healthwatch
Blackburn with Darwen

Report November 2019

People living in the East Primary Care Neighbourhood give Healthwatch BwD their views about the education and support on offer to help them manage type 2 diabetes

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Disclaimer:

This report is not representative of all service users in Blackburn with Darwen who have been diagnosed with type 2 diabetes. It is an account of those service users who chose to share their experiences with Healthwatch Blackburn with Darwen, either through direct engagement, completing questionnaires or by electronic means, about the diabetes educational programmes they were offered at the time of diagnosis.

# 1: Rationale

In the 2018 Locality Health Profile, just under 50% of Blackburn East Locality residents rated their health as 'good' compared with 62% across the Borough and 72% nationally. This pattern was mirrored when people were asked about long-term activity-limiting illness. More adults in the locality were likely to be obese. According to research, type 2 diabetes is very closely associated with weight, with over 90% of newly diagnosed type 2 diabetics above their ideal weight.

Diabetes was one of the key areas of concerns with service users when Healthwatch Blackburn with Darwen (BwD) consulted the public about their 2019/20 annual work plan.

The East Primary Care Neighbourhood (PCN) team (covering Shadsworth, Higher Croft, Audley and Queen's Park wards) has also identified type 2 diabetes as a priority to improve the health outcomes of residents in this area.

In view of this, Healthwatch BwD undertook this project to understand the education and support provided in the borough and what people with type 2 diabetes and their families need to manage their condition effectively.

# 2: Methodology

Healthwatch BwD, in collaboration with BwD Healthy Living, undertook engagement activities in the East Primary Care Neighbourhood locality.

A questionnaire based on NICE guidelines QS6 was developed to determine whether the current level of type 2 diabetes education awareness is effectively being met. The guidelines also state that 'family members should be included to help them support their relative manage their condition'.

62 people in total completed the questionnaire, however not all responded to each question. It should be noted therefore that where percentages have been used when analysing responses these have been supported by actual numbers in brackets to put it into context.

Ten respondents offered a deeper understanding by discussing their own experiences through interviews either by phone or face to face. These have been included in this report as case studies.

BwD Healthy Living, who work actively within the East Locality, completed questionnaires at face to face events using a stand promoting diabetes awareness.

All six General Practitioner (GP) Practices in the East Primary Care Neighbourhood were contacted, through the Practice Managers, and invited to complete questionnaires with patients diagnosed with type 2 diabetes or to signpost patients to Healthwatch BwD to share their views.

## 3: Acknowledgements

To everyone who agreed to share their own experiences as case studies.

BwD Healthy Living for supporting the engagement and completing questionnaires.

The six Practice Managers of the East PCN area for sharing the project information with their patients.

We would like to extend a special thank you to the Practice Managers at Pringle Street Surgery and Dr Nagpal Surgery for supporting patients to complete and return the questionnaires provided.

## 4: Structured Diabetes Educational Programme available in Blackburn with Darwen

According to the information provided by Lancashire and South Cumbria NHS Trust website, 'Diabetes Education and Self-Management for Ongoing and Newly Diagnosed (DESMOND), is a National 'Diabetes Structured Education Programme' for people with type 2 diabetes, whether newly diagnosed or who have had their Diabetes for more than one year.

'The aim of the programme is to increase an individual's knowledge of type 2 diabetes, share self-management skills, have a better understanding of poor glycaemic control and come away from the session with an understanding and empowerment to set clear, effective goals and improve their overall health and wellbeing.

Programmes run for a full day or 2 half days and are delivered to groups of up to 10 people diagnosed with type 2 diabetes; all of whom may bring along a friend or partner.

The DESMOND programme is free and sessions are delivered by specially trained NHS health professionals.'

Programmes are also available for people with type 2 diabetes of South Asian background in Blackburn with Darwen, delivered in Urdu or Gujarati.

The Desmond Programme is delivered from two different venues in the borough, one in Blackburn and one in Darwen. The sessions are held with groups of ten people but can also be offered on a 1:1 basis with the Educator. The referral form advises professionals that 'if they are considering referring a patient with learning disabilities, sensory disabilities or mental health issues or other barriers which may affect how they can benefit from group education, to contact the DESMOND office so that consideration can be made to each individual's needs and those of the group'.

Do health and care services know what you really think?

# 5: Questionnaire responses of 62 people living with a diagnosis of type 2 diabetes.

When questionnaires were devised to undertake this project, NICE guidelines were used to determine if people diagnosed with type 2 diabetes followed the pathway for referral to an educational programme and how effective they felt it was. They were also asked to comment on what they felt could have improved the education they were offered.

Out of the 62 respondents, 45% had been diagnosed with type 2 diabetes more than five years ago. 40% had been diagnosed between 1 and 5 years ago and 15% had been diagnosed within the last 12 months. Therefore, most of our findings are based on respondents who have been managing their condition for at least one year with the majority giving feedback on educational experiences of more than five years ago.

The most prevalent number of respondents were between the ages of fifty-five and sixty-five.

29% of respondents were White British and 31% were of South Asian heritage. 37% of respondents did not indicate their ethnicity.

(For a breakdown of demographical information please see the appendices)

NICE guidelines for education and lifestyle advice states that 'structured education should be offered to the adult with type 2 diabetes and/or their family members or carers (as appropriate) at and around the time of diagnosis'.

Results from our survey indicated that 79% (44), when initially diagnosed with type 2 diabetes, were offered a place on a course to help them understand and manage their condition. Of these 46% (26) said that they attended the course they were offered. The majority of those who attended a course did so within one year of being diagnosed. 37% said that they did not attend and 17% either could not remember or did not answer.

Research from the NICE impact report on diabetes indicates that nationally, 76.6% of adults diagnosed with type 2 diabetes were offered a structured educational programme with 7.1% of those attending within a year of diagnosis (less than 10%). (National Diabetes Audit 2016-17)

From data available for BwD in 2015, 61.1% of patients newly diagnosed with type 2 diabetes were offered a structured education programme to manage their condition with 6.7% of those offered the course attending within one year of diagnosis. In 2016, this rose to 75.9% of people being offered the course at diagnosis with 10.9% attending within one year, which appears to be 3.8% better than the national average.

| Organisation | Year | Newly diagnosed | Offered within 12 months of diagnosis | Offered within 12 months of diagnosis (%) | Attended within 12 months of diagnosis | Attended within 12 months of diagnosis (%) |
|---|---|---|---|---|---|---|
| 00Q | 2016 | 685 | 520 | 75.9 | 75 | 10.9 |
| 00Q | 2015 | 745 | 455 | 61.1 | 50 | 6.7 |

