



**MEDICATIONS AND HEALTHY WEIGHT
INSIGHTS AND EXPERIENCES**

NOVEMBER 2022

FINAL V1

TABLE OF CONTENTS

- Section 1** **Introduction**
- **Background and Objectives**
- Section 2** **Overview of approach**
- **Approach and methods**
 - **Demographics**
- Section 3** • **Headlines**
- **Experiences and insights**
- Section 4** • **The Future**
- **Conclusions**
- Section 5** • **Recommendations and agreed actions**

SECTION 1: INTRODUCTION

1.1 Background and objectives:

Activmob were commissioned by Kent County Council Public Health to investigate and undertake a behaviour insight study to explore evidence-based approaches to weight management, with a focus on approaches for weight management in those on medications that impact on increasing weight.

The requirements included undertaking interviews and/or focus groups to understand if there are any practices, expectations and perceptions, levels of knowledge and understanding which are impacting on the weight of this target group. The aim was to capture meaningful information that can provide clear insight into how current services or new services and support need to be designed, promoted, and provided or made more accessible to meet the needs of this group.

1.2 Summary of research questions:

Medications that impact on increasing weight

- Identify whether people (parents, carers, health professionals) understand that certain medications can lead to weight gain.
- Whether those on said medications are given any information about what they can do about it / the steps that can be taken and that there can be alternative medications.
- Weight management approaches for people on medications and with health conditions that can affect weight.
- What information, support with decision making or changes to delivery or access to weight management services could encourage people taking medications known to cause weight gain to engage in weight management programmes.
- A strategy to communicate information effectively and support across this population.
- A strategy to engage this population effectively and provide support.

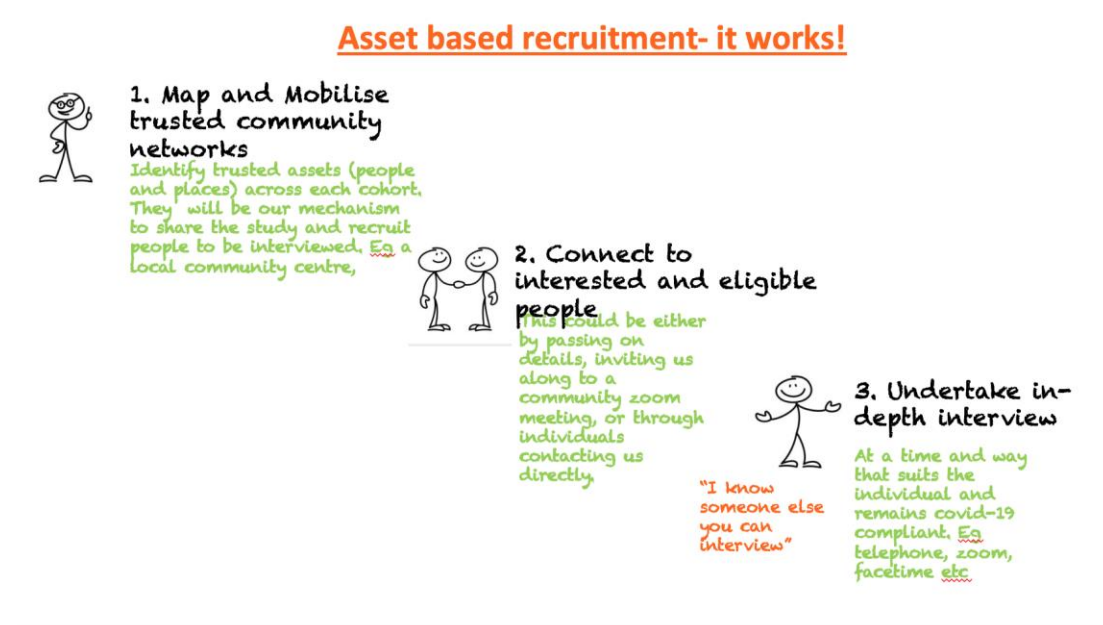
SECTION 2: OVERVIEW OF APPROACH

2.1 Approach and methods:

In discussion with Public Health, it was recognised that there was little literature of research available on this topic and therefore there it was agreed that we would conduct **in-depth interviews** to be able to truly get under the skin of the issue with a 'blank sheet'. The aim was to understand what people really think/know/do to develop deeper insight and understand behaviours.

