

# **Herefordshire Diabetes Project**

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# Introduction

## Background

We know nationally that the number of people in the UK diagnosed with Type 2 Diabetes has more than doubled in the last 20 years according to recent data released from Diabetes UK.

Figures from NICE recorded in 2018-2019 show that there are 3,919,505 people that have been diagnosed with Diabetes in the UK and around 90% of these are with Type 2.

It is also estimated that there are about 1 million people in the UK who are undiagnosed.

From its studies NICE estimates that by 2025 there will be approximately 5 million people in the UK with diabetes.

Each year the NHS spends at least 10 million pounds, which is around 10% of its entire budget, on treatment for diabetic patients. Almost 80% of this money is used to treat complications that arise from diabetes.

In 2019/2020 there were 57.7 million items prescribed for people with diabetes this rose from 35.5 million prescription items 10 years earlier.

In Herefordshire the prevalence of Type 2 Diabetes rose between 2012 and 2019 in line with the national trends, with the North and West localities in the county having the highest prevalence and the East having the lowest. (data taken from understanding Herefordshire People and Places 2019).

Research has consistently shown that for some people, combined lifestyle interventions, including diet, sustained physical activity and weight loss can be effective in reducing the risk of Type 2 Diabetes up to 50%.

Healthwatch Herefordshire alongside our primary care networks undertook a piece of work to research what effective self-management looks like and why some people are able to keep control of their diabetes and in some cases reduce their risk, while others have not been as successful.

Healthwatch Herefordshire want to increase the patient voice with those diagnosed

with a long term condition such so that this can be used in the planning and delivery of diabetic services in Herefordshire.

## What we did

Healthwatch Herefordshire designed a specific questionnaire that could be used as part of a telephone interview – we decided that at the time of the research through interviews with participants, this was the most suitable way forward due to the pandemic and the restrictions trying to meet our participants face to face.

Alongside this we also created a short online survey for those who did not want to be contacted for a telephone interview.

A consent form for participating was sent to our local primary care networks who were able to share with GP surgeries, who sent the consent forms to their patients with a diagnosis of Type 2 Diabetes. We allowed the consent period to run from the start of October 2021 to the end of November 2021.

In the survey we asked questions around people's understanding of their diagnosis:

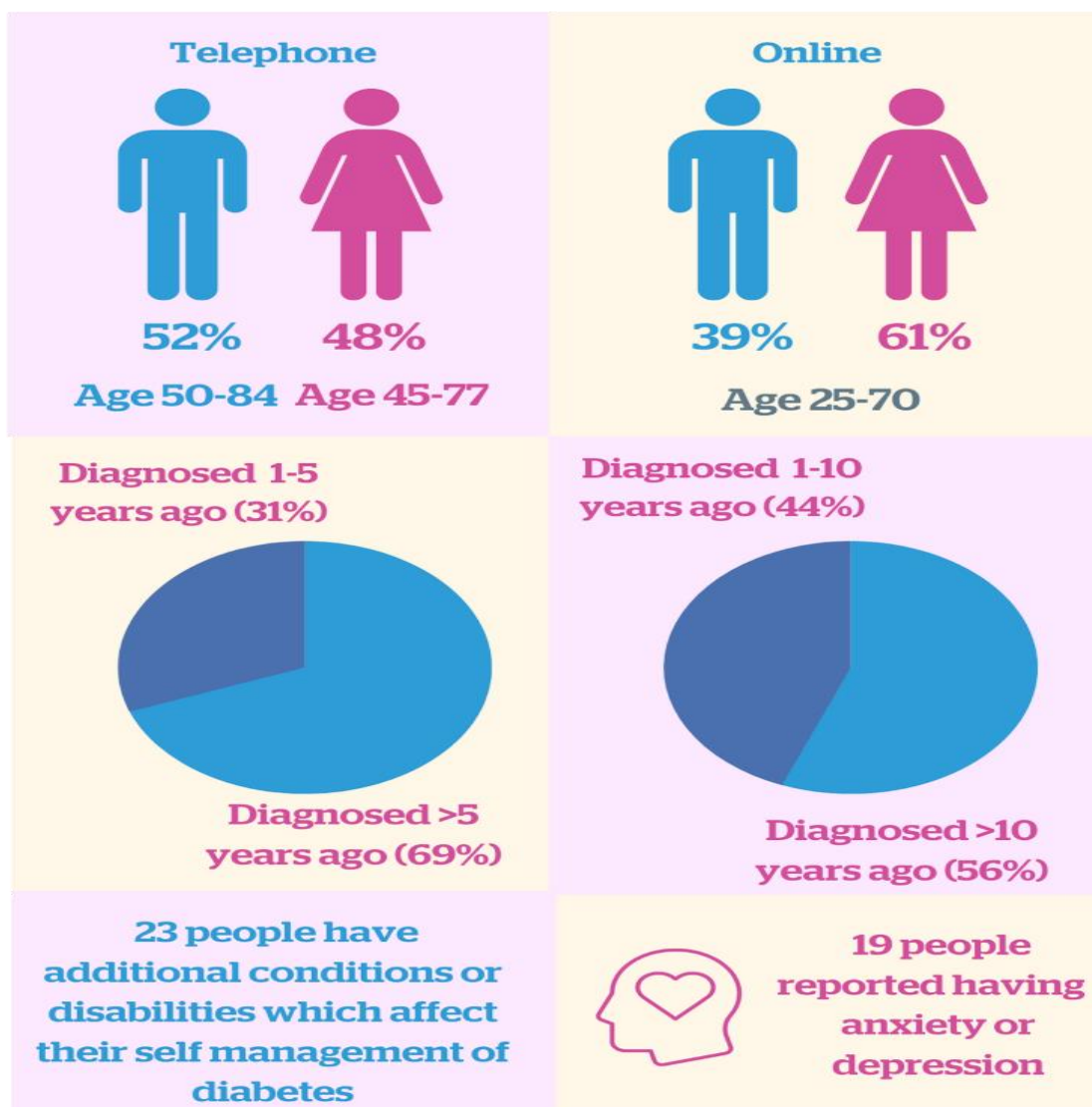
- Experiences of medical support they received
- How they felt they self-managed their condition
- Their understanding of blood sugars & medications
- What specific Type 2 Diabetes Services had they been able to access
- What services do they feel should available

A copy of the questionnaire and online survey can be found in **Appendix 1** and the analysis of the responses for the online survey in **Appendix 2**.

A total of 105 people consented to participate in the project. Through telephone interviews we were able to make contact with and interview 75 people.

Online we received 18 completed responses to the survey. Due to the way in which we targeted our participants through the local primary care networks, all of the people we spoke to have a diagnosis of Type 2 Diabetes as this was the target group (not people with Type 1).

## Participants at a glance



## National and Local Influences

We also took some time to carry out desktop research to look at findings from both local and national strategies to identify key trends and influences and how these have influenced local strategies and services, these included;

- NICE Guidelines – Type 2 Diabetes in Adults
- CQC – my diabetes, my care report (2016)
- NDA (National Diabetes Audit – NHS)
- Healthier You – NHS National Diabetes Prevention Programme
- Second Nature – Healthy Lifestyle
- Herefordshire & Worcestershire CCG Diabetes Network and Awareness Week Support
- Living Well to Take Control Programme – Hereford & Worcester (via NHS)

# What People Told Us

## Telephone Interviews

Feedback from our telephone interviews indicated the majority of those people who are successful in managing their Type 2 Diabetes, was due to early education and information about the condition and the simple and effective impact of diet and exercise.

The interviews demonstrated that in some cases, little to no information or education had been given at the point of diagnosis and that some patients still feel many years later they don't have a full understanding of the condition, other than that they should be on a restrictive diet.

*“Some professionals need to listen more and be less judgemental in order to understand the person they are advising. There needs to be a personalised approach and not a ‘one size fits all’ especially when combining Type 2 Diabetes with mental health issues”*

Another area highlighted in responses, was that many felt the national 'image' of diabetes is poor, as it portrays those who are overweight, and whilst this is a risk factor for the condition it feels more like 'fat shaming' as not everyone with the condition is overweight. This could stigmatise the condition and create a barrier for people to engage with GPs and considering early intervention and health check-ups.

80% of the respondents also felt that 'drop in appointments' with flexibility of time at evening or weekends that can be accessed around work and family commitments, would be hugely beneficial in keeping patients engaged and motivated in their management.

14 of our respondents suggested community support groups with 'experts by experience' running them who understand how difficult it is to self-manage. This is particularly hard when a patient has more than one long term conditions or other restrictive health conditions (co-morbidities). These groups could share advice around cooking, exercise and management suggestions that work in reality of day to day life.

Respondents with mental health conditions suggested that they need more support especially at point of diagnosis, also a mechanism of checking in with them and their condition more frequently as often anxiety can lead to lower motivation to self-manage effectively – some suggested that peer support can be useful in these situations.