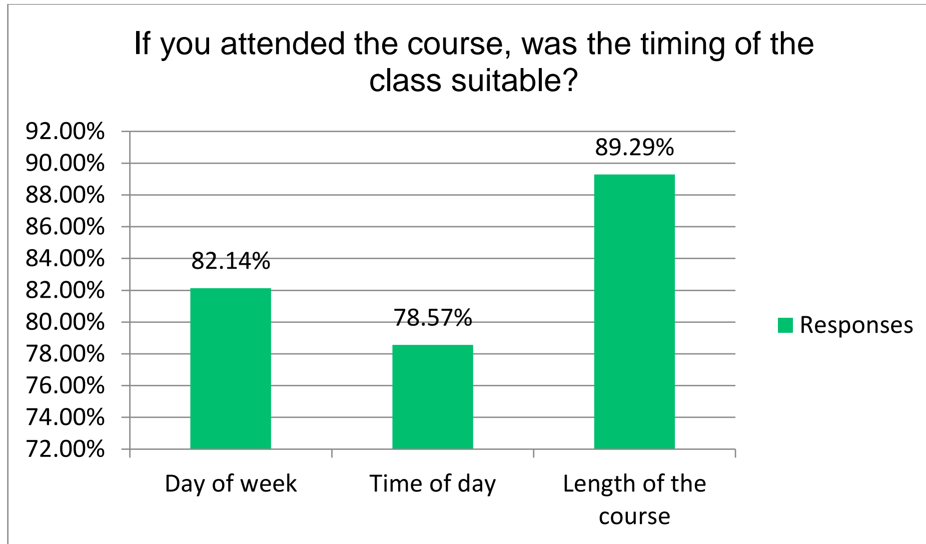
People were asked, in our questionnaire, if their family or friends, who may be involved to support them to manage their condition, were also invited to attend the course with them. 27% (15) said they were invited, whilst 49% (27) said that they were not. 24% (13) said that this was not applicable as they did not have anyone who could attend with them.

Of the 27% (15) of respondents who said that family or friends were invited to attend with them, less than half did attend.

"The group was good and I got a lot of information which I brought home as my husband does the cooking. He could not attend the course as he works. We would not stick to the diet anyway."

People were asked approximately how long it took them from being diagnosed to attending an educational programme to help them manage their condition. 82% (24) attended within twelve months of diagnosis and 22% (7) took over a year to attend an educational course.

People who attended a course were asked about the suitability of timing and length of the course provided. 82% (23) of respondents indicated that the day of the week that they attended was suitable, 79% (22) said the time of day was suitable and 89% (25) thought the duration of the course was satisfactory.




Out of 56 responses, 37% (21) of respondents indicated that they did not attend a diabetes awareness course and 16% (9) felt that it was not applicable to them. Out of 25 respondents' comments as to why they had not attended a course nine stated that they did not have enough time due to work or family commitments. Eight said that they had not been told about it or did not understand what it was about.

"I am very busy with work and cannot take time off to attend".

"I couldn't attend due my working hours".

"I wasn't offered it".

"I received a leaflet to explain about diabetes but they didn't encourage any courses or clinics".

"I didn't know what it was about".

"I'm not good with anything that is 'educational".

However, a number of comments received indicated that the days on which the courses were offered did not always fit around people's work or family responsibilities.

"I was working full time so had to take a day's holiday to attend during the day".

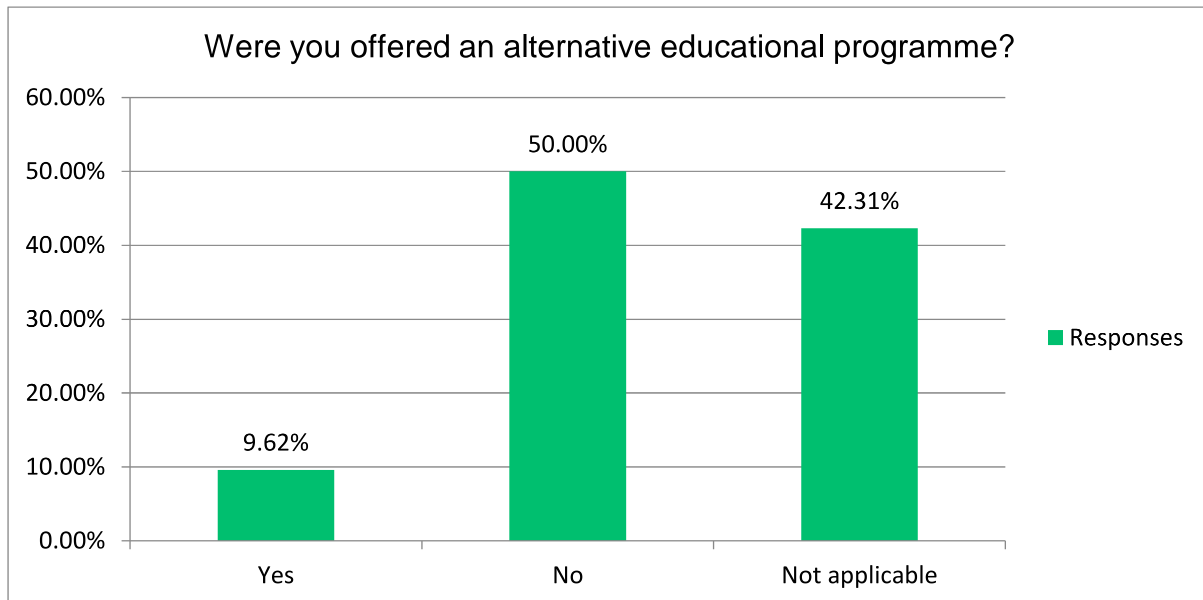
"Had to take two days off work. Why can't you run the sessions in the evenings and weekends?"

"I have four children, it's not easy to juggle with no childcare".

"I couldn't make the dates of the course".

Respondents were asked if they were offered an alternative educational programme, to which 50% (27) of respondents stated that they were not offered or were unaware of an alternative. 10% (5) said that they were offered an alternative course and 42% (22) said that it was not relevant to them.

NICE guidelines: ‘an alternative of equal standard should be provided for a person unable or unwilling to participate in group education’.




As a result of attending the diabetes education a total of 74% (26) who answered this question said that they had found the course helpful and had made some changes to their lifestyle as a result of attending the course. The changes ranged from making significant lifestyle changes such as sticking to a diet low in carbohydrates and sugar, increasing exercise and losing weight to more minor changes including cutting out or down on sugar and moving more.

