



EXPLORING DIABETES RELATED STIGMA

A REPORT BY MAGENTA
MARCH 2023

DiABETES UK
KNOW DIABETES. FIGHT DIABETES.



Disclosures

- Research funded by Abbott, Sanofi and Lilly
- Market research conducted by Magenta Research on behalf of Diabetes UK



PROJECT OBJECTIVES

Explore the prevalence, experiences and impact of stigmatising attitudes, language and behaviour on those living with diabetes.

01

Establish the breadth of personal experiences as a result of stigmatising attitudes

02

Understand the impact of stigmatisation both immediate, and long-term on those living with diabetes

03

Establish the range of views that people living with diabetes consider stigmatising

04

Identify the sources of stigmatising attitudes: direct and indirect

Enable Diabetes UK to become more informed on where and how they can take positive and impactful action to support those living with, and at risk of, diabetes.



WHO WE SPOKE TO

STAGE 1: 16 X 75 MIN ONLINE INTERVIEWS

- 6 x Type 1 diabetes
- 8 x Type 2 diabetes
- 2 x Gestational diabetes

Within the 16 interviews:

- 6 x South Asian participants
- 5 x participants diagnosed in the last 2 years
- 6 x participants have lived with diabetes for between 5-10 years
- 5 x participants living with for over 10 years

ACROSS THE SAMPLE:

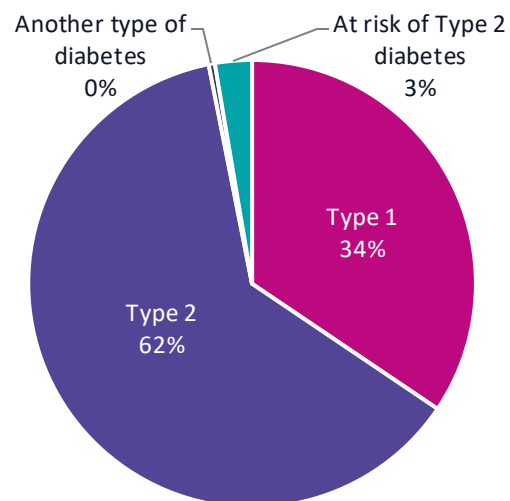
Diversity of ages, gender, social grade, disability, self identify as overweight or obese

STAGE 2: OPTIONAL 2 WEEK DIARY

- 9 x Participants from stage 1 interviews
- 4 x Type 1 diabetes
- 3 x Type 2 diabetes
- 2 x Gestational diabetes

STAGE 3: SURVEY N=450

- People living with, or at risk of, diabetes
- Type 1 n=155, Type 2 n=281
- Broadly representative by age, gender and ethnicity of those living with diabetes.
- Boosted sample of those living with Type 1





1

MISCONCEPTIONS SURROUNDING DIABETES



MYTHS AND MISCONCEPTIONS AROUND DIABETES ARE COMMON

THE VAST MAJORITY ARE AWARE OF MISCONCEPTIONS

9 in 10 (89%) have come across myths and misconceptions surrounding diabetes. Almost half (48%) have personally experienced the misconception that diabetes is caused by eating too much sugar.

PEOPLE LIVING WITH TYPE 1 AND TYPE 2 EXPERIENCE THE SAME MISCONCEPTIONS

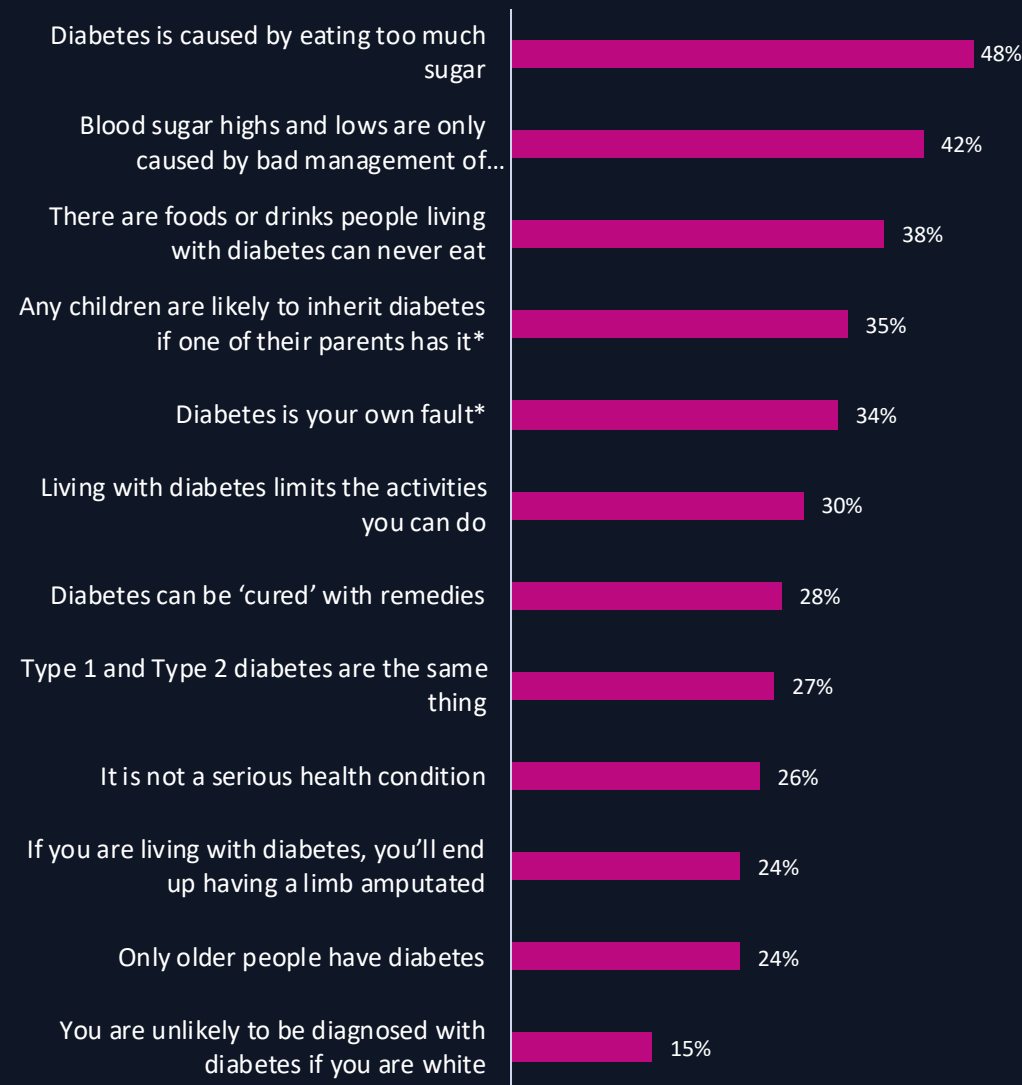
People living with diabetes broadly come across the same myths and misconceptions whether they are living with Type 1 or Type 2. The exceptions are:

- those living with Type 1 are more likely to come across the misconception that it is likely to be inherited from parents.
- those living with Type 2 are more likely to come across the misconceptions that diabetes is the person's fault.

THOSE LIVING WITH TYPE 1 ARE MORE LIKELY TO HAVE COME ACROSS MISCONCEPTIONS

15% of those living with Type 2 have *never* come across a myth or misconception about diabetes, compared with only 5% of those living with Type 1.

MYTHS AND MISCONCEPTIONS



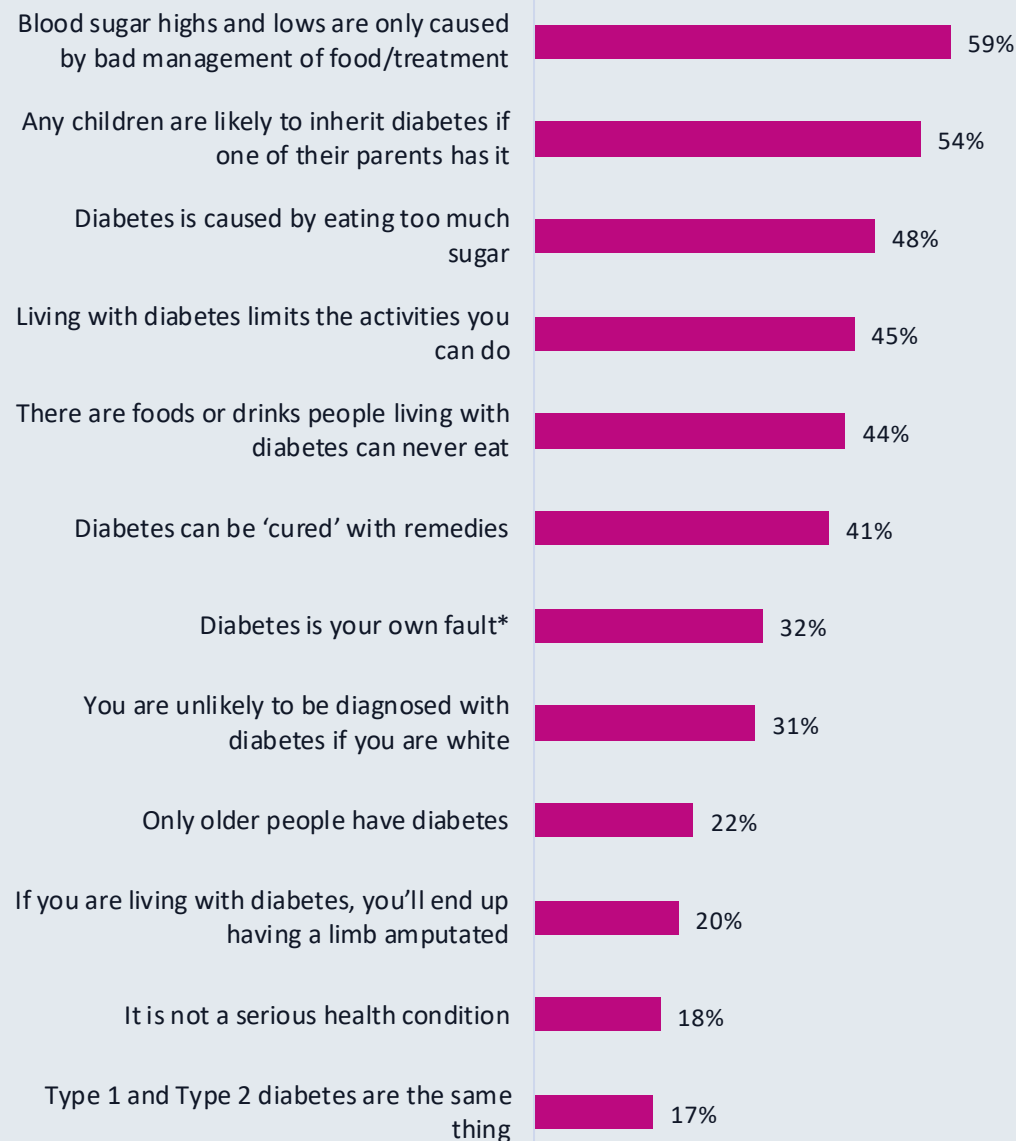
Q. What are the misconceptions or myths you've come across about diabetes? These answer options have come from discussions with people living with diabetes where they shared their real-life experiences. n=450

MISCONCEPTIONS ARE ALSO BELIEVED BY SOME LIVING WITH DIABETES

MANY BELIEVE THE MISCONCEPTIONS THEMSELVES

Half or more believe blood sugar highs and lows are *only* caused by bad management of food/treatment, that children are likely to inherit diabetes from their parents, and that diabetes is caused by eating too much sugar. People living with Type 2 are more likely to believe 'Diabetes is your own fault' (39%) compared to those living with Type 1 (14%).

SELF BELIEF IN MISCONCEPTIONS



Q. To what extent, if at all, do you believe any of these misconceptions yourself?
n=58-190



'I found someone who I thought I could really get on with and... I thought she was the one and she did a U-turn on me because we had a conversation regarding children... I did express that the likelihood is that it might be difficult to firstly have children and secondly, if we did have children, there would be a high risk of diabetes due to my genetics.'

Male, Type 1, 48yrs

ETHNICITY PLAYS A ROLE IN INTERNALISING BELIEFS

DIABETES IS CAUSED BY EATING TOO MUCH SUGAR

More likely to be believed by:

- Asian or Asian British
- Black, Black British, Caribbean or African
- Mixed or multiple ethnic groups.

LIVING WITH DIABETES LIMITS THE ACTIVITIES YOU CAN DO

More likely to be believed by:

- Asian or Asian British
- Black, Black British, Caribbean.

DIABETES CAN BE 'CURED' WITH REMEDIES

More likely to be believed by:

- Asian or Asian British.

BLOOD SUGAR HIGHS AND LOWS ARE ONLY CAUSED BY BAD MANAGEMENT OF FOOD/TREATMENT

More likely to be believed by:

- Asian or Asian British
- Black, Black British, Caribbean or African



“

‘When it's too high, when it's too low, or if I have a hypoglycemia in my sleep that really like ruined my day, I always feel like I could have done more to prevent it Why did this go the way that it did? And why did I have? I think I'm very hard on myself... when I do have it, I get very angry’

Female, Type 1, 28yrs



EXPERIENCES OF STIGMA



WHAT IS STIGMA?

NEGATIVITY DUE TO DIABETES

In its broadest sense, stigma is anything viewed as potentially negative by, or for, the person living with diabetes. This can be demonstrated through both beliefs and/or actions.

STIGMA IS EXPERIENCED DIFFERENTLY

Perceptions of what is considered stigma are subjective and the same comments can be stigmatising for some, but not for others.



“

‘People look down on you. They think you need help, you're not capable of managing yourself.’

Male, Type 2, 62yrs

‘I didn't realise how much they [sister's family] judged me until they came round and told me I should walk more...they went off on one and I had to leave the dinner and go upstairs, and I haven't spoken to them since.’

Female, Type 2, 50yrs

Social stigma in the context of health is the negative association between a person or group of people who share certain characteristics and a specific disease.

This may result in discrimination.

World Health Organisation

EXPERIENCES OF STIGMA VARY

EXPERIENCE AT DIAGNOSIS

Those who had a more positive experience when diagnosed feel more capable of brushing off potentially stigmatising occasions/comments and are less likely to internalise it.

HOW LONG A PERSON HAS LIVED WITH DIABETES

If someone has been living with diabetes since childhood, there will have been more opportunities for them to experience stigma simply due to time. However, a diagnosis later in life can also prompt questions, comments and assumptions from friends and family.

WHETHER THEY HAVE CO-MORBIDITIES

A person living with other medical issues such as obesity may be more likely to experience negative comments about their condition due to their weight or an unhealthy lifestyle.

STIGMA SENSITIVITY

Stigma can mean different things to different people. How sensitive the person is to 'perceived' stigma is also a factor. Those with anxiety, depression or simply a more 'sensitive' nature can feel as though they're being judged in more subtle ways such as 'looks'.



POSITIVE DIAGNOSIS EXPERIENCE

Aram, aged 25, was diagnosed with Type 1 diabetes a year and a half ago. He was told that diabetes would not stop him doing anything in life, as long as he manages it. A doctor from another department, whose wife and daughter are living with Type 1 diabetes, were brought in, to reassure him and answer any questions on the practicalities of living with diabetes.

Aram doesn't view misconceptions as stigma and believes people simply want to learn more.

THE MAJORITY EXPERIENCE STIGMA

People living with Type 1 are more likely to report experiencing stigma overall and 'to a great extent' compared to those living with Type 2.

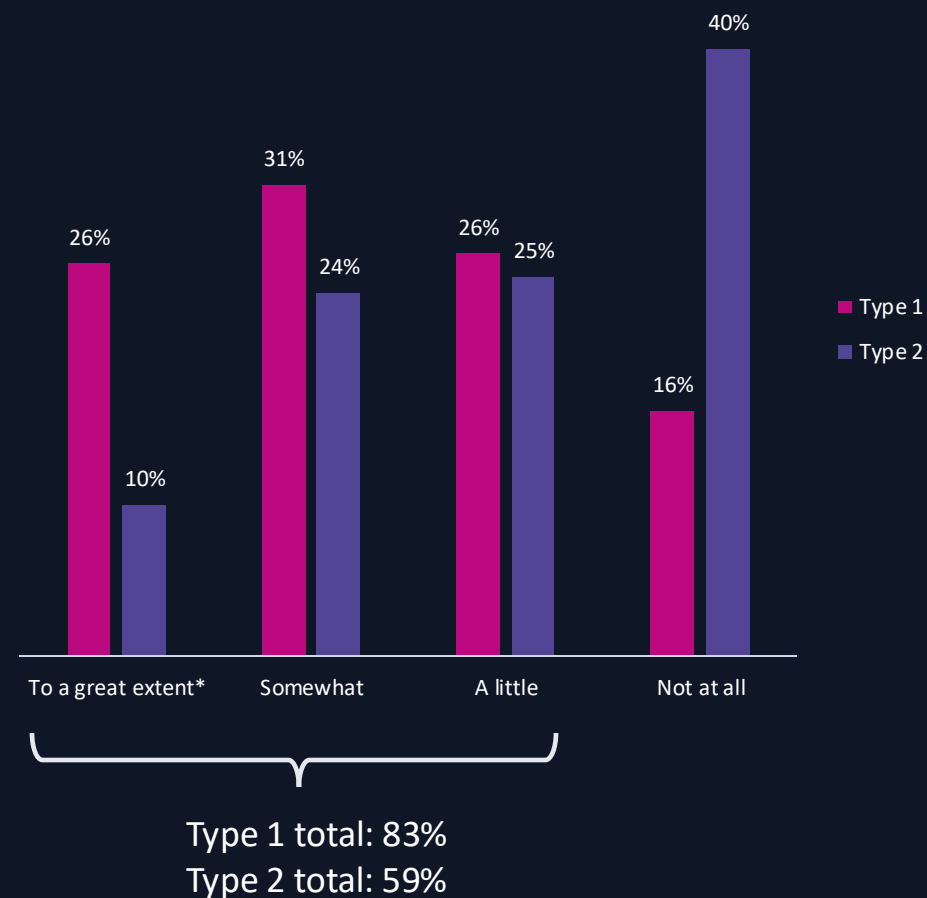
People living with diabetes are more likely to experience stigma if:

- They use an insulin or smart pen
- Aged 18-39 years and aged 40-64 years, compared to 65+ years
- Female
- Asian or Asian British
- Black, Black British, Caribbean or African

