

# WA HEALTHY WEIGHT ACTION PLAN 2019-2024



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HEALTH CONSUMERS'  
COUNCIL

## CONSUMER INSIGHTS

WHAT WE LEARNED:  
ENGAGING WITH CONSUMERS  
ABOUT OVERWEIGHT AND  
OBESITY



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## Background

Since 2018, Health Consumers' Council has been consulting and partnering with consumers through the development and implementation of the Healthy Weight Action Plan. Roll-out of the plan is being co-ordinated and stewarded by Health Consumers' Council, Dept of Health and WA Primary Health Alliance (WAPHA). Health Consumers' Council's work on this project has been funded by the WA Department of Health and partially by WAPHA.

A partnership approach to governance from the outset allowed Health Consumers' Council to advocate for consumers as project was scoped, planned and now implemented

Throughout the plan we have been funded to provide ongoing engagement with consumers, which has included a number of methods including community conversations and events, social media, direct emails, a consumer and community advisory group, and production of consumer video stories.

Partnering with consumers when planning, developing, delivering and evaluating health services is necessary to ensure the best possible outcomes for all involved. As has been well documented, the benefits of increased participation from consumers, carers, community and family members enables a greater sense of ownership over services, health options, and decision making.

"But the loudest voices we hear in any discussion about obesity are those of experts such health researchers, public health policy makers, medical and allied health specialists," states a report by Weight Issues Network titled [The Personal Costs of Weight Issues in Australia 2020](#).

"While these are valuable and necessary, they often come with a narrow view related to their field of expertise on how to address obesity. On the other side, we have the incessant advertising and promotions by the commercial weight loss industry, promising miraculous weight loss results...for a price. But in all this, the voices of people who live with the challenges of excess weight are missing.

"Today nearly 70% of Australians have overweight or obesity; and yet most of us will opt to remain silent on the topic and how it affects us, because of shame and embarrassment."

In the specific case of the Healthy Weight Action Plan, the value of consumer engagement was evident as lived experience was at the centre of the policy development process. The ongoing consumer focus harnessed lived experience and enabled people to be active agents for change; gave legitimacy to the Action Plan in the long run; and highlighted the complexity of the topic and each individual's experiences, underlining the need for a person-centred approach.

Importantly, consumer engagement made it possible to challenge assumptions in this space, ultimately increasing accountability. With such a strong focus on consumer input, this project has built capacity of the partner policy teams in seeking consumer input; and we expect this to have a flow on effect across other areas of health working in similar ways.

Overweight, obesity and health is of great interest to people, as evidenced by the responses to our engagement activities. However, people's responses, experiences and needs on this topic are very diverse, and are often particular to them. The key takeaway from this project for us, has been not to make assumptions about needs or preferences.

This is what we have learned through our experience of engaging consumers and community members in the area of overweight and obesity.

## Lessons learned – engaging with consumers about overweight and obesity

Experiences of overweight and obesity are diverse, but there are commonalities

There is no one ‘lived experience’ of overweight and obesity, which means there should not be a ‘one size fits all’ approach to engaging with lived experience consumers. The reasons for someone’s weight can be complex and individual, with links to a wide range of physiological, social and cultural factors creating a vast array of experiences. However, there are common themes of stigma and discrimination, multiple unsuccessful weight loss attempts over long periods of time, and feelings of being judged, unsupported or misunderstood by people from all facets of life, including health professionals. Support for people seeking help with their weight and health needs to reflect this wide range of experiences, and be tailored for the individual.

*“The same old pattern as long as I can remember. I gain weight. Diet and exercise to lose it. Lose motivation and energy to care. Gain weight again. Repeat, repeat, repeat.”*

*“Because of the medication I was taking for my mental health issues, I gained a significant amount of weight within 5 years...”*

*“After seeing the specialist and having many different tests it was found that I have PCOS. Once I was on a treatment plan that helped me manage that (a combo of medication, health eating and exercise) I began to see results.”*

### Weight stigma is harmful to health

We believe that access to high quality safe and person-centred care is a right for everyone. We also believe that weight stigma is an important public health issue in that it acts as a barrier to people accessing that care and can contribute to poor health outcomes independent of weight.