Whilst at the point of diagnosis being given leaflets or a website to access seems to be the most common approach, it would be more beneficial to have a follow up appointment arranged to allow the patients to discuss the importance of education and the various treatments so they fully understand what is available to them from the start. Many respondents suggest the amount of 'medical or support' hours given towards the treatment and support of those

living with Type 2 Diabetes (unless they become unwell) is very low in comparison to some other long term conditions, but the risks are equally as high in becoming very unwell it was felt.

Finally, when asked about the 'Living well to Take Control' Hereford & Worcester programme, only 4 of our 75 respondents had heard of this, none had been referred to the programme.

## **Medical Management**

Of the 75 Type 2 Diabetics we spoke with, all of the patients were routinely attending their diabetic check-up appointments with their General Practice, although between 2020/2021 due to Covid 19 majority had appointments for ophthalmology/retinopathy and podiatry delayed but most of these appointments are now back up and running.

85% of the patients were seeing their General Practice annually for a routine check-up, with the remaining 5% having quarterly or half yearly checks due to changes in their medications.

A common theme when talking to patients about their medical management is that over the course of a year a patient may only actually receive between 3-4 hours of medical support for this long term condition, which many felt was extremely low considering the risks and complications that Type 2 Diabetes can lead too if not managed correctly. It was felt that in many GP Surgeries that the presence of a Diabetic Nurse Specialist would be a huge benefit where more regular reviews or support could be obtained when needed.

Another element to the medical management we looked at with our participants are those living with co-morbidities. Living with a co-morbidity can significantly impact how you can manage your diabetes alone. 38% of those we spoke with were living with one or more additional long term condition or had a physical or mental disability.

Due to the co-morbidities of those we spoke with, physically getting to an appointment for their diabetes was very difficult and often meant relying on others to get them there or missing/re-arranging appointments many times. All of these participants said that the option of a home visit or even a version of the visits done online would be beneficial, allowing them the opportunity to discuss concerns specifically around the diabetes with a professional.

## **Diet & Nutrition**

This topic highlighted some varying results in terms of what participants understood about the impact of diet and nutrition on Type 2 Diabetes. Many of the barriers to following a healthy lifestyle are around, education of diet and nutrition, time constraints and affordability of healthy foods.

The information given to those diagnosed with Type 2 Diabetes in Herefordshire about diet and lifestyle appears to be very limited and the onus is on the individuals to research and find appropriate diets to help manage their condition. Some surgeries now have Health & Wellbeing Coaches in place who



can support people with long term health conditions for better outcomes so an improvement in this area may still be to come.

The interviews showed that women were more likely to seek out and follow diet advice or a certain type of diet and would rather follow this than commit to the regular exercise when time constraints impact them (such as being a career, looking after a young family). However many of the men in the survey felt it was more important to be active (even if this is through work) than it is to follow a certain diet or restrict foods. The single males among those questioned found the diet and nutrition the hardest to maintain and didn't regularly cook from scratch but would buy what was ready made or convenient – many men said that asking for help or needing to learn how to cook from scratch felt very uncomfortable, especially to a medical professional – but if this was offered as part of the education when diagnosed this could be much easier to accept and follow.

Those who are managing their condition well through diet and nutrition evidently showed that they had done lots of self-learning around various diets and had joined groups online to follow for diet and recipe advice, although very little or no diet and nutrition advice was offered by the medical professionals during diagnosis or reviews.

Overwhelming the majority of those interviewed raised that affordability of healthy foods was an issue, especially when preparing meals for families. This impacts on 'how' healthy those with Type 2 believed they could eat. Many felt that junk or unhealthy foods seemed to be lower in cost and often more available.

It also seems to be a common belief was that having Type 2 Diabetes means living with a very restrictive diet with not many alternatives – which many felt they couldn't realistically stick to in the long term.

Around 40% of the men and 60% of the women interviewed felt that early diet and nutrition education is the most vital part of learning to self-manage.

If at the point of diagnosis an education tool was offered to support learning on diet and nutrition and where to self-learn further, this would have a huge impact in the long term as healthy lifestyles is an education.

In our research we looked at the 'Second Nature' programme used by several NHS Trusts across the UK – this has been designed to support those living with long term conditions such as Type 2 Diabetes to help them understand their relationships with food and what different food groups do to the body and why it is important to use these food groups to better support your condition. This programme runs for 6 weeks in Scotland through their primary care services and is open to anyone with a new or an existing diagnosis of Type 2 Diabetes. Support for this type of programme was high amongst our responders and could be very beneficial to many.

## **Exercise**

Exercise was the category that as part of effective self-management has the most non adherence.



Our survey results showed us, that women in the working age categories found that time constraints due to working and having a family meant that taking part in regular exercise was a lower priority, meanwhile working age men felt that being in a 'active/physical' job meant that they were getting enough exercise already.

In comparison those in the over the 60 year old and retired category found that they could increase their exercise as time allowed so there were less barriers to this age group to be able to undertake additional activity/exercise. This was also the category that evidenced Type 2 diabetes remission – 2 of the respondents have been able to go into remission and come off their medications in time they were able to increase their exercise regimes once retired, a huge positive impact to effective self-management.

Most common forms of exercise detailed to us were walking and swimming. Some do participate in group exercise classes but we found in rural Herefordshire, finding groups that are suitable and on regularly can be more challenging and would mean often travelling into Hereford City Centre. It was noted also that the pandemic has had an impact on classes, as many that stopped during this time have not had the interest/numbers to restart or costs for the classed have been driven up to reflect increase in charges to use village/community halls for groups locally.

Those in our co-morbidity categories also expressed concern that exercise education for them isn't something that is given and unless 'standard' classes can be attended finding suitable classes or knowing what exercises can be done with a disability or other long term conditions would be useful – signposting from medical appointments or practice websites was suggested here to websites or information guides that patients can use, many also suggested the idea of online classes/videos that can be done at home.

Affordability of exercise classes seems to be a barrier for many too, 34 of the people we interviewed suggested that local exercise classes developed for those with Type 2 Diabetes were offered free for a period and at a reduced cost to encourage more into group activities or to the gyms.

## **Blood Sugars & Medications**

During our conversations in this section, we asked people to talk us through their understanding of blood sugar levels and their medications.

Over 70% of those we spoke too, have been on the same medication since diagnosis and although this is looked at during their review appointments, not many were offered advice or information on ways to reduce use of medications. Many felt this was important as effective self-management tool, as some have controlled and stabilised their blood sugar through diet, nutrition and exercise routines over the years but medication not reduced accordingly they felt.

The survey demonstrated that around 18% of the respondents felt they were unsure if they were on the right medication or dosage but felt they couldn't question their GP around this and often 6 monthly or annual check-ups felt more like a tick box exercise.

*“ The annual diabetic check should be more than a tick box exercise, which is what it felt like to me, more useful advice and information should be given especially around medications.”*

Of our 75 participants we had 9 people who are insulin dependent. Knowledge around insulin use showed to be a lot higher than other types of diabetic medication and the support they received from GPs or Diabetic Nurses was good in general.

A link back to early education here is important, not all have a full and clear understanding of what your blood sugars do and where to find more information out that is reliable. Some felt the internet can give varying answers around blood sugars. As part of an early education programme this would support those being diagnosed.

Blood sugar testing amongst our participants was hugely variable, of those who had been diagnosed within the last 5 years the majority were still testing regularly as shown one to two times per day. It was evident amongst those who had been diagnosed more than 10 years that they relied on how they felt more so and didn't take up regular testing unless they felt unwell or were expecting to have a non-stable reading if they had been out for a meal for example. It was also evident this was not checked with the professional at appointments to verify and confirm the importance of testing regularly.

Similarly there was also a disparity in those who understood what the HbA1C test was for and how this should be done at each review appointment and can be requested if required more regularly. Some assumed as they have not had any result feedback from their surgery then the test must have been ok. It would appear there is a variable difference in the education and knowledge given about blood sugars and HbA1C tests.

## **Digital Self- Management**

During our interviews, we heard that many people were advised to go online and had been signposted to websites such as Diabetes UK or the NHS website by medical professionals, to find more information about their Type 2 Diabetes.

Only 39% of those interviewed had actually gone online to find out information that was recommended to them by the medical professionals and this was for a number of reasons:

- Don't have access to the internet to do this in own time/in their own homes
- Didn't like to ask family members or relatives to help with this – felt like a burden
- Are not confident in going online alone or can be sure the advice shown is correct and suitable for them.
- Wanted to discuss it 'face to face' to begin with.

For those who did go online, most research was around relationships with food and creating healthy lifestyles which they found most useful and also a resource to find alternative recipes where needed.

5 of the women we interviewed had used the 'Noom' App and felt this had completely changed their lives and has created some solid lifestyle changes that have meant they have been effectively self-managing with few interventions. This issue raised around this App was the cost in the long term and it's not affordable to everyone and therefore is not accessible to all.