8 IN 10

have experienced negative attitudes because of their diabetes

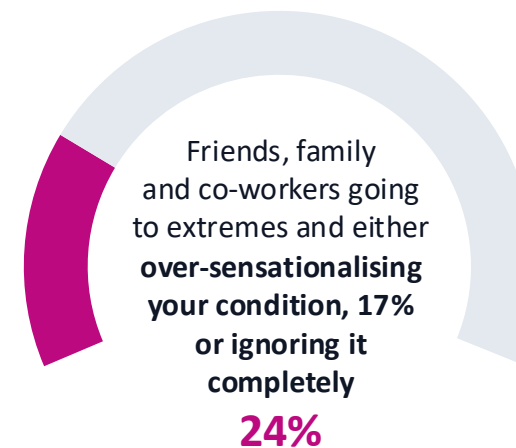
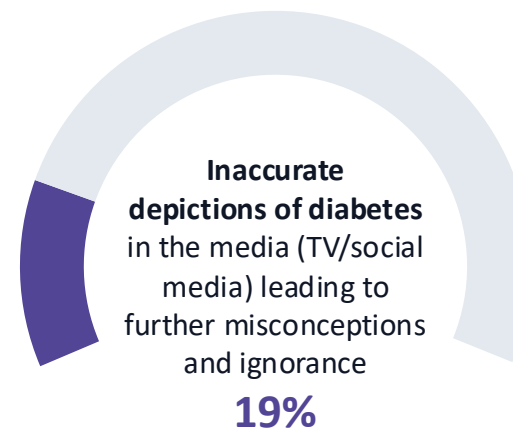
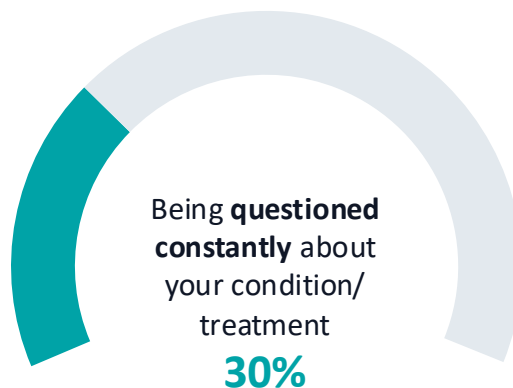
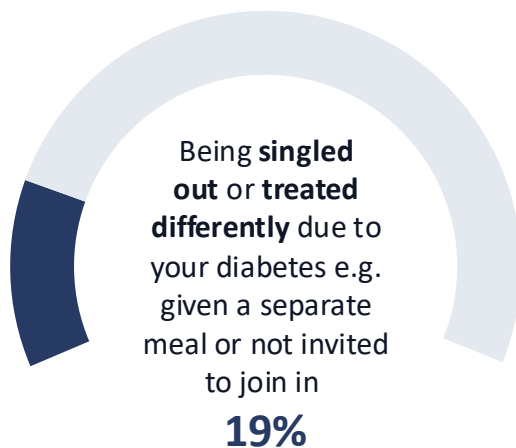
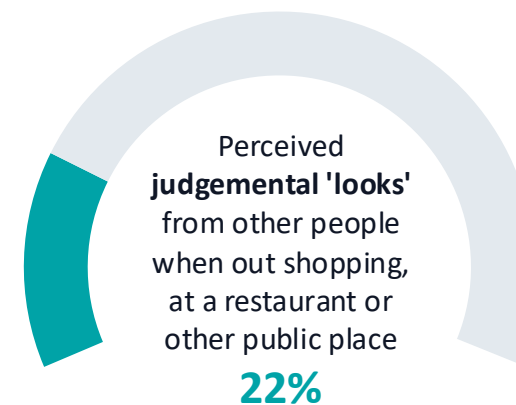
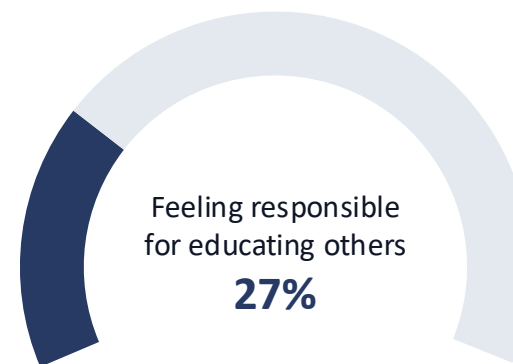
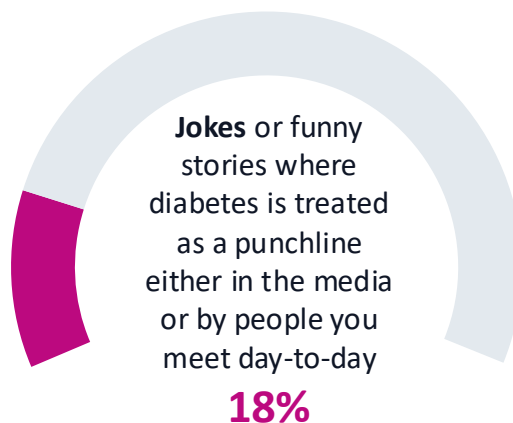
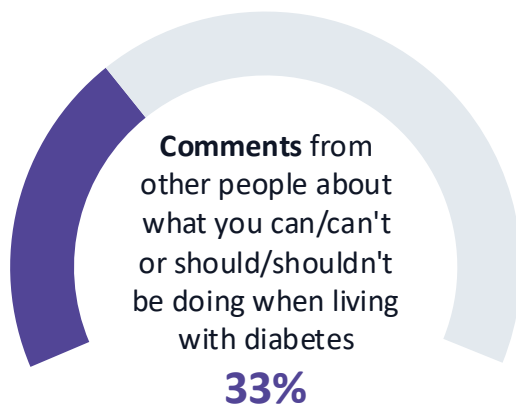
EXTENT OF EXPERIENCING NEGATIVE ATTITUDES FROM OTHERS



Q. To what extent would you say you experience negative attitudes from others in relation to your diabetes? N=450

PERCEIVED DIABETES STIGMA CAN TAKE MANY FORMS

8 in 10 people experience at least one of these types of stigma...



EXTREME RESPONSES DRIVE NEGATIVE REACTIONS

HAVING YOUR CONDITION IGNORED AND BEING SINGLED OUT AS DIFFERENT

The vast majority (94%) feel negative when their diabetes is ignored or minimised, and a similar proportion do when singled out or treated differently (91%) or receiving a judgmental look (90%).

JOKES AND BEING TREATED DIFFERENTLY

When considering the **strength** of the negative response, people living with diabetes feel a stronger negative reaction when they hear jokes or stories where diabetes is the punchline (30%) and when being singled out or treated differently (29%).

The latter occurs at the highest frequency of the different stigmas.

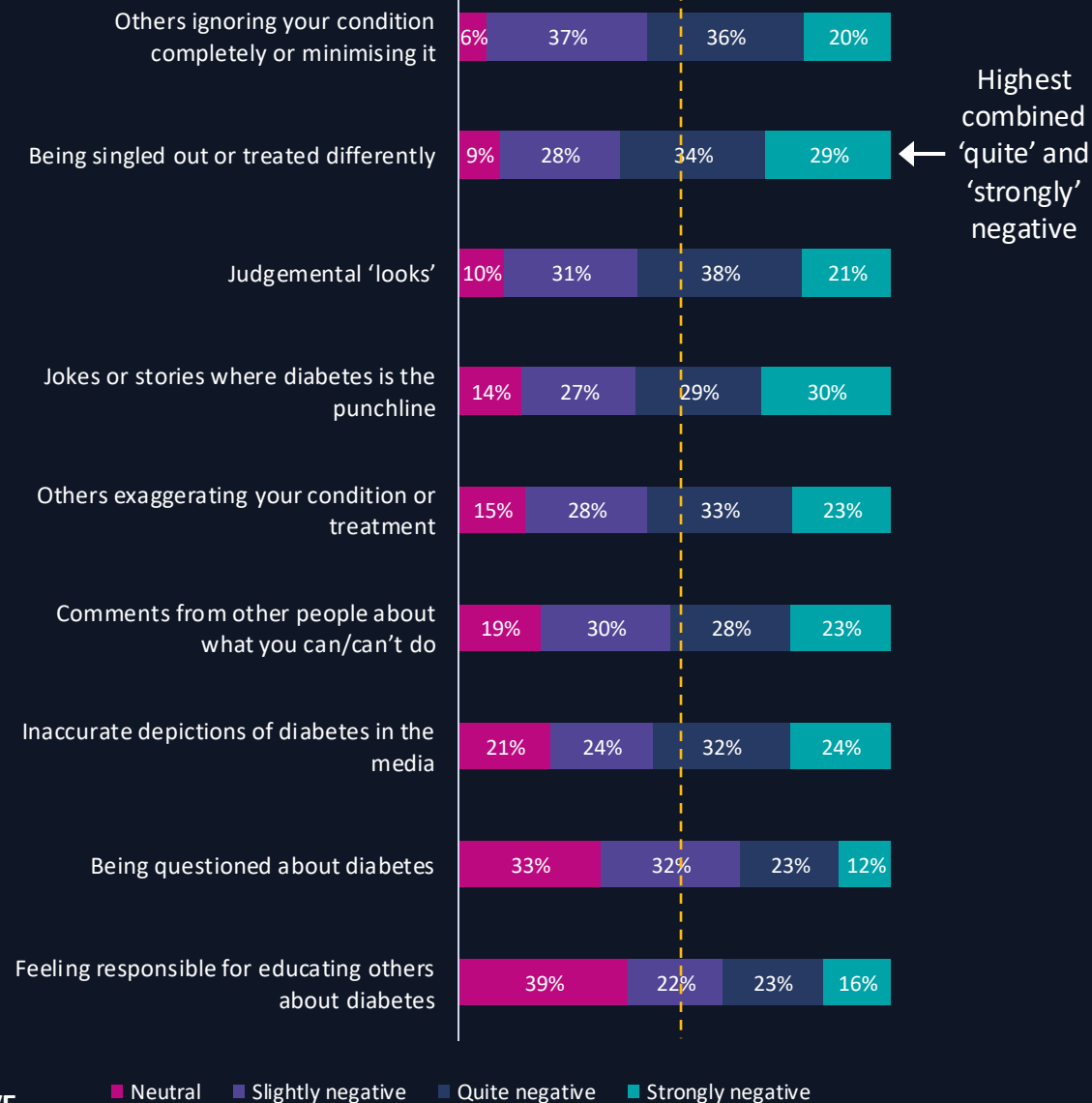
REACTIONS ARE SIMILAR FOR ALL

Those with Type 1 and Type 2 have similar reactions to stigma, the exception being 'comments from other people about what you can and can't do' generates more negative responses from those with Type 1 (66%), compared to those with Type 2 (45%).

MOST LIKELY TO
EVOKE A NEGATIVE
RESPONSE

How do you feel when the following happens...

50% quite or strongly negative



LEAST LIKELY TO
EVOKE A NEGATIVE
RESPONSE

CULTURAL HERITAGE PLAYS AN IMPORTANT ROLE IN STIGMA

SOUTH ASIANS EXPERIENCE HIGH LEVELS OF STIGMA

Despite the prevalence of diabetes in people with a South Asian background, many experience significant levels of discrimination or stigma from others in their community. For some, this leads to intense pressure to keep their diabetes a secret.

Asian or Asian British are more likely to say they experience negative attitudes in relation to their diabetes (80%) compared to white people living with diabetes (61%).

SOUTH ASIAN COMMUNITIES VIEW DIABETES DIFFERENTLY

Some Hindus explain their diabetes diagnosis using karma, that diabetes is a punishment for wrong-doings in a past life.

OTHER CULTURES ALSO SEE DIABETES DIFFERENTLY

Chinese beauty standards dictate that women are supposed to be petite and submissive, not cause a fuss by having 'dietary requirements'.



CASE STUDY: HUSSAIN

Hussain is 48 years old and from a Hindu Gujarati family. Hussain grew up in the UK and his family spend time both in the UK and India. He has many aunts and uncles with Type 2 diabetes and his 10-year-old niece has been recently diagnosed with Type 1 diabetes.

'Well, when I was diagnosed in 1999, my mother was very conscious and aware of people gossiping and stuff. So she and myself we've been shielding from my dad's side of the family. So we haven't at the moment, to this day, after 23 years of living with diabetes, we haven't officially told relatives and cousins and aunts on my dad's side that I'm Type 1 diabetic and no one knows about my niece having diabetes as well.'

Male, Type 1, 48yrs

STIGMA DOES NOT ALWAYS COME FROM STRANGERS IN PUBLIC, BUT ALSO FROM LOVED ONES IN PRIVATE

76% of those living with diabetes have experienced stigma in at least one of these places...



At home with friends
and family: 32%



In restaurants, or when eating
out of home: 29%



In supermarkets or when
food shopping: 22%



At work with colleagues or
customers: 37%



From healthcare
professionals: 21%



In the media: TV, radio,
film or online: 21%

STIGMA IN THE HOME IS VERY COMMON

The amount and tone of at-home stigma depends on whether a person living with diabetes has an empathetic and supportive family.

Often parents, particularly mums, are keen to 'help' their children by keeping them on-track or reminding them of their dietary needs. For those with Type 2 diabetes, comments can centre on their lack of exercise or unhealthy lifestyle. This kind of input is not always unwelcome as it can serve to motivate people to act or stick to their diet.

1

Comments around what you 'should and shouldn't' be eating or doing

2

3

4

Treating you differently to other family members e.g. preparing you separate meals



Wrapping you up in cotton wool OR acting as though your condition doesn't exist

**1 in 4**

experience stigma in the home at least weekly

43%

feel negative or strongly negative when stigma at home happens

SOUTH ASIANS CAN EXPERIENCE INTENSE STIGMA FROM FAMILY

Those from a South Asian background can feel extremely 'othered' by family members who believe they are somehow 'defective' or broken upon their diagnosis whether Type 1 or Type 2. This kind of stigma can be intensely damaging to a person's self-esteem.

1

Seeking to understand WHY you have this condition (when the rest of the family doesn't)

2

3

4

Asking you to hide your condition from other family members / potential spouses



Seeking to rationalise your diagnosis via religion or 'karma'



“

'When I was 5, I asked my grandpa who had his leg amputated why did it happen to him. He said in his previous life we all used to work in a sugar factory, and we used to steal the sugar. In this life for every time, we tasted the sugar, we get one year of diabetes. It's god's own 'sweet justice''

Male, Type 1, 48yrs

'Dating is difficult. Trying to arrange a marriage the parents of the bride would think that you are defective and would think our children will be like that too'

Male, Type 1, 48yrs

INPUT FROM FAMILY MEMBERS CAN RANGE FROM SUPPOSEDLY HELPFUL TO DOWNRIGHT CRUEL

'My family make plans around my diabetes, without even asking me. They say things like, 'we were gonna have pasta, but then we remembered you so we're doing grilled chicken instead.'
Female, Type 1, 30yrs

'My family will say 'do you have to do that right now' when my insulin alarm goes off...um yes! It's important!'
Female, Type 1, 30yrs



'Mum's wish is to 'cure' me of diabetes. She keeps suggesting home remedies like bitter melon ('karela' in Gujarati) to counter the sugar.'
Male, Type 1, 48yrs

'My sister at Christmas was trying to control what I ate. Now even my 11 year old son says – 'mummy you can't eat that'. It's so frustrating but I guess it does keep me on track.'
Female, Type 2, 37yrs

'My aunt said stop crying, you're only doing it to get attention, she thinks that's what I'm doing with the diabetes too – crying for attention.'
Female, Type 2, 37yrs

'My uncle suggested I stop eating carbs so I wouldn't have to inject so much insulin. He's trying to help but he just doesn't understand.'
Male, Type 1, 67yrs

'For my parents every high/low is a serious event. They think it's the end of the world. It's exhausting!'
Male, Type 1, 40yrs

FRIENDS OFTEN MEAN WELL, BUT...

Most comments from friends are well intentioned but even so can have intense negative effects over time.

Making light of the situation can be a way for a friend to feel less awkward themselves e.g. when seeing someone inject or eat 'unhealthily'. Friends trying to 'fix' them can become frustrating overtime for the person living with diabetes.

1

Praising you for being 'brave' or managing your condition well

2

3

4

Making jokes about eating sugar or carbs



Suggesting to those with Type 2 that they've 'let themselves go' and trying to 'fix' them



“

'My friend said 'I could never do what you do' and it annoyed me so much. I didn't choose this! I just woke up one day and had to start monitoring my glucose. If she were me she'd have to do it or die.'

Female, Type 1, 30yrs

'Sometimes I feel like my friends don't believe me when I say I'm having a hypo, they just think I'm looking for an excuse to have a chocolate bar. They give me funny looks.'

Female, Type 2, 37yrs

RESTAURANTS CAN BE STRESSFUL PLACES

Many can feel like their diabetes is a burden to others especially where food is concerned.

Having to medicate in public can also be awkward and embarrassing. A lack of safe, clean spaces can mean some feel the need to leave the building to inject.

1

2

3

4



Feeling judged when injecting at the dinner table or leaving to find a toilet cubicle

Having to do the mental maths of carb counting can feel awkward

Comments from waiters/friends about 'diabetes friendly' or low sugar options



“

'I go out and inject in my car. There's never a shelf or anywhere to put things in the bathroom. It just feels so unclean to me.'

Female, Type 1, 30yrs

'My friends had all ordered and I didn't want to make a fuss so I just said I'd already eaten to avoid having to eat the carb heavy food. Sat there feeling so hungry!'

Female, Type 1, 28yrs

1 in 3

experience stigma at restaurants at least every few weeks

HALF

feel negative or strongly negative when it happens

WHEN FOOD SHOPPING, THOSE WITH DIABETES CAN FEEL PRESSURE TO HIDE THEIR CONDITION

Particularly for those with Type 2 diabetes, who may be overweight, buying food can be a stressful experience.

Many instances of shopping stigma tend to be subtle or 'perceived' stigma. It's rare that someone will actually make a comment about the content of someone's trolley or basket.

1

Feeling judged when buying sweets or sugar heavy foods

2

3

4

Getting 'funny looks' from other shoppers while filling their trolleys



Questions from others about why they're paying so much attention to labels

**1 in 5**

experience stigma when food shopping at least weekly

41%

feel negative or strongly negative when stigma at the supermarket happens

MANY ARE HESITANT TO REVEAL THEIR CONDITION IN THE WORKPLACE FOR FEAR OF DISCRIMINATION

PERCEIVED DISCRIMINATION IS COMMON

Some people living with diabetes will not apply for jobs, or assume they missed out on a job, due to their condition. **They have internalised diabetes stigma to the extent that they hold themselves back.**

COMMENTS FROM COLLEAGUES CAN BE HURTFUL

Some report feeling like a burden to colleagues e.g. having to eat separate meals or refuse birthday cakes/work meals out. Comments and jokes from colleagues about what you should and shouldn't be eating can also be irritating and frustrating.