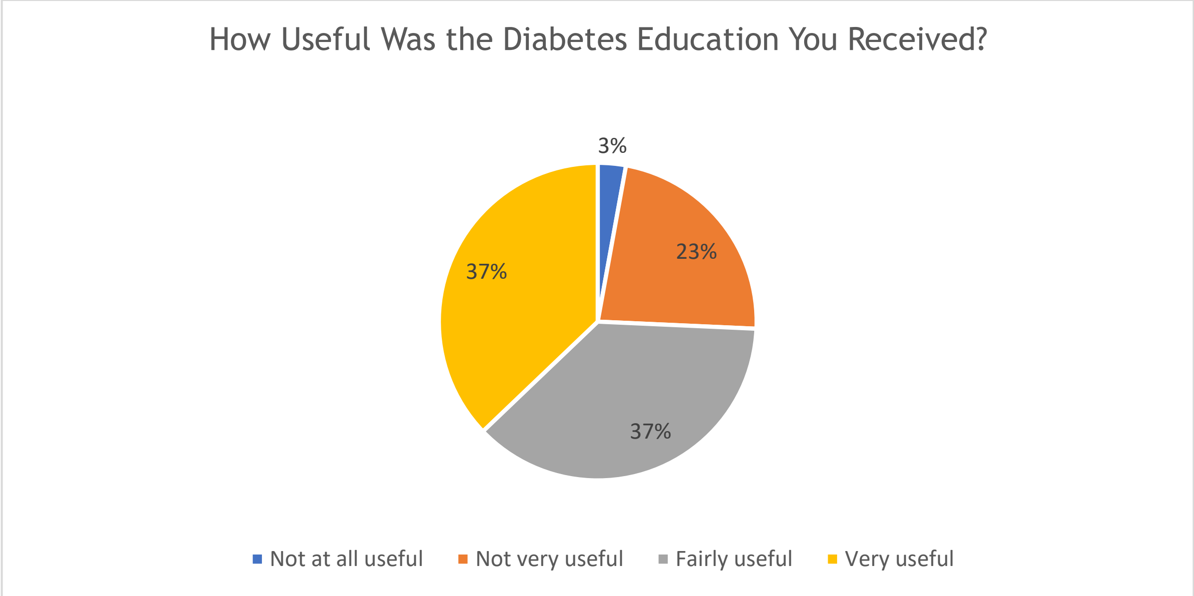
“I have been sticking to the routine rigidly and doing more outside activities like walking and swimming”.

“I have lost weight and look at food the labels for the sugar, carbohydrate and fat values”.

“I go for more walks and eat a good diet”.

“I have cut out sugar in my tea”.

Whilst the majority of responses indicated that people who attended the course offered were mostly satisfied, a further 26% (9) respondents had not found the education useful. When asked what could have been improved some respondents said that they would have liked more information such as, what to do when blood sugars are high and live demonstrations with recipes to try at home. Three people asked that courses be more culturally diverse, for example, to accommodate an Asian diet and offered in a different language. However, according to the information provided about DESMOND, programmes are available in Urdu or Gujarati.




*The majority (74%) of responses indicated that people who attended the course found the education useful or very useful.*

When respondents were asked how confident they were in managing their condition a total of 74% (37 out of 50) respondents said that they were fairly to very confident. Not all people who answered this question had attended a structured course.

When asked what could improve their confidence the most common response was that people wanted more support and information at regular intervals rather than just an annual check by their GP or Practice Nurse. Three people said providing a course in the person's own language. As this is already provided, it is not clear that General Practitioners and health professionals are making people aware that these alternatives are available when referring patients.

A few respondents said that they would like more blood sugar testing strips so that they can check their levels more frequently.

## 6: Summary of Survey Responses

From our survey 79% (44) of respondents indicated that when initially diagnosed with type 2 diabetes, they were offered a place on a course to help them understand and manage their condition. Of these, 46% (26) said that they attended the course they were offered.

27% (15) said family or friends, who may be involved to support them to manage their condition, were also invited to attend the course with them. whilst 49% (27) said that they were not. 24% (13) said that this was not applicable as they did not have anyone who could attend with them.

Of the respondents who said that family or friends were invited to attend with them, less than half did attend.

82% (24) attended within twelve months of being diagnosed and 22% (7) took over a year to attend an educational course.

Of the people who attended a course, most people found the time, duration and day suitable.

Out of 56 responses in our questionnaire 37% (21) respondents indicated that they did not attend a diabetes awareness course and 16% (9) felt that it was not applicable to them.

A number of comments received indicated that the days on which the courses were offered did not always fit around people's work or family responsibilities.

74% (26) said that they had found the course fairly to very useful and had made some changes to their lifestyle as a result of attending the course.

Whilst the majority of responses indicated that people who attended the course offered were mostly satisfied, a further 26% (9) respondents had not found the education offered useful.

People were asked what could be improved to support them to manage their diabetes and the most similar prevalent response was that they wanted more support and information at regular intervals rather than just an annual check by their GP or Practice Nurse.

# 7: Experiences of residents living with type 2 diabetes told through case studies

Ten interviews were undertaken providing case studies that generated a deeper understanding of service users' experience of living with type 2 diabetes and how they understand and manage their condition. Five case studies were provided by respondents from a White British origin and five case studies were provided from respondents of a British South Asian heritage.

The questionnaire formed the framework to support conversation and to allow analysis to be relatable to the overall survey.

It is recommended that the ten short case studies are read in full as the following is only a summary.

## Case Study One: Joseph

This elderly gentleman has lived with type 2 diabetes for nearly 20 years and was diagnosed in his early sixties. He lives alone and his family do not live locally.

When Joseph was diagnosed about 18 years ago he was offered awareness about his condition and how to manage it. This was provided within six months of being diagnosed. He says he has not been offered anything since but does see the practice nurse every six months when she checks his weight, feet and blood pressure. The GP manages his diabetes with medication.

Joseph states that the awareness he was offered many years ago was not very helpful and mainly focused on losing weight and cutting things out that he could eat. However, it did influence him to make some changes to his eating habits. This was reinforced a few years ago when he was offered an awareness update. Although he says it was not that helpful because he couldn't find the relevance to his own life and experience of type 2 diabetes. He has lost weight and knows he has to limit potatoes, rice and noodles, as well as cutting out sugary foods which he has stuck to. He said the only way he manages his condition is to eat less. He knows he needs to lose a lot more weight and be more active. He has microwave

meals because he lives alone and does not cook. I asked if he would like to learn to cook but he said not as he has had microwave meals for many years now.

He was aware that on the DESMOND course people are offered more practical advice such as going into a supermarket and looking at the food labels to help people make healthier choices, which he thought was a good idea.

**"I know that I won't live as long because of type 2 diabetes but I'm over 75 years old and I'm happy with that".**

He does not feel that his diabetes has any effect on his life so he is not motivated to stick to the advice he is given. When asked what would motivate him he said seeing the consequences of unmanaged diabetes as that would scare him literally into compliance.

**"I don't have the motivation to change. I've been living with type 2 diabetes for 20 years and don't see any effects that it has on my own health. If I met others where the diabetes was affecting their health I would be very scared".**

## Case Study Two: Edna

Edna was diagnosed with type 2 diabetes 5 years ago when she was in her late fifties. She states that she is only a 'borderline diabetic' but does take medication from her doctor to control it. The medication she is given for her diabetes is just one of a number of medications she has to take as she has other health problems.