The use of 'Zoom' type apps since the pandemic had meant that many more people are aware and can use this type of application now through a phone. Many of the respondents felt this was a great way to be able to interact as part of focus/support groups or one to one support without having to visit a GP. They supported the idea of a Health and Wellbeing Coach being able to conduct sessions like this online and would welcome evenings.

Likewise social media platforms are popular amongst those diagnosed in the working age groups to speak with peers but also to quickly access diet and exercise information. Some respondents were more dubious of this as they felt not all online information could be trusted but if more was shared and put out through the professionals websites this would make many feel more encouraged to access the information online.

## Case Studies

Of the 75 interviews we completed, some participants gave permission to share more in depth about living with their Type 2 Diabetes. These were a mix of males and females. they were all diagnosed at different ages and all are under a different Herefordshire GP surgery.

These case studies highlight the varying knowledge and understanding of self-management of Type 2 Diabetes and highlight the areas of success for recommendations.

### Case Study One - Timothy



Timothy was diagnosed with Type 2 Diabetes around 5 years ago when he was in his late fifties. He states that he is only a 'borderline' diabetic but does take medication to help control the diabetes and is one of several medications he takes to control some of his conditions.

At the point of his diagnosis Timothy doesn't remember being offered any additional learning or courses that could support him with this self-management of his condition and as a single man



living alone dietary and lifestyle advice in terms of cooking and exercises that he could use would support him and reduce the amount of readymade meals he relies on.

He still has regular medical check-ups, but still hasn't been offered any advice or learning that he feels would be the step he needed. Instead of medication, this could have been managed through diet and lifestyle. Timothy feels that whilst there is an option of going online to self-study, the greater benefits come from group or interactive courses.

## Case Study Two – Roger



Roger was diagnosed in 2017 and is in his early fifties, after he noted a change in his health in general. Soon after his diagnosis he was referred by his GP to a dietician, Roger advised this wasn't requested but was automatically done for me. He was under the dietician for around 18 months and during this time was offered some great advice and information he could use and share with his wife to ensure that he was able to alter his diet successfully – it was aimed at about losing weight more than lifestyle changes he felt.

Roger felt the information and support given around diet through the dieticians has been invaluable, as recently he has been able to reduce one of the medications he takes as he has been able to stabilise his sugars so well.

Roger said “all newly diagnosed patients should be offered some educational programme around diet but also about understanding the long term condition and what other issues poor management



can lead too – without this I wouldn't have been able to make the changes I did"

### Case Study Three- Jill



Jill is in her late seventies and was diagnosed with Type 2 Diabetes around two years ago.

Jill said "in my experience if you're not on medication then you don't get to see your Doctor annually, she made her appointment to see her doctor at 11 months but it was cancelled by the surgery as it was too soon and I ended up waiting 15 months to be seen" unfortunately Jill was experiencing some health complications due to her Diabetes, which she felt may have been picked up sooner if her appointment was kept, she is now seeing the nurse every six months due to these complications.



When Jill was diagnosed she felt there was little to nothing on offer for support or advice about the condition and felt it was straight to having the medications prescribed and not much of anything else. Jill feels that she would of benefited with some further advice and understanding of symptoms and signs of any worsening, as she lives alone and feels it's important to understand her health conditions.

When asked, Jill said she doesn't feel very confident in managing her Diabetes as she has no family nearby and feels the information from the GPs has been limited and poor and only get approx. 10 mins each time she has an appointment which she feels isn't enough to discuss her condition and ask questions.

### 3. Case Study Four – David



David was diagnosed with Type 2 Diabetes 25 years ago, had been having regular tests since he was in his thirties as it runs in his family – so he felt he was expecting this diagnosis.

Whilst his appointments with GPs and specialists have always been timely and reassuring – he has never been offered any education or support around living with diabetes. He said that “25 years ago I was told basically to cut out sugar and stick to a strict diet as the only way to manage this”



David said he is lucky to have family around him who either have the condition themselves or are supportive in helping research the condition to support his self-management. David said he focussed on lots of exercise that he could do, he followed suggestions on the Diabetes UK website for activities he could do and increased his walking wherever he could. He has found it hard to join activity groups locally as there is either nothing nearby or nothing affordable for him and this is something that David thinks should be more easily accessible to those with a diagnosis.

David said “ I have a fear of going onto insulin as I have seen this through other family members and it's not always been positive. Understanding the need for insulin really has driven me to control my Diabetes the best he can with diet and exercise”. He also added that he feels that peer support locally could be helpful with self-management and would

like to see more local networks of support and would be willing to volunteer and support others himself.

### 3. Case Study Five – Carol



Carol was 42 when she was diagnosed with her Type 2 Diabetes and it was only picked up when she was having other routine blood tests at her doctors.

She wasn't aware of any symptoms and even three years after her diagnosis she didn't take it seriously as she had no obvious symptoms.

Carol said "that being a busy mother within a family I felt like I didn't have time to really consider what this meant and as I wasn't unwell I didn't take it too seriously. After about 5 years I did start to have some symptoms and feel unwell and this scared me as I had not believed it was something I needed to manage in the long term."



Carol said that she returned to GP who prescribed medication to help, however even when asked she wasn't offered any support or learning around the condition and making lifestyle changes – she was advised to have a look online.

Carol said "I felt very disappointed that there was nothing on offer to give advice and practical things that I could do to support myself, especially after admitting to the Doctor I needed support as I had



not taken this seriously until now as I didn't really understand the condition."

With help of some friends Carol decided to look at lifestyle changes and diets and came across The Noom' diet and paid to subscribe to this. Carol said that although this was a little expensive for the 6 months she subscribed she felt the lifestyle and behavioural mindset changes it educated her with have been invaluable in making her feel better and managing her diabetes properly but without having to make lots of sacrifices. It changed her relationship with food and how she considers exercise and when to make time for it in a way that suits her busy family lifestyle.

Carol feels that the 'Noom' principles should be something that is offered as a standard programme for those diagnosed with Type 2 as it's simple to follow and reduces all the preconceptions around restrictive diets and view the changes positively, and something that can be applied to a whole family.

### 3. Case Study Six – Sylvia



Sylvia is 79 years old and was diagnosed whilst in hospital about 18 months ago. Sylvia said since her diagnosis in hospital she hasn't seen a GP or a diabetic nurse and hasn't been offered any advice or support.



When discharged from hospital following another acute illness, she was prescribed medication and insulin and sent home. Sylvia says that she has visits from a district nurse who comes to review her insulin but hasn't received any other support. Sylvia since her diagnosis has ended up in hospital four times after having severe hypoglycaemic attacks. Sylvia suffers with a respiratory condition also (COPD) and has oxygen most of the time so managing the two conditions have become increasingly difficult for her. She has felt that no one has supported her or her family in living with the two conditions, and having COPD she is restricted in the exercise she can do. She feels the risk of complications are higher to her yet no one seems concerned when she raises this even after four hospital admissions in the last twelve months.

Sylvia feels that if there was more support for those living with comorbidities and blood sugars then she may have the knowledge to know what is best to do to try and reduce the risk of any further hypo's. All Sylvia feels she can do is rely on family to help her

eat home cooked meals where possible and cut out sugar where she can.

Sylvias says “I doesn’t feel confident at all in the self-management of my diabetes and feels like I am always waiting for something to happen.”

### 3. Case Study Seven – Georgina



Georgina said that she had been diagnosed with gestational diabetes in all of her pregnancies some years ago, requiring injectable insulin. Unfortunately she found the diabetic nurse very unhelpful and condescending which affected her willingness to comply with her treatment at the time. Subsequently her diabetes was left uncontrolled for many years until she had a check-up with her doctor who after tests diagnosed her with Type 2 Diabetes.

Georgina says she hasn’t been offered any education of useful and useable advice, she does see her GP or nurse for check-ups and now has medication to control her condition which has made her feel better. However, the many years of the uncontrolled condition has affected her eyesight and caused peripheral neuropathy in her hands and feet.



When asked what could improve the self-management and treatment of Type 2 Diabetes she said “the option of having awareness sessions and peer support groups in local communities to help share and create recipes that are suitable for this condition and to talk about self-management ideas would be hugely beneficial. If delivered in community venues could be easily accessible to many in the rural areas also ‘pep talks’ from nurses or other professionals to keep motivated and on track would be very useful and could be done remotely, it doesn’t always need to be done in person.”

Georgina told us she now feels she is managing better and has her condition controlled and has lost weight and stabilised her blood sugars and feels much better for doing so.

As these case studies highlight, the support and advice is hugely variable within the Type 2 Diabetes Pathway in Herefordshire, when someone is diagnosed and similarly the support offered over the longer term seems to lessen generally overtime.

It also highlights the variation of understanding about of the condition and that some patients that have been diagnosed still don’t fully understand the longer term impacts to health that Type 2 Diabetes can cause. Almost all of the patients we spoke to felt that early education and support was the key to successful management.

