

 Support needs of diabetics aged 18-55, Type 2 diabetes. 

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Foreword

This report outlines the views of respondents who took part in the Diabetes survey which was carried out by Healthwatch Barking and Dagenham.

The main focus was to investigate the experiences of patients aged between 18 and 55 who have type 2 diabetes, in order to learn about their support needs.

Although 200 questionnaires were sent out, only 18 were completed and returned. Therefore, this report is a snapshot of the 18 responses.

This document represents a collective public response to the consultation and is a random sample which has been anonymised. This has been conducted impartially - Healthwatch Barking and Dagenham have no organisational view.

Copies of this report are available by contacting Barking and Dagenham Healthwatch on 020 8596 8200 or by emailing Info@healthwatchbarkinganddagenham.co.uk

Copies may also be downloaded from our website www.healthwatchbarkinganddagenham.co.uk

Background

According to Diabetes UK Right, there are over 3 million people in England living with the condition - 2,703,044 diagnosed and an estimated 500,000 people who have Type 2 diabetes but do not know it. In the UK, about 90% of all adults with diabetes have type 2 diabetes.

In local context, the Joint Needs Assessment 2013 for Barking and Dagenham states that by the end of March 2012, 9523 people had been diagnosed with diabetes in this borough. However, it is estimated that at least 1642 people remain undiagnosed as of November 2012. It is estimated that there will be a minimum of 14000 people living with diabetes in this borough by 2030 (JSNA, 2011).

According to the Action for Diabetes report published by NHS England, there are still more opportunities in England to improve the patient experiences of diabetic patients.

The Health and Adult Select Committee carried out an in depth review of diabetes services and support for diabetics in Barking and Dagenham last year. The review states “Type 2 diabetes is a serious health concern for Barking and Dagenham with more than 9,000 people already diagnosed. With the changes to the ethnic makeup of the population and the challenges associated with increases in adult obesity, experts believe that the numbers of people likely to develop diabetes in the next twenty years are set to rise by 50%.”

One of the recommendations from the review was to look at how young adults with type 2 diabetes could be supported in the borough.

Healthwatch Barking and Dagenham undertook this project to provide information in regards to the support needs of younger adults and their experiences of the diabetes services.

The questionnaire used was the same as the HASSAC but with additional questions about support. This enabled our organisation to look at a wider picture provided by respondents.

A letter and questionnaire were sent to participants through local GP practices. The letter explained that participation is voluntary and individuals are not required to answer any questions if they do not want to. It was also made clear that participation or non-participation will not affect access to their current diabetes services. It was also highlighted that all information collected will be kept strictly confidential.

Summary

Of the 18 respondents, 50% said that they fully understand what diabetes is. 44% said there are a few things they are unsure about. From the 44%, 3 respondents indicated that they needed more information on how to incorporate things like exercise, diet in their lifestyle and how they could change their current lifestyle to enable them to do this.

The majority of the respondents were given information by their GP or nurse. Only 11% went on line to find information.

All 18 respondents indicated that they received information from their nurse.

61% indicated that they had not been on any programme or course to help them learn and manage their condition. When asked if they would like to go on a programme or a course, all 61% said yes. This indicates that there is a need for sessions to educate individuals to help with the self management of diabetes.

It was apparent from comments respondents made that they would like to take up the diabetes exercise programme but at the moment it is only available in normal working hours. This raises concerns that available support services are not flexible for the diabetes community and a section of people suffering from diabetes are isolated from using the services.

Overall, a large proportion of respondents found that the information they received from professionals was either fairly helpful or very helpful. However comments received indicated that information is mainly in text form. There needs to more options available for individuals on how they would prefer information, for example; DVDs, peer support etc.

A large proportion of the respondents also indicated that a form of peer support group would be beneficial. The results show that an online option was preferred due to other commitments and this would allow diabetic patients to share real life experiences and updated information, as well provide a support platform for others going through the same problems.