2.2 Recruitment:

For the recruitment of individuals for the in-depth interviews we took an asset-based approach, using our already established and trusted Kent wide network and connections to identify trusted people/places who could connect and make introductions. We used a 'snowball' approach to widen our net and recruit further. The diagram below is a representation of our approach to recruitment.



2.3 Analysis:

Analysis was undertaken of the insights and evidence from the in-depth interviews. Insights were coded using the principles of thematic analysis based upon Braun and Clarke's model (2006). The findings were segmented, and behavioural analysis undertaken, and recommendations made documented in this report.

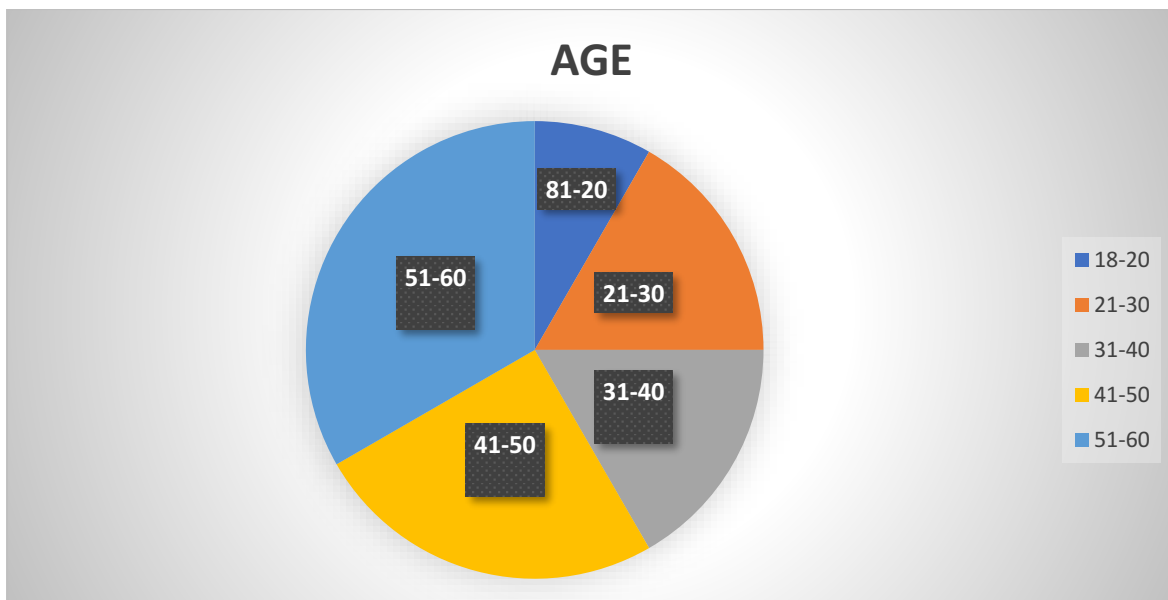
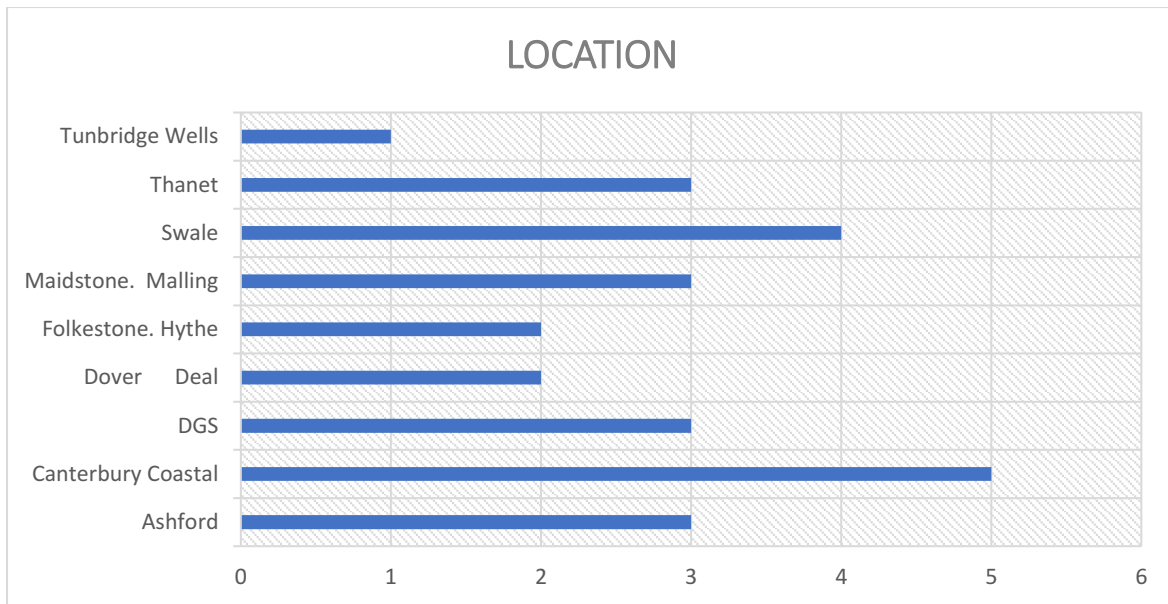
2.4 Covid Considerations:

Whilst some restrictions were still in place for this study, and confidence was still low we undertook in-depth insights using remote methods, such as telephone calls, zooms and facetime.

For each of the in-depth interviews we worked with the individual's involved to identify the most appropriate and convenient method.

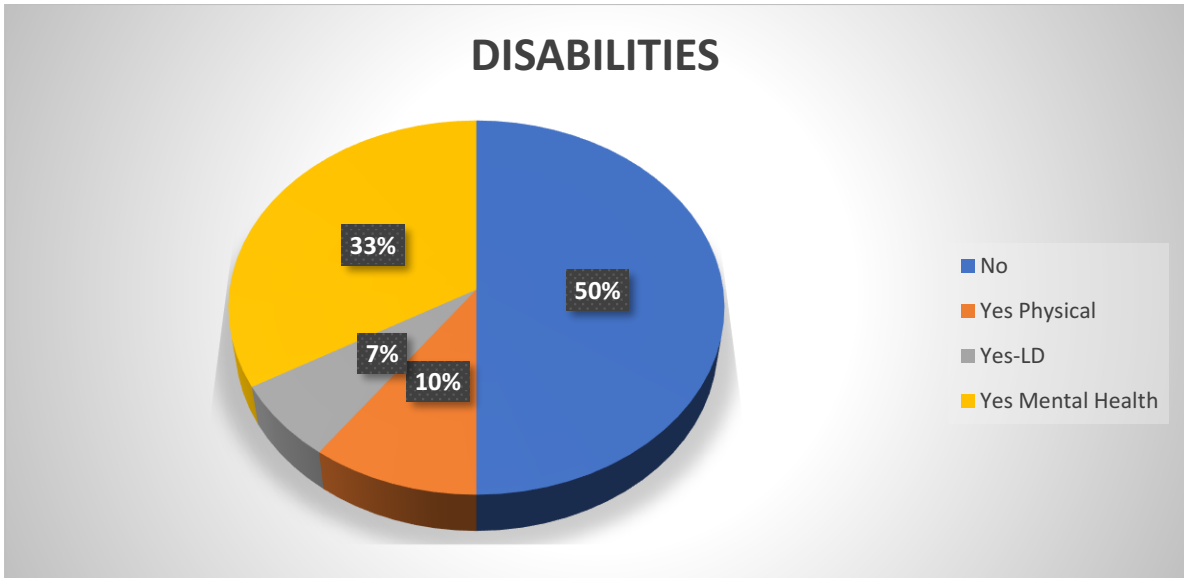
2.5 Who we spoke to:

We conducted 26 in-depth interviews with people across Kent. Male participants (c: 10) and female (c:16). 24 of the total number identified themselves as White British. The charts below show the numbers per area and by age.

