
BACKGROUND

In Blackburn with Darwen, the prevalence of diabetes is well above the England average at every age from the 30s onwards. The crude rate is the 18th highest out of more than 200 Clinical Commissioning Groups.*

With the higher than average diagnosis of diabetes in the Borough, Healthwatch Blackburn with Darwen identified the need to gather the experiences of residents living with diabetes, from diagnosis to management/ongoing support along with their views on what works and what needs improving with the local services.

**Blackburn with Darwen Public Health Joint Strategic Needs Assessment 2015*

METHODOLOGY

A questionnaire was designed and distributed to AGE UK, The Older Peoples Forum, One Voice and Blackburn with Darwen CCG. In addition Healthwatch staff also completed the survey with residents at luncheon clubs, coffee mornings and XPERT programme throughout the Borough. These took place at Accrington Road Community Centre, Bangor Street Community Centre, Green Lane Community Centre, Audley Sports & Community Centre and Derwent Hall.

An online version was also made available to be completed on the Healthwatch Blackburn with Darwen website.

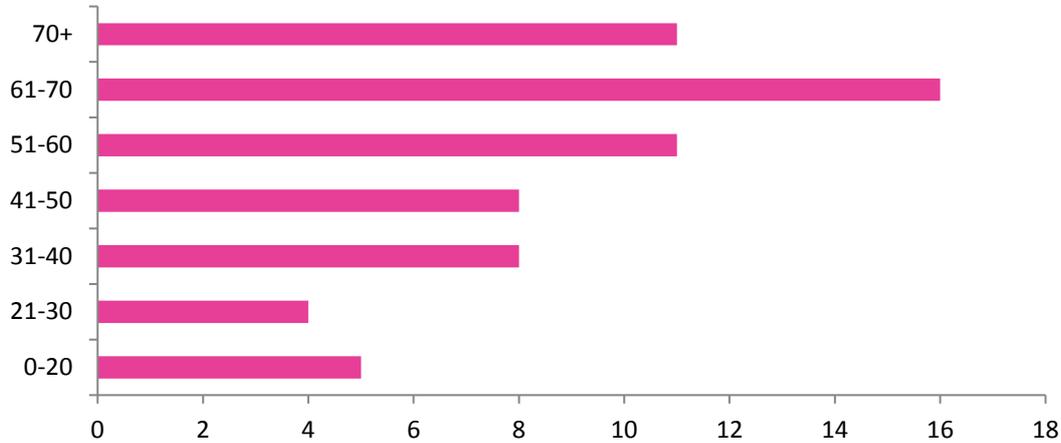
Three Your View Your Voice workshops were held at Your Support Your Choice, Blackburn and at The Old Chapel, Darwen. These sessions allowed residents to tell us their experience of living with diabetes from pre-diagnosis to management of their condition.

Two 1:1 interviews were also conducted in order to provide more in depth answers.

Via these three methods a total of 91 residents were engaged with in January to March 2016 with 65 questionnaires being completed.

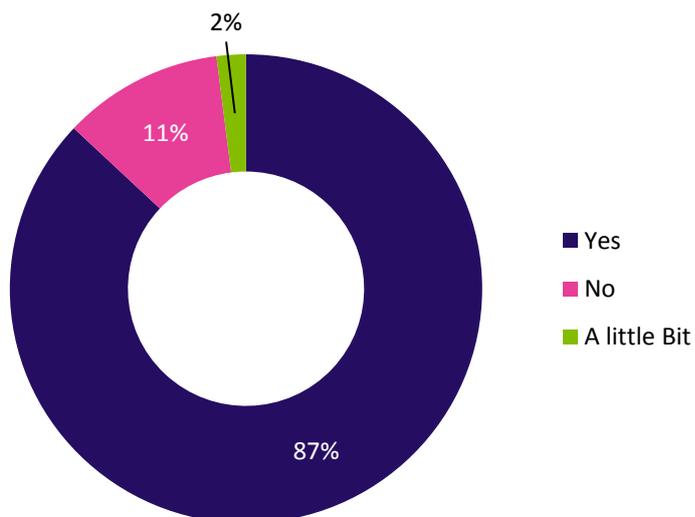
SURVEY RESULTS

How old were you when you were first diagnosed with diabetes?