Questionnaire

In total, Healthwatch Barking and Dagenham sent out the questionnaire to 200 patients and received 18 back. The questions asked were as follows:

- When were you diagnosed with diabetes?
- How well do you feel you understand what diabetes is?
- Did someone give you information you need or did you go on line to find the information?
- Who gave you the information? Which sites did you visit?
- What sort of information did they give to you? /did you look for on the internet?
- Was this information helpful? (Please tick the one which applies)
- Please tell us what was helpful or unhelpful about the information you received?
- Over the last 12 months, which of the following healthcare professionals have you seen through the diabetes team?
- What has your experience been like from these health professionals?
- How do you manage your diabetes?
- Have you been on any courses to help you understand what diabetes is and ways to manage it?
- Would you like to go on a course?
- Do you feel that an online forum or face to face group would help you manage your support needs?
- In the last year please tell us what checks you have had?
- Do you feel your support needs are meet?
- In order to help individuals self manage diabetics what do you think is needed?

Response to consultation

When were you diagnosed with diabetes?

The results showed that 11% of respondents were diagnosed with diabetes in the last year, 14% in the last two years, 11% between 2 and 3 years and 56% of respondents were diagnosed more than 3 years ago.

| When were you diagnosed? | In the last year | In the last two years | Between 2 and 3 years ago | More than 3 years ago | Cannot remember / not sure | Total |
|--------------------------|------------------|-----------------------|---------------------------|-----------------------|----------------------------|-------|
| Respondents | 2 | 4 | 2 | 10 | 0 | 18 |
| Percentage | 11% | 14% | 11% | 56% | 0 | 100% |

How well do you feel you understand what diabetes is?

The results reflect that 50% of respondents fully understood what diabetes is, 6% did not understand what diabetes is at all and 44% are not clear on a few areas.

| | Respondents | Percentage |
|---|-------------|------------|
| I fully understand what diabetes is | 9 | 50% |
| I do not understand it at all | 1 | 6% |
| There are a few things that I am not clear on | 8 | 44% |
| I do not understand what diabetes is and would like to know | 0 | 0% |
| Total | 18 | 100% |

How informative was your GP when you first found out about your diabetes? Here are a few comments from the responses:

- *GP was really good*
- *My Gp was good when I first got diagnosed and then has left me to it”*
- *“very informative, gave me a lot of information and leaflets and answered my questions”*

- *Excellent”*
- *“His knowledge was really poor”*
- *“really really good can’t complain”*
- *“Fantastic, but overload of information, too much to take in, and all leaflets”.*
- *“Diabetes is life long; support needs to be there throughout, not just when you find out.”*

Did someone give you information you need or did you go on line to find the information?

100% of respondents indicated that someone gave them the information. Only 11% indicated that they went online.

| | Did someone give you the information? | Did you go online? |
|-------------|---------------------------------------|--------------------|
| Respondents | 18 | 2 |
| Percentage | 100% | 11% |

Who gave you the information? Which sites did you visit?

100% of respondents received information about diabetes from the diabetic nurse. 11% of respondents said they received information from the GP. 6% looked on the diabetes website for information and 6% undertook a google search.

| | Nurse | GP | Diabetes Site | Google search |
|-------------|-------|-----|---------------|---------------|
| Respondents | 18 | 2 | 1 | 1 |
| Percentage | 100% | 11% | 6% | 6% |

What sort of information did they give to you? /did you look for on the internet?