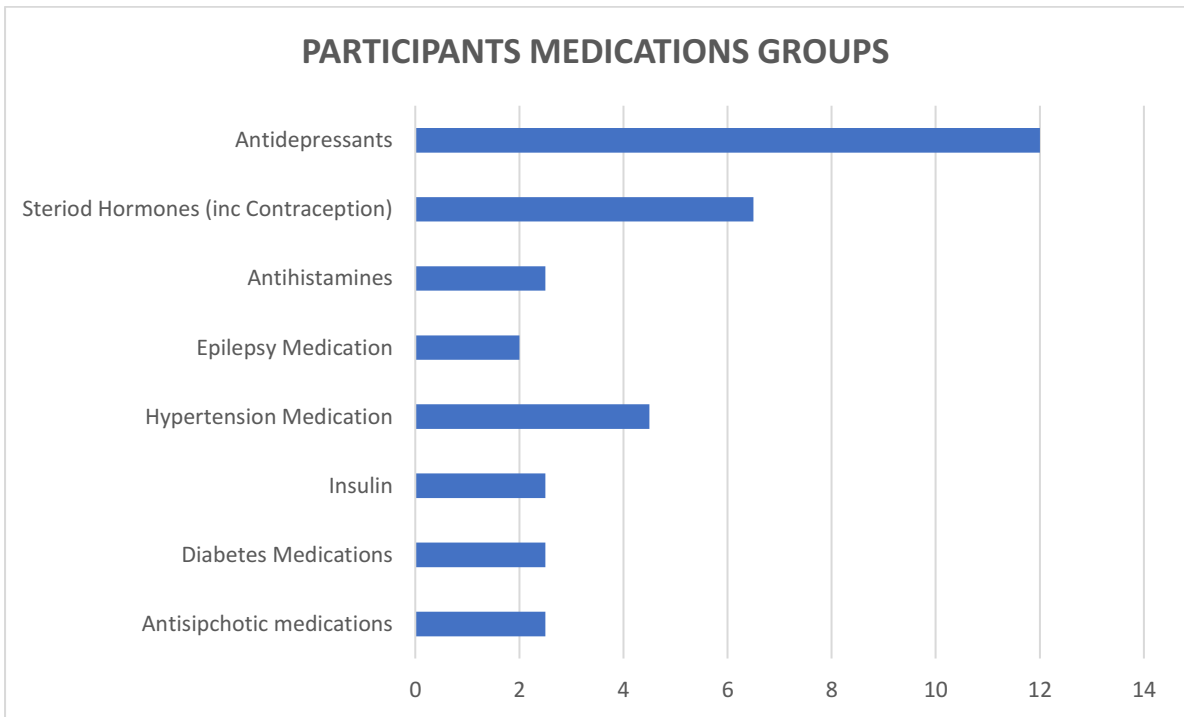


In terms of living arrangements, the majority (c:16) lived with a partner. The remainder either lived alone (c: 5) or with other family members including their children (c:6). Of the 26 participants, 18 were in work either full time (c:10) or part time (c:8). The remaining 4 classified themselves as carers, retired from work or other.

Participants were asked to identify any disabilities they had. The chart below summarises the responses.



As part of the in-depth interviews, participants were asked to share some details of the medications they were taking and the conditions they lived with. The charts below summarise this information with many participants reporting taking more than one medication from the study medication groups.



SECTION 3: EXPERIENCES AND INSIGHTS

This section of the report provides a summary of the **themes** that emerged from analysing what participants said during interviews and following the Topic Guide. Using an inductive approach to analysis means that themes emerge from people's insights and experiences.

Interviews and capturing people's experiences have not been used to prove or disprove specific hypotheses or statements.

Following the themes that have emerged, **key conclusions** are presented, drawn from what people have said and experienced.

3.1 Headlines

- **Risk management** is at the heart of everyday decision making especially for those on steroids and mental health medication. Balancing the risk of serious side effects of medication and contraindications, pain management and their conditions as well as other aspects such as weight management.
- **Choice** is normally limited across all medication groups with very few honest conversations about potential pathways. People experience no empathy for how important weight gain could be. This is particularly experienced by women seeking contraception, steroids, and those on mental health medications.
- People are **angry at the lack of involvement** and not being listened to. This is particularly experienced by those on mental health medication and those seeking contraception.
- The opportunities to have the conversations are there already
- The current approach for the system to talk about this topic with individuals is condition led rather than person centred

'I think there should be a 'more choice' based conversation, they don't know or understand what my weight means to me"

3.2 Insights and experiences – what people told us

THE REALITY

Case Study

I have been on medication for diabetes, high cholesterol, and high blood pressure for years. Then 2 years ago, I was diagnosed with complex heart condition and started more medication for that!