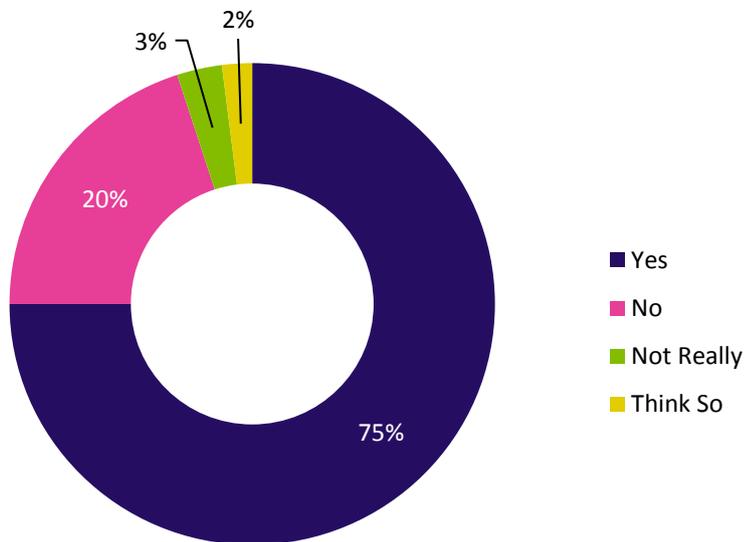
3 respondents did not know/could not remember the age they had been diagnosed.

Do you know the difference between Type 1 or Type 2 Diabetes?



87% of respondents knew the difference between Type 1 and Type 2 diabetes

If your GP told you that you are borderline diabetes would you know what that meant?

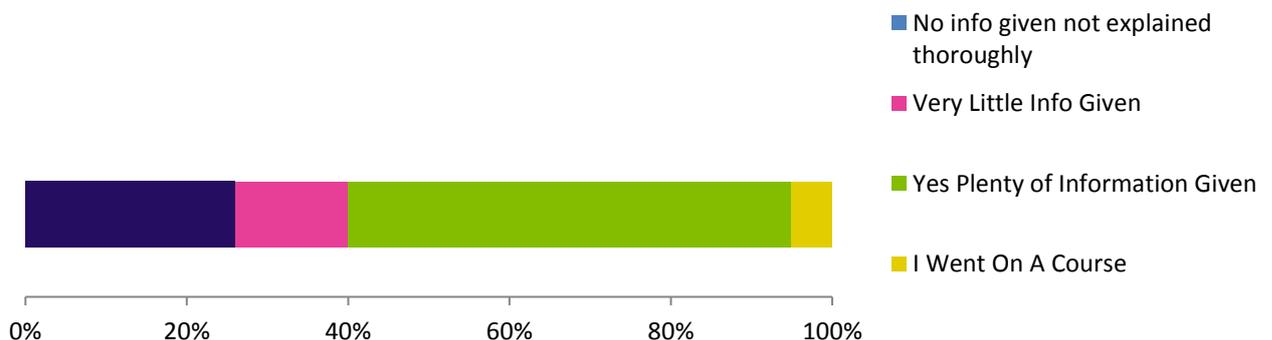


“I went to GP 9 times before diagnosis”

“I didn’t know I was borderline”

“Kept being prescribed tablets for different things”

How would you describe the amount of verbal and written information you were given when first diagnosed - was it explained thoroughly?



26% of participants stated that they had no information given to them when they had been first diagnosed, whilst 14% participants stated that they had very little information given. 55% of participants felt they had been given plenty of information.



“I was just told to look on the internet”

“Didn’t really know what to do wasn’t told anything”



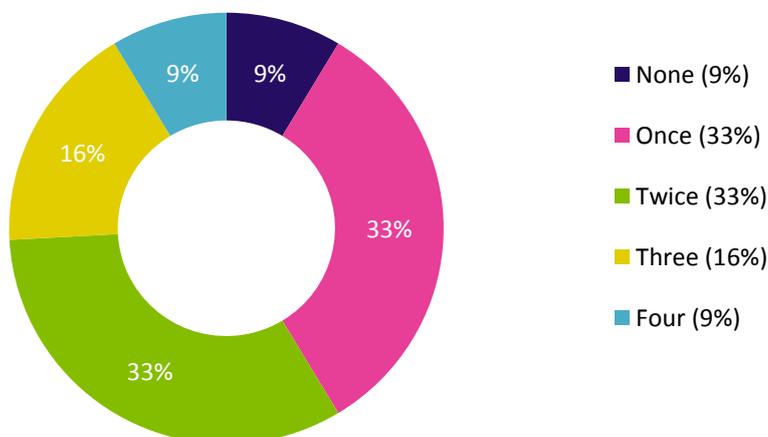
“Wasn’t satisfactory there wasn’t any immediate support, Doctors are very dismissive if you’re using alternative medicine”