MANAGEMENT OFTEN MISUNDERSTAND

Many feel that they're coming across as 'difficult' having to ask to take breaks, leave meetings to medicate or ask for any other kind of support.

1 IN 5

Experience workplace stigma at least every few weeks

HALF

Feel negatively when it happens

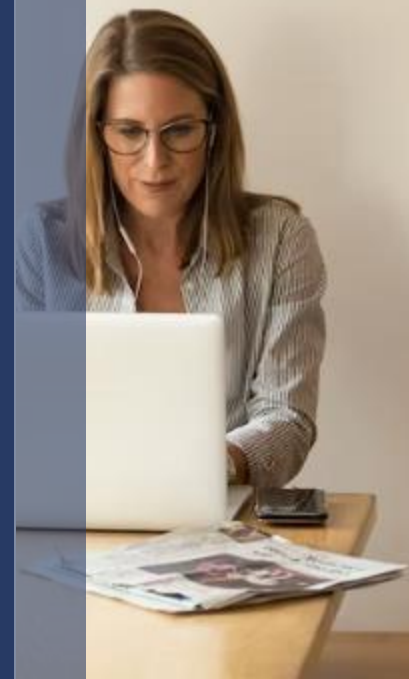
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'When I applied for and didn't get my first graduate job, I just assumed that it was because I said I had diabetes. That really stuck with me and now I never tick the box on the form in case someone judges me.'

Female, Type 1, 30yrs

'I only talk about it at work when it's absolutely necessary. I just don't need people giving me advice or trying to tell me what I should do. I hate the feeling that others are tiptoeing around me and wrapping me up in cotton wool, it's so frustrating!'

Male, Type 2, 62yrs



HCPs CAN BE JUDGEMENTAL OR PATRONISING

Although many may not expect medical professionals to be a source of stigma they too can make comments or suggestions that negatively impact their patients.

Some HCPs can fixate on the 'usual' typology for a diabetes patient and find it hard to work with others who may not fit the mould. Many, particularly Type 2 patients can feel judged or patronised.

People living with diabetes feel as though they are not being treated as an individual by HCPs.

1

Making comments that can confuse patients or make them feel even more 'othered'

2

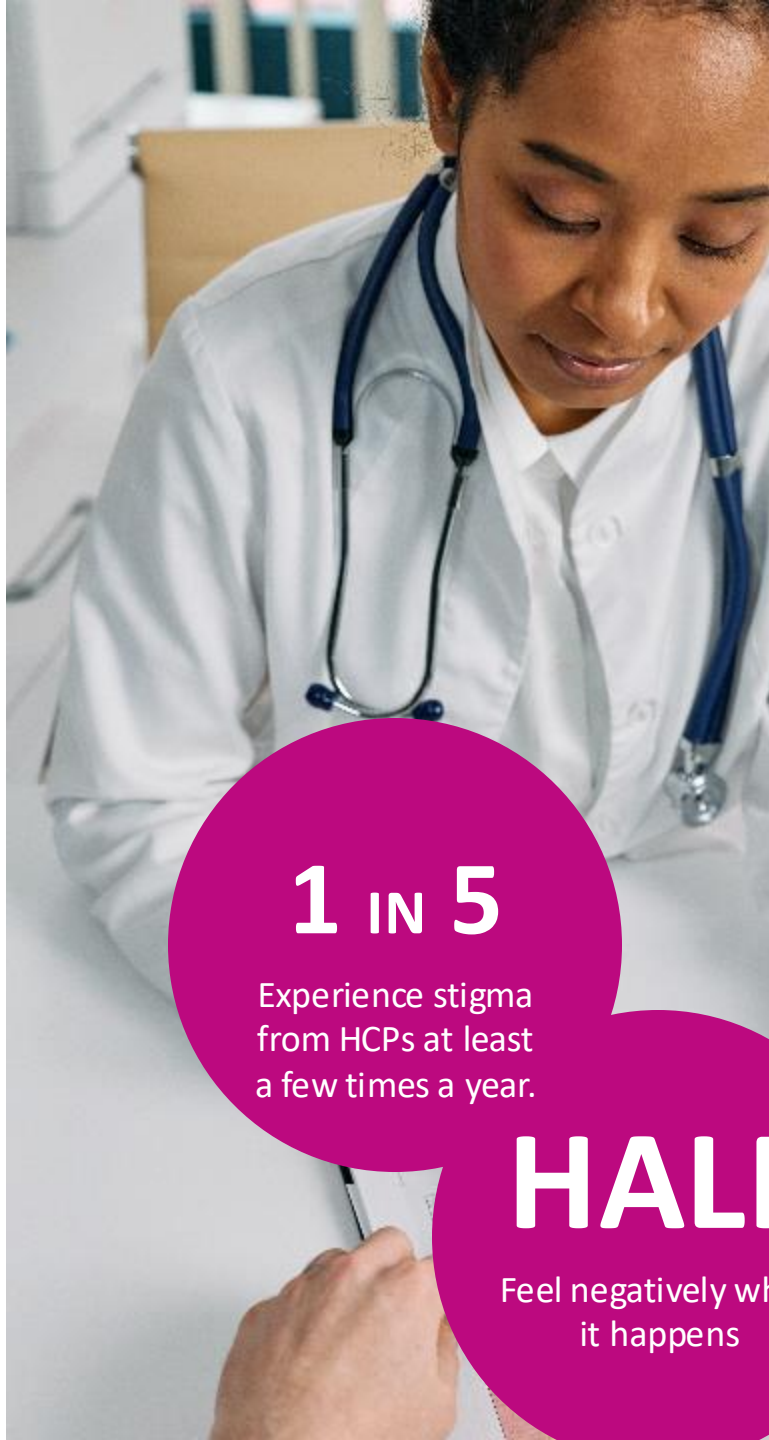
3

Feeling 'told off' if your sugar levels are fluctuating or your lifestyle has not improved

4



Being treated like 'a diabetic' rather than a person – HCPs not understanding that everyone's symptoms and experiences will be different



1 IN 5

Experience stigma from HCPs at least a few times a year.

HALF

Feel negatively when it happens

“

'He just laughed and said 'but you're white and you're thin!' He just couldn't get over that I wasn't like his usual patients – he just kept saying it. It made me feel like even more of an oddity.'

Male, Type 2, 67yrs

'When I was diagnosed I had a phone call and an e-mail sent to me with all the information on and zoom call from the hospital, there wasn't a one-on-one. They sent, it was like a YouTube video on how to do the test, you know, to check your bloods. And it was just a bit confusing, it would have been nice for someone to do it with me in person.'

Female, Gestational, 28yrs

THE MEDIA FUELS MISUNDERSTANDINGS

CONFLATION OF TYPE 1 AND TYPE 2

In traditional news media both Type 1 and Type 2 diabetes are regularly spoken of in the same breath. Many feel that the conflation of these separate conditions has led to public confusion about the causes of, and treatments for, diabetes.

LACK OF WELL-KNOWN ROLE MODELS

Most struggle to think of any well-known positive role models for diabetes. Instead, characters in media are often inaccurate representations of diabetes. For example, South Park's 'Captain Diabetes' who uses his condition as a superpower.

JOKES ARE COMMON

In media, diabetes (both Type 1 and Type 2 or not distinguished) is often linked to obesity and over-eating sugary/fatty foods. There are many jokes in TV and film (particularly South Asian TV) surrounding eating sugar and 'getting diabetes'.



2 in 3

experience stigma from the media at least monthly

6 in 10

feel negative or strongly negative when stigma from the media happens



South Park's
Captain Diabetes



3

IMPACT OF STIGMA



THOSE LIVING WITH TYPE 1 FEEL A GREATER NEGATIVE IMPACT OF STIGMA

THOSE LIVING WITH TYPE 1 ARE MORE LIKELY TO ANTICIPATE NEGATIVE IMPACTS

Consistently across the scenarios presented, those living with Type 1 are more likely to anticipate a negative impact, than those living with Type 2.

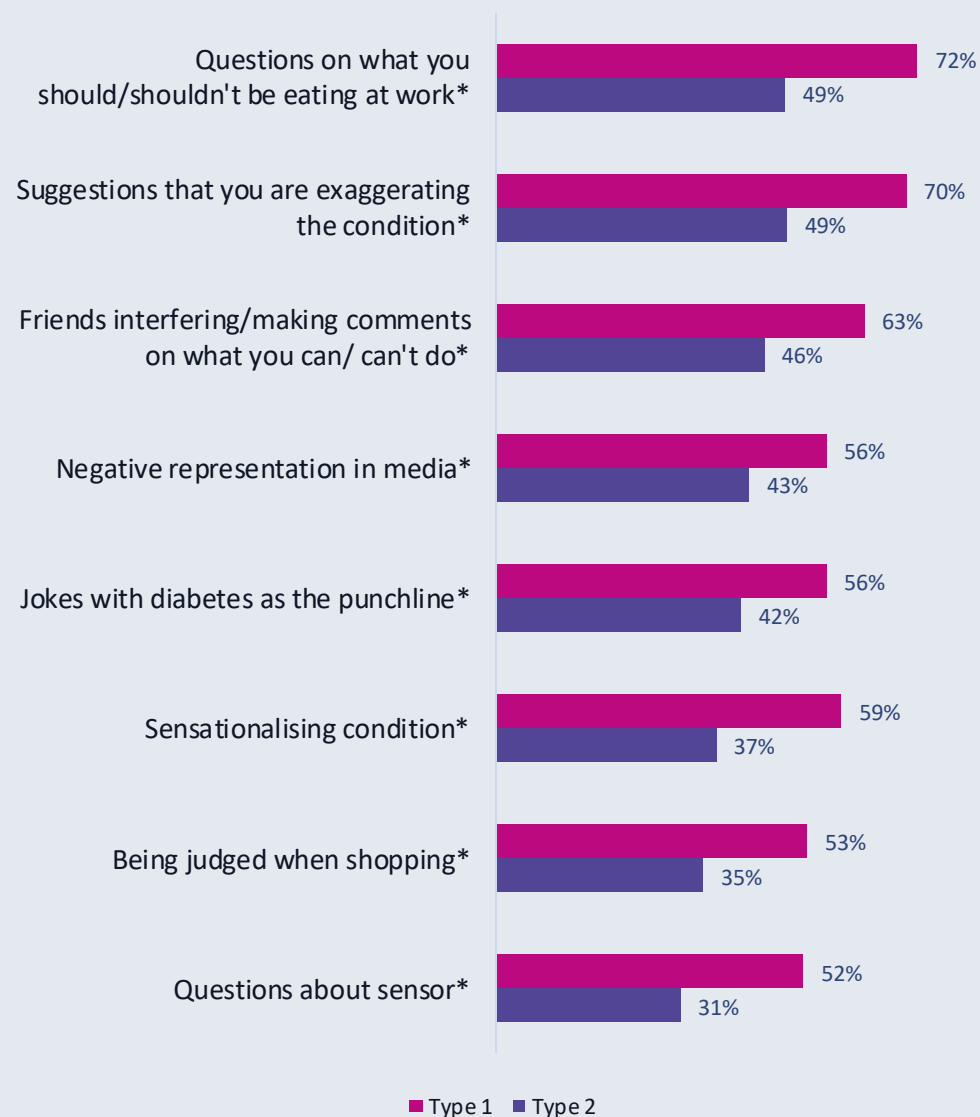
THE TYPES OF SCENARIOS FOLLOW THE SAME PATTERN

Regardless of Type 1 or Type 2, the ordering of negative impact from highest to lowest in the same.

QUESTIONS AT WORK AND SUGGESTIONS OF EXAGGERATION ARE MOST LIKELY TO CAUSE A NEGATIVE IMPACT

These would evoke a negative impact in about half of those living with Type 2 diabetes (both 49%) and for the majority of those living with Type 1 diabetes (72% and 70% respectively).

NEGATIVE IMPACT OF SCENARIOS



Q. If this experience happened to you, to what extent would it have a negative impact on you? Type 1 n=155, Type 2 n=281 (answer: moderate and major impact).

SCENARIOS IN SURVEY

1. I have a colleague who will constantly ask if I should be doing things: 'should you be eating that?' 'Isn't that really sugary for you?' It's really annoying.

2. My aunt just thinks I'm being overdramatic. She tells me to just sort myself out and stop 'faking it' for attention.

3.I was round at a new neighbour's house, and she offered me some orange juice and my friend jumped in and said, 'oh no she can't have that, do you have anything else?', I can drink whatever I want to drink!

IMMEDIATE RESPONSES TO STIGMA CAN VARY

IGNORING STIGMA IN THE MOMENT IS COMMON

Many choose to ignore stigma in the moment to avoid confrontation or defuse the situation. People express that it can be hard to know what to say and stressful feeling that it's up to you to 'educate' this person.

SAYING IT FIRST

Some people, particularly those with type 2 diabetes, mention 'making the joke' themselves before other people do to get it out of the way.

In the short-term stigma can lead to feelings of...

- **Annoyance** that this is happening again.
- **Frustration** that people refuse to listen or won't understand.
- **Embarrassment** or a wish to hide or leave the situation.
- **Sadness** that this is how life is when living with diabetes.

“

'When reaching for the biscuits I'll say 'you've got to treat yourself sometimes' or 'just one more' to try and make the joke before anyone else. I know I'm fat, it doesn't look good for me to eat junk food...'

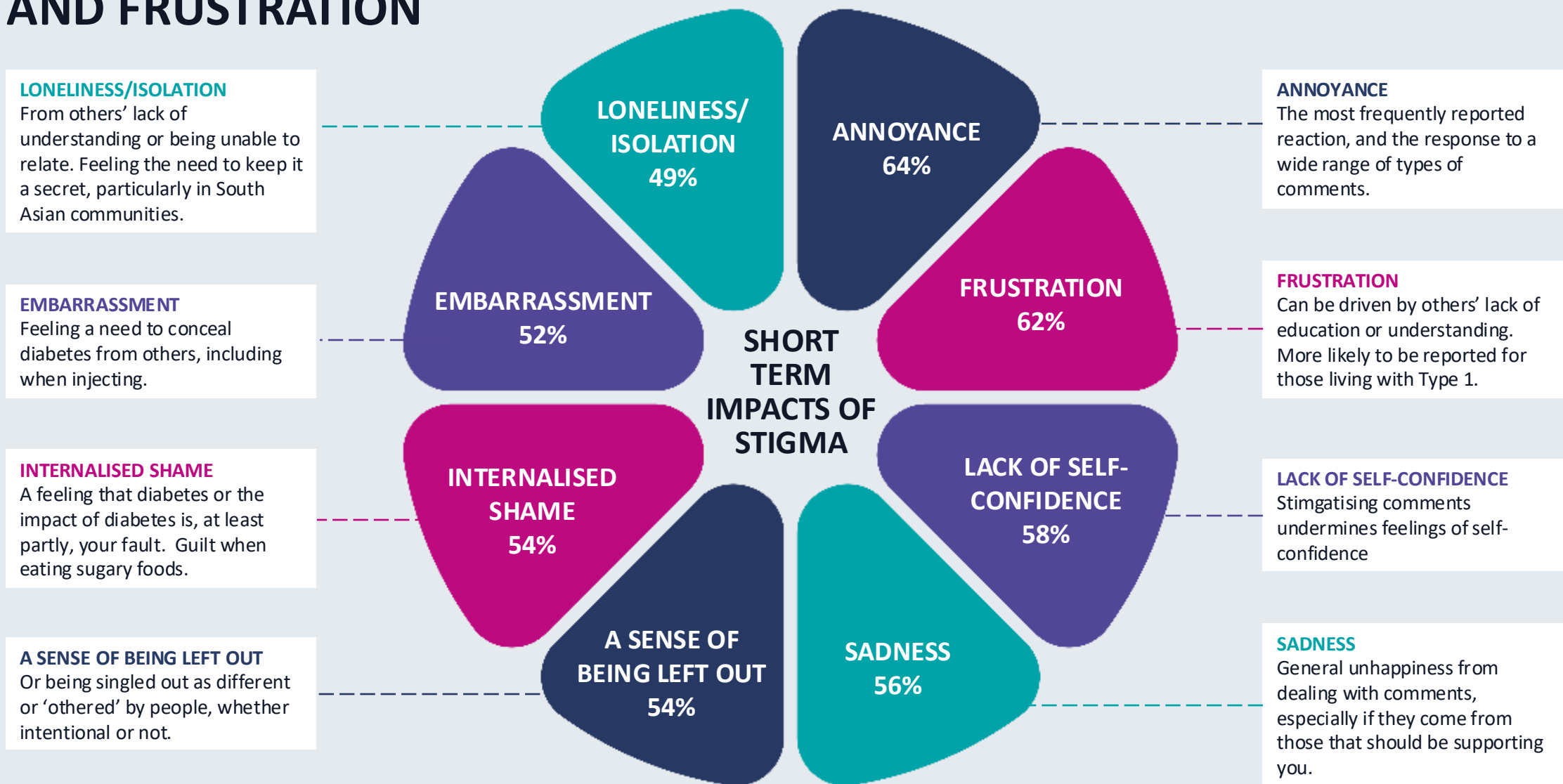
Female, Type 2, 50yrs

'I just give people this look sometimes. My wife laughs at me – I'm quite a big guy and I don't often get people making comments but when I do, I can't help rolling my eyes or glaring a bit.'

Male, Type 1, 40yrs



SHORT TERM IMPACTS OF STIGMA ARE PRIMARILY ANNOYANCE AND FRUSTRATION



Q. As a result of the negative views and attitudes you've experienced regarding diabetes, to what extent have you felt...? N=450 (answer: at least sometimes)

IN THE LONG-TERM, STIGMA CAN IMPACT LIFE CHOICES

MAKING DECISIONS BASED ON WHAT OTHERS THINK

The impact of repeated encounters with stigma can lead people to change their behaviours. Absorbing negativity over time often leads to internalised stigma that affects confidence.

HIDING DIABETES FROM OTHERS

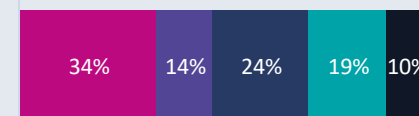
Many resort to hiding their condition from friends, family and any new acquaintances. It's just easier sometimes to avoid the conversations. Just over half of people living with diabetes (53%) do this at least some of the time, higher for those living with Type 1.

AVOIDING MEDICAL APPOINTMENTS

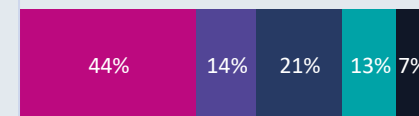
More than half (56%) of people surveyed admit to avoiding their medical appointments. About two in five (42%) do this at least sometimes. During interviews participants living with Type 2 told us they can often feel 'told off' by HCPs if they haven't been following their lifestyle advice. Whilst some participants living with Type 1 had some negative experiences, they didn't suggest missing appointments.