Around 80% of the people we spoke with felt it was difficult to make lifestyle changes required to control Type 2 Diabetes and it was due most commonly these factors:

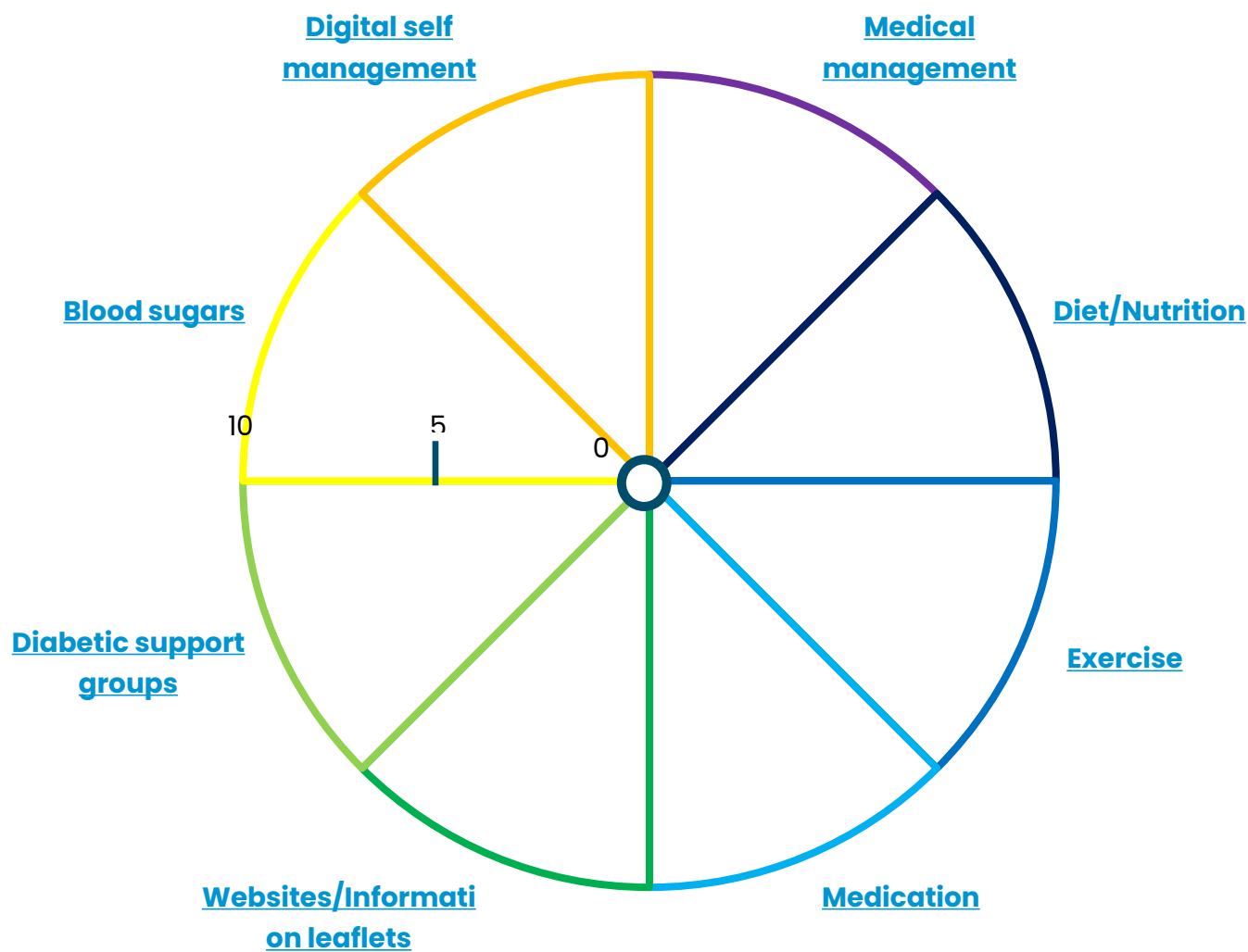
- They do not cook themselves or are not the person who prepares the family meals
- Time/daily life constraints, especially those in the working age category

- No education or group awareness courses we offered to give them the motivated start the needed and make it all relatable to daily life for them
- They couldn't connect with if any education provided, due to timing or location or just no availability of courses or online groups
- No support for those with comorbidities so they can access suitable exercise to support them
- They needed greater support for motivation due to anxiety and depression.

# Recommendations

- Set up local drop in and advice groups across the county, to help people 'stay on track'. These can be run by facilitators or peers that have experience of managing Type 2 Diabetes. – maybe utilising the Talk Community Hub locations.
- At the point of diagnosis a tailored 'Education Pack' that can be offered to individuals for the first 12 months, showing them where and what is available for support in Herefordshire- this can help them document the journey for the first 12 months so they can share this with medical professionals at review appointments, allowing them to demonstrate areas they may struggle with when it comes to self-management.
- Mental health support to increase motivation and compliance for those suffering with anxiety and depression, this needs to start at the point of diagnosis – utilising the Health & Wellbeing Coaches would be an option for these patients to be seen more regularly.
- There needs to be a joined up approach when supporting people with complex health needs and co-morbidities, so looking at a person holistic need's and not each condition in isolation. This will help ensure a consistent message is given reinforcing positive lifestyle changes that the individual can relate too.
- Making 'At Home' appointments available for those who are house bound or living with comorbidities so they can also receive the help and support from professionals on a regular basis and reduce risk of hospital admissions. These could be offered as telephone or video appointments to give a wide range of accessibility.
- A free Lifestyle programme (such as The Noom diet or Second Nature) to anyone diagnosed with Type 2 diabetes. Recommended and offered to those with an existing diagnosis at review appointments. The research shows they are effective, relatable and achievable for many people and reduce the perception of the restrictive diets that many don't wish to follow.

## Appendix 1



## Diabetes T2 Wheel



# A snapshot of how you are managing with your type 2 Diabetes.

## Overarching questions

- Why did you give ...that score?
- What would you say is working well? For you? And the diabetes services you receive?
- What is not working so well? For you? And the diabetes services you receive?
- What do you think could make this better?

## Questions relating to each heading.

### Medical Management

- Diabetic Nurse appointments
- Eye appointments

### Diet/Nutrition

- Meal planning and prepping
- Do you know what to eat and how to access information about that?
- Glycemic index
- Can You cook?
- Would you say you have time? Why?
- How would you say that your lifestyle affects your diet?

### Exercise

- Why do/don't you exercise on a regular basis?
- Do you understand the benefits of Exercise?
- How does your lifestyle influence your exercise commitment?
- Are there any other factors that may affect your ability to exercise?
- Could you tell me how you can access exercise?

### Medication

- Do you feel that you understand your medications and what they are used for?  
Explain?

- 

### Websites/Information leaflets

- Do you have access to information?
- How do you feel about the information provided in such websites/leaflets?

### Diabetic support groups

- How do you access support groups?
- How could these support groups be done differently?
- Where do you seek support from?

### Blood sugars

- Do you know how to access information about controlling blood sugar levels?  
Can you tell me?
- Do you understand how Blood sugar levels work? Expand?

### Digital Self-Management

- What is your understanding of apps etc.?
- Would you like to be included in the Healthwatch pilot scheme for digital inclusion?

### Equality & Diversity

1) Please select your age category:

- i) 16-24
- ii) 25-49
- iii) 50-64
- iv) 65-79
- v) 80 or over

2) What gender are you?

- i) Female
- ii) Male
- iii) No-binary
- iv) Prefer not to say

3) Please select your ethnicity:

- a) Asian / Asian British
- b) Black / Black British
- c) White British
- d) Gypsy, Roma or Traveler
- e) Prefer not to say

- Do you consider yourself to have a disability and if so please describe:
  - Physical or Mobility Impairment
  - Sensory Impairment
  - Learning disabilities or difficulties
  - Mental Health Condition
  - Any other please describe
  - Prefer not to say
  - Do you suffer from any long term health conditions (other than the diabetes discussed today)
  - Asthmas
  - Autism
  - Blindness or severe visual impairment
  - Cancer
  - Cardiovascular condition
  - Chronic Kidney Disease
  - Deafness or severe hearing impairment
  - Dementia
  - Epilepsy
  - Hypertension
  - Musculoskeletal Condition
  - Other – please describe
  - Prefer not to say
- .....

## Online Survey

# Effective Self-Management of Type 2 Diabetes

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### 1) When were you diagnosed with Type 2 Diabetes?