“The community nurse made up an easy read leaflet for me”

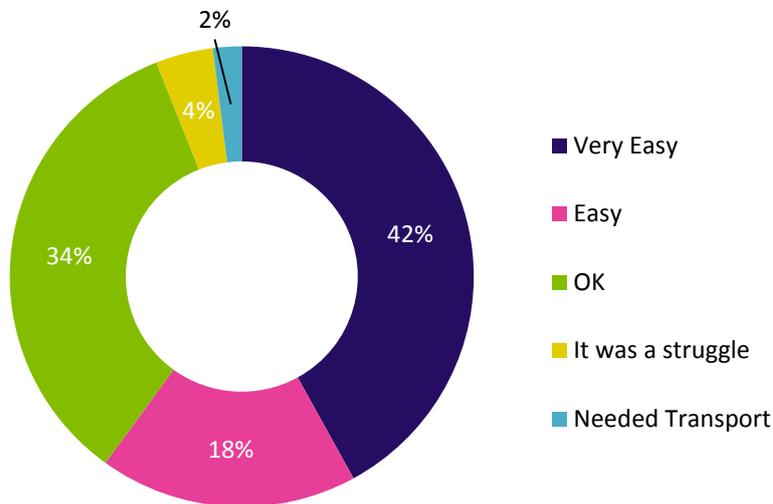
“I went on an X-Pert training course”

In the last 12 months how many times have you had a diabetes check up?



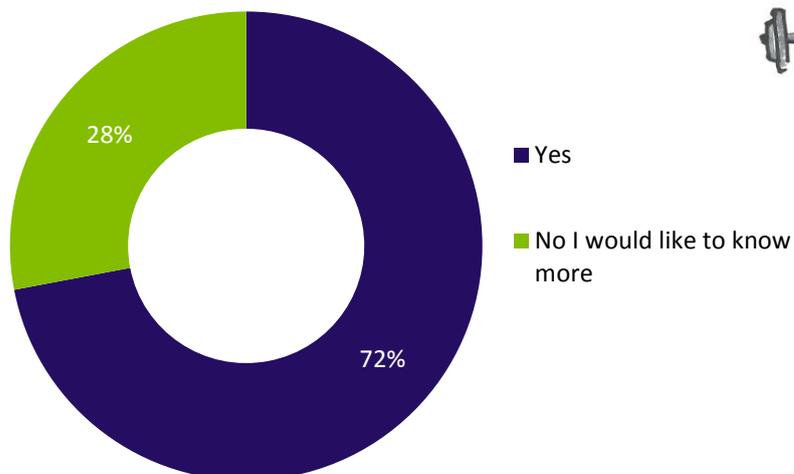
How convenient was it for you to get to your diabetes check up?

60% of participants felt it was very easy/easy to get to their check up with 4% stating it was a struggle.



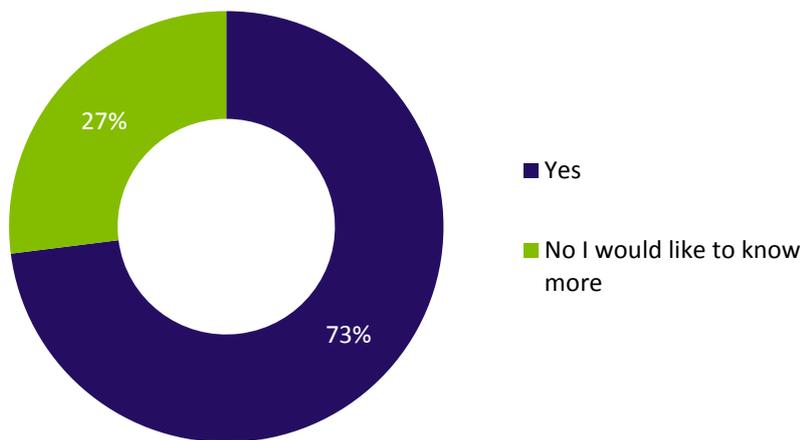
Do you know enough about the role of physical activity in managing your diabetes?