Edna does not remember being offered a place on the DESMOND educational awareness for type 2 diabetes but does remember attending a centre to learn about healthy eating. She says that her husband and son who live with her and do most of the cooking did not attend nor can she remember if this was an option. However, she said they would not have attended even if invited because they both work. Edna said she attended the healthy eating sessions soon after being diagnosed and found the group was very good.

She also found the classes were suitable in terms of day, time and duration but that they were not very useful to her because she doesn't stick to the diet because she is 'only borderline'.

"I don't mind taking the tablets and it doesn't concern me that I am at risk of diabetes type 2".

Some of Edna's extended family also have type 2 diabetes.

When asked what changes to lifestyle had her family made as a result of the awareness course Edna said none because her husband does the cooking. She said she brought home a lot of leaflets from the course but nobody read them. Edna

eats homemade meals such as Spaghetti Bolognese and Shepherd's Pie. They do not have microwave meals.

"I see the nurse at my doctors once a year for my diabetes checks and she is happy with my blood sugars and says that my diabetes is stable so we must be doing something right."

However, when asked how confident she felt in managing her diabetes she said she was not confident at all. When asked what could improve the information she had been given and help to make her more confident, she said 'nothing' because she was not concerned about her condition so did not feel that it was affecting her.

## Case Study Three:  Brenda

Brenda was diagnosed with type 2 diabetes 15 years ago in her late forties and although this was before the introduction of the DESMOND awareness course, she says she was offered support to understand and manage her condition which mainly consisted of what not to eat.

She remembers attending the course within a month of diagnosis with a neighbour who had also been diagnosed with diabetes. She found it to be accessible in terms of time and duration.

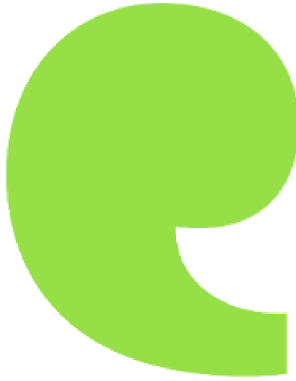
Brenda says that although she found it fairly useful in informing her about dietary choices it has not made a difference in her lifestyle choices. However, she is waiting to go on a more up to date course but family circumstances have prevented her from attending so far.

She has an annual diabetic check at her doctors and takes the medication prescribed for her. She says the nurses at the doctor's surgery are very helpful and realistic about what she can achieve in terms of weight loss as she has multiple health problems and takes around twenty tablets a day.

Brenda says that she can manage her diabetes with medication and doesn't feel that anything else would help because she has other health conditions that affect her life more adversely. She also has a partner who has serious health issues so her diabetes is not the focus in her life.

"I'm not frightened of dying (as a result of my diabetes), if my number's up it's up."

When asked if there was anything that would be helpful to support her in improving her health outcomes around diabetes, Brenda said she would prefer a one to one mentor rather than attend a group. Free testing sticks would also be helpful to people who pay for their prescriptions as they are very expensive which can make you more cautious about using them more frequently.



## Case Study Four: Deborah

Deborah, who is in her early seventies and lives alone, was diagnosed with diabetes thirteen months ago. She says that if you are not on tablets you cannot have your annual diabetes health check under twelve months and had her appointment cancelled because she had made it at eleven months. The practice nurse rearranged her appointment so that by the time she was seen it was thirteen months. When she attended the appointment, she says she only had five minutes with the doctor as he was running late by twenty minutes and the receptionist interrupted her consultation to speak to the doctor. Unfortunately, she was experiencing some health problems related to her diabetes which she felt would have been picked up sooner if the original appointment had been kept. She is now seeing the nurse every six months due to some complications that have developed.

Deborah was offered a place on the DESMOND course within a month of being diagnosed by her doctor. She attended the full day session which she said was appropriate in terms of the day, time and duration of the course. Deborah said that the information she received was very useful and has influenced her to make changes to her lifestyle and diet. She has found the books she was given about diabetes and food guidance helpful, especially the traffic light system, to help her make better food choices and manage her diet. She described it as 'hard work at first but by sticking to it' she lost two stone in weight which has got her diabetes 'under control'.

"I liked that you were shown what foods were okay to eat and the foods that were not. That made it easier to understand".

She manages her diabetes by diet alone and does not take medication. She says she sticks to the dietary advice and does not feel that the education course could be improved. She felt that it was delivered at the right level for her to understand. She says that initially it took her longer to do her food shopping but now she just goes straight to the traffic light label.

"I now feel very confident in managing my diabetes and feel that I am doing well. It's good that food labelling is clearer and the food traffic lights definitely help".

Deborah wanted to add that she would like the communication between the opticians and the doctor's surgery to improve as she has been asked to duplicate eye tests. Following her diagnosis an eye test was arranged at the eye clinic but early visual changes detected were not referred on for follow up. She now has more confidence that her local opticians will refer to a specialist and inform the doctor if they detect any changes. She has declined to attend eye appointments at the eye clinic preferring to visit her optician of choice.

## Case study Five: Jasmin

Jasmin is a lady in her late 60's who lives with her partner. She was diagnosed with type 2 diabetes more than 15 years ago when she was in her late 40's.

Following her diagnosis, she was advised to attend the 'X-PERT programme' which preceded DESMOND in order to help her understand about her condition. She has always worked full time and only retired recently. Jasmin told me that the X-PERT programme was delivered locally in the community. She said at the time she thought it was very useful because she didn't know anything about diabetes, but looking back she says it wasn't really very good. Her partner attended the course with her but again she says the dietary advice was very generic and not person centred which was not helpful. She has recently been given information about the DESMOND course as she has never had an update since that initial offer.

Jasmin says she does not intend to go on the DESMOND course because it doesn't seem to be 'telling her anything new'. She also gets anxious in a group of people and has experienced a lot of 'fat shaming' by people and professionals who do not 'walk the walk and have no understanding about the complexities that people have." She points out that "slim people also get type 2 diabetes but its overweight people that have become a poster for type 2 diabetes. Why would anyone want to engage with something that portrays you in this way?"

She states that people presume because you have diabetes you eat a lot of sugar and rubbish and are obviously overweight. People even judge you at work if you have a piece of cake because it's someone's birthday. They say,

'Should you be eating that?' or 'sorry you can't have a piece of cake because you're a diabetic'.

'What right have they to decide what you can and cannot do? The public and many health professionals have no real idea about what constitutes an appropriate diet for someone with type 2 diabetes, of course you can have a piece of cake! Potatoes, rice and pasta, which you would think are healthy, have sugar in them and need to be limited, but no one would comment if you had roast potatoes with a Sunday roast'.

"I feel that if I attend DESMOND I would be very depressed afterwards because of the lack of understanding and it would take me days to recover. There is no way I would say the things I'm saying to you if I was in an educational programme".

We discussed the possibility of attending the 1:1 session alternative which Jasmin said she had been thinking about.