According to the World Health Organization [‘Weight Bias and Obesity Stigma: considerations for the WHO European Region’](#), weight bias and obesity are associated with poor body image, low self-esteem and confidence, mental health impacts including depression and anxiety, poor eating patterns and avoidance of physical activity, and avoidance of medical care. Significantly, WHO states there is increasing evidence that shows when weight-biased attitudes are internalised they can cause as poor self-reported health and health-related quality of life, binge-eating and maladaptive health behaviours. It is important that those who need support around weight and health receive empathetic care that doesn’t worsen any stigma they may already face.

Weight stigma and bias is often based on the incorrect assumptions that overweight and obesity can be prevented through self-control, is caused by controllable factors, or is a condition of personal choice rather than a serious health condition. More on this is available at [Understanding Obesity Stigma: An educational resource provided by the Obesity Action Coalition](#).

We recommend learning about weight stigma and bias before engaging with consumers. Some consumer responses may need to be explored through the lens of internalised stigma.

*“My experience with the health system, I believe that the health system sees all overweight people as people who over eat and don’t exercise, they do not see you as an individual and look at your case in depth and take on board all your conditions/issues.”*

*“Shame is a huge issue it is the root of so much pain and inequity within health. Being judged from another’s position of privilege is a fact for many patients in health.”*

#### Stigma may act as a barrier to engagement

In the same way that stigma, shame and other psychological factors can act as barriers to people seeking or getting support from health services, they can also impact the ways consumers are willing to be involved in engagement around the topic of overweight and obesity. Some people may be hesitant to come forward to participate in engagement activities due to concerns about weight stigma or because of experiences of judgement in the past. We have found that some people in this group have become so used to weight stigma that they are very reluctant to share their experiences. This reluctance may often be further exacerbated by the fact that there are low expectations that anything will change for the better as a result of coming forward.

For these reasons, it is important to offer a range of ways for people to be involved, and make the engagement meaningful. There is more on both of these suggestions below. Likewise, the same hesitancy may be present when seeking support from health services, and should be considered if the engagement activities are for service design. For example, will the service offer telehealth (with the choice of using or not using a camera) as well as in-person appointments?

*“Very hard to want to feel involved when there is such stigma about being overweight.”*

*“I would be interested in staying in touch if I could do so anonymously”*

#### Engagement may be welcomed

While some may be hesitant to come forward, others will be eager to engage and share their experiences. Some people may be comfortable being identified in public facing materials, while others may prefer to only have their name attached when the resources are used internally in the health system. See for example, these [consumer videos](#) on our website and [these images](#) taken in a Heathy Weight Action Plan photoshoot available on the Weight Issues Network website. As always, give consumers options and allow them to choose engagement in a way that works for them.

*“I would like to help others or help others on their journey as I have lived experience. I want to have a say in improving the system regarding health, mental health and drug and alcohol issues.”*

#### Offer a range of ways for people to be involved

Because of the complexity of this issue and the considerations a consumer may face when deciding to engage, as discussed above, consumers will have different preferences about how they would like to be involved. To hear a broad range of experiences, it is necessary to offer a range of ways for consumers to engage. This might include general invitation events, targeted invitation and safe space events (for example, for women only, for people in larger bodies, or for people multicultural groups), in-person events, online events, informal online or in-person conversations, phone interviews, and surveys.

We have learned that some topics by nature won’t attract as many people, and that there may be a lot of no-shows when reaching out to people with health conditions, family or work commitments. Try to make it easy for the people you want to hear from to attend. We have found you can still get great insights from a small number of people, especially as some may feel more comfortable to open up and have deeper conversations in such a setting. However, when your insights are based on only a small amount of consumer voices you will need to check them against other information or sources to ensure a representative approach.

As part of our consumer engagement activities with the HWAP, we held an initial online survey in 2018 with 750 responses, generated a mailing list to keep approximately 270 members informed, held consumer focus groups (both open invitation and through established community groups), invited people to share their stories in a format that suited them, held an online group brainstorming session using GroupMap, formed a Consumer and Community Advisory Group, connected through a private, moderated Facebook group with about 110 members, and invited consumers to participate in forums with clinicians, researchers and policy makers.