Within months I started to notice the weight gain, and went to my GP, but he told me how important the medication was and didn't help with the weight issue. So, I decided to start Slimming World. I soon realised that they were great with the support around weight loss but didn't know about the medication and medical issues. They would advise things that went against the medical advice. For example, drink more water to aid hunger, but because the tablets and heart condition, I must limit my fluid intake to 1.5lt a day.

I felt the risk was too much, so had to stop going. My condition needs to be treated for me to remain well and that is my biggest priority.

KNOWLEDGE AND INFORMATION

Of the 26 participants only 1 person had been told about a link to weight gain by a health professional. However, many others (**c: 20**) **believed that there could be a link**, but for the majority this is an **assumption as well as a risk you must take when taking medication**. They recognise that often medications change how their bodies work. It wasn't just weight gain that people assumed could be linked but also weigh loss as well as weight fluctuating. For example, a medication could cause fluid retention or enable someone to sleep for longer. Both were considered to have a direct link to weight gain.

"You don't function mentally as normal, so you are not as aware of maybe eating too much"

"They can cause weight gain as it slows everything in your body down"

"You sleep longer – and all these things mean you can increase weight – because there is something about how the medication works that alters how you absorb food"

The remainder reported that they **did not have any awareness** at all until this conversation or that they were **not aware that their medications specifically could increase their weight**.

"I didn't know it did, I just thought it's because I eat the wrong food"

"The medications I take don't affect my weight – I don't think"

"Nothing, I have always been overweight so I wouldn't link it to my medications"

In terms of where people gained this information and knowledge, the majority (c: 16) participants had conducted their own research either by looking at the information leaflets in the packs or online about the potential medication.

“I know that Quetiapene (anti scicotic) leads to weight gain – this I found out from reading myself as I noticed rapid weight gain”

“Most mental health drugs make you put weight on”

“I don’t know why; I just know you have to watch the combined pill and keeping your BMI under 35”

“Steroids give you moon face”

The remainder (c: 10) said they had learnt this from informal and their trusted sources such as family and friends on the same medication or with the same health condition. Some even mentioned informal and opportunistic conversations in school playgrounds, gyms, and activity groups where knowledge had been gained.

“I also look at my closed Facebook group for rheumatoid arthritis to understand more about medication, my condition and weight gain”

“It was just the girls as school, the gossip in the playground that’s how I found out about the pill and weight gain”

Participants were asked to explain in more detail what they had researched regarding medication they were taking or could be prescribed. People felt it was important for them to be knowledgeable about medication they were taking and saw this as something they should take responsibility for.

“The impact the medication can have on my body, how they affect the benefits of other medication or cause issues with others”

‘I always read my patient info sheet, by it rarely if ever mentions your weight. I like to know what they do’

People are not generally looking specifically for information regarding potential weight gain other than those who may considering strong mental health medication or contraception.

“With my mental health medications, I read all about the side effects of the anti scicotic drug including weight gain. I wanted to wean myself off them and the GP offered nothing, so I used to shave a bit off the table every day to reduce the dose”

“When they tried to put me on anti-depressants for grief, I looked them up and saw they make you fat, so I refused them’

With this knowledge, many (c: 18) had asked or even raised a concern about the potential impact the medication could have on their weight and had been dismissed. Examples particularly focussed on those taking mental health medication or women taking the pill for contraception or HRT.

“From my own reading I knew there was a link to my mental health medication. I was dismissed by the GP who said it was more important to deal with my mental health. He offered me no discussion or options, so I felt I had no control over my body. With my asthma pumps, the nurse regularly weighs me but says nothing about weight gain – and I have gained weight”

“I asked my doctor as I was calorie counting and not seeing any difference and so started to panic. He said that it was probably the pill causing the weight gain and that there were other things that could help with weight loss, but he didn’t ever give them to me. He just said it was down to the pill”

As part of the interview, participants were asked how important weight gain was. The majority (c: 17) scored themselves 4 or more out of 5 where 5 was extremely important. When asked about knowledge of the risks of weight gain and obesity generally, most all participants had a clear, concise, and immediate response. For many there was some real **fear of the risk of obesity and how it could impact their health**. The following quotes reflects the more common responses.