Jasmin is affected by depression and anxiety and attended a mental health course which she found more beneficial in terms of actually getting exercise

and support. However, she says that when the ‘gym people’ came in to talk to the group it was like being in a lecture. I ‘could feel people around me were overwhelmed’.

‘One of the most helpful aspects of this course was that we heard from a lady who had been in a really bad place emotionally, mentally and physically. She told us about her own difficult journey and how she had struggled, the pitfalls and her journey to eventually losing the weight and getting her life back. This was more inspiring to me then the lecture type of education”.

Jasmin reports that the practice nurse at the doctor’s surgery has been understanding. She says that,

‘the nurse has got to know me and understands my needs. We discuss my care and I feel involved in the decisions. My weight is not made the issue and the nurse does not focus on it but rather supports me in making realistic dietary eating habits’

‘Dietary advice needs to be person centred and personalised, all my siblings have type 2 diabetes. The focus on weight and diet, especially where schools are weighing children and checking lunch boxes, may create different problems such as anorexia, which has happened to young people in her own extended family’. She feels that health professionals are making people unwell mentally by focusing on weight and diet.

“I think that there needs to be as much focus on emotional and mental wellbeing”.

I asked Jasmin what she thought would have helped her when she was diagnosed with diabetes and for the following years. She said she would have benefitted from ‘casual support groups initially where people with or at risk of type 2 diabetes could meet up and talk more casually, without feeling judged or being lectured at or your weight being the focus and only being told about dietary requirements that are not personalised.

“You can learn a lot from other people’s personal experience especially where they have overcome their own difficult journey”.

This could then be followed by a more personalised approach.

Jasmin reports that she is now ‘fairly confident’ in managing her diabetes.

## Case Study Six:  Farhan

"I need to feel involved and to see that they are listening to me when I am telling them why I am struggling, what factors are impacting on my life and affecting my diet and medication compliance. Once they stop listening to me I just mirror them and switch off".

Farhan is a gentleman in his mid 40's who was diagnosed with type 2 diabetes around five years ago. He says that following a blood test the GP only said two things to him, that he had diabetes and what his blood sugars were. He was given the information about the 'X-PERT prevention of diabetes programme' and advised to book on it. He was not informed that his wife could attend with him if he chose. A friend who was very knowledgeable about diabetes and its management offered to support him and provide him with the same information available on the X-PERT programme, which due to the hours he was working, suited him better. On requesting his blood results the nurse would not share them and asked that a further blood test be taken but would not say why.

Farhan said that it is very difficult for the nurses to obtain blood from him so he found this to be an issue; especially as no reason or indication was given that there may be a serious concern about the blood sugar levels.

He said that he finds visits to the doctors very difficult and avoids going when he can. He also has other health problems that need management. He has never been told since that first doctor's appointment what his blood sugar levels are despite attending the surgery when required.

Describing himself as a person who needs a consistent and honest approach, Farhan finds it difficult to engage with health professionals if they are not completely honest with him, in order to gain a trusting relationship. He said he found the doctor and practice nurse's approach problematic because they were not listening to his opinions. He decided not to attend the educational programme offered as he did not know how serious his diabetes was and also because the trust to engage with professionals was affected.

He says there have been many opportunities for the staff at the doctors to speak to him about his diabetes but they don't. He accepts his own responsibility in managing his condition but says that when health professionals have judgemental attitudes, are dismissive and do not listen, you switch off. You do not feel like they understand how you really feel and what is affecting you from complying with treatment.

He did take the medication at first and his blood sugar levels did improve but still remained high. Following a series of family tragedies this affected his mood which impacted on taking his medication. He did attend a talking therapy session as he thought it may help but the professional said that she knew him and his family which put him off attending again as he felt this was unprofessional and the trust was gone again.

In the last year Farhan was informed about the DESMOND course for type 2 diabetes and he did consider it but due to family bereavements he did not attend. He also works really long hours. He knows that he needs to lose some weight but due to pain in his feet, ankles and shoulder he finds it difficult to undergo high impact exercise which nobody seems to understand. He says people don't really understand how you feel and they don't really listen so I just switch off from it all.

Asked what would help him he said,

"I never go to the doctors so it's a big thing for me to attend. I get really annoyed when they say I have to come back but do not tell me why. I'm not afraid of knowing and would be more likely to take on board the advice and treatment if I understood the consequences. I need them (health professionals) to be honest and straightforward with me. I need to feel involved and to see that they are listening to me when I am telling them why I am struggling, what factors are impacting on my life and affecting my diet and medication compliance. Once they stop listening to me I just mirror them and switch off. They need to get rid of the judgemental attitudes, like you are to blame, instead of supporting you when things outside of your control are affecting you".

## Case Study 7 - Rehana

Rehana is a 47-year-old Bangladeshi lady who was diagnosed with type 2 diabetes about 4 years ago and at that stage she was informed that she was borderline diabetic and was prescribed medication to help her control it.

On diagnosis she was not offered a place on a course or an alternative to help her manage her condition. Since diagnosis she has tried to control her diet, eat less meat, manage her portion size and generally, eat healthier. She also stopped taking sugar in her tea. Her main diet is rice and curry. Over the years her sugar level has not been controlled and she says she doesn't feel very confident in her ability to manage her diabetes. She does not understand why she cannot control her blood sugar levels anymore.

Rehana just accepts her condition and thinks that it is 'natural for her condition to get worse' and her GP/Practice nurses have not offered an explanation.

She's never been offered a course but thinks if she was offered a course in a language she can understand, it would be easier for her to see what she's doing wrong.

## Case Study 8 - Mohammed

Mohammed is a 65-year-old Bangladeshi man who was diagnosed with diabetes over 5 years ago. He was offered a place on a course but chose not to attend:

"I don't wish to go; I don't see the point. I couldn't be bothered to fill the paperwork in, my heart condition is my priority".

He takes medication to control his sugar levels.

He has a very negative view of health professionals and doesn't have any regard for them. He also feels that they don't really care about him. Neither he nor his family have made significant changes to improve his diabetes. His wife also pointed out that he continues to smoke, even though he has had a heart attack, is diabetic and has a few other medical conditions. His wife continued to say, 'he does not listen to anyone, his kids, other family members if they try to give him advice.' Mohammed thinks he is going to be fine.

He feels fairly confident in managing his diabetes, and is not concerned.

"I am taking my medication on time and it's working, I think".

"I am doing what I can, so I think it should be ok".

## Case Study 9 - Aamir

Aamir is a 61-year-old male from an Indian heritage, who was diagnosed with type 2 diabetes about five years ago on a routine appointment. He was put on medication to help him manage his condition.

Aamir does not remember if he was offered a place on a course to help him manage his diabetes, so he has not been to any courses with his family or anyone, to help him understand it or manage it. He also added if 'they' did maybe I didn't take much notice! Aamir did point out that he goes to see his Practice Nurse every 6 months who informs him that his sugar level is well maintained and at a good level. The practice nurse has also provided dietary advice to Aamir, which he tries to follow.

