

What do people want from health and care services?

The future of diabetes



Diabetes is a long-term condition. People live with it every day and their needs may change over time. Getting the right care can make a big difference. But all too often people with diabetes are let down by the system.

“I would like to be asked ‘How are you?’ not ‘How is your diabetes?’, ‘How are your sugars?’. I can’t remember ever being asked.”

Common issues and challenges:

- Appointments at different times in different places.
- Different parts of the health and social care system not talking to each other.
- Conflicting advice.
- Having to battle to get the best care.
- Postcode lottery of services and support.
- Consultations that feel like tick box exercises.
- Lack of involvement in decisions about treatment and care.
- Being treated as a condition, not a person.

Key areas of concern

Care in hospital

Often hospital staff don’t understand diabetes, and hospital procedures stop people effectively managing their condition.



“On the maternity ward they didn’t have any training on diabetes. I was having to explain to the nurses about it through contractions.”

Emotional and psychological care

Diabetes is not just a physical condition. People talked about the difference it made when healthcare professionals took their emotional needs into account.



“I told my consultant that I felt horrendous. He replied: ‘I’m not here to talk about your emotions.’”

Access to technology and treatments

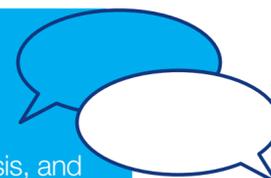
Getting the right technology and treatment can be life-saving, and life-changing. But 29% of people said they’d had trouble accessing the medication or equipment they need to manage their diabetes.



“I need information and data if I’m going to control my diabetes and I can’t get access to a blood glucose meter which leaves me fighting in the dark.”

Education, information and support

People want more information at diagnosis, and throughout their life with diabetes. We heard that when people were offered education and support, it can be transformative. But it’s not always clear where to turn.



“It’s the gorilla in your house metaphor – diabetes is like being given a gorilla and having to learn how to tame it.”

What would make things better in future?

“People need to get the right information at the right time. It’s a progressive illness. There needs to be constant update and it’s not happening.”

We need:

Time

- More than 10 mins if needed, especially at diagnosis.
- Take time to show where to get more help and support.

Availability, access and flexibility

- Direct contact by phone or text with diabetes team.
- Appointments that fit around daily life.
- Co-ordinated tests and annual checks to reduce the number of appointments.
- Signposting to support from other people with diabetes.

Expertise

- Access to specialised healthcare professionals.
- The right technology and equipment.
- More knowledge in primary care and on hospital wards.

More involvement and better co-ordination

- Consistent advice and better communication.
- Joined up care.
- Being included in planning own care.
- To see test results in writing or electronically before a consultation.