72% of participants stated they knew enough about the role of physical activity to manage their diabetes



Do you know enough about what you should eat to help manage your diabetes?

73% of participants felt they knew enough about what they should eat to help manage their diabetes with 27% stating they did not and would like to know more.



How do you control your diabetes?

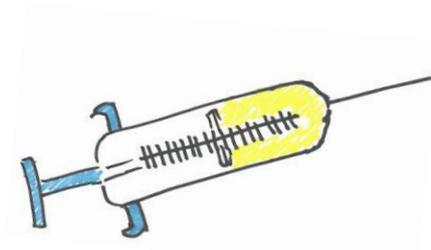
A number of participants used a combination of ways to manage and control their diabetes

How do you control Your Diabetes	Number of Respondents
Insulin	7
Tablets	45
Diet	30
Physical Activity	13
Other	2

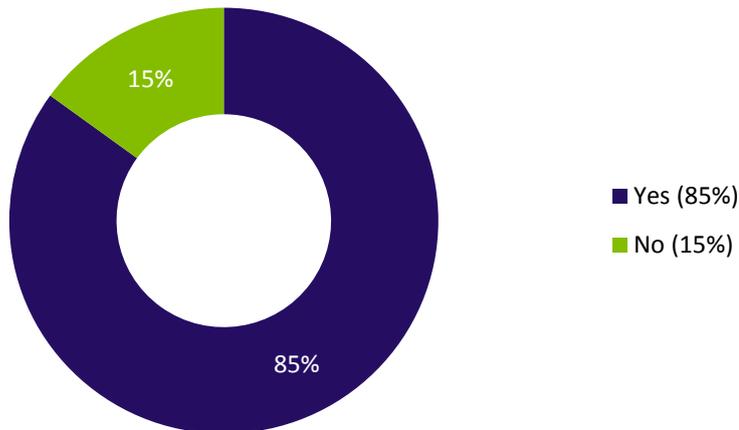


“Had to fight for diabetic strips”

“Easy to prescribe tablets don’t look at the whole person”



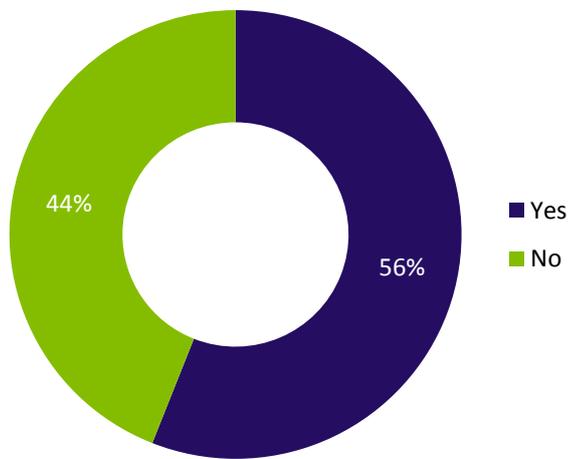
Do you take any medication for any other condition?



85% of respondents take medication for other conditions, which are shown in the table below:

Medication Taken For:	Number of Participants
High Blood Pressure	33
High Cholesterol	29
Heart Disease	16
Arthritis	4
Depression	3
Hypertension	2
Meniers	2
Cancer	1
Stroke	1
Pancreatitis	1
Bladder	1
Cramp	1
Hypothyroidism	1

Have you ever participated in an education or training course on how best to manage your diabetes?

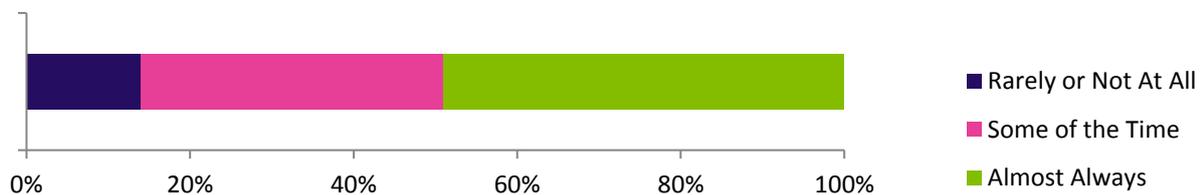


The table below shows how long ago 56% of participants attended a training course.