Question: “What do you know about any risks about weight gain and obesity in general?”

“It can kill you”

“It shortens your life”

“Risk of stroke”

“Out of breath”

“I real risk of diabetes”

“I already know my eyes have been affected”

“It has an effect on all your organs in your body”

“Puts more strain on your heart and your veins and arteries close up”

ACCESSING INFORMATION AND SUPPORT

Experience of accessing support.

Participants were also asked about their awareness, knowledge and experience of weight management services and support. The majority (c: 19) were able to quickly recall local and community-based weight management support such as Slimming World and Weight Watchers. Whilst there was awareness of these services, few (c: 5) had used the support. Many participants were cynical as to the value of these services, seen as groups with a focus on calorie counting, points, using their own pre prepared menus and generally making money.

“They all provide support to manage your eating either calorie counting or points”

A few individuals thought there could be something available via their GP or pharmacy such as a referral for exercise classes and support with managing their weight, but they felt this was means tested or something they would not qualify for.

“I think the GP can refer you for something, but I don’t think I would qualify so there is no good asking. I earn too much so I wouldn’t meet the criteria”

Motivation and asking for help and support with weight management.

Participants were asked to reflect and share their views on when they would want to access support around weight management and what would lead them not to seek help. In terms of seeking help, there were two key motivation factors that would influence seeking help both focussed on reactive approaches to dealing with the issue. Only one participant suggested that they regarded weight management as part of their general wellbeing and an important aspect of managing their health conditions, reducing their reliance on medication or even eliminating it. This example came from a diabetic patient.

“I want to change my lifestyle – including losing weight to reduce the medication I am taking”

The **top driver for seeking help** is when an individual has tried to lose weight themselves because they have seen a significant weight gain. They will have already used strategies from knowledge and experience from either themselves or family and friends but are now noticing that the weight is not shifting, and this is affecting their general wellbeing and mental health.

“When what I was doing wasn’t working – that would be the logical time to get some help”

“If my plan of no alcohol does not work after a couple of months”

“I take medication for my mental health. When I feel I cannot cope anymore on my own and my weight is really affecting my wellbeing. Last time this happened I got to the point where I could not finish reading a page in a book as I kept breaking down and I needed help”

For others, being told by a health professional that their weight gain could make them ill, have a negative impact on their condition or life threatening were all motivators to seeking support.

“I would never seek help unless my heart gave out and the GP said that if I didn’t lose weight I would die – then I would”

“If my GP told me I was fat I would ask him for help”

“If I became ill and they said I needed to into hospital, and this was due to my weight – I would want help”

Reasons for NOT asking for help and support with weight management.

Interviewees were also asked to reflect on when they would **NOT ask for help** and to explain what circumstances would be place and their rational for not seeking help even though they are experiencing weight gain.

“I would only access support to change my medications and not to lose weight”

The top consideration mentioned by most participants was the importance and daily challenges they face of managing their illness, pain, medicine complications and weight. *‘The total package’*

Medication for mental health conditions and steroids for a range of conditions are **critical** to people in managing their illness, pain, and wellbeing including their mental health wellbeing. Whilst weight management is not the most important consideration, **losing weight and getting support could be considered** if this was recommended as part of a medication change or beneficial as part of the total package.

“I would think about asking for help if I was getting fat, although my consultant for my COPD said its worse to be underweight as more weight means I can still fight infections”

“Medications vs side effects such as weight gain vs levels of pain I am in – this is a constant battle”

However, people and those taking medications for mental health conditions and steroids, are anxious to take the gamble of changing their diets to lose weight without fully understanding the risks or impact this could have on their medication. Individuals shared experiences of not feeling 'safe' in taking advice from some community-based support organisations such as Weight Watchers and Slimming World who were both mentioned.