When asked what lifestyle changes he has made, he pointed out that he has cut down on sweets and sugary foods as well as dairy products like cheese. He has increased his greens and fruit uptake and feels well for it. Aamir added 'I don't feel like a diabetic'. When asked "what is a diabetic supposed to feel like" he said 'I have never needed to have or eat sugary food to bring my sugar levels up, like when people say I feel unwell or faint' … 'I have no issues when fasting either and my practice nurse has advised how to take my medication when fasting, so it works for me'.

When asked "do you feel confident managing your diabetes", Aamir was very confident. He went on to say 'my sugar level is well balanced and the practice

nurse is always happy, I never feel any symptoms. I don't know where my diabetes has come from, I don't think there is a family history either'.

Aamir added that recently, his GP sent him a letter to say that his medication may need adjusting and that he recommends a new treatment that is being trialled. But Aamir does not understand why this is and said that he does not want to be 'someone's guinea pig' so he has not responded to that letter yet.

## Case Study 10: Zainab

This lady says that she had gestational diabetes with all of her pregnancies requiring injectable insulin. Unfortunately, she found the diabetic nurse very unhelpful and felt that she was condescending which affected her willingness to comply with treatment at the time and she stopped using the injectable insulin and attending appointments. Her diabetes was subsequently uncontrolled for many years until she had a check-up with her GP. She was sent for further tests and diagnosed with type 2 diabetes.

Zainab says that she was never offered any form of education 20 years ago except for regular check-ups with the diabetic nurse and consultant at Blackburn Hospital. She visits her GP and practice nurse who 'give her good advice'. The GP has prescribed medication to help control her blood sugar levels and she now feels better. However, the years of high blood sugar levels have affected her eyesight and caused peripheral neuropathy in her hands and feet. The practice nurse has sent her to see the podiatrist and she has to visit the hospital for treatment to her eyes.

When asked what could improve the education about diabetes, she says that it may be helpful if diabetes awareness sessions and peer group support were made available in local community centres and venues. She felt that people could benefit from cooking lessons and recipes that show the correct portion sizes to help control weight and blood sugar levels. These could also be delivered in community venues that are easily accessible with more options for people that work by delivering them in the evenings and weekends. Having access to continued support through.

"pep talks could help people to stay on track and manage their diabetes better".

Zainab says that she is now very confident in managing her diabetes and has learned how to cook and prepare appropriate food and portion sizes. She has lost weight and says she feel better for having her blood sugar levels controlled.

## 8: Summary of similarities identified in the case studies

Six out of the ten respondents had more than one health problem. Some of these also took multiple medications. As such, these respondents were unconcerned about having to take medication to control their diabetes because they already took several tablets a day.

Four out ten respondents were either not motivated or not concerned enough to make any significant changes to control their condition.

"I didn't see the point and I couldn't be bothered to fill in the paper work".

"I know I have type 2 diabetes and accept that it will naturally get worse".

Where respondents reported that they did not 'feel their diabetes affects them' adversely, there appeared to be less compliance with advice or educational programme provided.

"I'm only borderline diabetic so I don't think this applies to me".

Eight out of the ten respondents found it difficult to make the lifestyle changes required to control type 2 diabetes. This was due to the following factors: -

- They do not cook or they are not the person who prepares the family meals.
- They did not attend the diabetes awareness courses because they could not get time off work unless they took holidays.
- They were unable to connect with the education provided, or could not relate to it to follow in their day to day life.
- They needed greater support with motivation due to underlying depression and anxiety.

Many of the respondents commented that they had other problems in their day to day life which were of higher importance to them than managing their diabetes and undertaking significant lifestyle changes.

Most of the respondents from the South Asian community did not remember being offered information about the diabetes awareness course or attended.

Five out the ten respondents either did not make or did not understand how to make significant life style changes to control their diabetes successfully and relied predominantly on medication.

“I am taking my medication on time and it’s working, I think”.

“I don’t mind taking the tablets and it doesn’t concern me that I am at risk of diabetes type 2”.

Three out of ten were complying with dietary advice and trying to exercise more but found it difficult, especially as the majority of respondents were in their late fifties and early sixties.

Only one person was managing to control their diabetes with diet alone but said that they had found it extremely difficult at first but had now got used to it. They have managed to lose weight and stick to a diet.

One other person reported that they had made dietary changes and reported that the practice nurse had said that they were managing well.

All ten respondents attended an annual check-up at their doctors with the nurse being the main person to offer them advice and support.

what would you do?

It’s your NHS. Have your say.

## 9: Summary of what respondents said would help them

One person felt quite strongly that national diabetes awareness has become focused on ‘fat shaming’, with judgemental attitudes not only from health

professionals but the general public also. This person commented that ‘fat people had become the poster for diabetes’ and believes that until this attitude changes people will find it difficult to engage.

Some respondents suggested the use of ‘drop in’ appointments that fit in around their work and family life with flexibility of timings and weekends.

Support groups at community venues with facilitators that had ‘walked the walk’ and who understand how difficult it is to manage type 2 diabetes was also suggested by a service user.

This could also be supported by cooking sessions that show people how to cook the appropriate foods and portion sizes from both Western and South Asian recipes.

A couple of respondents stated that there needed to be better mental health support to increase motivation and compliance, especially when anxiety and depression were affecting their ability to self-manage their diabetes. Whilst respondents understood that exercise improves mood, other health and emotional issues often made this extremely difficult to engage in.

A couple of respondents said that one to one mentoring may have been more helpful to them.

It was felt that some ‘professionals need to listen more and be less judgemental in order to understand the person they are advising. It would be useful to get more support and set realistic and achievable goals. There needs to be a personalised approach rather than ‘one size fits all’. One lady of South Asian heritage said that she would have liked to have attended a course in a language she can understand and believed that if she could, she would be able to manage her diabetes better.

One person suggested that seeing the consequences of unmanaged diabetes would possibly scare people into complying with the advice provided. However, other respondents reported that being quite anxious already, they would find it difficult to engage using this approach.

