machine. You could use that black phone over there. So I did, and a young lady answered the phone and she said, we can't make an appointment until we've seen the referral, and I said I'm standing in reception with the referral in my hand, can I bring it up? No, you're not allowed up. Can you come down and

get it? Oh, OK, I'll come down. And then we'll contact you later... So that was a very negative experience for me. Participant Nine

The one recurring challenge for consumers during the referral process was lack of information about the process. This included lack of confirmation that the referral had been received, and lack of information about how long the wait time between referral to the service and entry to the service was likely to be.

Well so the GP sent that the letter off to them and then he didn't hear anything... Nothing at all. And I'm thinking, like, "Is anything happening? At all?" I may have got some kind of confirmation letter somehow. But I was expecting... I don't know what I was expecting... I guess I thought that there would be contact almost immediately... Participant Two

I would have liked to have had an email, just when I got the referral, just to say we've got it, we're going to put you on the wait list, the wait list is so long, you can expect to wait so long. Participant Thirteen

A number of consumers identified that additional information about the OMS and obesity management issues, provided after referral but prior to entering the OMS would support consumers to maintain motivation while waiting to enter the service.

Yeah, I think more transparency about where things up to... And also if there was kind of like an introductory letter that said, 'in the meantime here are some of the things that you can do to start the process off.' Because when you get into something like this that's when your motivation levels are highest. You've decided to do something! You're going to do something! But then you get asked to wait eight months you know? Participant Three

#### 5.2.4 Entering the OMS

With the exception of the wait time to enter the service, experiences in this area were generally positive. Consumers spoke about valuing the thorough first appointment, which involved meeting with the various clinical and allied health professionals for an assessment. As discussed in the analysis of person-centred care criteria at 5.1 above, consumers felt that detailed information was gathered at

the first assessment, and that the OMS professionals were respectful in gathering personal information that could be "confronting" to share (Participant 12).

One consumer described that the first appointment took considerably longer than they had been advised it would. This could have created difficulties for this consumer had he been taking approved leave from work for the advised time period. Another consumer found it difficult to find the Belconnen Community Health Centre and to find a car park with sufficient time to attend the 2.5 hour appointment:

I think they should send an email and letter advising of the appointment with a map and parking details. Participant Thirteen.

These experiences highlight the importance of consumer information about likely time commitments, location and other arrangements (such as parking) related to attending the first appointment.

#### 5.2.5 Support from the OMS

#### Group Education Sessions

Most OMS participants began their engagement with the service by attending five, or in some cases, 10, group education sessions. Experiences of these sessions varied, in part depending on how much of the information presented in the session was new knowledge to participants. Those participants who felt they had a strong existing foundation of knowledge about obesity management issues tended to be more negative in their assessment of the value of the group education sessions:

I found to it be for someone who had no knowledge whatsoever, but a lot of people in these sessions have a lot of knowledge. Participant Seven

I kinda thought that in these meetings we would get a bit more of an idea about things, but nothing so far is anything new. It's just repeating old stuff that everyone knows. Participant One Almost all participants in the consumer interviews felt that they gained at least some new knowledge and practical information about obesity management from the group education sessions. Consumers also recognised the challenge of providing information that meets the needs of an audience with diverse levels of existing knowledge in a group setting.

The most positive consumer feedback about the group education sessions was reserved for those sessions where the presenters encouraged questions, feedback and interactions between the group members. The group education sessions that consumers valued most highly were also those that successfully tailored the content to meet the needs of all participants:

Yes, in the first session it was very, this is what you have to do, this is how it is, in the second session it was, let's give that a try, see how you handle it and if it's not working let's try and find a way around it. Flexible approach and more personable approach. Participant Nine

As detailed at 5.1 above, the first group education session was a key negative experience for several consumers. This reflects the value of this first session as an opportunity to set a positive tone for the whole consumer journey through the service.

The last meeting was better, but once you start out feeling totally deflated from the very first meeting, it's going to be very hard for me to get to a point where I'm going to say this is positive, even if it is. Participant One

The first group session presents an opportunity to explain the aims of the OMS, and to provide information that will help participants to set realistic expectations of their consumer journey through the OMS, including reasonable expectations of what may have changed for them by the time they are discharged from the service. This session is also an important opportunity for members of the group education session to introduce themselves to one another and to establish rapport.

#### Individual Appointments

Consumers highly value access to individual appointments with OMS clinical and allied health staff. Some consumers recounted very positive experiences and outcomes of their appointments with OMS clinicians and allied health staff. Advice and support from the OMS health professionals was most valued when it was personalised, as these consumer quotes illustrate:

The woman who runs it is good... She says, 'What do you want again out of the physical training?' and 'What you will focus on?' and then sometimes she will go, 'I think you should also think about doing this, and that.' Then she will design exercises to address the specific things. Participant Three

Excellent. She actually got me aerobic. She showed me some things I'd never thought I'd be able to do, with my knees and everything. Participant Eleven

There was often a considerable wait time between finishing the group education sessions and having individual appointments with the clinical and allied health professionals. Waiting times both before and after entering the service were a source of frustration for consumers. For some, this time spent waiting compounded their concern that would not achieve their goals or access the full benefits that the service offers within the 12 month timeframe. Consumers also reported experiencing a lack of clarity about the process for arranging individual appointments. This reflects a broader uncertainty about what the "next steps" in the consumer journey through the service are at any given point, which the following consumer quotes illustrate:

I might talk to her about how I can get some of these services one on one, I don't know, is that on offer? Or is it just group stuff? Participant Thirteen

Well I thought what I would get out of it was more a program designed to me and my physical needs. Like the doctors and this and that, are there to help you from where you're physically at... And I thought and I don't know that I'm getting things correct or wrong, but I thought at the end of these five courses we would decide whether or not I should go on medication, or an operation to try to change my condition, what might or might not work for me. But I don't know that's going to happen now or not. Like, I would like to know that after the fifth education session does this continue? To me to be a bit more clearer, what comes next. Participant One