"I wouldn't ask for help if I didn't feel it was safe or the person giving me advice didn't have enough knowledge of the conditions and medications I am on and how they could impact. Slimming World told me to drink 2 litres of water a day to help with losing weight, but my consultants tell me I can't have more than 1.5 litres of fluid a day"

The second most important reason why an individual would not seek support for those taking hormone (including contraception) is dependent on who is providing the message and support. For this group the person supporting must be someone they trust that will listen and not judge them.

The quotes below were provided as examples:

"If no one understands or listens to me and speaks to me like an idiot"

"Actually, I think it is about who raises the topic (of weight) and who helps. She could raise it, but I don't think I would trust her to help"

SECTION 4: THE FUTURE

4.1 PROVIDING INFORMATION AND SUPPORT – WHAT IS IMPORTANT?

The in-depth interviews proceeded to hear thoughts about accessing information and support in the future.

The most important thing people want to know is the impact of the medication and how it interacts with other medications. Most people who participated across the medication range shared stories of actively seeking this information and very importantly felt this was their way of getting some control in how their conditions are managed.

Some were desperate but said that despite pushing they were not getting a clear way forward from their health professional. The current approach feels very medical and treating the disease rather than the whole person. Whilst people felt that their health professional sometimes discussed options with them there was no real help with making decisions.

“I knew I could put weight on with the GP suggested the medication. But he said his main concern was my 2% chance of breast cancer and that the weight gain due to the medication was not proven”
(contraception)

“My BMI is 30 and even though I was worried about gaining more weight he said that I should have the meds as this would give me more energy and feel better and would then maybe start being more active and reduce my risk of heart disease and diabetes”

For nearly all participants, there was a clear message about the information they require for them to manage the complex risk issues they face. People case a constant battle in balancing medication, pain levels, symptoms, contraindications etc.

They need the correct information to make an informed choice. They want weight gain and the risks discussed as part of an honest conversation when discussing medication options. This is particularly important for those taking mental health medications and steroids where they see their medication being central to them remaining well.

“But you have to realise I have to take my medications, my steroids or I wouldn’t be alive”

Weight gain or the potential of weight gain however is a concern, normally overlooked by health professionals who focus on treating the symptoms and conditions rather than the whole person. **Respondents want clear and honest information about links and side effects.**

Case Study

“I knew I could put on weight when the GP suggested the medication and from my experience from the Mirena. But he said that his main concern was my 2% chance of breast cancer and that the weight gain was not proven. My BMI is 30 and even though I was worried about more weight gain he said that I should have the medication as this would give me more energy and feel better and would then maybe encourage me to be more active and reduce my risk of heart disease and diabetes”

The example below is one person’s view on how a conversation with a health professional could go at the point when medication is being suggested and not after which is too late:

“The conversation should go ... I would like to prescribe medication x as it helps you with Y condition that you are living with. There is a high chance that you will put weight on. Let’s see if that helps Y (condition) and if it does come back to see me and I can help you with the potential weight gain”

4.2 WHEN - THE OPPORTUNITIES

Participants were confident in identifying many opportunities (**or missed opportunities**) for conversations regarding weight management and concerns with a health professional. Examples focussed on the number of regular appointments they had given their health conditions. Participants felt there were key points in their journey when this conversation should take place – specifically at the start or diagnosis of a condition/illness, medication reviews, regular check-ups with GP and specialists for example for those with asthma and finally with pharmacists. Pharmacists were seen as key touchpoints due to regular and long-term collection of medications with the same pharmacy.

The asthma nurse, I have a regular visit and there is normally time to talk. She has my notes, she weighs me and even when she temporarily put me on different meds for a couple of weeks because of possible COPD symptoms (meds known for weight gain) she said they did not cause weight gain even though I had read it did!”

A further point of disbelief for participants when talking about opportunities to have a conversation about weight was the number of times they are either weighed by a range of health professionals or simply asked for their weight. Weighed but with no conversation or observation even when they themselves can see they have gained weight or are overweight.

“I would want a conversation at any point when I am with a health professional, they really should have told me about the link of weight gain and these meds – they could see the weight gain because I was being weighed all the time due to my eating disorder”

“A conversation with the prescriber and pharmacy. The problem is that you can get prescribed from a telephone conversation or in casualty like me. There is no time now and they don’t tend to see me regularly anymore. But they do ask me how much I weigh – why do they ask me that? And make no further comment? Is it just to see if I am aware that I am gaining weight?”