*“Would like to remain anonymous and not via social media like Facebook, Twitter, Instagram.”*

*“I think surveys are a really good idea - even if it's a one question "share your thoughts" type survey as it can be done anon.”*

*“Having the ability to change my name (ie first name only) and choose if I want to have my video on or off in Zoom. I think being able to see just a face, and not have the judgement of the body that goes with it, would make me feel more confident.”*

### Relationships are key

Establishing relationships with consumers is beneficial for both partners. We found that building relationships helped consumers feel connected to the project, encouraging them to provide in-depth feedback, comment on important issues and share opportunities with their networks. We were able to call on people we had established relationships with to provide ongoing insights into long-term projects, as well as provide quick turn around when we were working to very tight deadlines for consumer input. The trust that comes through building relationships also encouraged consumers to feel safe in sharing their experiences, and participating in photography and video projects.

Some tips on building relationships:

- Relationships take time, but it's valuable to invest this time right from the start of the project
- When hosting events or community conversations, build in time for informal catch-ups at the start and end of each session
- Take the opportunity to help build capacity in consumers by providing training (or referring them to training such as that held by Health Consumers' Council), or paid opportunities to build their knowledge around the project with pre-reading or information sessions
- Reach out through established networks to connect with consumers
- Close the loop by letting consumers know how their input was used and how it affected change
- Where possible add a personal touch – for example, when our HWAP Consumer and Community Advisory Group was wound down, we sent hand-written thank you cards that were well-received.

*“I have a lot of empathy and passion for talking about this. Being able to have a conversation with the consumer advisory group, the pharmacist, with friends – it's a good thing to have and to hear other people's experiences.”*

### Include tailored activities to reach particular groups

Consider how people from different backgrounds are likely to be impacted differently by the issue you are exploring, and how you will be able to seek these insights. Be clear about why you are engaging and what perspectives you want to hear.

What will help the people whose perspectives you want to hear to participate? This may involve reaching people where they are. In our experience, the majority of people who answered surveys were women aged 45+; however, the HWAP target groups included men, young people and families, Aboriginal people, people with disability, people from culturally and linguistically diverse backgrounds, and people who live in remote areas – all groups who may not have engaged through traditional approaches.

We were able to reach these groups by meeting them where they are, at places such as Ishar Multicultural Women’s Health Services, Wadjak Northside, and Nidjalla Waangan Mia, and through the Aim High group at Down Syndrome WA, building on existing relationships with the community. Consider if you will need to provide interpreters, accessible locations, materials in different formats, or culturally sensitive spaces.

In our experience, people who are impacted by severe obesity, or who have lived with obesity for a long time including through childhood into adulthood, often have quite different experiences than people who are not impacted in this way. We believe it is important to understand the experiences, needs and interests of people with these experiences. This may involve creating specific opportunities for people to come forward. When it comes to weight and health, people’s experience of weight can be significantly different depending on the clinical stage of the condition, so if that is relevant to the conversation it needs to be made clear upfront. Be respectful in language around this, and create safe spaces for consumers living in larger bodies or with long-term experience of living in larger bodies to engage.

*“An event that is women only, something that is designed to be a safe space. Knowing that information will be collected, but not able to be identified.”*

*“Consider aligning obesity policy events with community events to engage those falling in the groups disproportionately impacted by obesity. Not everyone has access to the internet or is on social media; and providing feedback on proposed government policy is unlikely to be a high priority for many people.”*

### Make engagement meaningful

While it is important to engage with consumers, it’s also important that engagement is meaningful for both parties. Reflect on why you are wanting to engage, and how consumer feedback will be used. There needs to be willingness across all levels to act on the feedback provided. Health Consumers’ Council provides training for HSPs around consumer engagement that may be useful. If change is likely to take a long time, we believe it’s important to be clear about that up front so that people can decide whether or not to be part of the process. Relationships are central to good engagement, and relationships take time and investment.

*“I think it’s time the discussion became real, relevant and relative.”*

### Be clear about what area of health is being discussed

It’s important to communicate clearly about what area of health is being discussed when talking about overweight and obesity. Often people will go straight to talking about healthy food and physical activity – which may be more of a focus if you’re discussing primary prevention, but less so if you’re exploring medication side effects or the impacts of mental health. This may be linked in to internalised weight stigma, in which weight is seen as a personal responsibility. It can take time and encouragement to help some consumers look to further contributing factors.