Out of the 18 respondents, 83% received information about diabetes, 67% received information on diabetes medication, 61% were given information on how to manage diabetes and 83% of respondents were given information on how to live with diabetes. Furthermore, 83% respondents received information on diet and 72% of respondents were given information on the long term health impacts of diabetes. Please note that some respondents ticked more than one option. The percentages are calculated to show the percentage from the 18 respondents.

| | | |
|---------------------------------------|----|-----|
| Information about diabetes | 15 | 83% |
| Information about diabetes medication | 12 | 67% |
| How to manage my diabetes | 11 | 61% |
| How to live with diabetes | 15 | 83% |
| Dietary | 15 | 83% |
| Long term health impacts of diabetes | 13 | 72% |

Was this information helpful? (Please tick the one which applies)

Overall respondents found that the information was helpful. 44% respondents said it was fairly helpful and 39% said it was very helpful. However, a few respondents (17%) thought that the information was not very helpful.

| | Not at all helpful | Not very helpful | Fairly helpful | Very helpful | Total |
|-------------|--------------------|------------------|----------------|--------------|-------|
| Respondents | 0 | 3 | 8 | 7 | 18 |
| Percentage | 0 | 17% | 44% | 39% | 100% |

Please tell us what was helpful or unhelpful about the information you received?

- *Picture illustrations helped me*
- *There was a lot of information given to me, but would have been nice if I could take everything in slowly, was a lot of information.*
- *Helpful with the prognosis but not the care, takes a long time to get to see the GP or Nurse.*
- *Clear information was given about diabetes, but I didn't feel that real support was available. Peer support is needed. Something like the stroke club that meets.*
- *The information I was given gave me enough information on how to live with diabetes.*

- *Information needs to be given in other ways, there is so much information available, but its all in leaflets, a film or something would be different.*
- *All the information was a really good reading, gave me a good insight, I think the information given was informative but*

Over the last 12 months, which of the following healthcare professionals have you seen through the diabetes team?

39% of respondents were seen by a dietician. 17% saw the diabetes specialist team. 94% of respondents were seen by the GP. 1% was seen by Podiatrists service and 22% indicated that they were seen by other services.

Please note that some respondents ticked more then one option. The percentages are calculated to show the percentage from the 18 respondents.

| | Dietician | Diabetes specialist team | GP | Podiatrists service | Other | Total |
|--------------------|------------|--------------------------|------------|---------------------|------------|-------------|
| Respondents | 7 | 3 | 17 | 1 | 4 | |
| Percentage | 39% | 17% | 94% | 6% | 22% | 100% |

What has your experience been like from these health professionals?

Some of the comments are highlighted below.

- *An okay experience*
- *Really really good*
- *Dietician was excellent, everyone should be seen, it really makes a difference to how and what you eat.*
- *Gp has always been excellent.*
- *My GP was really good but now has left me to do it all on my own.*

How do you manage your diabetes?

89% of respondents manage their diabetes by taking medication. 33% of respondents manage their diabetes through physical activity. 11% of diabetes was managed through insulin. 61% of respondents use a controlled diet to manage their diabetes.

Please note that some respondents manage their diabetes through more than one option.

| | Insulin | physical activity | medication | diet | other please specify | Total |
|-------------|---------|-------------------|------------|------|----------------------|-------|
| Respondents | 2 | 6 | 16 | 11 | 0 | |
| Percentage | 11% | 33% | 89% | 61% | 0% | 100% |

Have you been on any courses to help you understand what diabetes is and ways to manage it?

61% of respondents indicated that they have not been on any course or programme to help them understand what diabetes is or how to manage it.

| | Yes | No | Did not answer | Total |
|-------------|-----|-----|----------------|-------|
| Respondents | 1 | 11 | 6 | 18 |
| Percentage | 6% | 61% | 33% | 100% |

Would you like to go on a course?

- *“Yes will be an opportunity to educated myself”*
- *“ I would rather go to the Gym but can’t afford to and this will help worth my diabetes”*
- *“Yes and meet the others who are on the course”*
- *“ Are the courses available out of hours or just normal hours for people who are at home, I would like to go but didn’t know there was and also I work so it would have to be on the weekend or evening?”*
- *“I would like to go to somewhere where they can tell me how to manage my lifestyle, being a single mother, two children, fit in exercise within my daily lifestyle and buy food within my budget as I hardly have any money left by the time I have paid my bills”*

- *I would love to go on a course, but I think a few small courses would be better, on different areas.*

Do you feel that an online forum or face to face group would help you manage your support needs?