Personalised, integrated, evidence-based and respectful care When it is working at its best, the OMS tailors the advice and support it offers to individuals' specific situation and goals. This aspect of the service is highly valued by consumers. Indeed, when consumers feel uncertain or dissatisfied with the care they have received from the OMS, it is sometimes due their perception that the service has failed to consistently provide a personalised approach that responds to their particular situation, aims and preferred approach to obesity management. This consumer illustrates this experience when she reflects her disappointment that the detailed information collected in the initial appointment did not appear to her to flow into a personalised approach to the services offered by the OMS:

So there's all this detailed, detailed information taken but then it's like, they treat you the same, go to the group sessions and see a trainer. So I can't quite see... how that all connects. Participant Two

Consumers most value the information and support that the service provides when this is delivered in a flexible and non-prescriptive manner. As an example, the group education sessions that received the most positive feedback in interviews were those in which the presenters provided time for participants to ask questions about how to apply their advice in their own lives, and to discuss issues and share perspectives with other participants in the group. The group education sessions on which participants reflected negatively tended to be those in which it was felt that information was presented in a "one size fits all" or overly prescriptive manner.

it was very much, 'you should do this, you shouldn't do this, you should do this'. And if you're trying to lose weight that's not the approach you should take because you're going to make people feel worse about themselves. I have to say I felt worse about myself after that session. And the only thing, the reason I kept coming back, at the end of the day, I can take the tools that I like and reject the ones that I don't. Participant Seven

Consumers value the OMS because it brings together allied health and clinical specialists to provide a personalised and whole of person approach to obesity management. This sets the OMS apart from other diet and lifestyle approaches to obesity that people may have tried in the past. One consumer reflected on previous experiences that did not acknowledge or respond to the inter-related psychological, nutritional, diet and lifestyle issues that can affect obesity and obesity management as follows:

I don't think it really changed anything, because it didn't deal with the whole psychology of things. There's a lot of information, because they're not dieticians, nutritionists, etc etc, there's a lot of things they don't cover. Participant Four

The OMS is also seen as being based in the latest evidence and science about health, obesity and obesity management. Again, this is in contrast with participants' previous experiences of approaches to weight loss and weight management, in which it can be difficult to know what information is credible:

When you look things up online, everybody looks like they're accredited, so you do this for a while then you do this for a while, and [indistinct]... then they're wrong and you go the other way. Participant Four.

In general, OMS staff were seen as being respectful, empathetic, helpful and professional.

Everyone I have dealt with seriously cannot be faulted they are so kind and approachable and I'm just impressed that they've managed to get so many people in the same spot that are that amazing. Participant Four

Consumers value that the OMS provides 12 months of assistance and support. From the consumer perspective, this allows the service to provide a degree of ongoing support and assistance that is necessary to help participants sustain their achievements and motivation over time. A number of consumers reported that this ongoing support was a missing component in other approaches to weight and obesity management that they had tried previously:

I have tried diets and diet programs and stuff but sort of independently, but because I didn't really have anyone following up it sort of went by the wayside. Participant Eight

Many but not all participants in interviews felt that peer support activities would be a valuable way in which the OMS could provide assistance to them, including over the longer term.

#### 5.3. Potential service improvements identified in interviews

## 5.3.1 Consumer information

Communication issues were among the most commonly occurring negative experiences for consumers. In this area, issues identified by consumers in interviews included a lack of consumer clarity about the OMS's aims and processes, uncertainty about the 'next steps' in the program, difficulty contacting the OMS, difficulty managing information provided by the OMS, and uncertainty about the role of the case manager including when and why to contact the case manager. This consumer quote illustrates how important clear information about the 'next steps' in the service is:

It's hard for me to get back on track, because I don't know where the tracks are. Participant One

In interviews, consumers identified a variety of possible changes to the service that they felt would improve consumer experiences in this area. For example, it was suggested that additional written information (either a letter or online information) about the service would be of benefit. This could be provided during the waiting time between referral and the first appointment. It could include information about the length of the wait list and likely wait time; aims of the OMS and the specific kinds of assistance the service can offer to people; likely time commitments over the 12 months of the service; information about the role of the case manager; and information about what people can do in relation to their health while they are waiting to access the service, as well as case studies of possible pathways through the OMS.

Like something that says this is your first step, you will be assessed by us, then you will do five weeks... And say clearly that you have to contact your caseworker. Then at the end of that, you will have this appointment or that appointment... Even if they don't know what the appointments are, just saying there will be appointments organised and dates and times will be arranged... So you know how it will continue on. Participant One

Some consumers also identified that they would have appreciated additional additional verbal and/or written information during their time with the service about what their "next steps" with the service would be, and what they could reasonably expect to have happened by the end of their time with the service. Consumers suggested that this could take the form of handouts or online information, and might include case studies of possible consumer journeys through the OMS and possible outcomes of participation.

Give us a case study, give us a case study so we know you know, Joe Bloggs did the service, did the five weeks of education then went on to do this and this, then this and this, you know give us a couple of case studies of how people, what it would like. Participant Thirteen

In this area consumers also made clear that both the first individual assessment, and the first group education session, are important opportunities to help consumers understand, discuss and ask questions about the aims of the service, and administrative processes such as when and how to contact the service, the role of the case manager and possible pathways through the OMS.

#### 5.3.2 Contacting the service

Some consumers would highly value the ability to contact the service and/or their caseworker by email as well as by telephone. Others would appreciate it if the OMS telephone number was more often answered.

I find phones extremely frustrating, either I can't get them or they can't get me, so I would go back to the electronic thing, it would make me feel better, personally. So if I could email them and say could you ring me back when you have a moment, that sits better with me mentally than me calling them and getting frustrated and... Participant Nine

#### 5.3.3 Accessing and storing information from the OMS

Some participants would value additional ways to access information provided by the OMS. This might take the form of an OMS folder in which all handouts from the OMS (particularly from group education sessions) can be kept, or an OMS booklet with copies of all the handouts that will be given out in the group education sessions, provided at commencement with the service. Other consumers would appreciate access to electronic copies of documents provided by the OMS, including in the group education sessions.