Less than 6 months	4
6-12 months ago	1
1-2 years ago	13
2 years ago	7
Cant remember	7

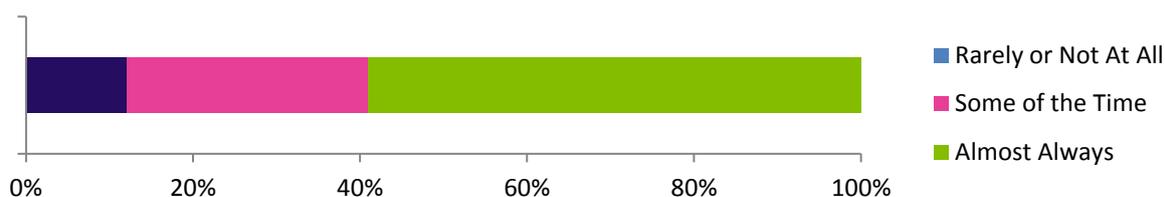
In the last 12 months when you received care for your diabetes did you:

Discuss the best way to manage your diabetes



14% of participants said they didn't/rarely discussed the best way to manage their diabetes, 37% said they had some of the time and 49% stated they almost always discussed the best way to manage their diabetes.

Were you given personal advice about the kinds of foods to eat?



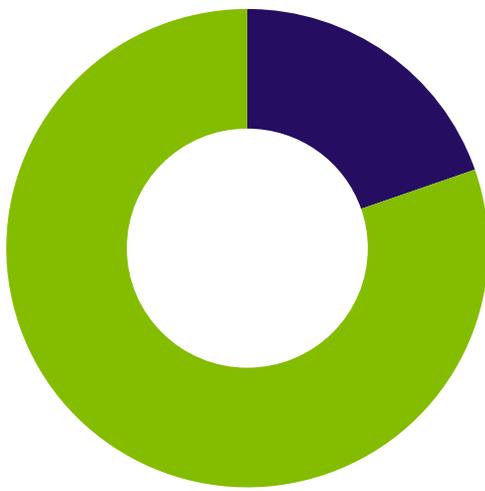
59% of participants felt they were almost always given personal advice about the kinds of foods to eat, 12% of participants said they rarely discussed this and 29% said they did some of the time.

In the last 12 months have you received emotional support from anyone to help you cope with your diabetes?

56 people responded to this question with 31 not having received any support in the last 12 months. The table below shows where the 25 respondents had received support

Received Emotional Support from	Number of Participants
Dr/Nurse at GP Surgery	14
Nurse	4
Specialist Nurse	2
X-Pert Training Course	2
Social Worker	1
Patient Support Group	1
Not Sure/Can't remember	1

Have you stayed in hospital overnight in the last 12 months for any reason?