- *“Online forum or group would be perfect for someone like me; I work so being able to go whenever I can would be a good idea. If people want to meet then I think they could meet then. People need to be given the chance to arrange meet ups and see how it works first.”*
- *“Meeting others online with diabetes type 2 would mean that people like myself are on their.”*
- *“An online group would be really, everyone can keep updated. A medical professional would be good on there two.*
- *I don’t have a lot of spare time; an online forum will keep me in contact with new things.*
- *I would prefer online to a face to face group.*
- *Online forum most defiantly, a face to face forum maybe quarterly for updates etc...*

In the last year pleased tell us what checks you have had?

Blood test to measure (HbA1C):

The information in the table below states that 89% of respondents have had their blood tested and 2% have not.

| | Yes | No | Never been checked | Didn’t know I should | Total |
|-------------|-----|-----|--------------------|----------------------|-------|
| Respondents | 16 | 2 | 0 | 0 | 18 |
| Percentage | 89% | 11% | 0% | 0% | 100% |

Weight and height

72% of Respondents have their weight and height checked once a year. 22% of respondents are checked more then once a year and 6% of respondents were not aware that they should have been checked.

| | Yes | No | Never been checked | Didn’t know I should | Total |
|-------------|-----|-----|--------------------|----------------------|-------|
| Respondents | 13 | 4 | 0 | 1 | 0 |
| Percentage | 72% | 22% | 0% | 6% | 100% |

Retinas check (Eye check)

78% of Respondents have their retinas checked. 22% have not had a retina check.

| | Yes | No | Never been checked | Didn't know I should | Total |
|-------------|-----|-----|--------------------|----------------------|-------|
| Respondents | 14 | 4 | 0 | 0 | 18 |
| Percentage | 78% | 22% | 0% | 0% | 100% |

Foot examination and foot care

56% of respondents have had a foot examination in relation to diabetes. 28% have not been checked and 11% have never been checked and 6% were not aware they should have been getting checked.

| | Yes | No | Never been checked | Didn't know I should | Total |
|-------------|-----|-----|--------------------|----------------------|-------|
| Respondents | 10 | 5 | 2 | 1 | 18 |
| Percentage | 56% | 28% | 11% | 6% | 100% |

Blood and urine tests to check kidneys

89% of respondents had blood and urine tests to check kidneys once a year, 6% more than once a year and 6% of respondents have never been checked.

| | Once a year | More than once a year | Never been checked | Didn't know I should | Total |
|-------------|-------------|-----------------------|--------------------|----------------------|-------|
| Respondents | 16 | 1 | 0 | 1 | 18 |
| Percentage | 89% | 6% | 0% | 6% | 100% |

Do you feel your support needs are met?

50% of respondents felt that their support needs are met and 50% felt they are not met.

| | Yes | No | Total |
|-------------|-----|-----|-------|
| Respondents | 9 | 9 | 18 |
| Percentages | 50% | 50% | 100% |

- *“I have spoken to a few people who have diabetes and they have received different information, there should be one pack available that is given to everyone who is diagnosed with diabetes. Also not everyone likes to read a DVD would be a good idea”.*
- *“My support needs would be met through meeting others with diabetes a few times in a year, a meeting every couple of months, I would like to talk to others who are in the same position as me”.*
- *“I would like access to the exercise programme, but the times available only favour those who do not work”*
- *My husband is my full time carer and supports me so in that sense I am supported but he can't help me understand what happens and why I get so ill, it would be nice to have a good explanation.*
- *“Would be a good idea to speak to others .Maybe encourages others to exercise together or something”.*
- *“There should be a reminder to take medication for those who need that support”.*
- *“I would like to exercise more but I cannot afford to pay for the gym and with the cold weather I do not enjoy going out”.*
- *“Is there grants available to people with long term conditions to buy exercise equipment for home, its hard for me to go anywhere because I am a single mum with children”.*
- *“I think what would have helped me when I first got diagnosed is the support emotionally; I wasn't sure what to expect, I got a lot of leaflets with information but to be honest that is not all I needed, I needed to speak to someone and maybe others who had to change their lifestyle and see what they had done”.*