If people cannot leave their job for three hours on a Friday, surely, or even in addition, if you're going to hand them out in the session, make them available somewhere where you can download them, and keep them. And they kept handing out these bits of paper, with nothing to put them in, initially, and I said, well do you think you could provide everyone with a 20 cent folder or something, or have them collated so we could keep them all together in some way. Participant Ten

#### 5.3.4 Pro-active check-in from the OMS

For some, proactive check-in by the case manager would be of benefit in terms both of explaining the next steps in the OMS consumer journey and supporting the participant to work toward their health goals. This might take the form of a phone call from the case manager at regular intervals. if you're busy at work, and you're not proactive, you're not... you will not get the benefits of the service particularly. Participant Three

5.3.5 Information about expected waiting times, and time commitment The consumer experience of the service is often one of waiting. This includes both wait times to enter the service and wait times to access individual appointments with the clinical and allied health staff. Some consumers suggested in interview that clear information about likely wait times would assist them to have realistic expectations of the service, and to have discussions with employers about when they are likely to need time away from work, or to make other arrangements in order to attend appointments.

## 5.3.6 Flexible service delivery

Flexibility to deliver the service in a second location on the south side of Canberra would be valued by some consumers. Additionally, greater flexibility in times to access individual appointments and group education sessions, including outside Monday to Friday, 9:00am to 5:00pm, working hours, would be valued by some consumers. Others would value access to the OMS gymnasium, outside of 9:00am to 5:00pm, Monday to Friday, working hours.

5.3.7 Access to specialist staff, in particular an OMS psychologist As well as feedback from some consumers that staff turnover and what were perceived as high staff workloads contributed to delays and wait times, consumers were of the view that access to an OMS psychologist (or psychologists) was very important to the success of the service and its integrated model. People saw the assistance of a psychologist as important to helping them sustain lifestyle and health-related changes after the 12 month service ends.

At the end of the day I really think the big thing for many people is going to be having a psychologist. And maybe even having more than one... it's more the triggers and being self-aware and putting in place better habits and so that's where the psychologist would be positive for me and that's where I would like to see one if possible. Participant Seven It's a hugely important component in that holistic approach, you've got to bring in the psychological side of it. Participant Eleven

## 5.3.8 Extending beyond 12 months

Consumers were strongly in favour of an extended OMS in which people could continue to access the service after 12 months. It was suggested that this could take the form of a regular OMS 'drop-in' service, group education 'refresher' sessions, regular individual appointments with the clinical or allied health staff at intervals for example 6 or 12 months, and additional ongoing peer support options.

And from my point of view I think it would be motivating to say, 'Yes but in a years time I'm going back to these people who saw me a year ago, and they going to weigh me and measure me, and do this, that, and the other.' And...And it's not that they're going to judge me exactly, but they going to notice. You know?.... Like a Check-in Day or a Check-in Weekend and we get a letter saying to go in on this weekend and check-in with everyone else and it's really basic. Participant Three

It would be nice, if it could be longer than a year. You have to be morbidly obese to get into the program, and there's no way, in a year, losing it the healthy way not the biggest loser way, can get that weight completely lost in a year. Or there might the odd person who can, like blokes. But it would be nice if you could have a check in afterwards, like 6 months. Participant Four

There was also clear feedback that consumers should be referred to appropriate supports or facilities in the community at the end of their time with the OMS. There was concern from consumers that few, if any, community facilities would meet their needs for long-term, affordable, appropriate and supportive exercise facilities, in particular for hydrotherapy facilities and welcoming gyms with appropriately trained staff.

#### 5.3.9 Peer support

Consumers had varied views on the value of peer support, and varied expectations of what peer support could or should deliver. Consumers also had varied understandings of what peer support was. Some described peer support as an important way of staying on track, and a valuable opportunity to share ideas, encouragement, information and experiences with a network of supportive people in a similar situation:

I think it's firstly being in touch with and aware of and being able to chat to other people who are in your situation. Um preferably at the same point in dealing with it all...Participant Three

Others felt that peer support was most valuable when it emerged spontaneously as a result of shared interests or activities. Still others felt that participation in peer support activities could be discouraging to them, for example, if they felt they were not achieving goals they had set for themselves and felt they would compare themselves negatively to their peers as a consequence.

Some felt that peer support was not a priority, or of interest to them. For these consumers the OMS is about individual work toward individual goals, best achieved with the active support of OMS professional staff.

For those with an interest in additional peer support, there was interest in both online and in-person peer support options. Consumers suggested a variety of ways to provide peer support in which they would be interested. Among these were:

- Fortnightly meetings, face to face;
- Refresher group education sessions;
- Social catch-ups;
- Walking or swimming groups;
- A closed OMS Facebook group; and
- An OMS email list.

The following consumer quotes illustrate the wide variety of possible peer support options suggested by consumers:

Even if it is something that is like meeting up twice a week or once a week for something very simple like a tai chi class or something like that. Participant Three

What I really struggle to find online is a community that is more locally based. There's a lot of forums for people who are losing weight but they're more at a national or international level. Something as simple as maybe a Facebook page, because they're pretty easy to set up, and you can restrict who can join and can't join in, those things can be really useful because you can share hints and tips and how people are going. Participant Seven

Consumers were mindful that not all modes of peer support would be accessible to, or suit, all consumers, as this consumer quote illustrates:

Maybe a Facebook but then we have to realise that not everyone is IT savvy so they might not be able to do it, I don't know, maybe quarterly meetings with tea and coffee, that's one way, it depends what the majority would want. Participant Nine

There were also a variety of views about how peer support should be managed or supported. While it was thought that there would be benefits to peer leadership, it was also generally felt that some level of ongoing OMS involvement and support would be appropriate. For example, OMS staff could moderate a Facebook group, or perhaps post links to information or be available to answer questions asked by members of the Facebook group. In terms of face-to-face options, which were preferred by some consumers, it was thought that OMS staff could play a role in supporting peer organisers of activities with information about facilitating a group and supporting group leaders in order to avoid burn-out.