Similarly, if you're looking for input on improving healthcare for people who have or are at risk of overweight and obesity, you will need to make that clear to make sure you're hearing from people who have that experience. Using vague terms like 'health' or 'weight and health' may not resonate with the people you want to hear from, while open invitations to a broad community may feel judgemental and be further stigmatising for those with experience of overweight and obesity.

*"That is why I have such an interest in the work that the Health Consumer Council is doing in their work with obesity and achieving healthy outcomes and working on ways to support the individual working with all areas of their lives."*

### Explore what the consumer wants

We always recommend that, at a minimum, consumer participation payments are provided for engagement activities (please refer to our website for our [consumer payment policy](#)). However if you plan to have ongoing engagement with particular consumers, such as regular workshops, focus group meeting, or a Consumer, Community or Carer Advisory Group, we recommend exploring what the consumer hopes to get out of their engagement around the topic of weight and health. When we asked the consumers in our HWAP Consumer and Community Advisory Group what they would like HSPs to know about engaging in this space, they spoke of a 'giving something back' model (in addition to the consumer participation payment), wherein the sharing was mutual and the benefits mutual, rather than just the HSP gaining from the group. What this looks like would need to be established based on the group and the project, but some suggestions are info sessions for the consumer from relevant third parties (for example, we had someone from Foodbank come to a CAG meeting to share information about the healthy cooking programs they run); and resources such as brochures or information packages for relevant programs that may be of interest.

One example that stuck in our minds was based on consumer feedback following a session for a particular weight management trial program being run through the HWAP. Consumers were involved in the planning and provided feedback around setting up the trial program, but didn't realise at the time that they might not be eligible to actually participate in the program once it was running as eligibility was based on location. Being clear upfront about the consumers' goals and any limitations on program participation would have made this a better experience for the consumer.

*"Speakers who are investigating different approaches to weight loss and maintenance of a healthy weight and focused on patient-centred approach."*

*"...not just information but practical advice like specifically what to eat displaying quantities etc."*

### Language is important

Language is very important when engaging with people with lived experience in regard to health services for overweight and obesity – and there is no easy answer for the best language to use. People will respond differently depending on their personal experiences, however from our experiences some suggestions include:

- Use "people first" language such people with overweight or obesity; people who are impacted by obesity. Avoid "obese people" or "the obese".
- Many consumers talk very negatively about the word "obesity" or "obese". While these terms might have a clinical definition and meaning, they also have a negative context in a general social context.

- The same negativity can be felt towards the term “morbid obesity”. The phrase we use is “people impacted by severe obesity” as we believe this recognises that obesity is a condition that people are impacted by, not a personal characteristic.

We recommend exploring some of the resources listed at the end of this document, including [Shift. A guide for media and communications professionals](#).

*“The term morbidly obese is really hurtful.”*

*“It’s such a deeply personal thing and yet so obvious – I know I’m fat, being judged or negatively referred to as if I am my fatness is deeply off putting.”*

### Consider your own bias

In many circumstances, weight bias is ingrained and casual. While we know most people have good intentions, and wouldn’t set out to be hurtful or cause harm, the truth is that old ways of thinking, lack of knowledge of the complex contributing factors related to weight and health, and the fact that weight stigma often goes unchallenged, remaining one of the last socially acceptable forms of prejudice, all mean that many people aren’t aware of their own biases around weight.

Through the course of the development and implementation of the HWAP, some of our team have been on a personal journey of increased awareness and understanding about overweight and obesity, as well as the impacts of weight stigma. This has included becoming aware of their own internalised weight stigma (including thoughts about their own weight, ‘if I just had more willpower I could lose weight, I just need to make more effort’) to recognising the prevalence and acceptability of weight stigma in the community (such as the way people who lose weight are often praised and told how good they now look). For our team, this work has led to increase awareness of cultural norms in Australian society that mean healthy options are often limited – celebrating a colleague’s birthday with cake, fundraising by selling chocolates, and placing bowls of lollies on tables at conferences – and the cumulative burden of mental effort it can take to find healthy options, as well as constantly declining or avoiding less healthy options.

It’s only through being able to define and recognise weight bias in all aspects of life that we can begin to increase awareness and education to reduce the significant impacts of negative stigma.