ACTIONS AS A RESULT OF STIGMA

Hidden your diabetes from friends/ family/ colleagues/ when you meet new people



Avoided going to medical appointments/ check-ins for your diabetes



■ Never ■ Rarely ■ Sometimes ■ Very often ■ Always

**OVER
HALF**

admit avoiding
their medical
appointments

Q. As a result of the negative views and attitudes you've experienced regarding diabetes, to what extent have you...? n=450

“

'I often don't go to appointments. I know I'm stupid. I make up all these ridiculous excuses. Oh, it's raining. Oh, I'm tired today. I just feel so bad when I'm there that it's better for me not to go.'

Female, Type 2, 50yrs

'I don't tell people I've got it. I feel ashamed for people to know, I used to inject in secret. More than half my friends still don't know I have diabetes.'

Male, Type 1, 41yrs

BEING A 'GOOD DIABETIC' VS A 'BAD DIABETIC'

'BAD DIABETICS' LET THE SIDE DOWN

For those with Type 1 especially there can be an internalised pressure to live a healthy life and carry on as normally as possible despite a diabetes diagnosis. Some people living with Type 1 can feel resentment towards others who don't take the necessary diet and lifestyle steps to help themselves, typically those with Type 2. People who allow their diabetes to 'make them the victim' can be viewed as giving up.

'GOOD DIABETICS' TRY HARD TO AVOID LIVING UP TO THE STIGMA

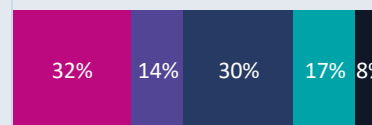
Some people have internalised so much stigma when it comes to their diabetes that they are willing to go to extraordinary lengths to prove that they are not 'a bad diabetic'. These people may run marathons, take on other intense fitness challenges and eat super healthily in an attempt to overcompensate for their condition.

- 54% fight against misconceptions by overcompensation at least sometimes. 14% of people living with Type 1 do this all the time.
- 49% have given up at least sometimes.

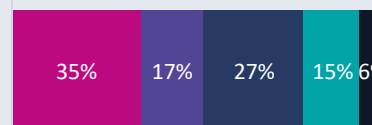


ACTIONS AS A RESULT OF STIGMA

Fought against the misconceptions through overcompensating in other areas e.g. running marathons, eating very healthily



Given up and not felt able to manage symptoms



■ Never ■ Rarely ■ Sometimes ■ Very often ■ Always

“

'I feel like there're 'good diabetics' and 'bad diabetics.' Good ones continue to live their life, exercise regularly, eat healthily and don't let their condition stop them from doing anything they want to do. Bad ones let the side down. They're what people think of when they think of diabetes, overweight, lazy, eating junk food all the time. I try hard to be a 'good' diabetic.'

Male, Type 1, 40yrs

THE IMPACT ON SELF FROM DIFFERENT STIGMAS VARIES

STIGMA AT WORK AND AT HOME HAS THE HIGHEST IMPACT ON SELF: A combination of strength of response and the frequency it happens results in stigma experiences at work and at home having the highest impact on self.

MEDIA EXPOSURE IS ANNOYING AND FREQUENT BUT HAS LESS IMPACT ON SELF: Whilst experiencing negative attitudes in the media: TV, radio, film or online is mostly likely to evoke a negative or strongly negative response, people living with diabetes say it has a low impact on them.

	STRENGTH OF RESPONSE	FREQUENCY IT HAPPENS	IMPACT ON SELF
At work with colleagues or customers	HIGH	MEDIUM	HIGH
In the home with friends and family	MEDIUM	HIGH	HIGH
In restaurants or when eating outside of the home	HIGH	LOW	MEDIUM
In supermarkets or when food shopping	MEDIUM	MEDIUM	MEDIUM
From doctors, nurses or other healthcare professionals	HIGH	LOW	LOW
In the media: TV, radio, film or online	HIGH	HIGH	LOW

Q. Of the different locations/people you've experienced negative attitudes which has the biggest negative impact on you? n=143-280



4 SUGGESTIONS FOR SUPPORT



HEALTHCARE PROFESSIONALS COULD BENEFIT FROM TRAINING

SOFT SKILLS MATTER

Most participants mention that it's not that Drs or Nurses are giving out false information or are badly educated when it comes to diabetes. The problems tend to lie in how they talk to their patients.

TREAT ME LIKE A HUMAN

HCPs can tend to talk to patients as though they're 'case studies' or just another statistic. They can be unaware of the realities of living with diabetes on a daily basis. Patients are not just a blood sugar level.

WORDS CAN HURT

Making seemingly innocuous comments on a patient's lifestyle choices, appearance or background can really lower their confidence when it comes to attending medical appointments.



'I wish my doctors and specialist were more understanding. They ask me how much insulin I'm taking and I say it varies everyday...they just don't get it! They're so academic whereas I'm more interested in the practical side of things.'

Male, Type 1, 40yrs

'One time I was trying to vent to either a diabetic nurse or a Consultant and you just get this really kind of blank stare and there's almost no understanding there's no sympathy for your situation.'

Female, Type 1, 28yrs

72% would find education for medical professionals in the ways diabetes affects people differently useful

INCREASING VISIBILITY

MORE VISIBILITY OF CELEBRITIES LIVING WITH DIABETES

People living with diabetes would welcome anything that raises the profile of diabetes and normalises it.

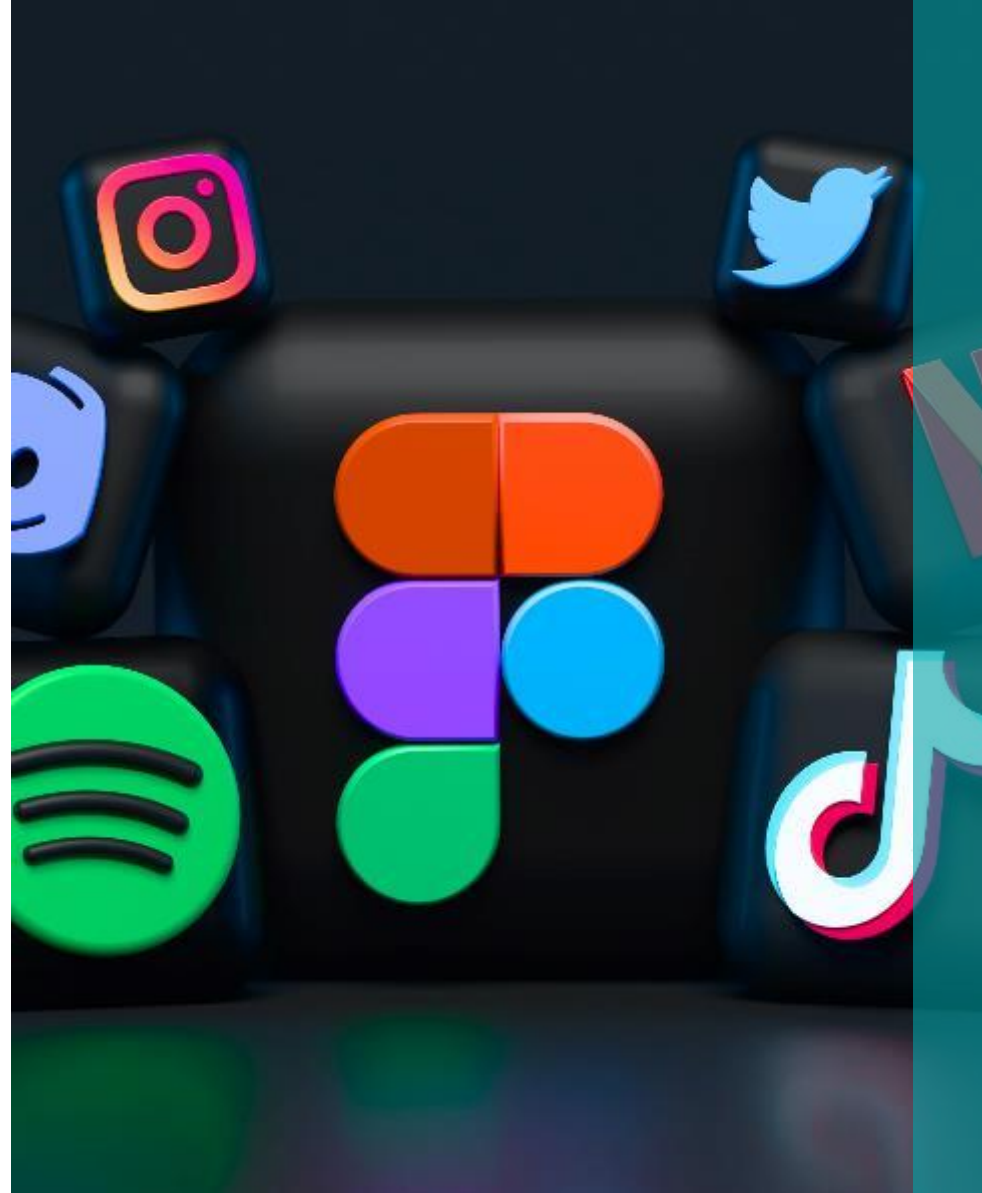
ACCURATE REPRESENTATIONS IN THE MEDIA

Beyond visibility, seeing more accurate representation of diabetes in the media is desirable. When diabetes is portrayed it's often in extremes, such as portraying people falling into comas, rather than the day-to-day reality of living with diabetes.

INCREASED VISIBILITY ON SOCIAL MEDIA

Raising the profile of diabetes could also be done through social media. Suggestions include:

- Collaborations with a well-known restaurant or food brand
- Adverts depicting FreeStyle Libre and people injecting insulin
- Collaborations with content creators to raise the day-to-day profile of diabetes
- Proactively address misinformation on social media and forums



69% would find more visibility of people/celebrities living with diabetes in the media useful, higher for those with Type 1

“

‘Someone sent me a picture of a model wearing the FreeStyle Libre. She was just doing a normal shoot and you could see the Libre on her arm, and he was like ‘oh my God, you got it too’... I actually tried to look for YouTubers that have Type 1 and you don't really get that many I think.’

Female, Type 1, 28yrs

‘[Diabetes UK could] be out there more. Go on social media and have debates about it. Distil the myths that it's not their fault, not for everyone.’

Male, Type 2, 37yrs

TOOLS TO MANAGE MISINFORMATION WOULD HELP

REMOVING THE BURDEN OF EDUCATION

It can be difficult for those living with diabetes to explain what the condition means for them and what it is like. The tools suggested are for lightening this mental load, as well as correcting misinformation.

SUGGESTIONS INCLUDE:

- One-page visual summary to share with friends and family
- Short answers to key questions
- Videos of 'day-in-the-life'

BEING SHAREABLE IS KEY

Being able to send images and videos quickly and easily, for example through WhatsApp would be helpful. Being short, snappy and easy to absorb also lowers the burden on the recipient.



“

'Sometimes I just don't have the right words to hand. I want to be able to have a one sentence answer in my back pocket for the common questions.'

Male, Type 1, 40yrs

64% would find 'short answers to key questions that could be shared or used as a reference' useful.

61% would find a 'short graphic to share to take away burden of educating others' useful.

EDUCATION IN THE WORKPLACE WOULD BE IMPACTFUL

STIGMA IN THE WORKPLACE IS COMMON AND HURTFUL

Employers and managers can be inflexible and misunderstand the needs of employees with diabetes. Colleagues can be flippant and prone to making jokes.

A SHORT COURSE

An educational course for all staff members that helps to debunk common myths and information on how best to support someone living with diabetes would ensure that the information is embedded in the business. However, it's recognised that courses can't be undertaken for every healthcare condition.

FUTURE READING

Providing a pamphlet to take away or a link to an information site means that employees can read in their own time.



68% would find 'education for employers debunking myths and how to best support' useful.

“

'The thing is, I don't expect people to know the ins and outs of diabetes and because if it doesn't apply to you, why should you know, right? It's like me learning about epilepsy and I don't have epilepsy.'

Female, Type 1, 28yrs

PEER SUPPORT TO BOOST CONFIDENCE

CONNECTION TO OTHER PEOPLE LIVING WITH DIABETES HELPS EASE THE IMPACT OF STIGMA

Those living with diabetes value the idea of being in touch with other people living with diabetes. A support network helps build resilience and confidence through knowing you're not alone, it helps overcome internalised stigma, and it also makes it easier to not see comments or actions by others as stigmatising.

SIMILARITY IN CIRCUMSTANCES OR BACKGROUND HELPS

Being put in touch with those in similar situations is also welcomed by those living with diabetes. Whether gestational diabetes or being from a specific cultural background, a support network that can empathise helps navigate nuances in circumstances that exacerbate feelings of being alone.

CASE STUDY: MINA

Diagnosed with Type 1 diabetes aged 10, Mina did not know anyone else living with diabetes, except for a grandfather with Type 2. She didn't meet anyone else living with Type 1 until she was 15 and only as a result of coincidence.

Going on the DAFNE course entirely changed Mina's perception of diabetes, and a big part of that was sharing struggles, issues and tips with other participants on a WhatsApp group.

‘Honestly, when you have Type 1, sometimes you feel like you’re the only person in the world that’s going through the issues that you’re going through. Being able to see other people with this condition and talk about very similar experiences that you go through... that would have helped me immensely.’

65% would find 'links to other people living with diabetes' useful.

65% would find a 'links to other people living with diabetes in similar circumstances or from a similar background' useful.

HELP NAVIGATING CULTURAL DIFFERENCES WOULD BE APPRECIATED

Participants from a South Asian background particularly, highlight how hard it can be to approach their family and friends with their feelings around their diabetes.

Certain situations that can be particularly difficult:

COMMUNAL EATING

Being expected to eat the same food and the same amount of food as everyone else at the table can be stressful.

RELIGIOUS 'RATIONALISATIONS'

Some family members can use their religion to attempt to rationalise or understand someone's diabetes. E.g. Blaming it on karma due to sinful conduct in a past life. This can be very hurtful and stressful for those with diabetes.

Culturally specific resources would help to reduce the mental load of patients from different backgrounds.



“

‘I'd like some help with navigating typical moments like when I have to say no when my mum tries to fill my plate AGAIN or explaining my conditions to them. How do I tackle the 'd-word' (depression) in a way they can understand. It's a hard thing for people in our culture to get.’

Male, Type 2, 25yrs

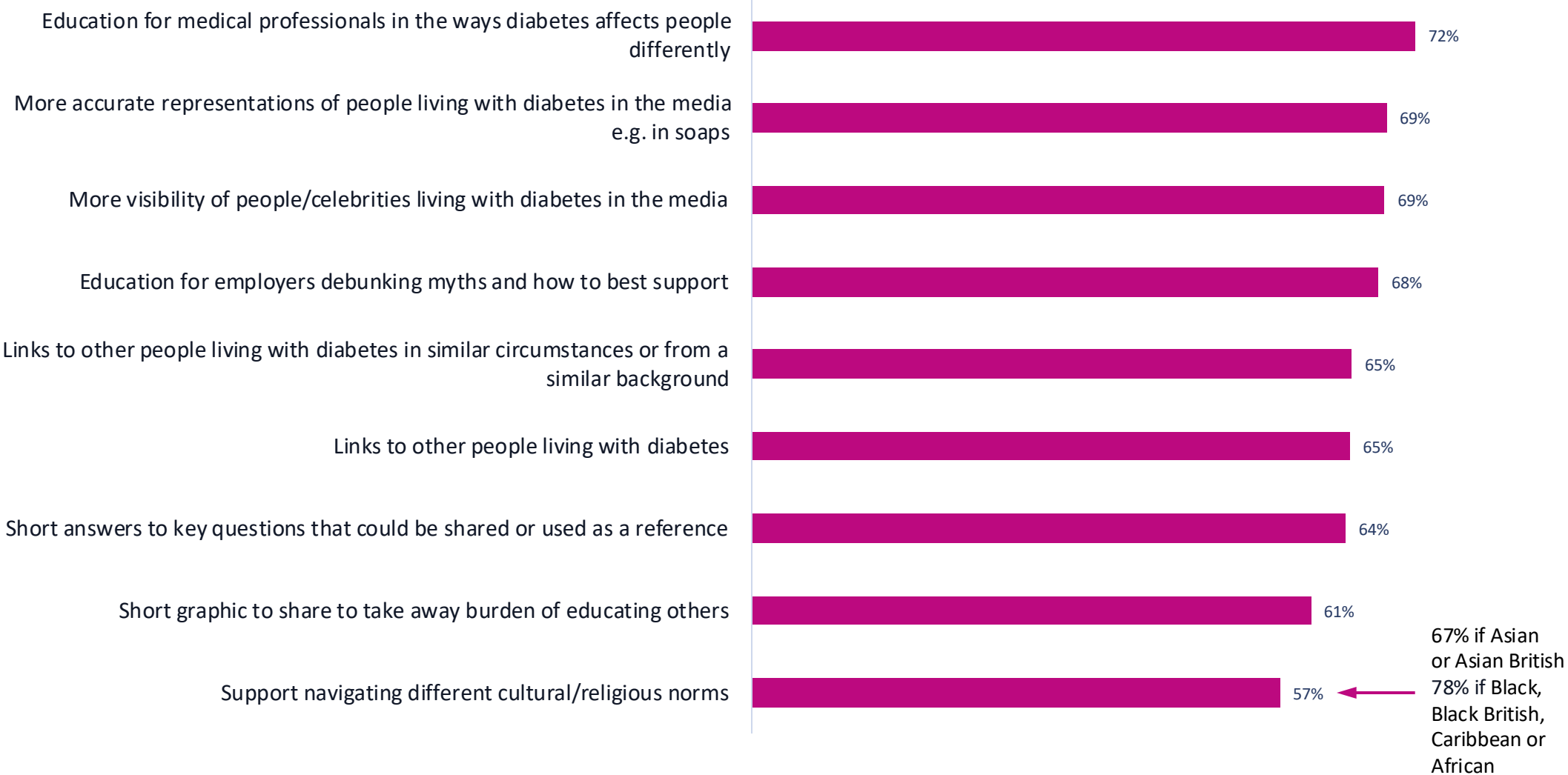
57% would find ‘support navigating different cultural/religious norms’ useful

IN SUMMARY

INCREASING
USEFULNESS



USEFUL SUPPORT TO ADDRESS THE IMPACT OF STIGMA



Q. Would the following be useful in supporting you relating to the negative attitudes and actions you have experienced? n=450 (answers: probably, very probably, definitely)

5 SUMMARY



SUMMARY

1

PEOPLE LIVING WITH DIABETES BELIEVE MANY OF THE MYTHS AND MISCONCEPTIONS THEMSELVES

The most commonly believed by those living with diabetes are that sugar consumption causes diabetes, that blood sugar highs and lows are caused solely from poor management, and that children are likely to inherit diabetes from parents.