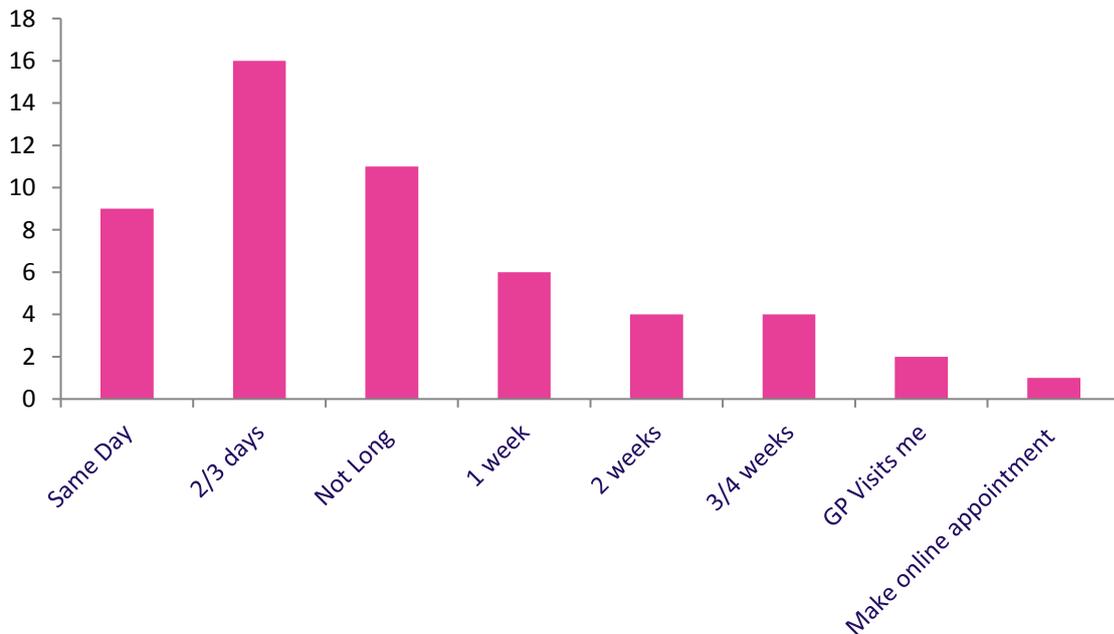


■ Yes
■ No

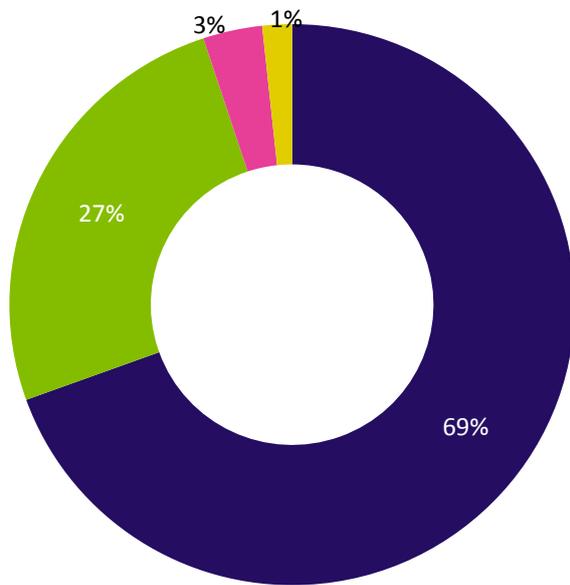
“In for 2 weeks with diabetes couldn’t get my levels right”

“15 months post op gastric bypass now suffering from hypoglycaemia”

The last time you made an appointment to see a Doctor at your GP surgery for any reason how long was it until you were seen?



Have you been involved as much as you wanted in the decisions about your diabetes care and treatment?

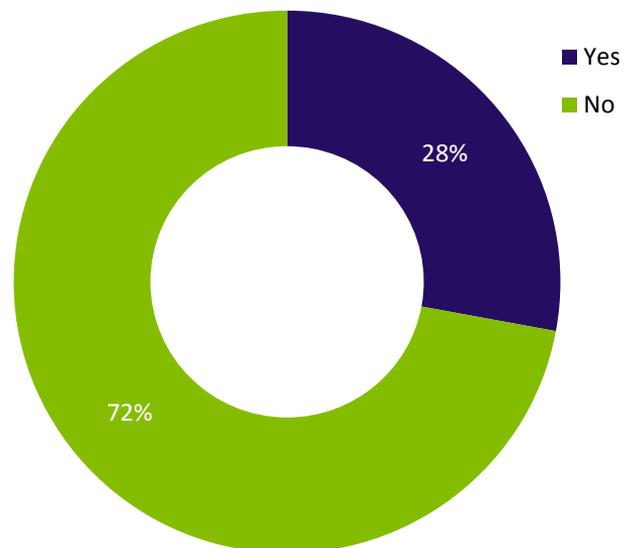


- Yes
- No
- Sort Of
- Don't Care

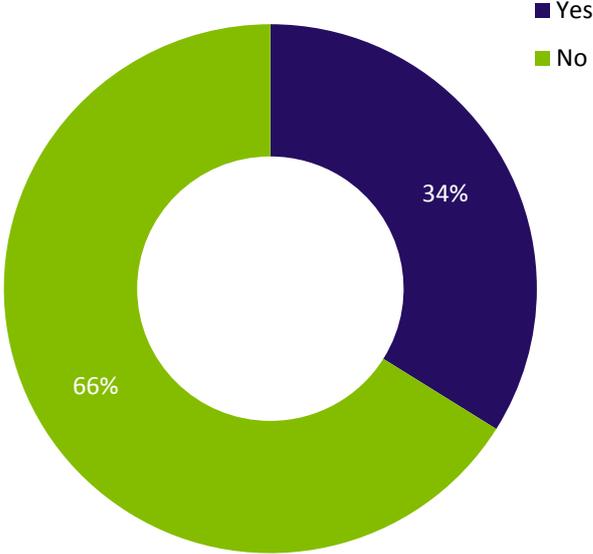
69% of respondents said that they had been involved as much as they wanted in the decisions about their care and treatment

Do you have a long standing physical or mental health condition?