*“It’s the well-meaning man in my TAFE class who noticed how much weight I had put on and thought something must be wrong. It’s the workmate who congratulated me on my pregnancy when she walked in on me changing after work.”*

### Normalise neutral conversations about weight

Weight can be a sensitive issue for many people. But we think it’s important to normalise discussions about overweight and obesity in a judgement-free way. Plan how you will talk about the subject in advance and get used to talking about it with the right language so you don’t hesitate or stumble over words – which might indicate to some people that you feel uncomfortable with the subject. During initial engagements it is useful to ask how people prefer to refer to weight, and then use their language. This is also a good time to establish the terms of reference or even an informal charter, and include notes on language, respect and the value of people’s varied experiences.

Ensure that this same neutral and respectful language is reflected in conversations with peers and particularly in reports, even if consumers will never see them.

*“Not to make them feel bad about their weight (they may already feel bad. They may not feel bad either, they might be happy with their body but don’t need any judgement either way.)”*

### Hold space for people's stories

We have learned that experiences of overweight and obesity are diverse, and the contributing factors are rarely simple. In talking to consumers we have heard experiences of overweight and obesity linked to mental health, trauma, inequity, disability, chronic health conditions, poverty and disadvantage. It is no surprise then, that talking about experiences of weight can, for some consumers, be emotional and have an impact on mental wellbeing. If you want people to open up about these topics you will need to provide safe spaces for them to do so. This might include considering the support needs of consumers who share their stories with you, guidelines around engagement activities and how stories will be shared, options to provide feedback anonymously, or support to help consumers access training to tell their story. You will also need to consider what support may be needed by the project team who will be hearing and recording these stories.

We also acknowledge the importance of showing the complexities of experience and not reducing people to their stories. There needs to be a balance that shows the joy as well as difficulties, achievements as well as struggles, and the full, richness of the human experience.

*"This started a lifelong cycle of diets, binging, dieting again, extreme weight loss, extreme weight gain, Hospitalisation at my lowest weight for bulimia and extreme weight gain presently and because of my age I am seeing now what this lifetime of extremes has done to my health. I have many physical ailments that now include a very low metabolism, diabetes and back and joint pain. My life has completely been dominated by my weight and the severe mental health issues and family and relationship loss that come with this type of illness and addiction."*

*"When I was young I was too caught up in my weight. Who I am is more important than what I look like."*

*"Overweight people are human with many complexities in their lives just like everyone else and deserve to be treated as such and not to be made to feel ashamed, outcast or an object of ridicule and blame. No one knows what each of us has been through."*

### No data is data

If an attempt at engagement is less than successful in terms of the number of participants, remember there is still plenty to be learned. It is possible to gather good insights from individuals or very small groups. More importantly there are opportunities to ask questions about why you didn't get the volume, diversity or depth of responses anticipated. Look at the wording around the opportunity – was it engaging, free of jargon, and easy to read? Was it clear what steps the consumer needed to take to be involved, what would be required of them, and how they would be remunerated? How was the opportunity shared, who did it reach and how might have been missed? Was the planned activity accessible, were there opportunities for people to be involved in different ways, or would a different format have worked better? Could more have been done to reduce stigma or create a safe space?

## About

### Health Consumers' Council

Health Consumers' Council (WA) Inc. is an independent, not for profit organisation established in 1994 with the purpose of giving a voice to health consumers in Western Australia and improving health outcomes by encouraging and supporting consumer engagement and involvement in health services.

### Healthy Weight Action Plan

The [WA Healthy Weight Action Plan 2019-2024](#) is a joint initiative of WA Health, WA Primary Health Alliance, and Health Consumers' Council to create a roadmap for sustainable changes to support people and families who are at-risk of overweight and those with overweight and obesity. It is the first step of many to create a coordinated approach across health to tackle the complex causes of overweight and obesity and work with our partners across WA to drive long-term change.

### Resources

[WA Healthy Weight Action Plan 2019-2024](#)

[Partners in Change – Healthy Weight](#)

[Shift. A guide for media and communication professionals](#)

[The Personal Cost of Weight Issues in Australia 2020](#)

[Healthy Weight GP Project](#)

## WA HEALTHY WEIGHT ACTION PLAN 2019-2024

Health Consumers' Council received funding from the WA Department of Health to connect and involve people impacted by overweight and obesity.

We have a number of documents available for people working within WA health services to contribute to improving health services in this area.

\* Please note these insights are not exhaustive and in some cases come from small numbers of people. We share these in the hope that they add value to the evidence-based information on this topic.

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