2

FRIENDS, FAMILY AND COLLEAGUES ARE THE MOST PROMINENT SOURCES OF IMPACTFUL STIGMA

Stigma that takes place at home or at work is the most impactful for those living with diabetes. Whilst comments from family can mean well, comments at work are never welcome.

3

THE SAME COMMENT CAN BE SEEN AS NEUTRAL FOR SOME, STIGMATISING FOR OTHERS

Experience at diagnosis, comorbidities, length of time living with diabetes and general sensitivity all impact how people respond to comments or actions, and the level of impact it has on them short and long term. Those living with Type 1 diabetes are more likely to find comments/actions stigmatising.

4

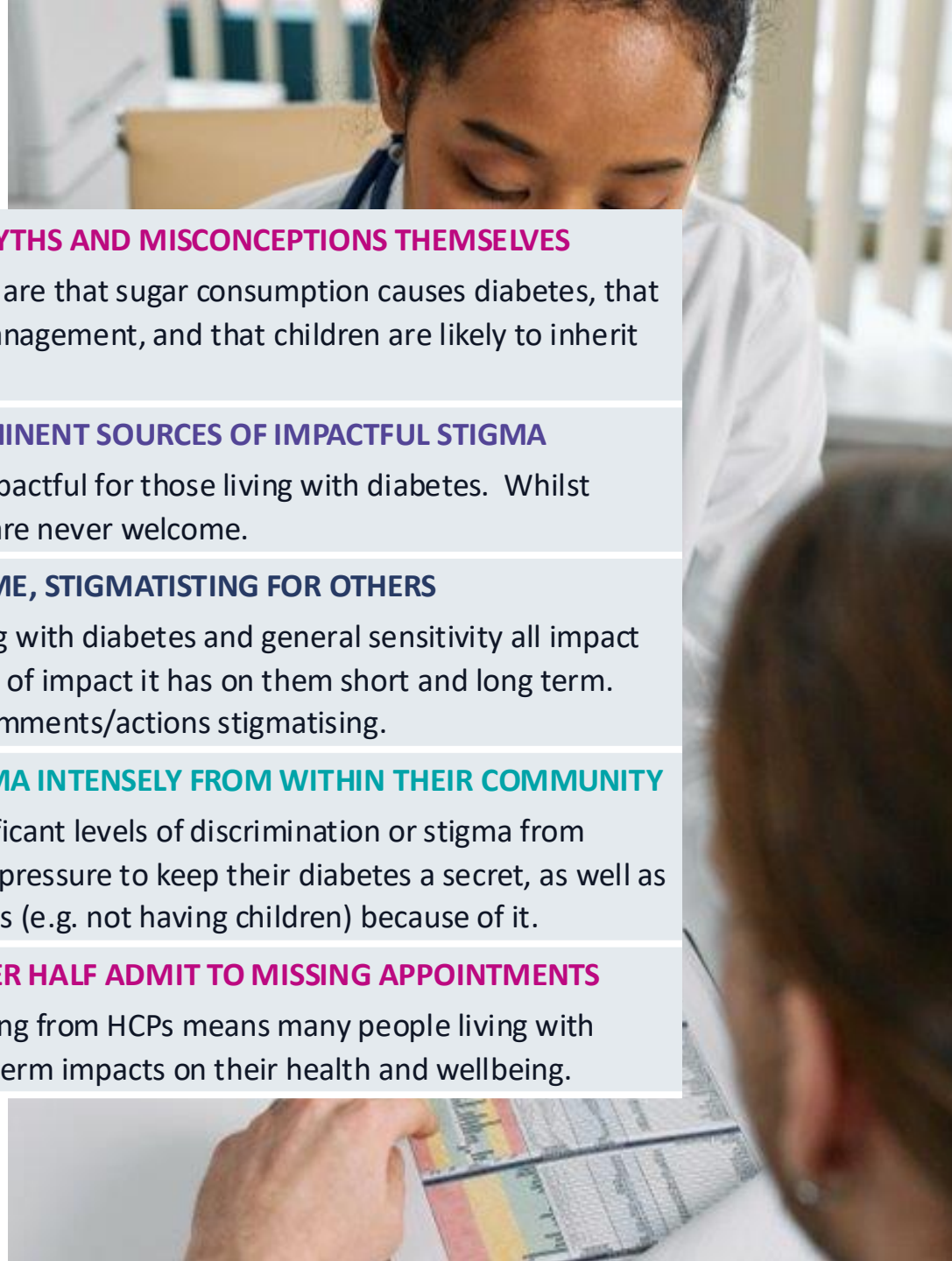
PEOPLE WITH SOUTH ASIAN HERITAGE EXPERIENCE STIGMA INTENSELY FROM WITHIN THEIR COMMUNITY

Despite the prevalence of diabetes, many experience significant levels of discrimination or stigma from others in their community. For some, this leads to intense pressure to keep their diabetes a secret, as well as internalising the stigma and making significant life decisions (e.g. not having children) because of it.

5

STIGMA FROM HEALTHCARE PROFESSIONALS MEANS OVER HALF ADMIT TO MISSING APPOINTMENTS

Poor care, perceived judgements and a lack of understanding from HCPs means many people living with diabetes actively avoid appointments, with potential long-term impacts on their health and wellbeing.



MOVING FORWARD

1. TURN FRIENDS, FAMILY, & COLLEAGUES INTO ADVOCATES

It might not be possible to educate everyone everywhere, so this aims to create a ripple effect. They are an engaged audience and have the power to reduce negative impacts on people living with diabetes.

Target communications using:

'Do you know someone living with diabetes? Did you know that...?'

Content should be short, snappy, visual and bitesize. These comms could also be used by those living with diabetes to share with others.

3. CREATE AND DISTRIBUTE A MEDIA TOOLKIT

Develop a toolkit for broadcasters, content creators and journalists. Give them the dos and don'ts when covering diabetes so they can create content that is more likely to resonate positively with mainstream audiences: language, tone of voice, types of story to tell, what not to say etc. Also send to community/forum moderators.

2. HEALTHCARE PROFESSIONALS MUST DO BETTER

HCPs need to appreciate that the experience at initial diagnosis is formative in how people go on to think about diabetes, how it plays a role in how people internalise stigma, and the longer-term impact on their health.

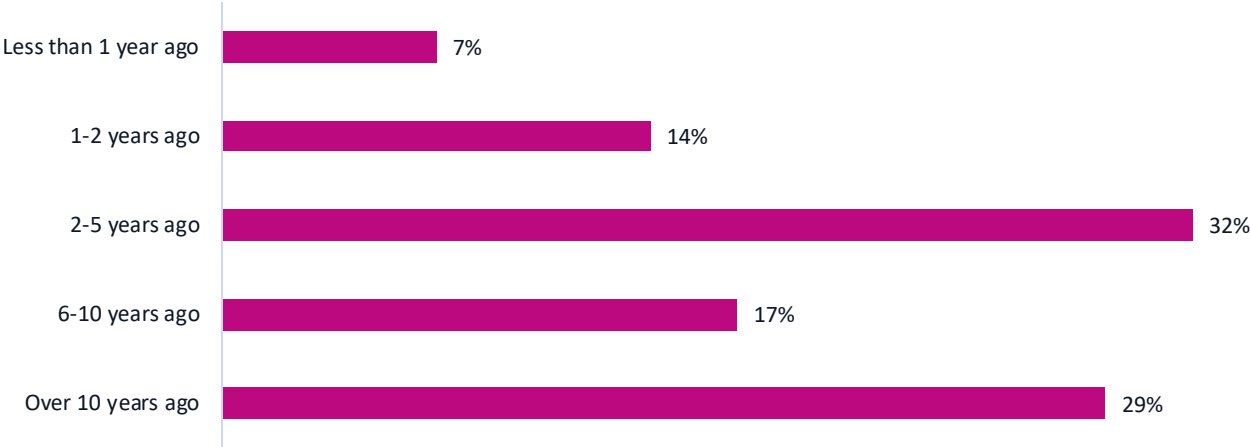
4. MITIGATING INTERNALISED STIGMA NEEDS TO BE CAREFULLY TIMED

After diagnosis (a period of information overload) but before beliefs set in, is the right point to address misinformation for those living with diabetes. Understanding the condition more confidently will help people living with diabetes to not view misconceptions as stigmatising.

Online communities, particularly that allow connection with others in a similar circumstance help provide the confidence for people to laugh it off. A webinar, include a panel discussion that addresses misconceptions from a first-person perspective could also act as a myth-buster.

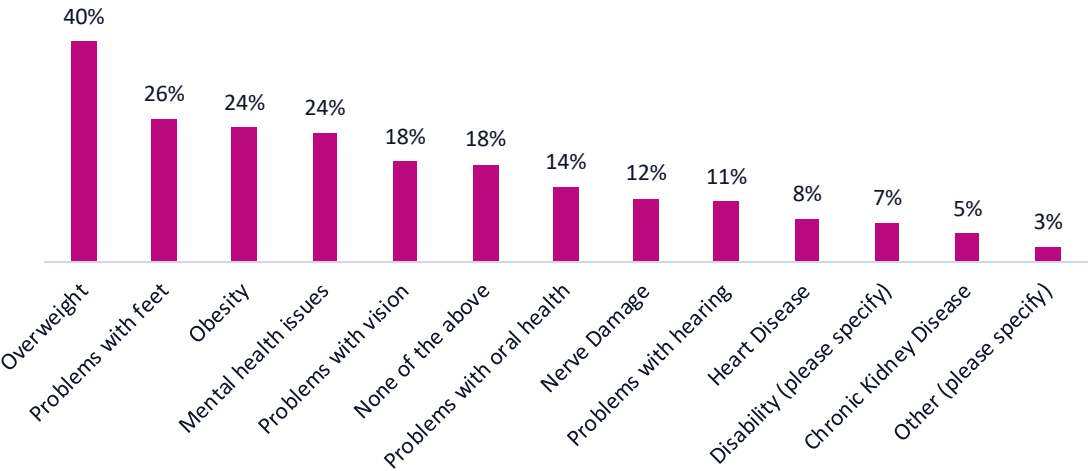
Survey sample

Diabetes diagnosis



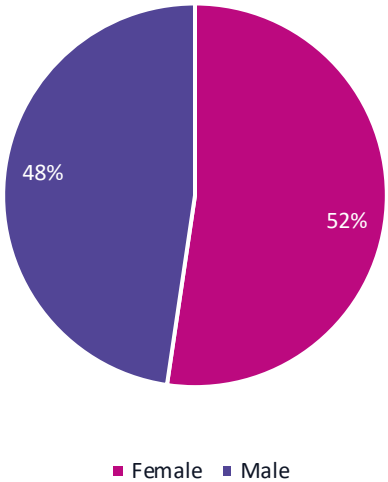
Q. About how long ago were you diagnosed with diabetes? n=450

Living with other health-related conditions

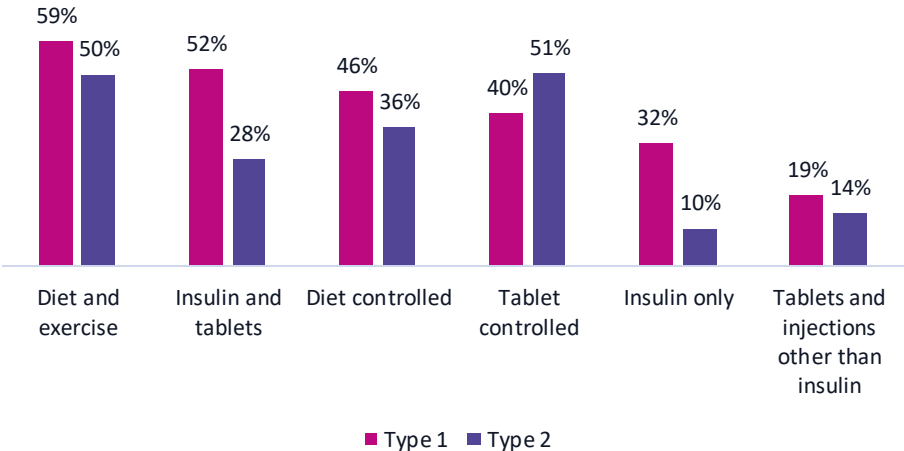


Q. For us to better understand your health situation, would you mind telling us if you live with any of the following health-related complications? n=370

Gender of participants



Treating diabetes



Q. How do you currently treat your diabetes? n=450



DIABETES STIGMA GLOBAL MAJORITY GROUPS

December 2024

DiABETES UK
KNOW DIABETES. FIGHT DIABETES.



PROJECT OBJECTIVES

To understand the experiences of diabetes-related stigma and its impact upon South Asian, Black African and Black Caribbean people.



01

To establish an understanding of people's experiences of stigmatising attitudes towards diabetes

02

To understand the impact of stigmatisation upon individuals, both immediately as well as long-term

03

To explore what people living with diabetes view as stigmatising comments, views or experiences

04

To identify where stigmatising attitudes towards diabetes originate from

05

To assess differences in the experience of stigmatising attitudes in Global Majority groups vs. the wider population

This research will enable Diabetes UK to become informed on where and how they can take positive and impactful action to support those living with diabetes from South Asian, Black Caribbean and Black African backgrounds.

WHO WE SPOKE TO

STAGE 1: 24 X 75 MIN ONLINE INTERVIEWS

- 10 x Type 1 diabetes
- 14 x Type 2 diabetes

Across the 24 interviews:

- 6 x Black African participants
- 8 x Black Caribbean participants
- 10 x South Asian participants
- 2 x participants diagnosed in the last 2 years
- 10 x participants diagnosed in the last 2-5 years
- 6 x participants have lived with diabetes for between 5-10 years
- 6 x participants living with diabetes for over 10 years

STAGE 2: OPTIONAL DIARY TASK

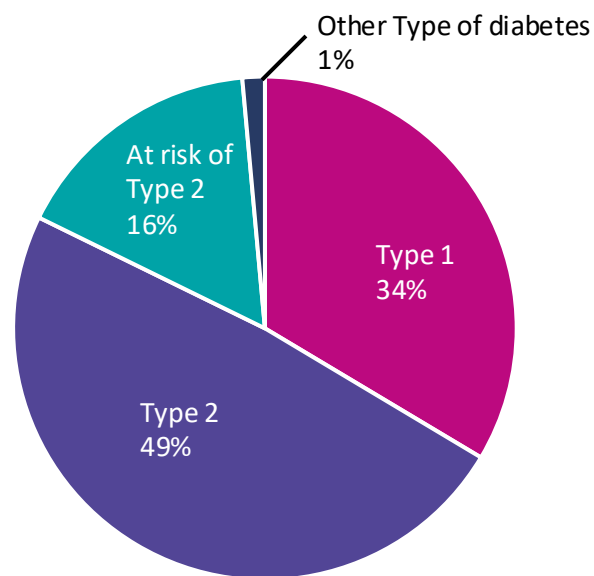
- 16 x Participants from stage 1 interviews
- 6 x Type 1 diabetes
- 10 x Type 2 diabetes

STAGE 3: SURVEY N=417

- People living with, or at risk of, diabetes
- Type 1 n=140, Type 2 n=271

ACROSS THE SAMPLE:

Diversity of ages, gender, social grade, disability, those who self-identify as overweight or obese/those who do not.



Statistically significant differences highlighted and denoted in the charts with *

A NOTE ON LANGUAGE

CULTURAL AND ETHNIC IDENTITY IS COMPLEX

Cultural or ethnic identity is incredibly complex and personal to individuals. We are using three different descriptors throughout this report, 'South Asian', 'Black Caribbean' and 'Black African', for the purpose of clarity. In reality, people describe themselves in a range of different ways and this can change over time or shift depending on the context and who they are with. Diabetes UK should be mindful of this when looking to target and communicate with different groups.

SOME OF THE TERMS WE HEARD:

SOUTH ASIAN

'Indian', 'Gujarati Hindu', 'Pakistani', 'British Asian', 'Asian', 'British Bangladeshi'.

Note: No-one referred to themselves as South Asian

BLACK CARIBBEAN

'Black British', 'Jamaican Londoner', 'Black Caribbean', 'British born, but West Indian parents', 'Caribbean', 'Nottingham with Jamaican heritage'

BLACK AFRICAN

'Ghanian', 'Black African', 'African', 'Black British', 'Nigerian'



The term Global Majority is a shortened version of the term 'people of the global majority'. It is used to refer to all ethnic groups, except white British and other white groups (including white minorities), who make up about 80% of the world's population.

The term is used to challenge white-centric perspectives and to reframe conversations about race, identity, and ethnicity. Some say that the term is more empowering and positive than other terms, such as 'ethnic minorities', 'BAME', or 'BIPOC'.

THE KEY TAKEOUTS

People from Global Majority groups living with diabetes are more likely to have come across stereotypes and misconceptions than those in the general population living with diabetes, and they have come across a greater number of myths and misconceptions. Global Majority groups encounter many misconceptions about diabetes relating to their cultural background, such as diabetes is caused by their ethnic origin and it's a result of traditional diets.

People from Global Majority groups experience numerous negative experiences relating to diabetes but are reluctant to label them as stigmatising. Negative experiences often occur around food in the form of judgements and comments from family and wider community members at mealtimes and social gatherings. However, negative experiences are also common outside of the home, such as in the workplace, on social media and in healthcare settings. Healthcare professionals sometimes make assumptions based on ethnicity, and can be judgemental, dismissive and critical.

For many, culturally specific tailored support would be welcome, and Diabetes UK is considered a trusted source in which to provide this. However, Diabetes UK need to strike a balance between not making assumptions based on someone's cultural background and the influence this has on their experiences of living with diabetes.



EXPERIENCES OF LIVING WITH DIABETES



DIABETES IS NORMALISED AND ALMOST SEEN AS INEVITABLE

‘I HAVE IT BECAUSE I’M BANGLADESHI’

South Asian, Black African and Black Caribbean individuals recognise that diabetes is prevalent within their communities and link this to genetic disposition and traditional diets which are high in carbohydrates and rich ingredients. They often know many people living with diabetes. This leads to a widespread belief that developing diabetes is almost inevitable.

HOWEVER, BLAME IS COMMON

Despite the view that diabetes is likely to occur because of their cultural heritage, close family members can accuse individuals of not having taken preventative measures to change their diabetes diagnosis. This leads to self-blame as individuals internalise these views, and feel they are responsible for their own diabetes. This is particularly common amongst those from South Asian backgrounds.