It's been my experience that that kind of thing needs someone who is very committed, one or two, who has the capacity to hold things together, to stop

the garbage, to build relationships, to reinforce relationships, to keep the tone of the group, and not allow it, because people will get offended and it can be dragged off. And that's a skill. And if it's a voluntary person, they need to support that person. Participant Eleven

# 6. Co-Designing Service Improvements

The co-design phase of this project (Phase Three) built on the key findings from interviews conducted by HCCA with OMS consumers (Phase One), and the key findings from interviews conducted by the CDMU with OMS clinical staff (Phase Two). In the co-design phase of the project HCCA with support from the CDMU built on the interview findings by facilitating two workshops: one consumer workshop, and one co-design workshop that brought OMS staff and consumers together. In this process HCCA employed a modified co-design approach in order to respond flexibly to emerging issues for staff and consumers. Workshop agendas are provided at Appendix F.

# 6.1 A modified co-design approach

To prepare for the co-design phase of this project, HCCA used the information collected from interviews with consumers in Phase One to identify key themes and issues in consumer experiences of the service. HCCA also discussed with the CDMU the key themes emerging in initial analysis of the semi-structured interviews conducted with consumers and clinicians. Based on this information, HCCA with support from the CDMU was able to plan a co-design process that began from a strong foundation of understanding of consumer and clinician experiences and the views of both groups with regard to the current and potential future delivery of peer support within the OMS. This information provided the themes and issues presented and discussed at two modified co-design workshops.

It was initially anticipated that the co-design process would involve two (2.5 hour) co-design workshops bringing together consumers and staff together in a guided discussion format to identify the priority service changes that would improve consumer experiences of the OMS, and to work together to identify appropriate

ways to implement these priority service improvements. HCCA envisaged that the first workshop would provide an opportunity to report back to staff and consumers participants on the key themes and issues emerging in analysis of the semi-structured interview data, and to invite consumer and staff attendees to prioritise the possible service improvements identified by participants in the interview processes. The second workshop was envisaged as an opportunity for the same group of staff and consumers to work together to identify practical and appropriate ways that these priority service improvements could be implemented over the short, medium and long term.

This process was modified in order to respond flexibly to the situation of OMS staff, and to ensure good practice consumer engagement in the co-design process. Specifically, as OMS staff were unable to attend the full 2.5 hours of the first codesign workshop HCCA negotiated with the CDMU to run the first workshop (26 May 2016, 1:30-4:00pm) as a consumer workshop rather than a co-design workshop. Demands on OMS staff time would have meant that staff could only have attended the second half of the workshop, in which it was planned that consumers and staff would work together to identify priority service improvements. Without having heard feedback on the findings from the interview processes with consumers and staff, OMS clinical staff would have been asked to work with consumers to identify priority service changes without having heard the necessary information to contextualise this discussion. Good practice co-design processes involve all parties having access to the same information, and time to establish rapport and trust within the group. Inviting OMS staff to work with consumers to identify service improvements without having had access to the necessary contextual information about consumer experience would have risked creating a defensive stance among the staff team, as well as an unproductive differentiation in the base of knowledge and understanding from which staff and consumers proceeded in the co-design process. Therefore HCCA and the CDMU agreed that the first workshop would run as a consumer workshop rather than a co-design workshop.

In order to provide OMS staff with the necessary information about consumer experiences to allow them to take part in the co-design process, HCCA with assistance from the CDMU, convened a presentation for OMS staff on the key findings from the consumer interview process. This was provided on 2 June, 12:00 to 1:00pm at the Belconnen Community Health Centre. HCCA also circulated a summary document that reported on the key initial findings from the consumer interviews to OMS staff and to consumer participants who had registered their interest in attending the second co-design workshop. This information was provided in order to ensure that participants at the co-design workshop would have already have had access to the necessary contextual information about consumer and staff experiences of the OMS and their views about the current and future delivery of peer support within the service.

The co-design workshop was held on 9 June (1.00-4.30pm) with participation from both consumers and OMS clinical and allied health staff. This was an opportunity for staff and consumers to work together to identify priority service improvements that would support improved consumer experiences of the service, and to discuss practical ways of implementing these changes over the short and medium term.

This modified co-design process responded flexibly to the situation of OMS staff and consumers, ensured that OMS staff and consumers were provided with the necessary information to participate in co-design, and supported consumers and staff to take part in an inclusive process that encouraged mutual respect and cooperation.

The limited availability of OMS staff to attend the first workshop was a challenge to the co-design process. While the process generated valuable information about staff and consumer views on priority service improvements, the inability of staff to attend the full first workshop limited the opportunity for co-design. This also meant that the group attending the second workshop was not the same as those present at the first workshop, whereas it had been envisaged that the second workshop would be an opportunity for the same group of staff and consumers to continue a detailed conversation building on work they had begun at the first workshop.

Therefore HCCA suggests that future co-design process proceed from a clear understanding of the likely demands on staff time and their realistic ability to participate in a co-design process. Alternative processes, such as holding a series of shorter workshops (e.g. three one hour workshops) rather than two longer workshops (2.5 hours), could be explored with staff in the project planning phase. Alternative or additional methodologies to face-to-face workshops could also be explored as ways to invite staff participation in ways that best suit their situation. Online surveys or other online approaches to co-design that provide more flexibility in terms of when participants take part are examples of potential areas for future exploration. Such methods may also provide additional opportunities for consumers to participate in co-design.

### 6.2 Consumer workshop

#### 6.2.1 Aims

HCCA worked with the support of the CDMU to deliver a (2.5 hour) consumer workshop on 26 May. The workshop was held in Group Meeting Rooms 3 and 4, Belconnen Community Health Centre, from 1:00 to 4:30pm.

The aims of the workshop were to:

- Share the initial findings from a detailed qualitative interview process undertaken by ACT Health (with OMS staff) and HCCA (with health consumers) in order to better understand consumer and staff experiences of the service; and
- 2. To prioritise opportunities for service improvements, from a consumer perspective.