- *“Sometimes a load of leaflets with information is not the support you need.”*
- *“Although I am working, I am still not in financial position to join a gym, I cannot afford it and because what is available to diabetics is only available during work hours, it basically excludes me from gym work. What happens to working people? The support that would help me is have something for us too.”*
- *“Some of us take more medication then others, some of us diabetes really gets us down, when your on so much medication it can effect you emotional and to be fair there is a lot of information about diabetes in general, but for support there needs to be something or somewhere who people can turn to, or something.”*
- *Support needs to be there when diagnosed and after, I feel aftercare is quite poor, people need to connect with one and another and the health service should encourage learning from others and supporting others in the same situation as you”*

In order to help individuals self manage diabetes what do you think is needed?

- *More options for people to use the gym, should not just be in work time. This is not fair.*
- *Money, not everyone has money.*
- *As I said before different ways of giving information what about a DVD?*
- *Emotional support, when someone first finds out that they have diabetes it is scary, its there and will never go away and all the professionals can be there, but some people need someone to talk to who is not family. I think there is this thing that people only go to counsellors when they are not with it, people go because they need so someone to listen, this needs to be told. People do not go to the counsellor because they are mad.*
- *Help to cope with the changes that you will need to make as a person. You are given loads of leaflets, but I needed a guide someone to help me slowly change the way I do things.*

- *After care really needs to improve, a load of information given and then what just left to manage without the right services there.*

Points to consider

In conclusion, according to the responses received, Healthwatch Barking and Dagenham recommend the following to ensure the needs of the respondents are met:

- Commissioners of diabetic services need to have another look at the exercise programme for diabetic patients and ensure that the service is flexible enough so individuals can access without compromising their employment. It has been highlighted that people would like to access these services but the service only seems to be valid during working hours. Commissioners need to ensure that support is being provided to fit in with the needs and lifestyle of diabetic patients.
- Many of the respondents have not been on any course/programme to increase their knowledge of their condition. Promotion of available courses needs to reach all diabetic patients and they need to be given the opportunity to attend. All GP practices need to write to their patients to see if they would like to attend a course and who to contact if they would like to go on one.
- The findings from the questionnaires clearly show that individuals would like an online forum where individuals can; share their issues, exchange information, provide advice, receive advice and meet others who also suffer from type 2 diabetes. Therefore, commissioners and public health need to consider running an online forum as a pilot to see the impact of this on self management for diabetic patients.

Demography

Age

| 18 -25 | 26-35 | 36-46 | 47-55 |
|--------|-------|-------|-------|
| 2 | 3 | 9 | 4 |

Gender

| Male | Female |
|------|--------|
| 8 | 10 |

Do you consider yourself to have a disability?

| No | Yes |
|----|-----|
| 12 | 6 |

| Mobility Impairment | Hearing Impairment | Visual | Severe medical condition |
|---------------------|--------------------|--------|--------------------------|
| 3 | 1 | 1 | 1 |

What is your religion or belief?

| Christianity | Hinduism | Islam | Prefer not to say |
|--------------|----------|-------|-------------------|
| 10 | 1 | 1 | 6 |

How would you describe your ethnicity?

| White British | White English | Black or Black British - African | Black or Black British - Caribbean | Black or Black British – Other Black background |
|---------------|---------------|----------------------------------|------------------------------------|---|
| 2 | 2 | 4 | 2 | 1 |

| Asian or Asian British – Bangladeshi | Asian or Asian British - Indian | Prefer not to say |
|--------------------------------------|---------------------------------|-------------------|
| 2 | 2 | 3 |