EXPECTATIONS OF THE WORST

Even though it is normalised, those diagnosed experience shock, fear and panic upon diagnosis. They have seen many examples of others, often older relatives or people within their community, who have not managed their diabetes well, leading to health complications. They fear this may happen to them.

Within the Black African community, there is a sense that diabetes is not as serious compared to other conditions such as malaria and cancer. These conditions are seen as more severe and requiring more urgent action.

South Asian individuals are worried about the limiting impact upon their life and other conditions diabetes could cause, whereas those from Black Caribbean and Black African communities are more likely to fear amputations.



KNOWING OTHERS LIVING WITH DIABETES CAN ALSO BE A SOURCE OF COMFORT

SEEING SOMEONE THRIVING INSPIRES HOPE

If those diagnosed see a close family member living well with diabetes and leading a 'normal' life, this makes them feel hopeful that they can also do the same.

A SOURCE OF KNOWLEDGE AND LEARNING

Those diagnosed find it helpful knowing others living with diabetes and often exchange advice around diet tips, recipes, exercise and medication.

UNDERSTANDING AND CONNECTION

It's considered comforting and less isolating knowing and talking with others who have a similar lived experience. This can also facilitate stronger connections with others.

ACCOUNTABILITY

Knowing someone else living with diabetes can be a source of motivation and encouragement, for example, around making lifestyle changes.



“

'It's been very helpful to know others in my community who are dealing with similar health issues. It makes me feel less alone and gives me a sense of community support. Knowing that I'm not the only one facing these challenges is reassuring and helps me feel understood.'

**BLACK AFRICAN, MALE,
TYPE 2, 55-59 YEARS**

REACTIONS FROM FRIENDS AND FAMILY TEND TO BE NEGATIVE

Reactions vary from denial and shock, to blame and lack of concern.

DENIAL AND SHOCK

Many individuals living with diabetes are met with shock from relatives after sharing their diagnosis. Family members struggle to believe it, especially if someone does not 'look diabetic'. This shock is common even in families where several members are already living with diabetes.

SHAME

Some people newly diagnosed with diabetes are told to keep this a secret from extended family and the wider community. For some families it's shameful, particularly those who blame the individual for bringing diabetes on themselves.

FEAR

Relatives and friends will have a severely limiting impact on the person's life. Some describe diabetes as a 'death sentence'.

UPSET

This is due to the perceived negative impact it is considered to have on the person diagnosed, as well as the stigma within the wider community.

WHAT DID YOU EXPECT?

For those who are overweight or have a history of eating 'unhealthy' foods, family members are not surprised and blame the person diagnosed.

NOT CONCERNED

For some Black African and Black Caribbean people, diabetes is not taken as seriously as other conditions and there can be a lack of concern upon diagnosis.

INTRODUCING SHIV, SONIA AND BWAL

SHIV



Shiv is a 49-years-old and Black Caribbean person living in London. He was diagnosed with Type 2 diabetes in 2018. For Shiv, diabetes is something he is familiar with as his mother had it and sadly passed from related complications. However, the shock from friends and family to his diagnosis was unexpected for Shiv, and he was left feeling like dying from diabetes would be inevitable. For Shiv, the reactions of his close network were scarier than the diagnosis itself and made the post-diagnosis adjustment much more challenging for him.

SONIA



Sonia moved to the UK when she was 18 years old but was born in Pakistan. Whilst pregnant, Sonia developed Gestational diabetes which then led to Type 2 diabetes. Her own father has diabetes and offers her helpful advice, and her father-in-law helps her to stay on track with her diabetes management. However, Sonia can find support from family difficult too as it leads to scrutiny, especially with the foods she eats. These comments make her feel under pressure and guilty for eating any sugary foods.

BWAL



Growing up, Bwal was used to the sight of her grandmother's insulin pump in the fridge. Yet for Bwal, her own diabetes diagnosis in 2020 felt like a death sentence. Her relatives in Africa however did not share the same level of concern. Despite their own diabetes diagnosis, diabetes is often ignored in favour of "more serious conditions" such as HIV and AIDS. Cancer was also previously ignored but Bwal feels it is being taken more seriously now in her African community and hopes diabetes will be next.

FAMILY CAN BECOME DEEPLY INVOLVED IN DIABETES MANAGEMENT

MONITORING AND 'POLICING'

Close family members can take an active role in managing a loved one's diabetes. This involvement can include monitoring food choices, overseeing portion sizes, and ensuring adherence to dietary recommendations. In some cases, they might go as far as keeping meticulous records of blood sugar levels and medication schedules. This is more pronounced amongst South Asian families and may reflect tighter-knit families and cultural expectations of family involvement.

PROVIDING SOLUTIONS

The news of a diabetes diagnosis often prompts family members and people within the wider community to provide solutions. This may be in the home at mealtimes, or at social events such as weddings and gatherings. This ranges from herbal remedies to diet tips.

MIXED RESPONSE TO COMMENTS AND QUESTIONS

For some, solutions are helpful as they offer hope and advice on managing diabetes. For others, it can be overwhelming, especially as they are often unsolicited and/or misinformed.

“

'They know that you have diabetes, they don't act differently, but obviously they keep an eye on you especially whenever you are eating. They say "you shouldn't be doing this or you shouldn't eat this." So that kind of discrimination, you know, obviously does happen.'

**SOUTH ASIAN, FEMALE,
TYPE 2, 35-39 YEARS**





2

STEREOTYPES AND MISCONCEPTIONS



STEREOTYPES AND MISCONCEPTIONS OF DIABETES ARE WIDESPREAD AND WIDE-RANGING

PEOPLE FROM GLOBAL MAJORITY GROUPS ARE MORE LIKELY TO COME ACROSS MYTHS AND MISCONCEPTIONS

97% of people from Global Majority groups have encountered myths and misconceptions, compared to only 89% of the general population living with diabetes (Magenta 2022 study). Furthermore, people from Global Majority groups are more likely to have come across a greater *number* of myths and misconceptions.

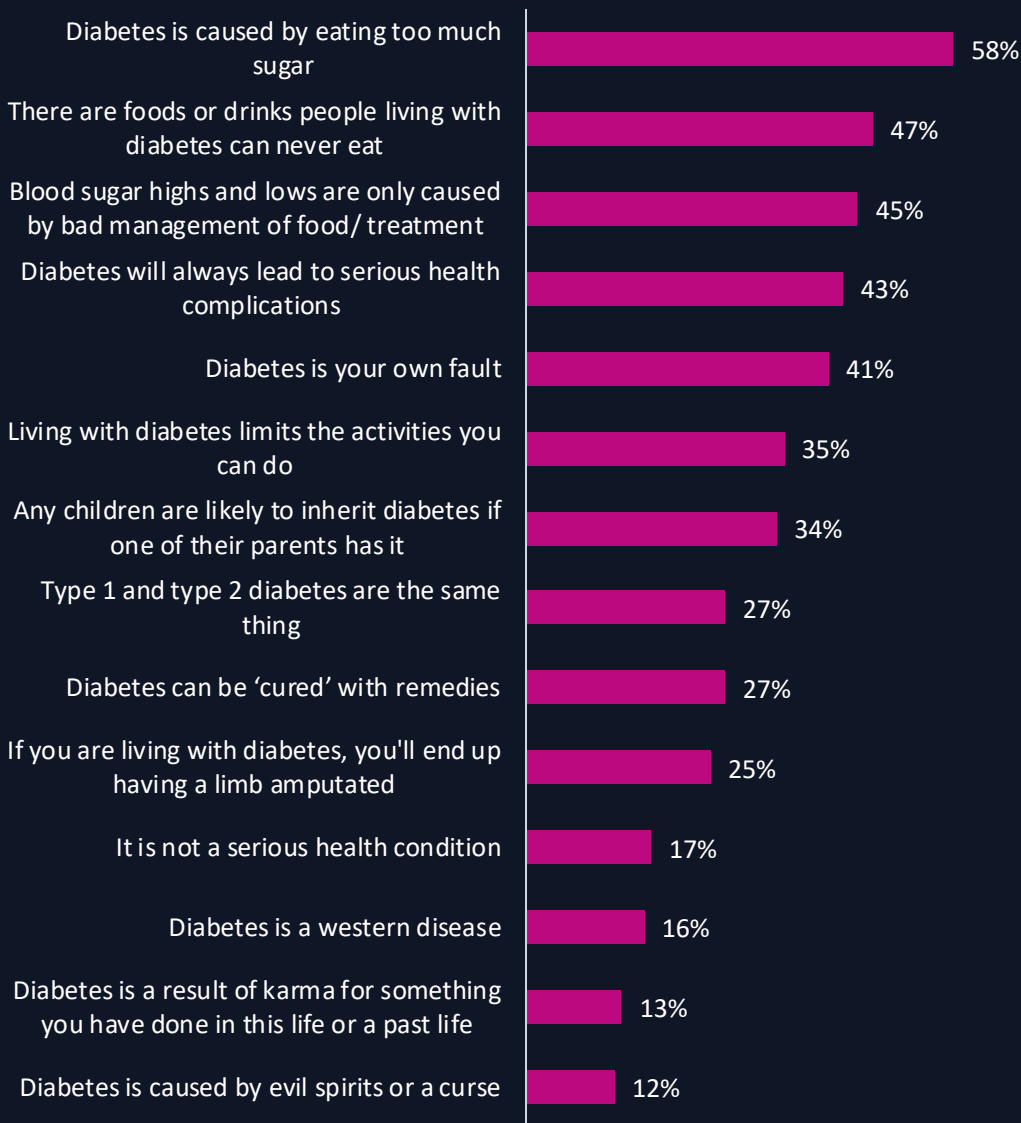
'IT'S CAUSED BY TRADITIONAL FOODS'

South Asian, Black Caribbean and Black African people often hear that their diabetes is a result of traditional dishes and ingredients which are high in sugar and carbohydrates. This comes from within their cultural community, as well as from healthcare professionals and colleagues, and is heard amongst those living with both Type 1 and Type 2 diabetes.

ASSUMPTIONS ARE MADE BASED ON ETHNICITY

Some feel there is an assumption that being from a Global Majority background automatically means you have diabetes. Many report hearing remarks such as 'Oh, you have diabetes because you're Jamaican'. This can come from healthcare professionals and colleagues and makes those living with diabetes feel 'othered' and homogenised.

TOP 10 MYTHS AND MISCONCEPTIONS ACROSS GLOBAL MAJORITY GROUPS



Q. What are the stereotypes or misconceptions you've come across about diabetes? These answer options have come from discussions with people living with diabetes and reflect real-life experiences. n=417

A COMMON MISCONCEPTION IS THAT DIABETES WILL LEAD TO SERIOUS HEALTH COMPLICATIONS

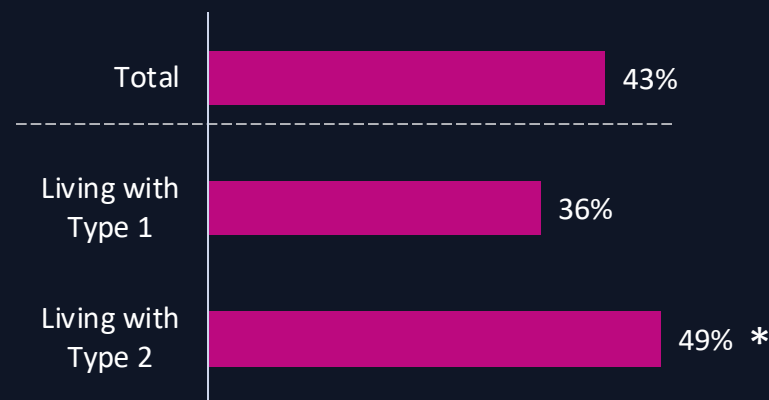
43% HAVE HEARD THAT DIABETES LEADS TO SERIOUS HEALTH COMPLICATIONS

There is a sense of fear about diabetes across all three Global Majority groups, particularly relating to the impact on health outcomes in the future. There is a sense that other health conditions have clear treatment options and can be managed more easily. Diabetes, on the other hand, is perceived to be more complex with the potential to severely impact one's future health and limit their day-to-day activities. Those living with Type 2 are more likely to have encountered this.

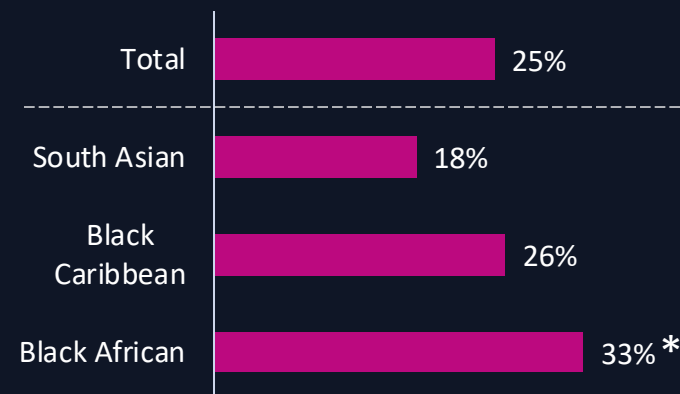
THE MYTH OF AMPUTATION IS MORE PREVALENT AMONGST BLACK AFRICAN PEOPLE

People who are Black African are more likely than South Asian and Black Caribbean people to have come across the myth that diabetes will lead to having a limb amputated. Some report seeing family members or strangers in hospitals with limbs amputated in their or their family's country of origin.

THOSE WHO'VE COME ACROSS 'DIABETES LEADS TO SERIOUS HEALTH COMPLICATIONS'



THOSE WHO'VE COME ACROSS 'YOU'LL END UP HAVING A LIMB AMPUTATED'



Q. What are the stereotypes or misconceptions you've come across about diabetes? These answer options have come from discussions with people living with diabetes and reflect real-life experiences. n=42-179 and 27-104 (caution: low base sizes with second statement)



BLACK AFRICAN PEOPLE ARE MORE LIKELY TO ENCOUNTER MYTHS LINKING DIABETES TO SUGAR

OVER TWO THIRDS OF BLACK AFRICAN PEOPLE HAVE HEARD DIABETES IS A RESULT OF EATING TOO MUCH SUGAR

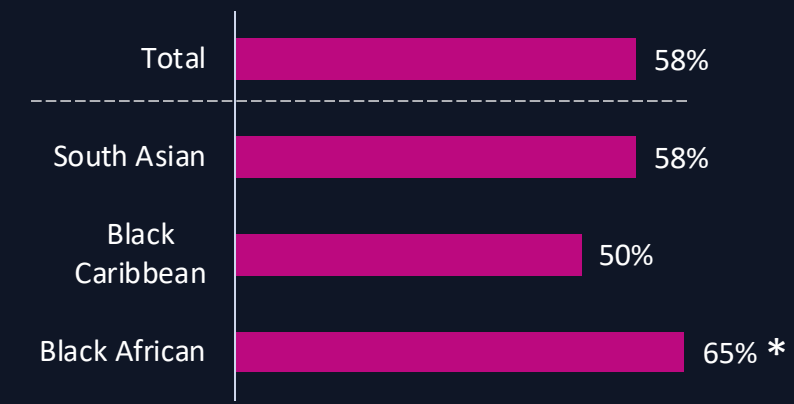
Amongst Black African people, diabetes is closely associated with sugar. It is often referred to as "sugar sickness" or simply "the sugars," reinforcing the belief that sugar consumption is the sole cause of diabetes.

BLACK AFRICAN PEOPLE ARE ALSO MORE LIKELY TO HAVE COME ACROSS THE MYTH THAT DIABETES IS A WESTERN DISEASE

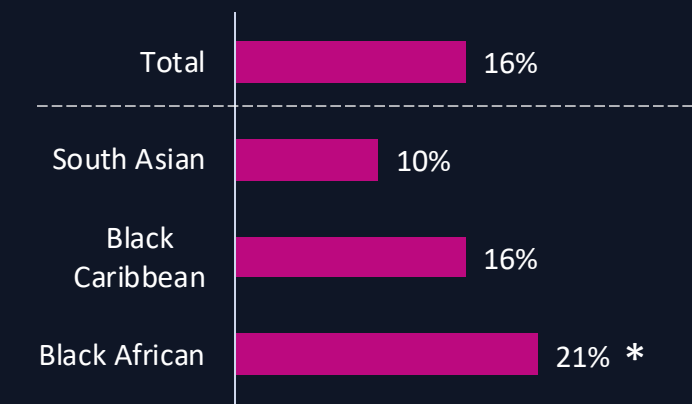
1 in 5 (21%) Black African people have come across the myth that diabetes is a Western disease, compared to only 10% and 18% of South Asian people and Black Caribbean people, respectively. The association of diabetes with Western lifestyles, such as consuming processed foods and leading sedentary lives, is seen to contrast with traditional African diets and practices.



THOSE WHO'VE COME ACROSS 'DIABETES IS CAUSED BY EATING TOO MUCH SUGAR'



THOSE WHO'VE COME ACROSS 'DIABETES IS A WESTERN DISEASE'



Q. What are the stereotypes or misconceptions you've come across about diabetes? These answer options have come from discussions with people living with diabetes and reflect real-life experiences. n=51-243, n=18-65 (caution: low base sizes with second statement)

MANY MISCONCEPTIONS HAVE LINKS TO RELIGIOUS ORIGINS

MYTH

Diabetes is a result of evil spirits; it's a curse or punishment; it's to do with the devil; it's because you've upset God/Jesus

Diabetes will lead to amputation and amputation means you can't get into heaven

There is nothing that can be done because there is a reluctance to medical interventions, such as medication and operations.

It's Karma - a form of punishment or consequence for negative actions or wrongdoings committed in a past life.

GROUP

Black African and Black Caribbean

Black African

Black African

South Asian

SOURCE

Pentecostal origins, which draw heavily on faith-based interpretations of health and illness, often attributing physical health conditions and ailments to spiritual causes, such as sin, demonic influences or curses.
Afro-centric knowledge systems are turned to in seeking an explanation of diabetes.

In some Black Caribbean Christian communities, there is a belief rooted in traditional or cultural interpretations of **Christianity** that individuals must enter heaven "whole" or with an intact body.

The **Rastafari religion**, originating in Jamaica in the 1930s, emphasises a spiritual connection to Africa, natural living, and holistic health practices. Rooted in resistance to colonialism and Western influence, Rastafari beliefs often challenge conventional medical interventions, favouring natural remedies and a lifestyle that aligns with their interpretation of divine law.

