

Value of Voice: Diabetes

Listening Event capturing Diabetes Feedback 2022

Contents

Statutory Requirements of a Healthwatch

Healthwatch Luton's Listening Events

Diabetes Information

General Feedback overview

What worked well?

What didn't work well?

What could be improved and how – using Diabetes Service users views

Recommendations

STATUTORY REQUIREMENTS of a LOCAL HEALTHWATCH

1. To obtain the views of Luton residents on health and care service, to help shape the delivery and improve the quality of designing and commissioning services
2. To make recommendations to service providers and commissioners in developing, designing, shaping and improving the quality of service delivery
3. To support the involvement of Luton residents in the designing and commissioning of local services
4. Provide information and advice to inform Luton residents on choices available to them
5. To escalate findings to local commissioners, providers and nationally to Healthwatch England along with recommendations for service change.

Healthwatch Luton's Listening Events

How do we capture insights?

Healthwatch Luton have the statutory remit to gather resident views on health and care. During the COVID-19 Pandemic, Healthwatch Luton (HWL) moved some methods to online teams forums – called Listening Events. These forums allowed members of the public affected by certain topics a way of providing their experiences.

Listening Events are one method HWL use to gather Luton residents data.

If you would like to join one of our events – please visit our website www.healthwatchluton.co.uk or call 01582 817 060

Listening Events are run throughout the year and online, and are managed by our Communications and Volunteer Development Officers. They are forums in which HWL use Open question methodology and capture people's experiences. We then anonymise these views, and report on our findings. They also formulate into our wider data insight analysis quarterly and yearly on themes from Luton residents.

Diabetes Information

Diabetes (medical term, diabetes mellitus) is a complicated condition and there are many different variants and types.

Diabetes is a serious condition where your blood glucose level is too high. It can happen when your body doesn't produce enough insulin, or the insulin it produces isn't effective. Or, when your body can't produce any insulin at all.

There are two main types of Diabetes, Type 1 and Type 2.

Type 1 – you can't make any insulin at all

Type 2 – the insulin you make either can't work effectively, or can't produce enough

They are both different conditions, but are both serious conditions.

Other types include

- Gestational diabetes (which is developed in pregnancy for some women)
- Type 3c

- **Latent Autoimmune Diabetes in Adults (LADA)¹**

One in 15 people in the UK have diabetes, including 1 million people who have type 2, but have yet to be diagnosed.

Diabetes UK have recorded that almost 4.1 millions people are now living with a diagnosis of Diabetes and cases have doubled in the last 15 years. COVID-19 research shows that people with Diabetes were disproportionately affected by COVID, particularly in terms of poorer outcomes when contracting the virus.

Luton has a recorded prevalence of around 8% of the population in Luton are living with diabetes, which is the highest prevalence in East of England.

There are many programmes of work to support people with prevention of Type 2 Diabetes, as well as support and projects for people with Type 1, 2 and other diabetes. Some of these are listed below.

- Cambridgeshire Community Services: [Diabetes service \(cambcommunityservices.nhs.uk\)](https://cambcommunityservices.nhs.uk)
- Bedfordshire Hospitals Trust: [Diabetes and Endocrinology service - Bedfordshire Hospitals NHS Trust](#)
- [Luton Integrated Community Diabetes Service | Luton Directory](#)
- [Luton – DESMOND](#)
- [Bedfordshire, Luton and Milton Keynes \(preventing-diabetes.co.uk\)](https://preventing-diabetes.co.uk)

General Insights from Event:

- Individual had a blood test at GP surgery. Doctor picked up on results and said they would end up being diabetic. Then had glucose tolerance test in hospital and got diagnosed with type 1 diabetes. Joined the Diabetes Support group at GP surgery. Nurse at Diabetes Support Group at GP practice mentioned that only half of the individuals diagnosed with diabetes come in for annual checks.
- Another individual had a blood test at Bell House GP practice and when away on holiday got told of the results which were a shock and ruined the holiday. Individual's mum had sever diabetes and struggled to cope with diet and also with language as English wasn't first language. Individual, upon returning from holiday, asked questions and found out that they were borderline diabetic. They also have high cholesterol and on medication for that.
- Another individual was diagnosed over 20 years ago as type 1 diabetic. They had lost weight, were craving chocolate and were pregnant. Due to symptoms, they were taken to hospital and nurses showed how to prick fingers and inject. Over the years it has improved.