- Less than 1 year ago
- Between 2-5 years ago
- Between 6-10 years ago
- Between 11-15 years ago
- Between 16-20 years ago
- over 20 years ago

### 2) Please tell us what is working well in your diabetes management? (Thinking about, diet/nutrition, medicine management, exercise, blood sugar/testing and support)

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### 3) Please tell us what is not working so well in your diabetes management (again think about diet/nutrition, exercise, medicine management, blood sugars/testing and support)

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**4) Thinking about blood sugar levels - do you understand how these work - please tell us what you understand?**

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**5) Do you exercise on a regular basis, if so how often?**

- No
- Yes - once per week
- Yes - between 2-4 times per week
- Yes - everyday

**6) Does your lifestyle/work routines etc, make it hard to include more exercise in your regime for self-management?**

- Yes
- No

**7) Thinking about your diabetes appointments you attend (such as GP appointments/reviews, diabetes nurse, podiatry, retinopathy etc), how often do you have appointments, do you make them or do the services make them and do you always follow through with these appointments?**

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**8) Now thinking about your medication, do you feel you fully understand the purpose of the medication you are on, was this well explained to you and do you take all your relevant medication regularly?**

**If no, what are the reasons for this?**

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**9) What services/groups or information have you been offered to support you in your self management of your diabetes (this can be online services, reading material or local groups) and what do you feel about the information provided?**

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**10) What services do you think can be improved or offered/created to those with Type 2 diabetes in Herefordshire which would improve their self management?**

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**11) Please select your age category:**

16-24

25-49

- 50-64
- 65-79
- 80+

## **12) Please let us know your gender identity:**

- Male
- Female
- Non-binary
- Prefer not to say

## **13) Please select your ethnicity:**

- White (English, Scottish, Welsh)
- White (Northern Irish)
- White (Gypsy, Irish Traveller)
- Mixed/Multiple Ethic Groups (White & Black Caribbean, White & Black African, White & Asian)
- Asian/Asian British (Indian, Pakistani, Bangladeshi, Chinese)
- Black African, Caribbean, Black British (African, Caribbean)
- Other - Write In: \_\_\_\_\_

## **14) Please select your marital status:**

- Single
- Co-habiting
- Married
- Civil Partnership
- Separated or Divorced
- Widowed

## **15) Do you consider yourself to have a disability? (please select those that apply)**

- No disability
- Physical or mobility impairment
- Sensory impairment



- Learning disabilities or difficulties
- Mental health condition
- Long term condition
- Any other - Write In : \_\_\_\_\_\*

**16) If you have a long term condition please select which applies:**

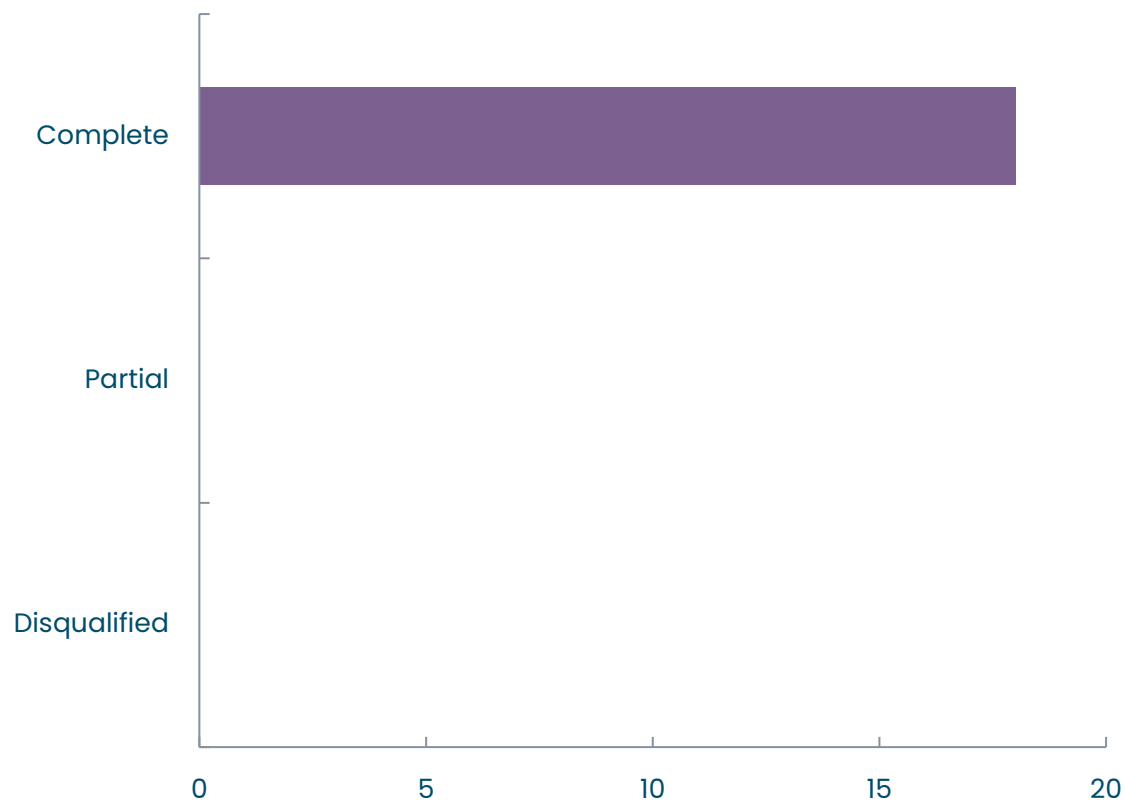
- Asthma, COPD or respiratory condition
- Cancer
- Cardiovascular condition
- Chronic kidney disease
- Epilepsy
- Hypertension
- Musculoskeletal condition
- Other - Write In: \_\_\_\_\_

**17) Finally please indicate what part of Herefordshire you like in (please select the option that best describes)**

- Hereford City
- A Herefordshire market town
- Herefordshire rural
- I only live in Herefordshire for some of the year (e.g., seasonal or overseas worker)
- Other - Write In: \_\_\_\_\_

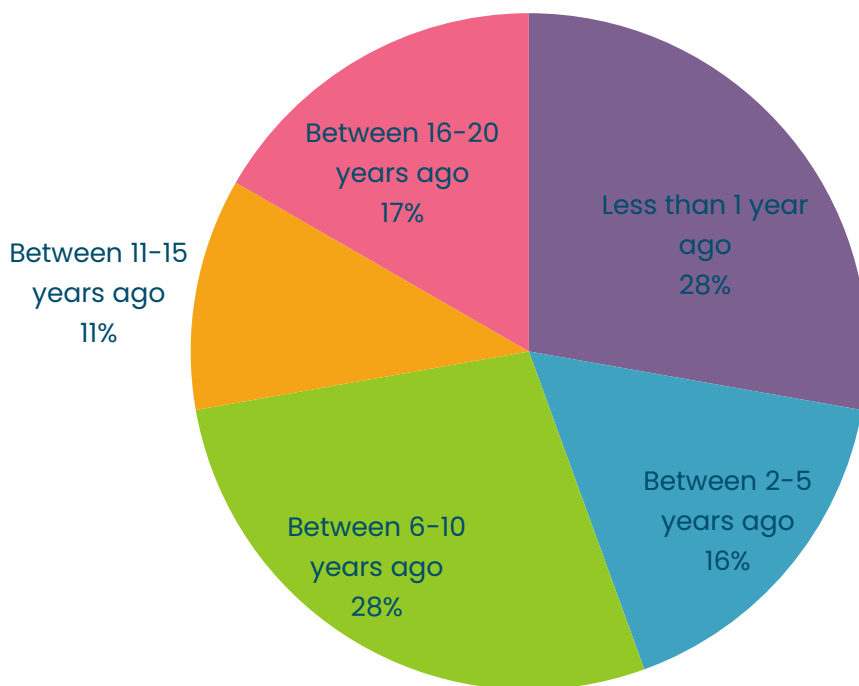
## Appendix 2

### Response Statistics Online Survey



	Count	Percent
Complete	18	100
Partial	0	0
Disqualified	0	0
Totals	18	

## 1. When were you diagnosed with Type 2 Diabetes?



Value	Percent	Count
Less than 1 year ago	27.8%	5
Between 2-5 years ago	16.7%	3
Between 6-10 years ago	27.8%	5
Between 11-15 years ago	11.1%	2
Between 16-20 years ago	16.7%	3
Totals		18

**2. Please tell us what is working well in your diabetes management? (Thinking about, diet/nutrition, medicine management, exercise, blood sugar/testing and support)**

ResponseID	Response
1	I don't know. I've been told not to get a blood sugar monitor and I'm not being tested at GP. I'm not on any medication but I am trying to make low GI decisions
2	All of the above.
3	Diabetic retinopathy. Self-management of diet and weight loss.
4	Retinopathy, well organised service proactive call up every year.
5	No problems of any sort, just take the tablets and don't over indulge.
6	Only just started
7	Switched to low carb ketogenic diet in 2016 and was able to control blood sugar levels within 3 months and come off metformin and victosa within 9 months. Have lost 50kg in weight since 2016 as well.
8	Diet
9	Using my own professional knowledge to manage my thoughts and behaviors. I have been declined prescription medication from my GP as their opinion is that I should be able to manage through diet control, therefore I purchase Victoza injectable therapy by private prescription; self-administer 1.2mg once daily.
10	Nothing currently is has been difficult to accept the diagnosis and the medication regime has been hard
11	Diet, exercise ok but very early days for me
12	Not sure anything is working well. I'm managing diet but numbers not coming down.
13	Medicine
14	Cuttings down on foods
15	Self managing
16	I support my long acting insulin with a low carb diet which In have followed for 10 years, long before it was recommended for diabetics, as it just makes common sense.