Physical or Mental Health Condition	Number of Participants
Arthritis	10
Heart Condition	6
Blood Pressure	5
Depression	2
Cancer	2
COPD	2
Menieres	2
Asthma	1



Does your diabetes or additional condition affect your day to day activities?



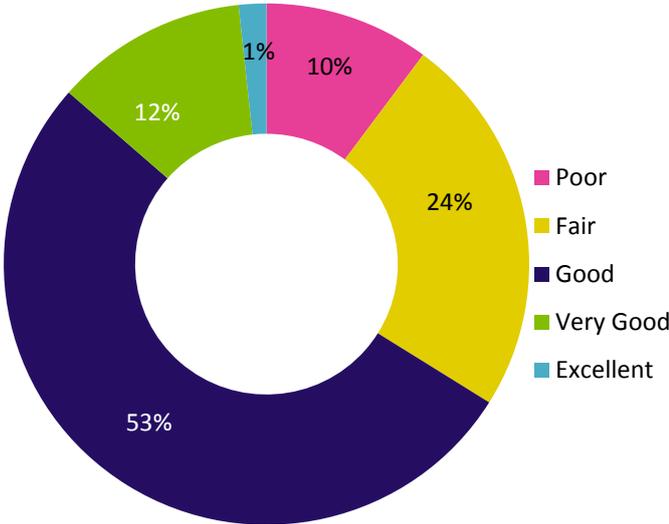
How would you rate your health during the past month?

“15 months post op gastric bypass now suffering from hypoglycaemia”

“When sugar goes low can’t walk or do anything”

“3 years on crutches”

“Unable to do everyday chores”



Summary

1. 40% of participants felt they had received very little or no information when they were first diagnosed.
2. 91% of participants had received a diabetes check up within the last 12 months, 60% of these felt that it was very easy/easy to get to their check up.
3. 72% felt that they knew enough about the role of physical activity in managing their diabetes but 28% felt that they would like to know more.
4. 73% felt they knew enough about what they should eat to help manage their diabetes, 27% felt they didn't and would like to have more information.
5. 59% of participants said they were given personal advice about the kinds of foods to eat when discussing their diabetes care in the last 12 months.
6. 45% participant took tablets to manage their diabetes, with 30% managing with diet and 13% with physical activity.
7. Some participants felt that it was too easy for tablets to be prescribed and they were not looked at individually.
8. 85% of participants took medication for other conditions.
9. Some participants felt that professionals were very dismissive of them when they were using alternative treatment and medicine.
10. 56% of participants had participated in an education or training course on how best to manage their diabetes.
11. In the last 12 months when receiving care for their diabetes 49% of participants stated they almost always discussed the best way to manage their diabetes. 37% stated they did some of the time and 14% said they rarely or not at all.
12. 67% of participants had been involved as much as they wanted in the decisions about their care and treatment.
13. 34% of participants said their diabetes affected their day to day activities.
14. 53% of participants felt their health had been good in the past month.

Recommendations

1. 40% of participants felt they had received very little or no information when they were first diagnosed. It is recommended that health care professionals provide patients with the information they require, and allow patients to ask questions to ensure they are confident and able to manage their condition. This is in accordance with NICE clinical guideline CG138 1.5.11.
2. 91% of participants had received a diabetes check up within the last 12 months, with 60% of these feeling it was very easy/easy to get to their check up. It is recommended that services review the time and locations of check ups and support patients who did not find it easy to get to their check ups. This is in accordance with NICE clinical guideline CG138 1.3.1.
3. 28% of participants felt that they would like to know more about the role that physical activity can have on managing symptoms and 27% on diet. It is recommended that health care professionals provide information on diet, exercise and signpost patients to further information and local services. This is in accordance with NICE clinical guideline CG138 1.3.2 & CG138 1.5.18.
4. 51% of patients stated they were not involved in discussions about their care either some of the time or all of the time. It is recommended that health care professionals ensure patients are encouraged to be involved in their care. This is in accordance with NICE clinical guideline 1.5.20.