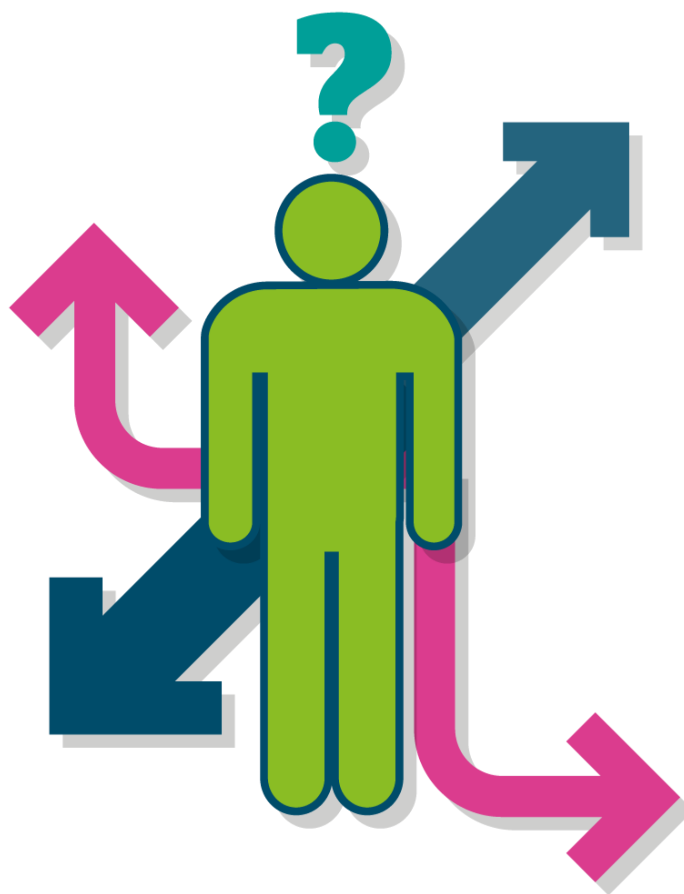
Some respondents said that nothing would help them because they are not concerned about having diabetes, particularly those who believed that their diabetes did not have an adverse effect on their overall health and wellbeing. This was also true of some respondents with other health needs that concerned them more.

At the point of diagnosis, whilst being given leaflets about the diabetes educational programme and advised to contact them, patients could benefit from a follow up appointment so that dedicated time is available to discuss the importance of education and treatment and to ensure that patients understand what is available to them. It was evident in speaking to people that they were not aware that DESMOND was provided in Urdu and Gujarati, or on an individual basis rather than a group.

Patients who may need mental and/or emotional help should be identified in order to ensure they get the right level of support needed.

Many respondents reported not bothering to ring up about the DESMOND programme following their initial diagnosis as they did not see that it was relevant to them or did not really understand what it was.

At this second appointment the patient could be supported and referred onto the right programme to meet their needs.



## 10: Recommendations

- There needs to be clearer information about the diabetes programmes on offer, especially what they are, how the needs of the patient can be met and how to access them, with support if needed. Ideally this should be following or at the diagnosis stage and should be supported with literature that the patient can understand including easy read.
- There needs to be a more personalised approach to diabetes awareness and education with some targeted diabetes education for the South Asian community delivered by people who can speak directly to participants and can relate to the culture. Although this is said to be available it is not clear if patients are made aware of this option.
- People need to be made more aware that if they cannot attend weekday sessions due to work and family commitments, alternative times and weekend dates are available.
- Set up local drop in advice and support groups to help people 'stay on track', run by facilitators or peers who have experience of type 2 diabetes and managing it successfully.
- There needs to be better mental health support to increase motivation and compliance especially for people struggling with anxiety and depression.
- The same local groups could also help with the emotional health and wellbeing of people struggling to engage with their diagnosis and comply with the lifestyle changes required to effectively control their condition.
- People should not feel stigmatised for being overweight and having diabetes. A more positive approach, not only by health professionals but also the general public, would be more effective in supporting people to affect change in their lifestyle choices.
- There needs to be a joined-up approach when supporting people with complex health needs so that a consistent message is given to reinforce how to make positive lifestyle changes that the individual can relate to.

# 11: References: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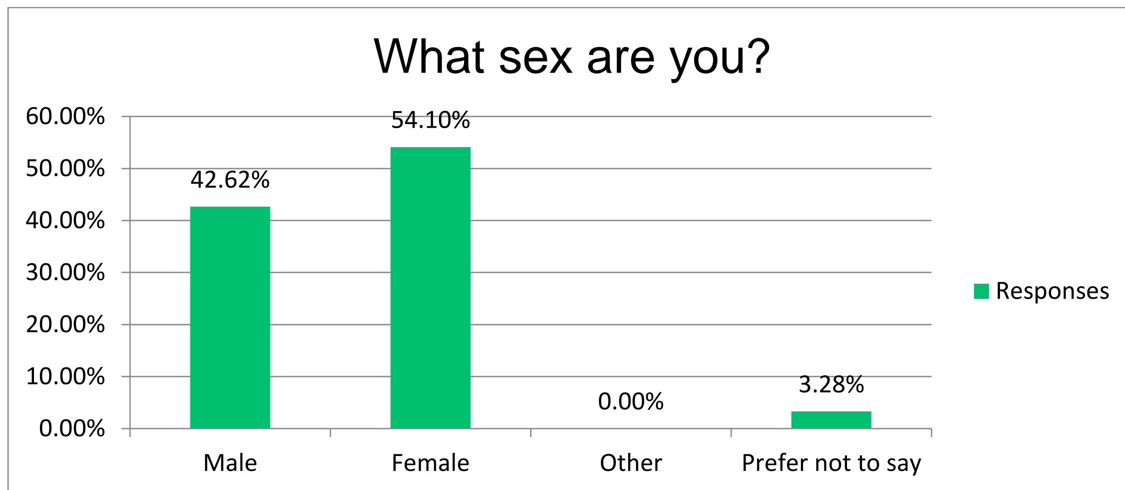
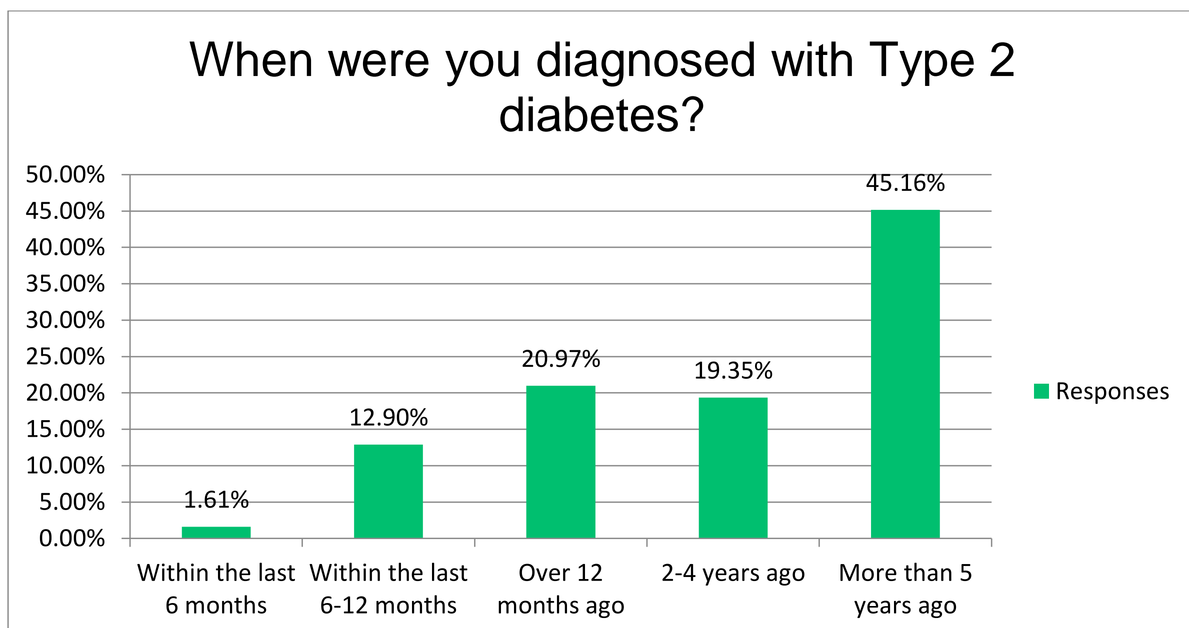
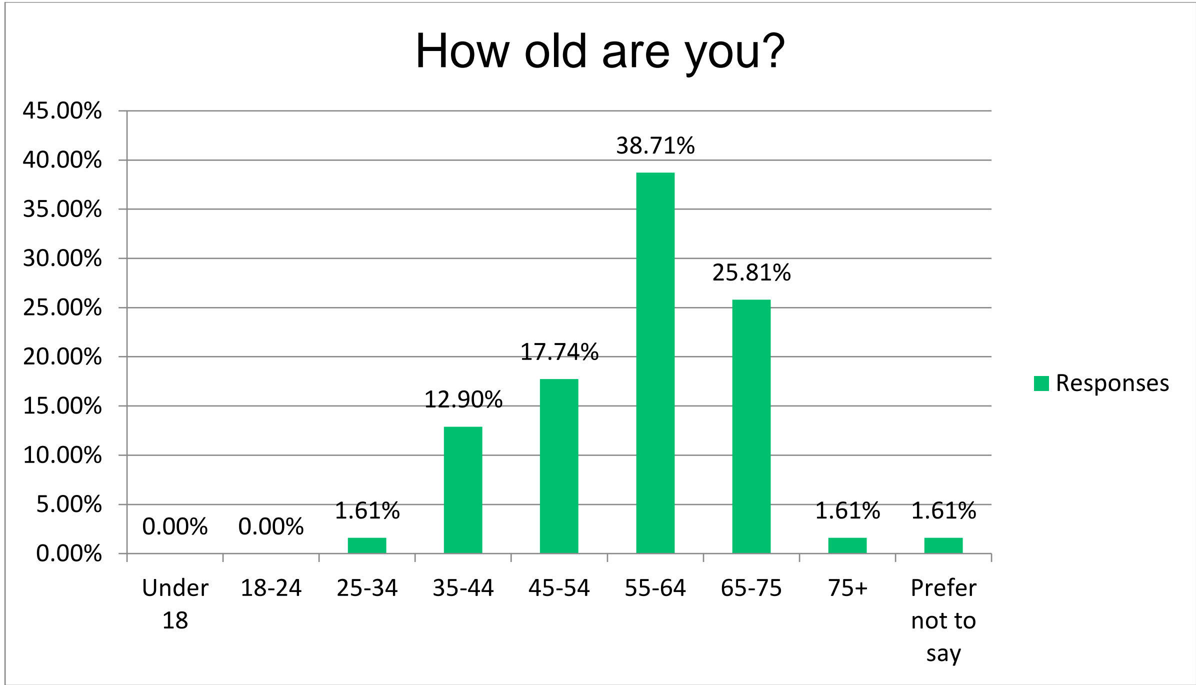
# 12: Appendices