#### 6.2.2 Participants

Six consumers registered to attend the event. Four consumers unfortunately were unable to attend on the day due to caring responsibilities or ill-health. Rebecca Phillips, Senior Project Officer, CDMU, also attended the event.

While there were only two consumer participants, the workshop generated valuable discussion of issues for consumer in the context of the OMS, and provided an

opportunity to report back and to validate and confirm the importance to consumers of the key themes identified in the qualitative research process.

### 6.2.3 Process

At the workshop consumer participants heard feedback from HCCA and the ACT Chronic Disease Management Unit about the key findings from qualitative interviews with consumers and staff, and were supported to take part in a prioritisation exercise. In this exercise, all the possible improvements to consumer experience of the OMS that consumers had identified in semi-structured interviews were typed on pre-prepared cards, grouped into the following thematic areas:

- Communication
- Access
- Staffing
- Support for the longer term
- Peer support

In a guided discussion format, facilitated by HCCA staff, consumers were asked to sort the cards in each theme into categories of Very Important, Important, Not Important and Not at All Important, in terms of the impact consumers felt these changes would have on improving consumer experiences of the OMS.

The reasons why consumers had prioritised the different suggestions were discussed. Some general feedback from participants was that there were very few, if any, suggestions that were not important. All, or most, of the suggested service improvements would assist in improving consumer experiences of the OMS.

Consumers were then asked to identify up to three most important suggestions in each category.

While views about the relative importance of the various suggested changes varied, there was a degree of consensus around the most important changes identified in each category. It should be noted that the small number of consumer participants (two) means that the prioritisation exercise is not reflective of the views of the cohort of OMS consumers. Nonetheless the exercise provided an opportunity for valuable discussion of the issues for and by consumers, and confirmed the importance to consumers of issues raised in the interviews. The

prioritisation exercise also suggested areas for further discussion at the second workshop, which involved both staff and consumers in jointly prioritising areas for service improvement and discussing ways to achieve these changes.

The list below reproduces the most important changes that the two consumer participants identified in each area. While participants were invited to identify the three most important changes in each area, in some instances consumers weighted one or two of the suggested changes as particularly important and hence identified one or two changes, rather than three. The list below identifies where both participants ranked the same potential service improvement as among their (up to) top three suggested improvements in each area. The list also identifies all the other service changes identified by both participants as among the (up to) top three service improvements in each area. Given the small number of workshop participants, it was not the aim of the discussion to reach consensus around a list of up to three key changes in each area. However, this list does give an indication of key consumer issues and suggestions for improvement. Note that some possible service improvements appear in more than one thematic area, reflecting that some service improvements will impact on consumer experiences in more than area.

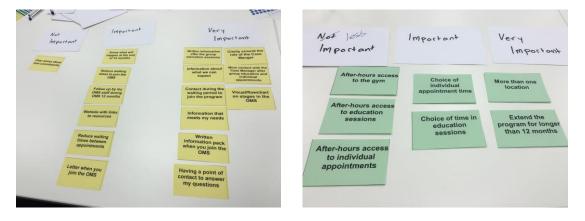


Figure 4 Card Sort Prioritisation Exercise Examples

### 6.2.4 Key issues and themes

Communication

In this area, both participants identified *Written information, to be provided after* the group education sessions as among the top three changes that in their views would improve consumer experiences of the OMS. For one participant, this was the single most important change that would improve her experience of the service. This participant was about to complete her group education sessions was unsure what the "next steps" in the service would be, thus this was a particularly relevant and important area for improvement for her. Participants acknowledged that the changes that are most important to OMS consumers will reflect the particular stage that they are at in terms of their experience of the service. Nonetheless, the high ranking given to this potential service change by both participants suggests that the time between finishing group education sessions and accessing other forms of OMS support is a key opportunity for the service to prove written consumer information. Based on findings from interviews as well as discussion at the consumer workshop, this might include information about the "next steps" and likely consumer pathways through the OMS, as well as likely waiting times to access additional forms of support provided by the OMS.

The other areas selected by the two consumers as very important service improvements confirm the importance to consumers of clear and timely consumer information about the service, provided both in written form (in this case online), and by OMS staff and in particular by a case manager or other consistent point of contact for questions or concerns. The importance to some consumers of more pro-active follow-up by the OMS of consumers is also reflected in this list. Please note that this list is *not* ranked in order of importance, rather it provides an indication of the key areas for service change as identified by two consumer participants at the workshop.

- Website with links to resources
- Follow up by OMS staff during my 12 months
- Having a point of contact to answer my questions
- Clarity around the role of the case manager

#### Access

In this area, participants considered potential service improvements that related to access to the service. The single very important service change identified by both

consumer participants was to *Extend the program for longer than 12 months*. This is reflective of findings from consumer interviews as well as guided discussion at the workshop, which raised the importance of ongoing follow-up and engagement to ensure that OMS consumers have the support they require in order to maintain health goals and health changes achieved during their time with the service. In interviews, consumers identified a variety of ways that OMS support could be provided after 12 months, among them an extension of time to take part in the service, a regular drop-in with OMS clinicians, or 'refresher' group education sessions. Participants at the consumer workshop observed that waiting times to access individual appointments with clinical and allied health staff in effect lessen the time they have to actively participate with the service during the 12 month timeframe.

Other potential service improvements identified by the participants as very important included:

- After hours access to the gym
- Choice of time in education sessions
- Choice of individual appointment time

These potential improvements reflect the importance to consumers of flexibility in the delivery of the OMS.

#### Staffing

In this area, both consumer participants identified *Having the staff to run the services* and *Staffing levels so appointments are not cancelled* as among the top three changes that would make a positive difference to consumer experiences of the OMS. This reflects a finding from the consumer interviews, namely that consumers perceive that staff turnover, delayed recruitment processes and an overall limited staffing profile relative to consumer demand, contributes to delays, wait-times, cancellation of appointments and rationing of the service as a way of managing consumer demand.