For those on **hormone treatments (including contraception)** there were additional opportunities for a conversation about weight management. Opportunities included smear tests when women said they would value a conversation with the nurse recognising that this would require the appointment to include a weight measure and conversation which would be different to the current approach.

“Maybe as it is to do with hormones and sexual health – with the nurse at a smear test – if they have time to fit in weighing me? Or at any well women check-up?”

“A conversation at any check in point, including when you get the pill re prescribed and when you get the check-ups to continue to have it. But they do weight checks, data collection but never a discussion. I would be told if I had put weight on, change my pill but offered nothing else”

Whilst participants considered opportunities for a conversation about weight management some now recognised that they felt angry, let down and disappointed that no one had had this conversation with them. They told us of experiences of when they had been weighed, raised their concerns, and yet still dismissed by the health professional. This was particularly highlighted by those taking contraception and medication for mental health conditions.

There was a very clear message across all medication groups that there should be a weight conversation at the start when you present with symptoms and medication is being discussed. The potential impact and conversation about risks of weight gain should be discussed at each check-up too and not just once.

4.3 WHAT SHOULD SUPPORT BE LIKE?

Weight management support as part of a full package of professional help whilst living with health conditions is important. Participants were very clear about the support they wanted. The image below highlights the key points.

MEETING OUR NEEDS – THE FUTURE



4.4 SUPPORT – WHO FROM?

All respondents said they wanted to receive the support from a medical professional, who **knows them, their medications and condition and how they interact**. For most the GP was identified, **but only if they liked them**, closely followed by the specialist nurse, pharmacist or other specialist.

For younger women on contraception (as part of the hormone cohort) there was a clear message that they would **not want to access support from their GP practice and would prefer to talk to someone like themselves such as a female younger nurse**.

“People in the same boat as me – my nurse for contraception – a younger female nurse”

Their **preference** would be from places (physical as well as online) that they go or use such as university or the gym. For younger people in this cohort, social media was identified as an important opportunity to access information and support. It was considered as an easy way of gathering information and some even suggested professionals hosting online forums on health topics.

“Easily accessible and convenient, where I regularly go such as my gym or university. I really don’t go to the GP or into a pharmacy – I am young – why would I?”

“I think social media is huge in providing support easily. Things generally online like Instagram and Tiktok”

4.5 Conclusions – what the insights tell us

This section of the report draws out the key conclusions from the themes of experience and insights from participants.

1. Taking medications prescribed for certain conditions is not an option for individuals.

For many, not taking the medications could be life threatening. They **do not have the choice** to stop taking a medication due to weight gain.

2. Managing complex risk issues is a daily concern for individuals.

Life is about balancing medication, pain levels, symptoms etc.

3. The individuals are constantly on health professionals’ radar.

Regular reviews, check-ups, tests etc and having conversations about pathways and medication. At the same time, everyone has a clear role in self-management around other life choices.

4.Managing weight is important to those who took part in the study.

Many appointments and reviews **include a weight check** and yet there is **no conversation** about support to manage weight.

5.Respondents want clear and honest information.

Information about links and side effects including impact on their weight of medications.

6.The opportunities are there with a clear remit to have a conversation about weigh management

We need to understand the barriers, assumptions and stigma that may be preventing this to happen.

SECTION 5: RECOMMENDATIONS AND ACTIONS

This section of the report provides details of key recommendations and priorities for agreed Kent County Council Public Health.

Recommendation 1:

As GP's are the service which prescribes the medication which is impacting upon individual's weight gain it is important to talk with the GP to better understand the issue for the client and be able to adequately support them through their weight loss journey.

ACTION:

One You Kent Commissioner to discuss with OYK providers at Partnership meeting about talking with GPs when a client presents to services taking certain medications to be able to support them.

Recommendation 2:

Providers need to understand and investigate the root causes of weight gain to be able to better support individuals through their weight loss journey.

ACTION:

To be discussed at the next One You Kent Partnership meeting with OYK Providers.