This belief reflects the broader **Hindu** understanding of karma, which suggests that one's current circumstances are influenced by the accumulated actions from previous lives

14% and **15%** of Black Caribbean and Black African people respectively have encountered the myth that diabetes is caused by evil spirits or a curse, compared to only **6%** of South Asian people

MISCONCEPTIONS ARE ALSO BELIEVED BY SOME LIVING WITH DIABETES

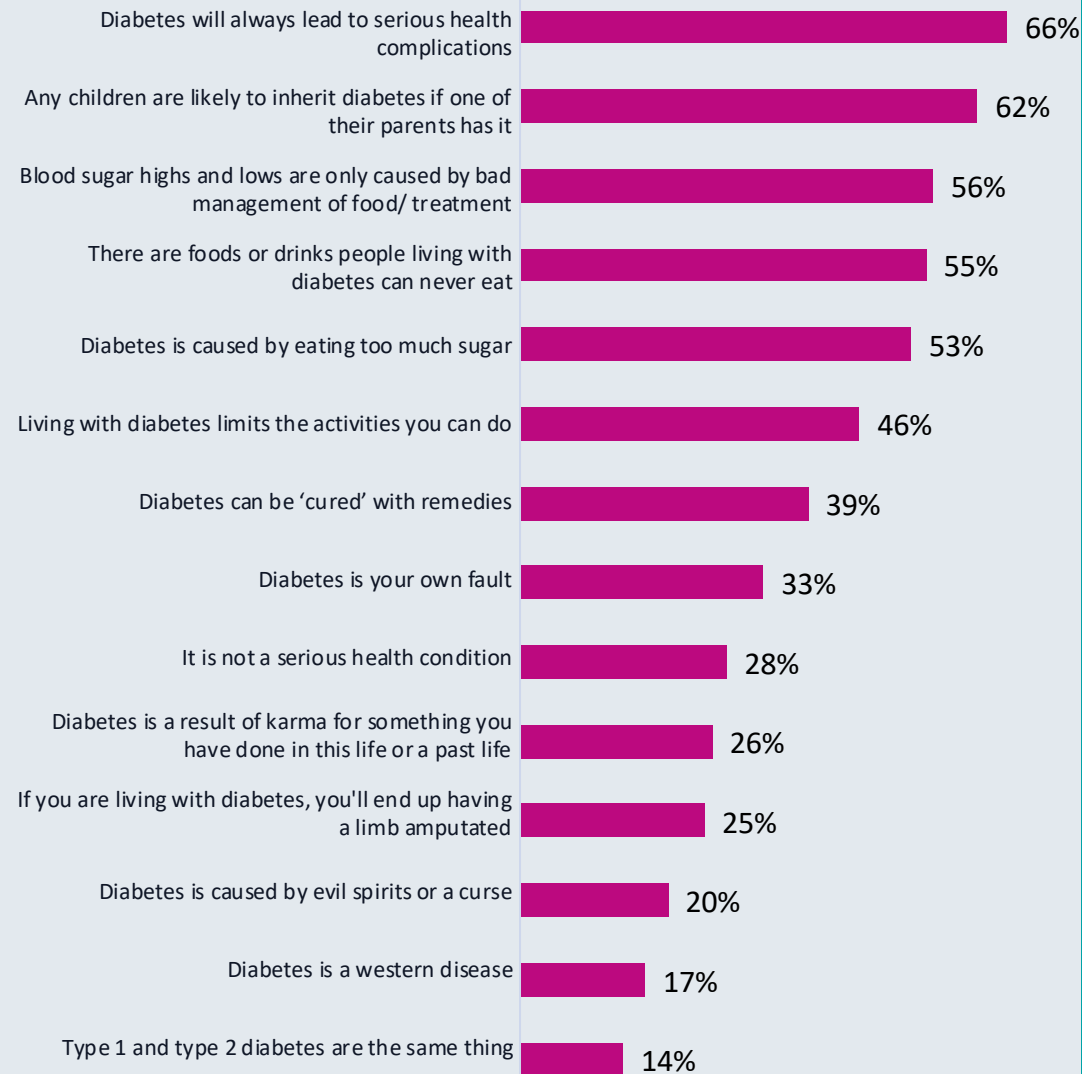
MANY BELIEVE THE MISCONCEPTIONS THEMSELVES

Two thirds (66%) think diabetes will always lead to serious health complications, just under two thirds (62%) believe any children will inherit diabetes if their parent has it, and just over half (56%), believe blood sugar highs and lows are only caused by bad management of food/treatment.

SOME TYPE 1 INDIVIDUALS BLAME THEIR DIABETES ON DIET

Although Type 1 diabetes is unrelated to diet and lifestyle, several people internalised views from others and said they felt they must have brought their Type 1 diabetes on themselves through eating too much or not eating 'the right foods'.

SELF BELIEF IN STEREOTYPES AND MISCONCEPTIONS



Q. To what extent, if at all, do you believe any of these stereotypes or misconceptions yourself? n=54-243

66
'I initially thought it was going to shorten my lifespan. You hear worst case scenarios about people getting kidney failure and having to go on dialysis and this and that and that's scary.'
SOUTH ASIAN, MALE, TYPE 2, 45-49 YEARS

'When I went to the GP the first time they told me it would help if you lost weight. That's one of the major things they focus on. And I get it but at the time you're internalising and thinking "this is all my fault. I've brought this on myself. I'm not slim".'

BLACK CARIBBEAN, FEMALE, TYPE 2, 45-49 YEARS

DIFFERENT BELIEF SYSTEMS LEAD TO TENSION IN DIABETES MANAGEMENT

STRADDLING DIFFERENT KNOWLEDGE SYSTEMS

Global Majority groups are often straddling two different knowledge systems about how to manage diabetes. Older relatives, as well as friends and family living abroad, often reject the medicalised model and see medication as a Westernised solution. Those diagnosed are often trying to reconcile this belief system against the advice they receive from healthcare professionals. Some are managing their diabetes by combining management styles, for example, taking medication but taking it less frequently than what has been prescribed.



“

‘People in the wider community like my friend's mother or an auntie, they start telling me “you should try this” or “we have seen people trying this remedy and they cured themselves”.’

**SOUTH ASIAN, FEMALE,
TYPE 2, 35-39 YEARS**

INTRODUCING MARCUS, ANGIE AND SAMIRA

MARCUS



AMPUTATIONS ARE INEVITABLE WITH DIABETES

For Marcus, his diagnosis was viewed by some in his Caribbean community as a curse placed on him either by an evil spirit or by God for upsetting him. Marcus's Christian views and diabetes are also in conflict due to the belief that you do not get into heaven if you have an amputation – something Marcus feels at risk of due to diabetes.

ANGIE



SUGAR AND DIET ARE RESPONSIBLE FOR ALL TYPES OF DIABETES

Angie is living with Type 1 diabetes. She has found that when opening up about her diabetes, many immediately associate it with sugar. Angie and her family often enjoy traditional Ghanaian recipes, but she has become more conscious of the high starch content and sugar in those foods. Angie admits she internalises others' misconceptions on diabetes and sugar, and worries enjoying traditional recipes is responsible for impacting her own diabetes.

SAMIRA



FAMILY ATTEMPTS TO CURE DIABETES LEAVE LASTING DAMAGE

Diagnosed with diabetes when she was still a child, Samira's mother had heard from Pakistani relatives that putting a particular cactus sap in food could reverse it. For Samira, not only did it not reverse it but it has had a lasting impact on her views of food – as she still distrusts what is in food if she has not prepared it herself.



DIABETES RELATED STIGMA



VERY FEW OVERTLY ADMIT TO EXPERIENCING 'STIGMA'

NEGATIVITY IS ACCEPTED

It is clear that South Asian, Black Caribbean and Black African people experience negative attitudes from others but there is a reluctance around labelling them as 'stigmatising'. Negativity is often accepted and normalised, with many of the attitude that you 'you just get on with it'.

NATURE OF RELATIONSHIP IMPACTS PERCEPTIONS

Comments from loved ones who are close to the person with diabetes are more likely to be perceived as supportive and constructive, compared to remarks from individuals who are less familiar with their situation such as colleagues or strangers. Colleagues and strangers often do not know the challenges the person with diabetes is facing and the steps they are already taking to manage their diabetes, so comments and negativity is more likely to be perceived as ignorant and hurtful.



'I would like to know more about stigma. I haven't come across these terms yet, so I'm not really sure what would be diabetes stigma. So far, no I have not experienced anything like this. My friends or my family, if they say something it's out of their good concern. So it's not something negative for me. So I haven't experienced anything negative in my social circle.'

**SOUTH ASIAN, FEMALE,
TYPE 2, 35-39 YEARS**

43%

have experienced negative attitudes. This is similar (41%) amongst the general population living with diabetes (Magenta 2022 study).

ETHNICITY, CO-MORBIDITIES, AND LENGTH OF DIAGNOSIS IMPACT LIKELIHOOD OF EXPERIENCING NEGATIVE ATTITUDES

BLACK CARIBBEAN PEOPLE ARE MORE LIKELY TO EXPERIENCE NEGATIVE ATTITUDES

Over half (57%) of Black Caribbean people have experienced negative attitudes from others in relation to their diabetes, compared to only 39% of South Asian people and 38% of Black African people.

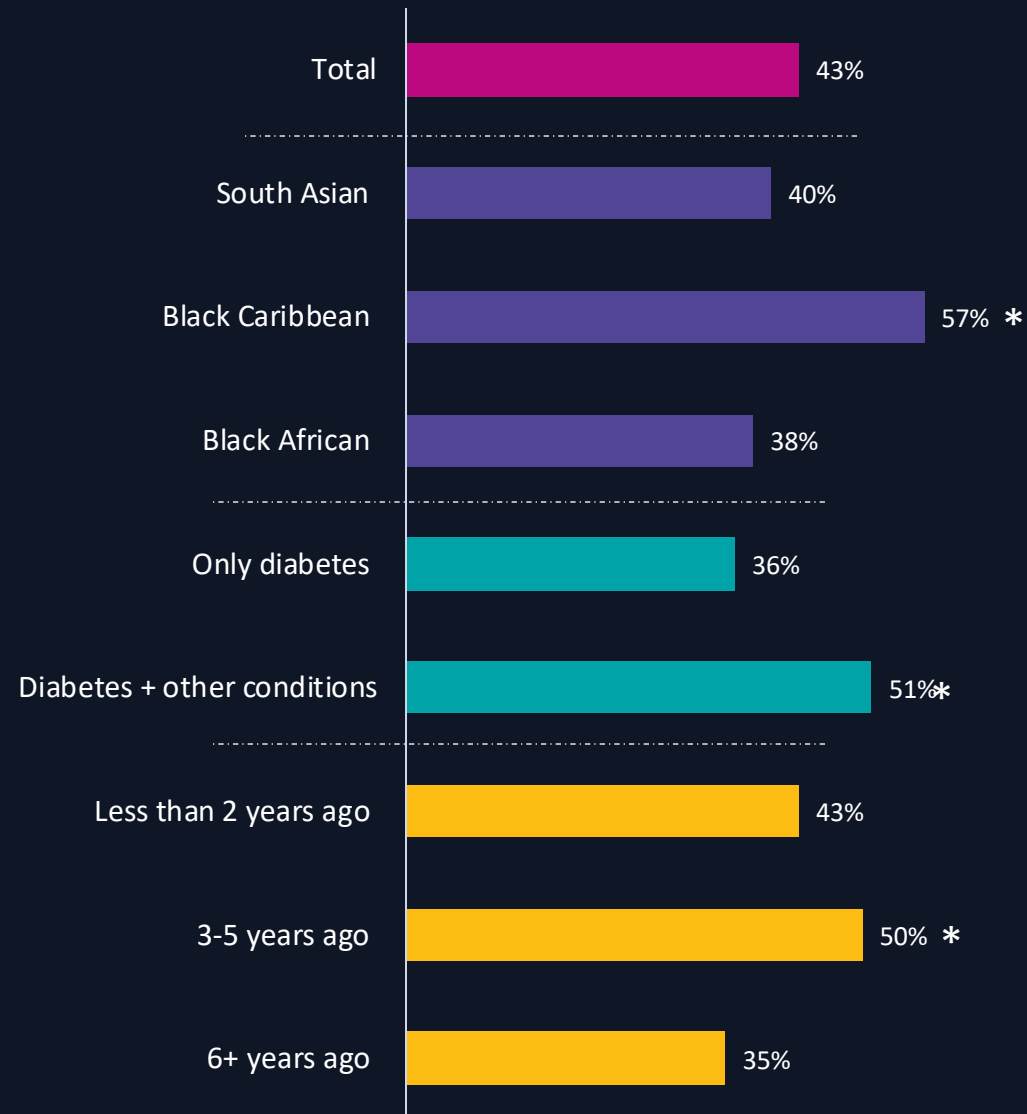
1 LENGTH OF DIAGNOSIS

Overtime, individuals gain a better understanding of how to manage their diabetes, which helps them feel more empowered and resilient. As a result, they are more likely to interpret others' comments and actions as well-meaning rather than negative or stigmatising. In contrast, those who are newly diagnosed tend to feel more vulnerable and are more easily affected by others' behaviour.

2 LIVING WITH CO-MORBIDITIES

People living with other medical issues such as obesity are more likely to experience negative comments about their condition due to their weight or an unhealthy lifestyle.

EXPERIENCE OF NEGATIVE ATTITUDES (TO A GREAT EXTENT/SOMEWHAT)



Q. To what extent would you say you experience negative attitudes from others in relation to your diabetes? n=417

NEGATIVE EXPERIENCES ARE OFTEN CENTRED AROUND FOOD

FROM QUESTIONS AND COMMENTS TO PEER PRESSURE

Half of South Asian, Black Caribbean and Black African people have received comments and questions around food consumption. This is compared to **only 33% of the general population living with diabetes**. These involve:

- comments and questions when eating 'unhealthy' food
- comments and questions when eating 'healthy food'
- peer pressure to eat specific foods, often traditional dishes; and
- negative comments around traditional dishes not being 'authentic' if using substitute ingredients.

50%

of people from Global Majority groups have received comments from others about what they can/can't eat and drink

74%

can relate to the statement "When I'm hosting for friends and family, I substitute some ingredients to help me manage my diabetes. My friends and family ask why I don't stick to the original recipe or make negative comments about the food"

80%

can relate to the statement "I was round at a relative's house, and she offered me some dessert and my auntie jumped in and said, 'oh no she can't have that, do you have anything else?', I can eat whatever I want to eat!"



COMMENTS AND QUESTIONS ARE PERVASIVE

'Well, I've had it where people tell me what I need to eat, shouting out in the queue at a Caribbean wake "diabetics come up first. Come on, get up, go and get your food" that sort of thing.'

BLACK CARIBBEAN, FEMALE, TYPE 2, 60-74 YEARS

'They keep an eye on you especially whenever you are eating something...Whenever I'm with my friends and if someone asked me for a tea and I say "yeah please put one sugar there" they'll be like "why are you taking sugar? You should not be taking sugar".'

SOUTH ASIAN, FEMALE, TYPE 2, 35-39 YEARS



'For example, if I'm seen eating a chocolate, "Oh, my God, you've got diabetes, how could you even eat that chocolate?" but how do you know when I last had a chocolate?...it might have been three weeks since I last had a chocolate, but no one's going to ask that question. They're just going to make that initial assumption.'

SOUTH ASIAN, FEMALE, TYPE 2, 40-44 YEARS

'I do get that a lot when we'd have a meal not with our immediate family and I'll get a cake, "Oh, should you be eating that?" even though they know and I've spoken to them about it before. I don't know if they're trying to make a joke of it or what but they still feel the need to say it.'

SOUTH ASIAN, MALE, TYPE 1, 35-39 YEARS

'Workplace wise, we do student Masterchef...when it came to the food tasting, I didn't get to because I'm diabetic and she thought particularly tasting the desserts might have a bit of a negative impact on my body.'

SOUTH ASIAN, MALE, TYPE 2, 45-49 YEARS

'It's a bit frustrating because it's like just because I've got diabetes doesn't mean I'm not allowed to have a little treat.'

BLACK CARIBBEAN, MALE, TYPE 1, 35-39 YEARS

'People have a view on what's safe for you to eat and what's unsafe. If we go back to a restaurant and if people know I've got diabetes they might say "you want to stay clear of the potatoes" or little comments like that, which is not helpful. I've been out at Christmas dinner with my work colleagues and that is mentioned.'

BLACK CARIBBEAN, FEMALE, TYPE 2, 60-74 YEARS

BESIDES FOOD-RELATED COMMENTS, STIGMA MANIFESTS IN NUMEROUS OTHER WAYS

BEING QUESTIONED ABOUT DIABETES

Over a third (35%) have been questioned about their diabetes. Questions are not only centred around food, but also include the impact of diabetes, what people living with diabetes can/can't/shouldn't do, how they manage their diabetes, how they are feeling as a result of their diabetes and even questions around glucose levels.

EXAGGERATIONS AND BEING SEEN AS VULNERABLE

Friends, family and co-workers can go to extremes and over-sensationalise the condition. Just under a third (32%) have experienced others' exaggeration their condition or treatment. Similarly, over a quarter (28%) have been seen as someone that is vulnerable and needs taking care of.

Black Caribbean and Black African people report a significantly greater number of negative experiences vs. South Asian people.

Those who are younger (aged 18-34 years) are also more likely to report a significantly greater number of negative experiences compared to those who are aged 35+.

NEGATIVE ATTITUDES EXPERIENCED



Q. Please think about the different ways you may have experienced negative attitudes relating to diabetes. Which of the following, if any, have you experienced? n=417

NEGATIVE EXPERIENCES EVOKE STRONG NEGATIVE REACTIONS

EXAGGERATING DIABETES OR TREATMENT, OR BEING SINGLED OUT

Nearly two thirds feel ‘strongly’ or ‘quite’ negatively about others exaggerating their condition or treatment (60%). This was commonly discussed within the context of loved ones being overly protective about diabetes management, or perceiving diabetes as a death sentence. 58% feel very negatively about being singled out or treated differently. This was commonly discussed within a range of contexts from mealtimes to work events.

JUDGEMENTAL LOOKS

Nearly two thirds (58%) feel very negatively about judgmental looks from others. This was commonly reported within the context of eating foods not deemed ‘healthy’.

PERCEIVED AS VULNERABLE

58% feel very negatively about being perceived as vulnerable. Vulnerability was discussed within a range of circumstances such as being seen as someone that needs extra care or taking care of and being perceived as someone who is weak and unable take part in activities such as sports and driving.