Other possible service improvements identified by the two participants included:

- OMS psychologist
- Point of contact to answer my questions

These suggestions reflect the importance to many OMS participants of access to an OMS psychologist as a key professional involved in the delivery of whole of person obesity management services. They also reiterate the importance to many consumers of access to information about the service and in particular ready access to a consistent point of contact who can answer questions.

### Support for the longer term

In this area, consumers were asked to prioritise the various suggestions made by consumer interview participants, about practical ways that the OMS could provide support over the longer term. These findings should be considered in light of the unequivocal feedback from participants during the discussion of **Access** (discussed above) that the OMS should be extended beyond the 12 month timeframe that currently applies to participation.

Both participants selected **Be able to email** as among the potential service changes that would improve consumer experiences of the OMS. As identified in the consumer interviews as well as the workshop, this reflects the strong preference of some consumers for electronic forms of communication with the service and particularly for access to email contact with the service. In the context of changes that would improve the support that the OMS offers for the longer term, this reflects a consumer view that ongoing email contact with the service – for example to ask questions or "check in" about about their progress – would be a valuable addition to the current service model.

Participants also identified the following as valuable ways to provide ongoing OMS support, including after consumers exit the service:

- Individual appointments
- Attend drop-in sessions
- Group education refreshers

These option reflect the value that consumers place on individual appointments with the OMS clinical and allied health staff, as well as the information provided in group education sessions. In discussion, participating consumers reported that having the ability to arrange individual appointments with particular OMS clinical or allied health staff after exit from the service would be of benefit in terms of achieving and sustaining health goals achieved through participation in the service. The importance allocated to individual appointments in this context may also reflect that one participant had yet to access any individual appointments with OMS clinical or allied health staff. Participants identified that a "drop-in" model, in which previous OMS participants could visit the service on a designed day and time to speak with OMS clinical and allied health staff and have their progress monitored would be a valuable form of ongoing support. Participants also felt that group education refreshers would be an opportunity for previous OMS participants to remain engaged with the service and to benefit from the latest knowledge about areas relating to obesity management.

### Peer support

In this area, both participants identified *an Email list* and a *Closed Facebook group* as among the top three areas for improvement in this area. For one participant, the email list was the single most important possible change and this reflected her strong preference for greater opportunities for email use generally within the OMS. Both participants felt that email contact with other OMS participants would allow those with an interest in ongoing contact and peer support to arrange this. While participants acknowledged that a closed Facebook group would not suit or be accessible to all OMS participants, it was considered a relatively simple way of supporting peer support with the program. Participants acknowledged that email and Facebook peer support options would create considerations for the OMS in terms of how active a role the OMS should play in creating, supporting or participating in these peer support forums.

Participants also identified **Refresher group education sessions** and **Swimming or walking groups** as very important potential improvements to the service. This reflects the importance to some consumers of in-person as well as or in preference to online peer support options. It also reflects consumer interest in ongoing access to the information that the OMS can provide (refresher group education sessions), and to peer activities that have both a social and an active lifestyle component (walking and swimming groups).

### Other issues

In guided discussion, the workshop participants also raised a number of other relevant suggestions and valuable reflections on their experiences. Among these:

- SMS appointment reminders would be of benefit to consumers.
- OMS services that are very important to some consumers (such as a psychologist or exercise physiologist) may be less important to others if they already access the same or similar services elsewhere (for example via referral from their GP).
- It is important that the OMS communicates and connects seamlessly with other health care providers. In particular GPs or specialists may need to have a clear view of a consumer's progress within the OMS and have a process to prioritise consumers' access to the OMS.
- There is a risk that consumers may injure themselves while under the guidance of the OMS, and this presents safety and quality issues that the service must actively manage.
- Online delivery of group education session content may be an option, for example adopting some of the methods used for online delivery by universities to engage groups in learning and discussion.
- Case studies of previous participants' progress through the OMS would be valuable in terms of setting expectations and supporting consumer understanding of the service model.
- A calendar of expected OMS activities by month could be a useful way of seeing what participation in the service entails.
- Participants agreed that an introductory session for people on the OMS wait list is an excellent way to introduce people to the service, its requirements and opportunities.

- The particular difficulties of accessing appropriate hydrotherapy services in the community were discussed.
- Attention was drawn to the Housing ACT Quality of Life grants as one avenue that may be of interest to ACT Housing tenants who participate in the OMS.

In addition to providing valuable information about consumer experiences and suggestions for service improvement, the issues and themes discussed at the consumer workshop also shaped the delivery of the co-design workshop on 9 June.

### 6.3 OMS staff presentation

In order to ensure that all participants planning to attend the co-design workshop on 9 June received the same information as consumers who had attended the first workshop, HCCA prepared a document summarising the key findings from consumer and staff interviews, and circulated this to OMS staff and to consumers who had registered to attend the second workshop. HCCA with support from the ACT Chronic Disease Management Unit also presented to OMS staff on the key findings from consumer interviews. This took place on 2 June 2016 at the Belconnen Community Health Centre (12:00 to 1:00pm), and was followed by a discussion by staff of some of the key issues raised in the consumer interviews.

### 6.4 Co-Design Workshop

### 6.4.1 Aims and process

This workshop was held on 9 June, 1:30 to 4:00pm at the Belconnen Community Health Centre, Group Meeting Rooms 3 and 4. The workshop brought together nine staff and four consumers to jointly identify priorities for service improvement, and to discuss practical ways of implementing these improvements over the short and medium term. Participants were advised that the aim of the day was to prioritise and discuss implementation of service improvements, in the context of clear feedback from consumers that the OMS is a highly valued service. Participants were invited to provide targeted feedback about three areas identified by consumers as priority areas for service improvement: peer support, the group education sessions, and consumer information about the OMS.