[Patient experience in adult NHS services: improving the experience of care for people using adult NHS services: NICE guidelines \[CG138\]](#)

- 1.3.1: Adopt an individualised approach to healthcare services that is tailored to the patient's needs and circumstances, taking into account their ability to access services, personal preferences and co-existing conditions. Review the patient's needs and circumstances regularly.
 - 1.3.2: Inform the patient about healthcare services and social services (for example, smoking cessation services) that are available locally and nationally. Encourage and support them to access services according to their individual needs and preferences.
 - 1.5.11: Give the patient information, and the support they need to make use of the information in order to promote their active participation in care and self-management.
 - 1.5.18: Advise the patient where they might find reliable high-quality information and support after consultations, from sources such as national and local support groups, networks and information services.
 - 1.5.20: When discussing decisions about investigations and treatment, do so in a style and manner that enables the patient to express their personal needs and preferences.
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TRUST RESPONSE

Re: Response to Healthwatch Blackburn with Darwen report on Diabetes: the experience and provision of local services.

Results of the report were given to Christine Pearson, Director of Nursing for East Lancashire Hospitals NHS Trust.

“Healthwatch volunteers and staff are thanked for the work undertaken to support the Trust in highlighting positive findings from patients and their families, as well as highlighting some areas for improvement. We take all feedback seriously and work hard to ensure all our patients and their relatives have a good experience when using the Trust’s services.”

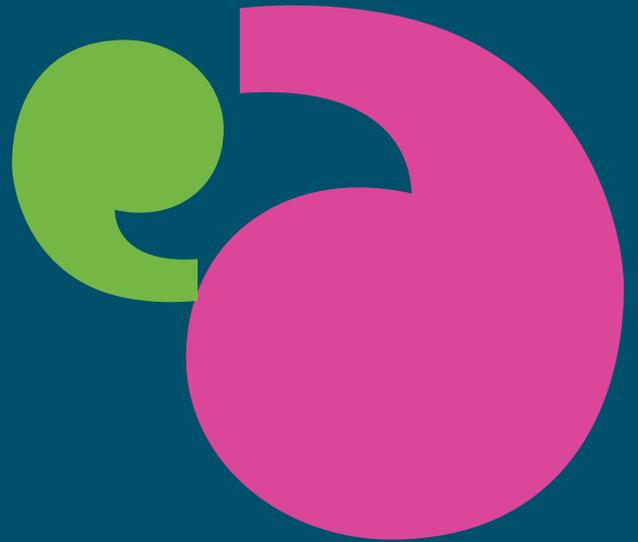
After reviewing the comments from patients and the recommendations made by Healthwatch BwD, we want to advise that:

- When patients are newly diagnosed with diabetes within the hospital, this is usually Type 1 Diabetes. Patients are provided with advice and information leaflets regarding their insulin regime, how to inject and store their insulin, how to manage hypoglycaemic episodes, diet and driving with diabetes.
- So we do not overload patients with information at this time, our Diabetes Specialist Nurses contact each patient on discharge from hospital and then review on a weekly basis to support self-management of their condition.
- Patients diagnosed with diabetes are given an individualised care plan from the Diabetes Specialist Nurse and receive on-going support and education to manage their condition.
- Diabetes patients are offered an appointment with the dietician who can offer specialist dietary advice and provide information leaflets.

We note the report covers both Hospital (Secondary Care) and Primary Care and our response relates to care provided by East Lancashire Hospitals NHS Trust.

We are pleased to advise that an audit undertaken by the Royal College of Paediatrics and Child Health (National Diabetes Audit 2014-15) shows an improvement in the health of local children and young people living with diabetes. Particularly significant is the fact that the number of young patients at the Trust with high HbA1c - those at high risk of diabetic complications - is significantly lower than other areas within the northwest and nationally, reflecting the huge amount of work diabetes doctors, staff and families at East Lancashire Hospitals NHS Trust continue to invest in high risk younger patients

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