17	Adopting a keep diet and exercise and home monitoring bloods
18	Being part of the expert diabetes program was very good it's taught me about diabetes

**3. Please tell us what is not working so well in your diabetes management (again think about diet/nutrition, exercise, medicine management, blood sugars/testing and support)**

ResponseID	Response
1	I don't feel supported or informed about my condition. Feel like I've been left to my own devices and not being monitored.
2	From my annual tests and, 6monthly reporting of BP most seems OK but have to work hard to lose weight.
3	GP nurse reviews not automatically arranged annually and disappeared with COVID restrictions.
4	Annual reviews, I have to chase these, don't get them annually, even worse in covid. When I asked for one because I had unexplained weight loss I had to have a GP appointment first, when I was 2 years without an annual review, the GP to say I could have an annual review. I don't really know what the future holds for me and my condition, what the holistic picture is and what I could be doing better other than move more eat less. I feel like I'm on my own with it. At annual review I am asked what I want to achieve out of it, which is nice and person centered, but I don't know what I should be expecting or asking for.
5	Again nothing not working well.
7	What I was told to do by my medical professionals. They did not really want to solve the problem they were happy to just medicate me. I was told I would be on diabetes medication for the rest of my life and I proved that wrong.
8	Not being able to exercise enough because of problem with knees
9	GP will not accept my own thoughts and opinions on how to best manage my condition and symptoms.
10	As previous answer medication does not agree with me
11	I've had very little support so far

12	Struggling to exercise due to long covid. Feel constantly judged by diabetic nurse and she doesn't believe what I tell her about my diet. Don't feel supported.
13	The occasional cake
14	Giving up sugary things
15	Support
16	Was waiting for the usual letter to tell me to have a diabetes check so mentioned it to receptionist and she said they no longer send them out, I last had a check 14 months ago! How many others don't know to ask for a check up. At least we should have been told to book our own check -ups.
17	Being monitored by the GP surgery isn't working well they don't have the staff or up to date knowledge
18	I was able to get access to my health checks with the intention of filling in the monitoring health pages in the workbook but found that the medical details did not really match the workbooks.

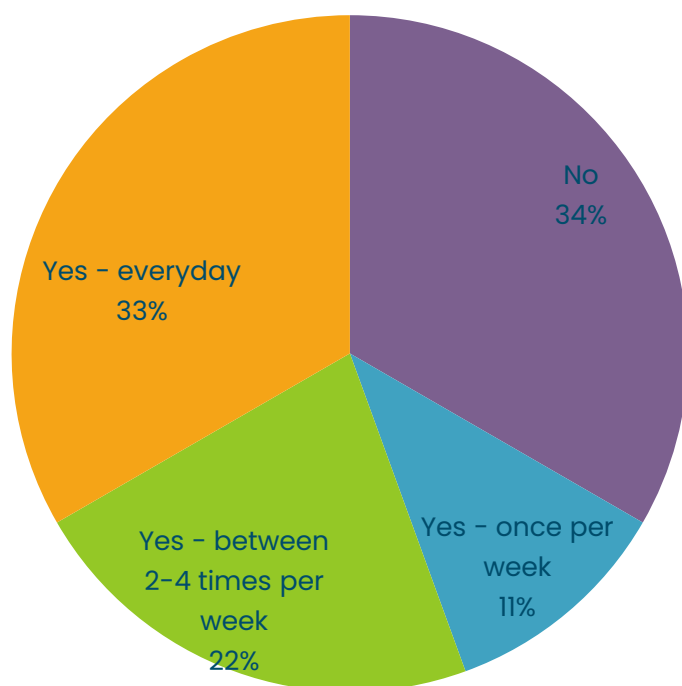
#### 4. Thinking about blood sugar levels - do you understand how these work - please tell us what you understand?

ResponseID	Response
1	Blood sugar levels increase after eating. High GI foods mean they increase rapidly, low GI means they increase more slowly.
2	Sort of- was v good in checking and understanding in the early years. Foods like porridge and berries to start the day. Slow release - no peaks n troughs in blood sugar levels. Low gi.
3	Yes, and I got a continuous blood sugar monitoring device for a while to track them in detail. Have regularly used finger pricks in the past.
4	I understand the impact of high GI foods on sugar spikes and highs and lows. I know when I have low blood sugar by the way I feel. I don't do testing strips, it has never been offered or suggested. I would like more regular hba1c blood tests, currently about once every 2 years.
5	Basic idea only, confuse when there appear to be two different measuring scales.

6	Yes.
7	I understand that whenever you eat that blood sugars are raised due to the body converting starchy, sugary carbohydrates into glucose for use to fuel the body. Any glucose that is not used is helped into fat storage cells and saved for another time. The issue for most T2 diabetics is the bodies ability to use insulin as efficiently as a healthy person does and many are insulin resistant meaning an over production of the hormone. Eating a keto diet mean I have changed the fuel system my body uses for energy and I burn ketones which are fats. I normally eat less than 20g carbs a day.
8	Have 2 yearly Hb1a which gives good idea of my glucose levels over those previous few months
9	I have sound understanding of HbA1c readings, the effects of elevated readings both long and short term, and factors that can cause these to rise.
10	Yes I understand that the food that I eat can cause my blood sugars to be unmanageable and spike
11	Not really
12	Glucose is managed in the body by insulin. Glucose comes from carbohydrates. Body can be insulin resistant which means glucose stays in the blood stream.
13	If lo no good
14	No
15	Yes my sugar levels should be around certain figures
16	Hypoglycemia is when blood sugar is below about 4.0 (I get signs about 4.6) and Hyperglycemia is for me is over about 12.0 when I also have symptoms.
17	Sugar levels raise after eating and they lower back down 1-2 hours after eating, the body regulates sugar levels with the release of insulin. It's very important to keep sugar levels with set ranges Some people have high levels in the morning due to the Dawn phenomenon Certain foods badly affect sugary levels and keep them high
18	Yes from the course

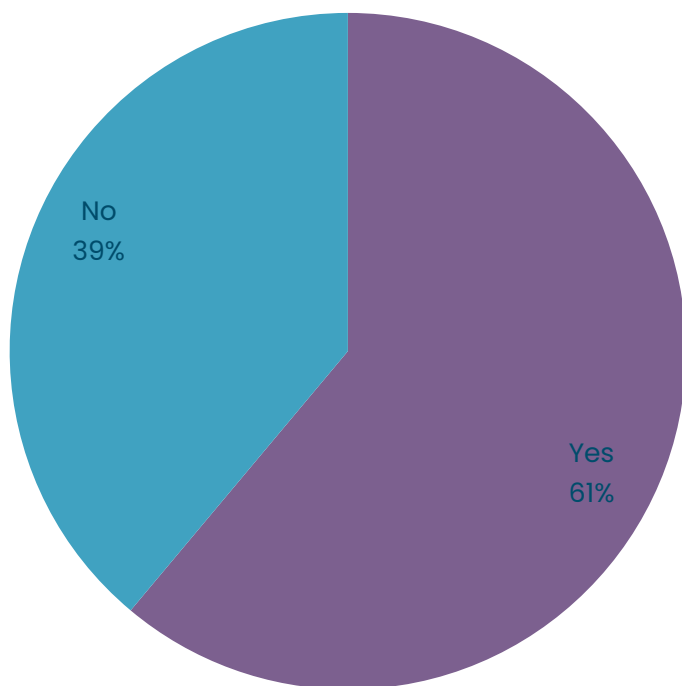


## 5. Do you exercise on a regular basis, if so how often?



Value	Percent	Count
No	33.3%	6
Yes - once per week	11.1%	2
Yes - between 2-4 times per week	22.2%	4
Yes - everyday	33.3%	6
	Totals	18

**6.Does your lifestyle/work routines etc., make it hard to include more exercise in your regime for self-management?**



Value	Percent	Count
Yes	61.1%	11
No	38.9%	7
	Totals	18

**7. Thinking about your diabetes appointments you attend (such as GP appointments/reviews, diabetes nurse, podiatry, retinopathy etc.), how often do you have appointments, do you make them or do the services make them and do you always follow through with these appointments?**