## 6.4.2 Peer Support

Participants began by undertaking the same prioritisation exercise that was used in the first (consumer) workshop. The aim of this exercise was to invite the group to work toward consensus around the changes to this area that would most significantly improve consumer experiences of the OMS. The three areas identified by the group as most important potential service improvements in this area were:

- Walking and swimming groups
- Refresher group education sessions
- Online peer support

There was some divergence in how staff and consumers prioritised the walking and swimming groups. While this was prioritised collectively by the group as important, all but one staff member included walking and swimming groups in their (up to) three most important changes, while the consumer perspective on the key service changes in this area was initially more diverse.

After identifying these three areas, in guided discussion the group then considered how these priority improvements to peer support could be implemented over the short to medium term.

## 6.4.3 Walking and swimming groups

Workshop participants articulated that the value of walking and swimming groups for OMS participants could include:

- A supportive environment of people sensitive to the particular issues, benefits and challenges of exercising as part of obesity management;
- A peer support option focused around a shared activity that supports wellbeing and health as well as social interaction;
- Inclusion of socially isolated people or those who would be less likely to exercise on their own;

- Ongoing motivation to be physically active and/or improve fitness;
- An OMS-supported group, or group of current or prior OMS participants, may provide an environment that would be less intimidating for people who may feel self-conscious or not fit enough to take part in other organised exercise groups in the community.

There were a variety of suggestions about how these groups could be established and managed. This discussion acknowledged that the three key peer support options identified as priorities by the group could be inter-related and mutually supporting. For example, it was suggested that members of the group education sessions could swap email contacts and then organise to form a walking or swimming group, or that people who choose to be active in an OMS online peer support forum might be able to advertise their interest in joining or forming a walking, swimming or other exercise group. People active in an online peer support forum might also be able to share information with one another about various activities available to people in the community, for example information about the location, cost and times of activities such as water aerobics, swimming, walking and running groups.

It was considered that one key role for the OMS would be for an OMS exercise physiologist or doctor to approve participation in a walking or swimming group. The group also identified that it may also be appropriate or necessary for the OMS to play a role in providing information to members of the groups and potentially facilitating groups, or providing training and support to peer facilitators of these groups.

Participants would require information, advice and potentially support to access appropriate clothing to undertake these activities (for example appropriate footwear, and advice about appropriate exercise wear), and advice about appropriate stretching exercises.

There was also an acknowledgement from the group that the role played by the OMS in support of walking or swimming groups may be limited by insurance, liability and risk considerations.

### 6.4.3 Online peer support

There was consensus among participants that offering some form of online peer support forum would improve the consumer experience of the OMS. There were a variety of views about what form this could or should take, for example a closed Facebook group (or groups), or participant email lists. There were also diverse views about the role that the OMS should play in terms of actively managing, facilitating or participating in this form of online peer support. Suggestions ranged from inviting group education session participants to share email addresses, inviting OMS participants to establish Facebook pages, establishing an OMS-moderated closed Facebook page for all current and past OMS participants, or establishing a peermoderated closed Facebook page in which OMS staff participate for example by answering consumer questions, posting links to information or participating in regular online Q and A sessions. The group reached consensus that online peer support of some kind would support valuable exchange of information among participants, and potentially between the OMS and participants. Participants acknowledged that active moderation of social media by the OMS could place a heavy workload on staff members, and that there may be issues of risk and liability in terms of providing advice or information that the OMS may need to consider.

It was also suggested that an online information portal providing a variety of information resources relevant to participants would be of benefit, and would support the provision of refresher group educations discussed below, including sharing information with people unable to attend these sessions.

### 6.4.5 Refresher group education sessions

There was consensus among participants that refresher group education sessions could provide a valuable forum for OMS participants and former participants to stay engaged with the OMS after exiting the service. Refresher sessions could be offered at regular intervals and provide an opportunity for participants to hear the latest or updated information on a particular topic; to return to discuss experiences, achievements, challenges or questions related to particular topics discussed at the original group education sessions; to access more detailed or additional information on a topic; and/or undertake practical exercises such as cooking particular dishes or

undertaking particular activities under the guidance of an OMS exercise physiologist. It was suggested that these sessions should be organised and facilitated by OMS clinical and allied health professionals, with a focus on allowing participants to share experiences and ask questions as well as accessing additional information. Some participants felt it would be valuable for these sessions to be advertised well in advance, perhaps in the form of a yearly OMS events calendar accessible to former participants, so that people could plan to attend those sessions of most interest or relevance to them. There was some consideration of whether a model of Shared Medical Appointments might also be appropriate to provide information and support to consumers.

### 6.4.6 Group education sessions

Discussion in this area identified that the content delivered in the group education sessions is appropriate and valuable, although participants acknowledged the difficulty of providing information appropriate to the needs of groups where participants may have diverse levels of exiting knowledge and understanding of health issues. In guided discussion the group identified a number of changes that could be made to support positive consumer experiences of the group education sessions. Among these there was support for:

- Introduction of an SMS reminder system to advise participants when group education sessions are cancelled;
- Provision of fact sheets and information or resources to take away, including copies of hand-outs that should be made available both in hard copy and electronically;
- Consistent attention to the importance of introductions to other group members and group discussion of issues as part of the first group education session, which is a key opportunity to build rapport within the group;
- Altering the consumer journey through the OMS so that participants attend five group education sessions prior to attending their first appointment with a case manager, so that they are better equipped with information to set personal goals and to ask questions of their case manager;

- Considering possibilities to run group education sessions outside of Monday to Friday, 9:00am to 5:00pm hours and at locations other than the Belconnen Community Health Centre. It was considered that the Canberra Hospital could be an appropriate facility to run group education sessions on the Southside and to trial the provision of information sessions outside of usual OMS working hours.
- Consumer participants would also welcome the possibility of attending group education session and/ appointments outside Monday to Friday, 9:00am to 5:00pm hours at the Belconnen Community Health Centre, however staff advised their understanding that this was not possible at this facility.