## Breakdown of Demographics

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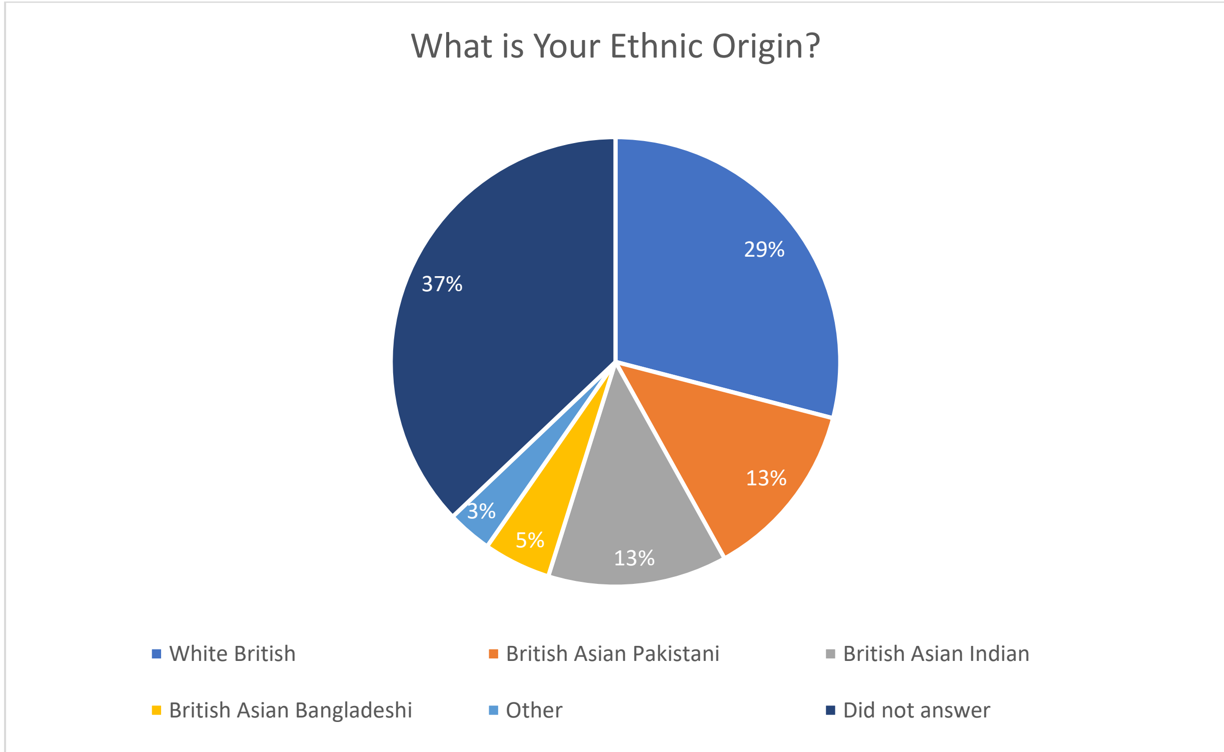
25.00%
20.00%
15.00%
10.00%
5.00%
0.00%
0.00%
0.00%
1.61%
12.90%
17.74%
38.71%
25.81%
1.61%
1.61%
Under 18
18-24
25-34
35-44
45-54
55-64
65-75
75+
Prefer not to say
Responses


What is Your Ethnic Origin?
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13%
13%
5%
3%
37%
White British
British Asian Pakistani
British Asian Indian
British Asian Bangladeshi
Other
Did not answer