ResponseID	Response
1	I had an appointment with retinopathy. I asked for an appointment with podiatry but they discharged me. I booked a follow up appointment. But not heard any more.
2	Excellent local surgery. Always email/message a reminder, but in my diary too. I never miss arranging and attending appointments.( Weobley / Staunton on Wye surgeries.
3	Annual diabetic retinopathy, replaced by Specsavers during COVID. Poor recall from GP for nurse appointments, including but not only due to COVID.
4	retinopathy annual and proactive call up which works well Annual review, every 2 years and I have had to push for it. I haven't had podiatry, not needed. Would like more regular hba1c tests in addition to the 2 yearly annual review, but I don't ask the surgery as I know they will say no unless a doctor recommends it. So much for the patient being in control of their own condition and management.
5	The surgery always call me in when they want me and I do attend though it might be once per year.
6	First review in 3 months' time
7	Supposedly once a year but since the pandemic that has reduced and I have not seen a medical professional in two years specifically for my diabetes. When I spoke with my surgery they told me that I was no longer on the diabetic register as there had been no red flags in my blood screens between 2017 - 2020. I have had no eye or foot examinations in over three years.
8	Twice a year the surgery remind me I make the appt. Have always attended
9	I attend the GP surgery annually for blood tests. It is variable who will arrange these, on occasions I receive notification from the GP practice, other times I have to chase this up to book. Due to Covid I have not been offered the annual physical health parameter checks. I have not attended annual retinopathy for the first time in the last year due to my hectic NHS work schedule.
10	My doctor checks in every two weeks and I see the nurse every three months
11	Only had nurse appointment so far

12	GP and diabetic nurse appointments are annual (covid allowing). I attend all appointments.
13	Services make them and I follow up
15	Once a year if I'm lucky
16	As above re appointments. Have been told can't have podiatry anymore unless there is a problem. Just now been given retinopathy appointment but not last year. Always keep appointments if I am given them.
17	I have to make appointment with the diabetic nurse it's an annual check I always attend I book my blood test annually before seeing the nurse and always attend Retinopathy was annual before covid but I have had no tests for 2 years I always attend they send me an appointment Never been offered podiatry No diabetic GP service at practice
18	I always make the appointment that I am given

**Now thinking about your medication, do you feel you fully understand the purpose of the medication you are on, was this well explained to you and do you take all your relevant medication regularly? If no, what are the reasons for this?**

ResponseID	Response
1	I'm not on medication.
2	Yes, yes and yes.
3	No medication, diet controlled.
4	I'm on the following tablets statins (reduce cholesterol and prevent stroke CVD etc.) Slow release metformin & Forxiga don't know the science but reduce the sugar in the blood and the way the cells use sugar and get rid of it. I also have a self administered injection weekly diglutide - appetite suppressant, affects the way your body processes sugar, have seen a massive benefit since starting this a year ago.
5	Yes, it was adjusted after a few years.
6	Yes , well explained
7	When I was taking it yes I understood what it was supposed to do.

8	Not on medication
9	I understand the mechanisms of, and protocol for, the injection I administer. I take this medication regularly.
10	I understand the medication but it makes me feel so ill
11	Was explained but very negatively and not very well
12	Yes I understand my medication because I researched it myself.
13	Always take them refuse to take gliclazide side effects include thrush symptoms
14	No medication
15	Yes
16	Yes, I understood why I needed Insulin for my type 2 diabetes.
17	Yes I take all and my medication, I fully understand what I take and why I worked hard with a high protein low carbohydrate diet and exercise to keep sugar levels low and reduce reliance on my medication.
18	Yes

**9. What services/groups or information have you been offered to support you in your self-management of your diabetes (this can be online services, reading material or local groups) and what do you feel about the information provided?**

ResponseID	Response
1	I attended a session online. It was very low level, didn't feel it really helped me understand what being diabetic means for me personally or what to do.
2	Think am often ahead of the game, so discuss/email with appropriate expert at surgery when new research comes in. 20 years ago was low gi diet, now Prof Roy Taylor's research is turning some old ideas upside down. Michael Moseley's books follow this eating regime.
3	Very poor. Dietician wasn't really interested, especially as my weight was in the normal range. Most difference has been from me reading about the 800 calorie diet from Prof Roy Taylor, doing it, and losing 32 lbs.

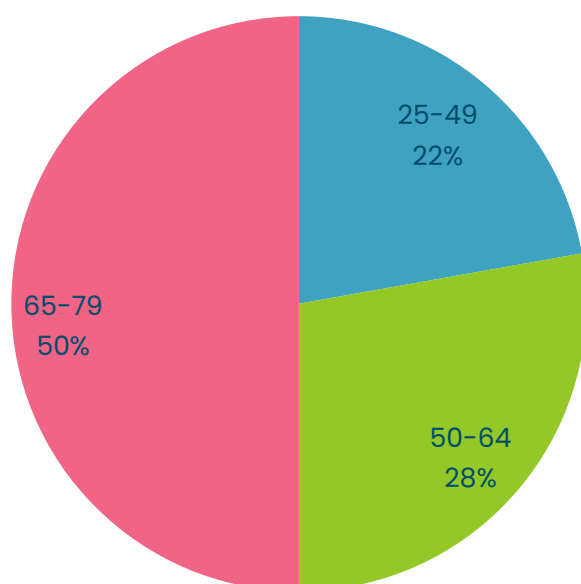
4	Map my diabetes website tool, looks great I just don't have time to use it nothing else.
5	Doctor organised a very disjointed Zoom meeting. Gave up after a while, don't really need it.
6	Online and reading report
7	At this point none.
8	None
9	Since moving to Hereford I have been offered no support or services. In addition, once I moved to Hereford I was told I no longer had access to podiatry or diabetic nurse support.
10	Only one group that does not fit my working patterns
11	None
12	Diabetic nutrition course with dieticians. That's all.
13	Reading material
14	Local group
15	None
16	Don't remember being given any information. Know there is a group in Hereford but as I don't drive I can't get there. No knowledge of a Ross-on-Wye group or support group. Had written info a long time ago.
17	When diagnosed very little was offered by my GP, just a booklet and a lot of medication, a very outdated booklet not up to date with current research. So not impressed I did my own research and followed Michael Mosley diet plan as well as using diabetes UK online. My GP Practice didn't understand my approach.
18	The expert program was excellent and I'm still digesting information

**10. What services do you think can be improved or offered/created to those with Type 2 diabetes in Herefordshire which would improve their self-management?**

ResponseID	Response
1	Exercise groups designed for people who are obese/limited mobility. Specifically that are not in the middle of a week day which prevents attendance for working age people
2	Not easy, but found in the early years, my research was more up to date than nutritionists. I suspect they are much more up to date now.
3	I live in Powys so not familiar with what is available in Herefordshire. I would strongly recommend rolling out 800 calorie diet for 8 weeks with meal replacement plan based on Prof Roy Taylor's work. Could make a huge difference, and it is a huge failing that I have had to find it and do it completely off my own efforts.
4	diet group advice and support how to cope with the burden of managing the condition, mental health feeling lumbered with it and the long term impact Knowledge of what is to come for diabetes patients what there is available Time is the issue!
5	No idea, mine seems to work well.
7	Don't know I live in South Wales. Where I live people need to be educated nutritionally so they know how food is going to react in there bodies. They need to understand that processed and refined foods are often lacking any type of nutritional value and they need to learn the detrimental effects of sugar (in all its forms) has on the human condition.
8	Can't think of anything
9	This is a complex question. With limited budget locally, healthcare staffing issues and a general reluctance to self-manage and take responsibility within the patient population I am uncertain whether real improvements are realistic or achievable.
10	Diet
12	Regular dietary advice/workshops. Diet plans to avoid contradictory advice. Exercise classes to help with cost of joining gyms etc.
13	Food advice groups
14	I live in Worcestershire so probably the same
15	More appointments

16	Regular appointments with letters as previously. Maybe a group at surgery to discuss any problems with a professional as the best info I got was when I attended a day course and could also talk to the others attending. Don't know if they are still held in Hereford.
17	A dedicated regional diabetic service, multi professional team who are diabetic specialists. Who are up to date on medication and management, Annual service that offers blood tests, medication reviews, diet advice, education, podiatry and retinopathy not operated at local level by the GP practice and GP practice staff
18	The introduction to the possible complications on the course were enough to focus me on weight loss exercise and diet

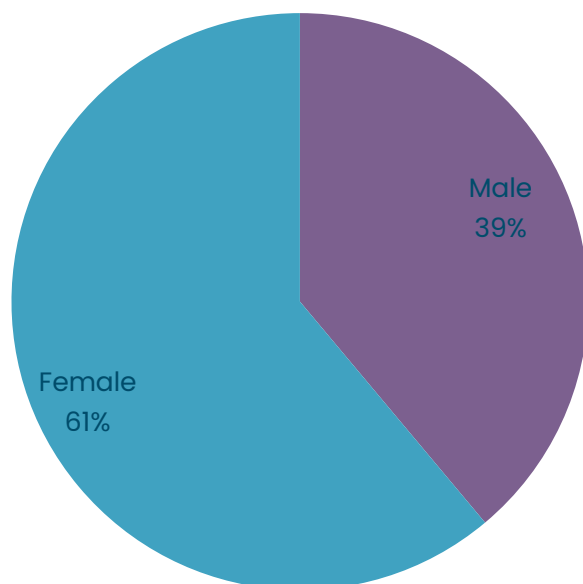
**11. Please select your age category:**