### 6.4.7 Consumer information

There was consensus among participants that improved consumer information, provided in a written and/or visual format and easily accessible to participants, would improve consumer experiences of the service. Participants suggested that people be provided with an information pack or service brochure and/or online information prior to commencing with the OMS. This information could include links to appropriate online resources with information about obesity management issues and relevant services available to people in the community. It might also include information about what consumers will be expected to do during their time with the OMS, the principles of self-management that inform the service, and information about the assistance that the service provides. It was suggested that this information pack should also include an indicative calendar, timeframe or map of the consumer journey through the service and the different forms of support it can offer. It was also felt that consumers would appreciate this information acknowledging that the OMS is a popular service and that their experience is likely to be characterised by wait times, an estimate of indicative waiting times, and information about what consumers may like to do in the meantime before entering the service in terms of diet and lifestyle changes they could consider. This information pack might also include FAQ and templates of OMS resources such as a food diary, as well as other resources that will be provided to participants in the group education sessions.

It was also suggested that there would be value in providing an updated information leaflet or information session for GPs who refer patients to the service, to assist them to provide up to date and consumer-centred information about the service.

## 7. Recommendations

### 7.1 Priority service improvements

• Develop a clearly articulated OMS program approach.

Many of the challenges that consumers describe in navigating the OMS relate to their perception of having committed to a year-long health intervention, yet lacking information on which to base realistic expectations of their likely consumer journey through the service or the possible outcomes of participating in the service. Where consumer experiences of the service are less positive, this is sometimes because consumers feel the service has failed to consistently deliver or fully embed a personalised, integrated and whole-of-person model of support.

A program approach would outline the principles of self-management and integrated and personalised care that inform the OMS, as well as the various possible consumer pathways and possible outcomes of participation. Articulating a program approach, and conveying this in written consumer information as well in group education sessions and individual appointments, would assist consumers to understand the service, the possibilities it offers, and what it cannot deliver. This would strengthen the delivery of an integrated and person-centred approach.

• Develop and provide additional consumer information for people waiting to enter the service and using the service.

Participants in interviews and the co-design process drew attention to the importance of written consumer information about the service. This could be provided online, as a service brochure or as an information kit that should include consumer-centred information about the OMS model and its aims, likely wait times, indicative OMS consumer pathways, possible outcomes for consumers, consumer FAQs about the service, and links to further information and resources about nutrition, exercise and other aspects of obesity management that would be of benefit to consumers while they wait to enter the service. In line with principles of consumer partnership, HCCA suggests that the OMS establish a consumer reference group to advise on the development of this consumer information.

• Establish a peer-led online peer support forum

There is interest from consumers in additional online peer support. This could take the form of inviting members of group education sessions to share email contacts with one another as a standing item during the group education sessions; or establishing a closed Facebook group to allow information sharing by participants. Feedback from the co-design process suggested the OMS explore possibilities for OMS staff to participate in these online forms at regular intervals, for instance by taking part in a Q and A session with consumers.

• Introduce exercise groups (walking and swimming) as a form of peer support

Interviews drew attention the importance that many consumers place on the provision of additional peer support options. In the co-design process it was identified that walking and swimming groups were among the preferred peer support options, with the OMS to provide assistance potentially in the form of practical information about exercising safely, and assistance to establish the groups for example providing initial training to peer organisers of these groups.

• Introduce electronic communication and resources

Interviews and the co-design process found that some consumers have a strong preference for electronic communication with the service, and would welcome the introduction of an OMS email address through which they could contact the service or their case manager. Similarly, some consumers would welcome the option for information and resources from the OMS to be delivered by email (or to be accessible online). This would include information and resources provided in the group education sessions. Consumers would also welcome the introduction of an OMS SMS reminder system, to be used to notify consumers of upcoming appointments, group education sessions and cancellations.

• Extend the program beyond 12 months

Consumer interviews and the co-design process drew attention to the consumer benefits of providing ongoing support after 12 months with the service concludes. This might take the form of 'drop in' access to the service, regular check-ups or monitoring by the OMS clinical staff, an extension of time to participate in the service, and/ or group education refreshers that previous participants can attend.

• Develop and provide refresher group education sessions

The co-design process identified refresher group education sessions as one specific and valuable way that past participants could maintain engagement with, and continue to access support from, the OMS over time.

 Deliver core service components (group education sessions and/or appointments) outside of Monday to Friday 9:00am to 5:00pm hours and in locations other than the Belconnen Community Health Centre.

Consumers experience barriers to access resulting from the delivery of the service in one location, and the limited flexibility in delivery of core service components (group education sessions and individual appointments). Through the co-design process it was identified that the consumer experience of the service would be improved if the service, or aspects of it, were delivered with greater flexibility. In particular, the co-design process identified the value of providing group education sessions on the south side of Canberra and outside of Monday to Friday 9:00am to 5:00pm hours.

• Consider how best to integrate the OMS with support provided to consumers by their General Practitioners (GPs) and other treating health professionals.

A longer-term challenge identified by this research is to ensure that the support offered by the OMS is integrated with the support provided to individual consumers by their GPs and other treating health professionals. For example, policies and procedures relating to information sharing with GPs and other treating professionals, and the involvement of GPs in escalating referrals to the OMS, could be introduced.

• Update information provided to GPs about the service

Providing an updated OMS information leaflet or information session for GPs who refer patients to the service, would assist to ensure that up-to-date and appropriate

information about the service is provided to consumers by GPs. HCCA recommends that consumers be involved in the design and delivery of information for GPs.

### 7.2 Future research and co-design processes

• Continue to implement co-design approaches to identify service improvements.

Based on learning from this process, HCCA suggests that future co-design processes carefully consider and work with ACT Health staff to identify processes most suited to supporting staff engagement. This may include considering online engagement methods or a series of shorter face-to-face co-design workshops that better account for demands on staff time.

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# 9. Appendices

Appendix A: Phase Two Approach and Findings: *Clinician Perceptions and Need* 

**Appendix B: Project Summary Report** 

**Appendix C: Project Information for Participants** 

**Appendix D: Consumer Interview Transcripts** 

**Appendix E: Consumer Experience Wheels** 

**Appendix F: Co-Design Workshop Documents**