¹ [What is diabetes? | Getting to know the basics | Diabetes UK](#)

- One individual has had better experiences in Harlow than in Luton.
- Another individual found it unnerving that they were pre-diabetic.
- A diagnosed individual has a family member who is pre diabetic and would like to help them but not much information out there.
- Being diabetic means a change of lifestyle and it can be sometimes hard to control the cravings.
- One individual breaks rules and has sweets but in moderation. Another individual mentioned that as long as you are monitoring your sugar level you can know what you are having. One individual stopped eating crisps.
- One individual got referred to Desmond (Diabetes Education and Self-Management for Ongoing and Newly Diagnosed people) right away. It was online as they didn't have time to attend the course and were asked to come back
- One individual said that the diabetes journey is brand new for them. Lifestyle and challenges are ongoing. They keep themselves busy but medication is annoying and already on a long term medication for the last 26 years. This gets them down that they have to take so many medications. They were able to work for 9 hours but can't now as have rheumatoid arthritis so can't even dress themselves.
- There is a reliance on a working fridge to keep insulin for a type 1 diabetic– there should be a level of control and autonomy. One individual thought she was dying and asked how long she has got. She had a 6 month old baby

What worked well?

- Individual mentioned that as a type 1 Diabetic everything had changed for them and it had all gone digital. They don't have to inject and finger prick anymore. Although it took five years for them to get the insulin pump option they are happy now as it is much easier to handle and manage.
- Pre pandemic there was a diabetes support group being run in Luton, they had guest speakers attend to give information but there were only about 8 or 9 people who attended and as there was no funding, a room in Hightown was used. Since the pandemic it hasn't restarted. This group was good for gathering information and supporting each other.
- One individual mentioned that support and meetings since lockdown had been online and people want face to face contact.

- One individual is pleased that they get a choice as they don't want to take tablets.
- Mum of an individual attending was type 2 diabetic and reversed it by cutting sugar out completely.
- Desmond course is excellent.

What did not work well?

- At a recent hospital appointment individual was shown how to change the insulin in the pump and got told that what they had learned previously was wrong. It was supposed to be done with a vial and not a cartridge. Individual was upset and has left a feedback.
- It was mentioned that an individual left a message on the diabetic telephone line at the hospital for the diabetic clinic or diabetic nurses but had not heard back.
- One individual felt that eye clinic and podiatry discharged them because they want to get rid of patients.
- Chiropody appointments: As a diabetic, individual was able to access Chiropodists for foot care but during the pandemic they were discharged from the service giving the reason that they no longer qualified and that there are far too many diabetics. Individual has been accessing this service for 25 years and finds it financially challenging to afford a private chiropodist

What could be improved?

- It was mentioned that there should there be more support for dealing with diabetes as it comes across as a shock.
- Face to face support groups
- Instead of giving the excuse to patients that services are short staffed, services need to sort it as Diabetes type 1 is a life threatening condition. There shouldn't be an excuse.
- Need better communication with diabetic team at hospital.
- Very different experiences as different types of diabetes – Gardenia and Marsh Farm surgery couldn't get prescription right for the vials. Waiting for the prescription to be reissued
- Mental Health – There should be more support as it is a chronic condition and affects people's mental health.
- At diagnosis there should be more support for all long term conditions.
- Suddenly you are not allowed any sugar or chocolate – it's a shock and other life stressors – impact mental health.

- No faith in GP's as it is not one GP looking after patients anymore. Talking to a new GP every time and repeating story. Got told about iron levels only when individual asked and got told that they are anaemic. GP suggested getting some iron tablets but wasn't forthcoming with how many should be taken.
- Individual feels that GP doesn't have time to talk to them. Individual can communicate and ask questions but not everyone can and this includes the Asian community as they can be reluctant to talk.
- Diabetes is prevalent in Asian community and there should be more awareness about this. Volunteers are making a difference.
- Volunteers run an Asian health and wellbeing club, which gives people a healthy diet, exercise and a meal, which might be the only meal they are having. They educate but it shouldn't be on volunteers only.
- One individual ended up being in a diabetic coma. They finished a night shift, went to bed and were howling and unaware. They woke up surrounded by paramedics and spent 12 hours in Accident and Emergency. They weren't aware that this could happen. So there should be better awareness and education.
- Individual learned that there are three types of diabetic coma – people either howl or become violent and then the third one where people are normal. More awareness about diabetic coma.
- When asked about health checks in relation to diabetes, individuals regularly have a Retina scan and get their feet and weight measure with the diabetic nurse and fees well monitored
- There is no support for diabetic type 1 other than monitor beeps when they are in hypo.

Recommendations

- More awareness was a theme running through our experiences – awareness for the general public, and awareness of more detailed information around an individual's diagnosis; as well as culturally specific communications to diverse communities
- More crisis support for people with Diabetes – trying to get hold of primary care / GP was becoming difficult, and support with apparatus and medical machinery would be recommended
- Further support to Voluntary led support groups which took place prior to Pandemic – some people found these invaluable but now are hard to find / join.



Healthwatch Luton
Marsh Farm Futures House
Luton LU3 3QB

www.healthwatchluton.co.uk
t: 01582 817 060
e: info@healthwatchluton.co.uk