Value	Percent	Count
25-49	22.2%	4
50-64	27.8%	5
65-79	50.0%	9
	Totals	18

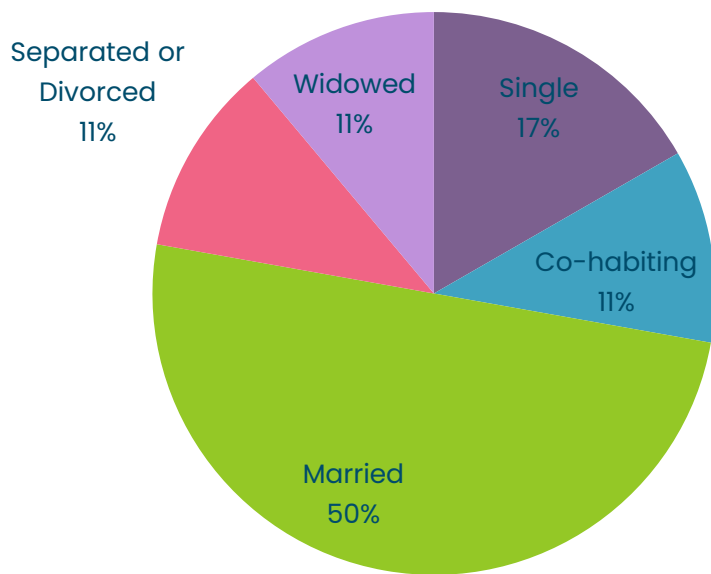


## 12. Please let us know your gender identity:



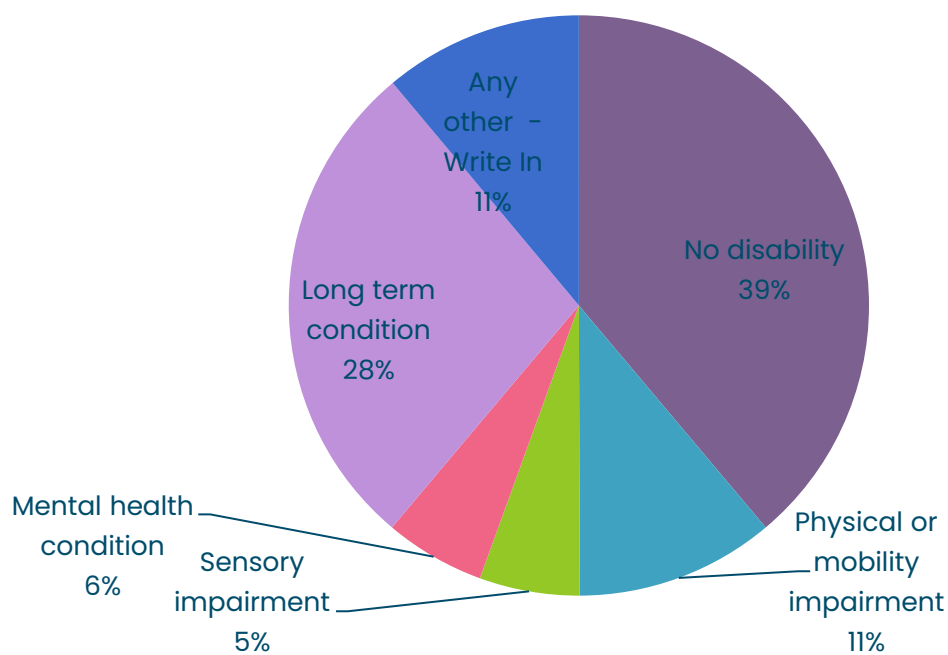
Value	Percent	Count
Male	38.9%	7
Female	61.1%	11
	Totals	18

**13. Please select your marital status:**



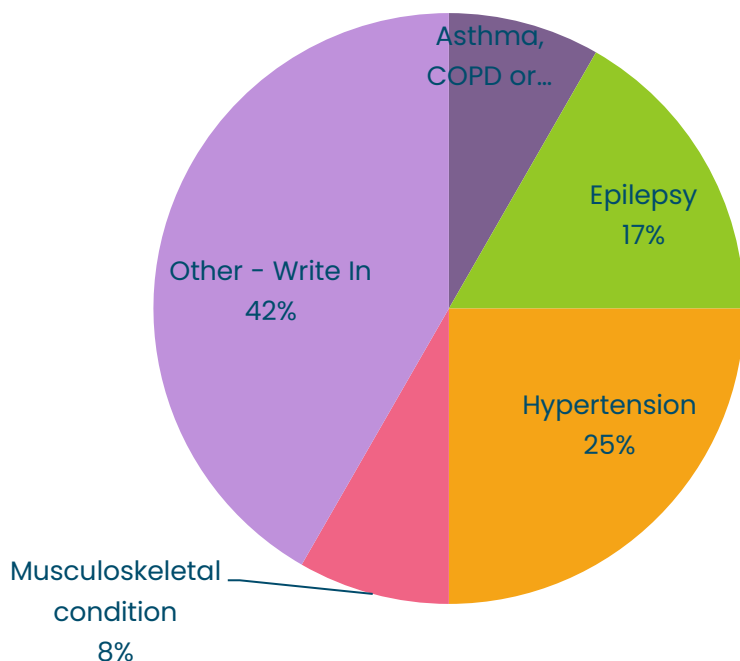
Value	Percent	Count
Single	16.7%	3
Co-habiting	11.1%	2
Married	50.0%	9
Separated or Divorced	11.1%	2
Widowed	11.1%	2
	Totals	18

**15.Do you consider yourself to have a disability? (please select those that apply)**



Value	Percent	Count
No disability	38.9%	7
Physical or mobility impairment	11.1%	2
Sensory impairment	5.6%	1
Mental health condition	5.6%	1
Long term condition	27.8%	5
Any other - Write In	11.1%	2
	Totals	18

16.If you have a long term condition please select which applies:

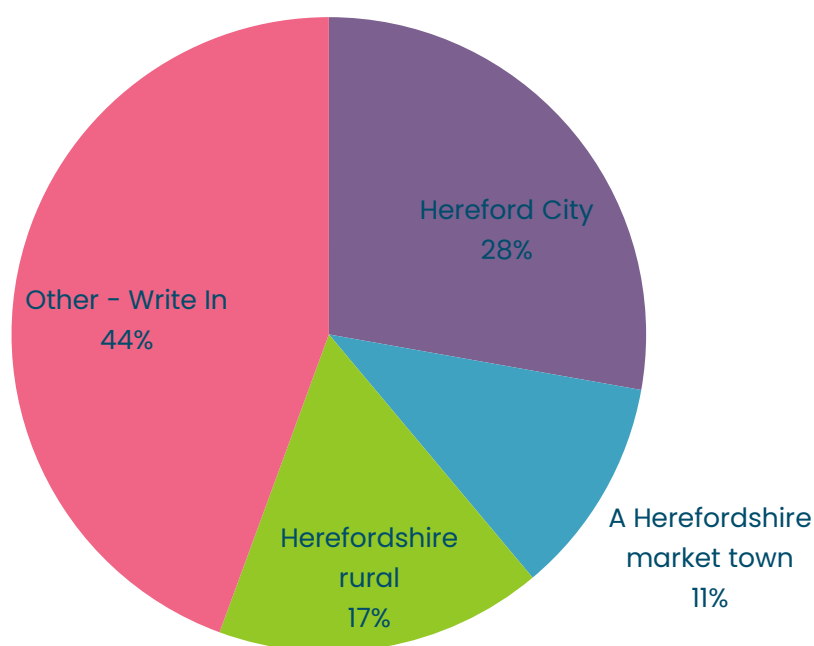


Value	Percent	Count
Asthma, COPD or respiratory condition	8.3%	1
Epilepsy	16.7%	2
Hypertension	25.0%	3
Musculoskeletal condition	8.3%	1
Other - Write In	41.7%	5
	Totals	12

Other - Write In	Count
Arthritic gout	1

DVT	1
Mental health	1
Reflex sympatic dystrophy	1
neurological	1
Totals	5

17. Finally please indicate what part of Herefordshire you like in (please select the option that best describes)



Value	Percent	Count
Hereford City	27.8%	5
A Herefordshire market town	11.1%	2
Herefordshire rural	16.7%	3
Other - Write In	44.4%	8

	Totals	18
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Other - Write In	Count
Worcestershire	2
4 miles from a market town	1
Cwmbran, South Wales.	1
Powys	1
Stourport	1
Wales	1
Worcestershire	1
Totals	8

## Acknowledgements

Healthwatch Herefordshire would like to thank all the participants who took part in this project for their time and contributions.

We would also like to thank the local primary care networks, General Practices and the Wye Valley Trust who assisted us in this work.



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