MOST LIKELY TO EVOKE A NEGATIVE RESPONSE

FEELINGS WHEN NEGATIVE EXPERIENCES OCCUR... (TOP 2 BOX STRONGLY/QUITE NEGATIVE)



LEAST LIKELY TO EVOKE A NEGATIVE RESPONSE

Q. Of the different ways you've experienced negative attitudes, how do you feel when the following happens...? n=96-209

STIGMA IS COMMONLY EXPERIENCED CLOSE TO HOME

AT SOCIAL EVENTS WITH EXTENDED FAMILY AND/OR COMMUNITY MEMBERS

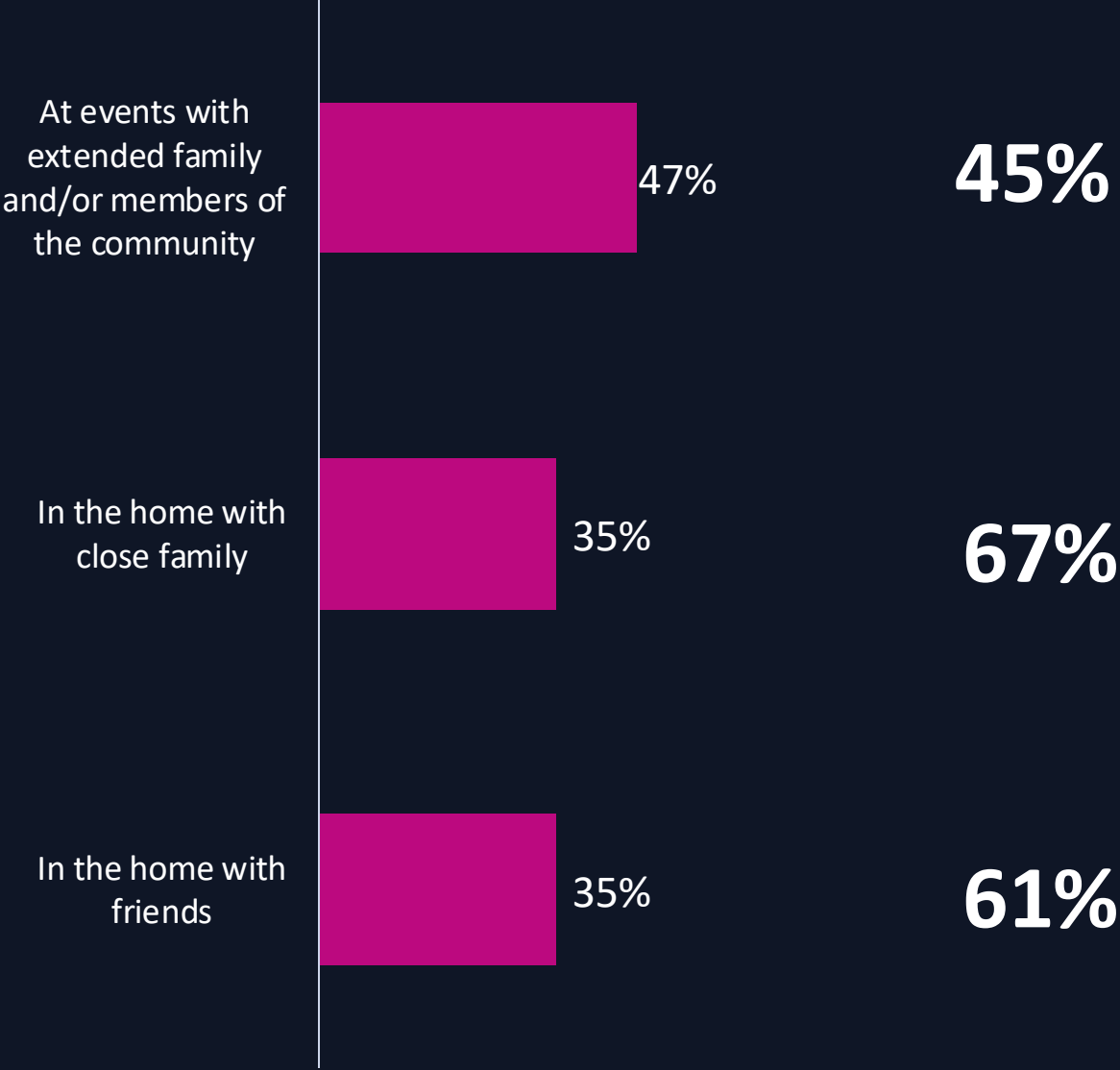
Nearly half report experiencing stigma at social events with extended family members and/or members of the community, such as weddings. Of those that do experience stigma on these occasions, 45% report experiencing this monthly or more.

IN THE HOME

A third experience stigma in the home with close family, as well as at home with friends. This happens frequently. 67% experience negative attitudes in the home with close family monthly or more, and 61% experience negative attitudes in the home with friends monthly or more.

PLACES WHERE NEGATIVE EXPERIENCES HAVE OCCURRED

THOSE EXPERIENCING THIS AT LEAST MONTHLY



Q. Please think about the different places/people you may have experienced negative attitudes at any point since diagnosis . At which of the following locations, if any, have you experienced this? n=417 Q14. And about how often have you experienced negative attitudes in the following places/from the following people...? n=75 -195

MEET SEEMA: THOSE WITH DIABETES CAN BE SEEN AS LESS VALUABLE

Seema is living with Type 1 diabetes and was first diagnosed at age 13. Being diagnosed at such a young age sparked concern not only from her parents but also her wider South Asian community who made her feel like a victim, as though it was a really bad condition and she'd need taking care of.

Later in life, Seema found her diabetes also impacted her marriage prospects. In her culture, marriage is arranged between two people of 'equal calibre', but Seema's diabetes was seen to detract from her value. When Seema was engaged, she had several comments from people in her community telling her they were pleased for her – which she interpreted as they doubted marriage would ever happen for her due to her diabetes. Even after her engagement, Seema's fiancé was warned by others of her diabetes and the community were surprised she had managed to find a husband willing to look past it.

“

'I got married against all odds. People in the community judge you - especially if they're Asian.'

SOUTH ASIAN, FEMALE, TYPE 1, 55-59 YEARS

WORKPLACE STIGMA IS ALSO COMMON

COMMENTS ABOUT FOOD

Colleagues often comment on and question the food people are eating. In some cases, individuals have been blamed for their diabetes because of their traditional diets or have been told they have diabetes because of their ethnicity.

FEELING 'OTHERED' AT WORK EVENTS

Many mention feeling othered and singled out at work events involving food. Colleagues can make uninformed decisions on the person's behalf, for example, not offering them cake at social events or not allowing them to be involved in competitions centered around food.

'FUNNY' LOOKS

Some mention receiving funny or judgemental looks from colleagues, for example, if needing to go to the bathroom frequently and when eating food deemed 'unhealthy'.

A LACK OF UNDERSTANDING FROM BOSSES

Some feel their bosses fail to understand how diabetes affects their lives, leaving them feeling scrutinised and judged for taking time off for medical appointments or administering injections.

A CHALLENGING WORKPLACE ENVIRONMENT

Some report not having appropriate places to inject nearby, and also being unclear about workplace policies relating to medical appointments.

Nearly **HALF**
experience
workplace
stigma

Nearly **TWO
THIRDS**
experience this
monthly or
more

CASE STUDY: MARVIN

Marvin is British Indian man in his 40s and in his previous workplace encountered a lot of negativity around his diabetes. His boss wasn't very understanding of his condition and its impact on his day-to-day life. He was told he should inject in the toilets, even though healthcare professionals told him it's unsafe there. They then gave him the option to inject in the first aid room which was a 10-minute walk away, disrupting his workday. He also felt the sick leave policy wasn't clear and said when he had to take time off for medical appointments it would be reported as a normal sick day. It felt like he was being punished and the whole environment was generally unsupportive.

INTERACTIONS WITH HEALTHCARE PROFESSIONALS CAN BE DEHUMANISING

ASSUMPTIONS BASED ON CULTURAL BACKGROUND

Healthcare professionals can make assumptions about people with diabetes based on their cultural background. For example, assuming someone eats a lot of rice because they are South Asian or cooks with certain ingredients, and that someone has a history of diabetes in the family.

DISMISSING CULTURAL BACKGROUND

Conversely, some feel that healthcare professionals do not take their cultural background into account when providing information and advice. For some, advice provided can be generic, based upon 'Westernised' ideals and not relevant to the individual. This was particularly mentioned within the context of food advice but also around management approaches to diabetes such as medication. There is a 'right' way to treat diabetes, and any other way is dismissed.

In both circumstances, people with diabetes feel like they are 'othered', judged, not fully understood and 'just another diabetes patient'. This fosters mistrust between them and the healthcare professional.

JUDGEMENT, CRITICISM AND A LACK OF SENSITIVITY AT DIAGNOSIS

Some individuals experience judgement from healthcare professionals about their approach to diabetes management or their weight. In addition, for some, their initial diagnosis was handled insensitively by healthcare professionals, who focused on worst-case scenarios and left them feeling frightened. This fear was further amplified by comments from friends and family, deepening their anxiety and uncertainty about the future.

1 in 5
experience
stigma in
healthcare
settings

**Nearly
HALF**
experience this
monthly or
more



For Global Majority groups, there is a lot of residual collective trauma, especially around healthcare and education, that exist today. **Healthcare and education** are two key areas where the legacy of marginalisation is especially pronounced. The reluctance of some individuals in these communities to seek medical care or mistrust westernised approaches to medical care, may be rooted in a history of neglect, exploitation, or systemic bias.

The underlying theme in Western healthcare is that there is a problem that needs to be solved and someone in authority is going to tell you what to do. Your status as a patient is a disempowered one.

SOCIAL MEDIA CAN PERPETUATE STEREOTYPES AND STIGMA

ATTRIBUTING DIABETES SOLELY TO DIET

Social media perpetuates negative perceptions of diabetes, often portraying it as solely caused by consuming too much sugar, cake, or having an unhealthy lifestyle. It often fails to portray the complexities of the condition and differences between various types of diabetes. This can foster self-blame among those living with the condition and is also considered responsible for the misinformation provided by well-meaning friends and family.

EDDIE EBBEW AND CULTURALLY INSENSITIVE CONTENT

Eddie Ebbew, a social media influencer married to a South Asian woman, was mentioned by several South Asian participants. On his Instagram account, Ebbew publishes posts which criticise the South Asian diet, claiming it is solely responsible for diabetes. Those who mention him see his posts as derogatory, disrespectful and culturally insensitive.

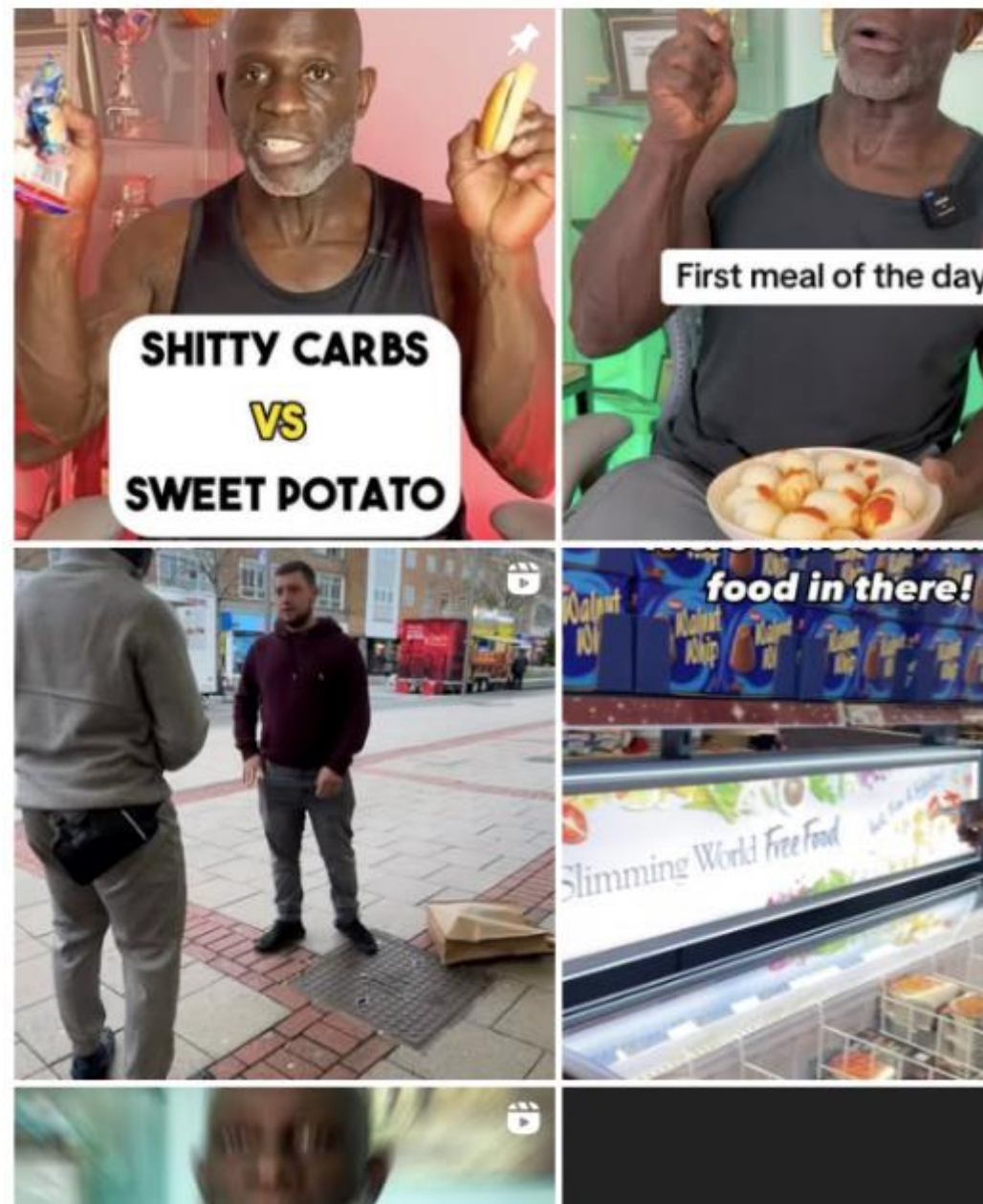


Image from Eddie Ebbew's Instagram page

1 in 4

have experienced negative depictions of diabetes in the media

Nearly **two thirds** come across this monthly or more



4

IMPACT OF STIGMA



THERE IS A TENDENCY TO POST-RATONALISE NEGATIVE EXPERIENCES

'I TRY NOT TO THINK TOO MUCH ABOUT IT'

When discussing negative experiences, people from South Asian, Black Caribbean and Black African backgrounds tend to minimise the impact of stigma upon them and rationalise negative experiences, particularly from family and wider community members, as 'well-intentioned'. Many say they try not to let it affect them and 'just get on with it'.

DIGGING DEEPER, IT IS CLEAR THAT STIGMA HAS A PROFOUND IMPACT

When probing in more detail, it is clear that many stigmatising experiences have been buried away and, upon reflection, have been incredibly hurtful in both the short-term and the long-term. Furthermore, immediate responses to negative experiences are raw and full of emotion.

IMMEDIATE RESPONSES TO STIGMA

These can vary, and include:

- Annoyance/frustration
- Embarrassment
- Feeling 'othered'
- Uncomfortable
- Shocked
- Useless
- Worried
- Stressed

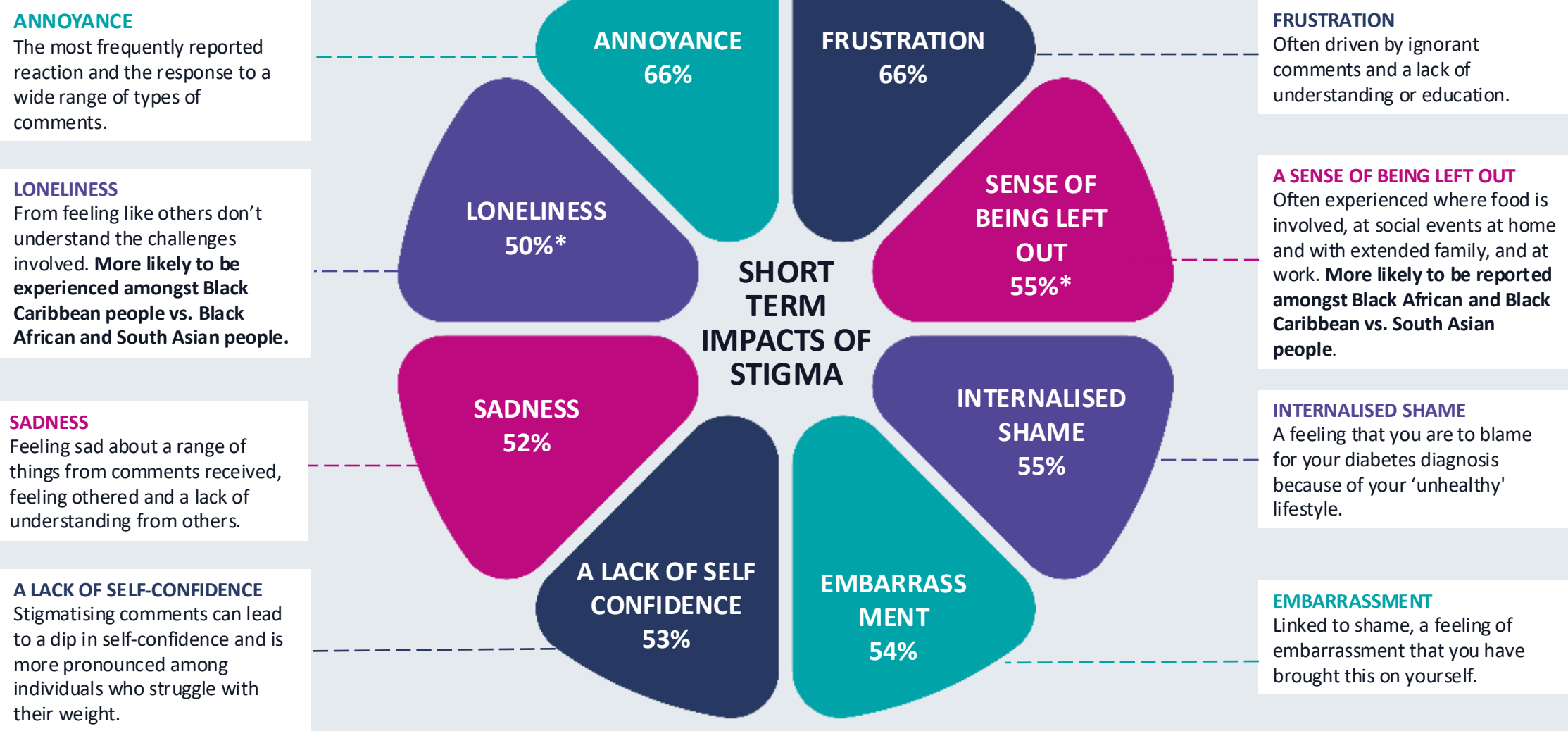
IN-THE-MOMENT REACTIONS

In the moment, stigma evokes a range of reactions, including:

- Angry comments/snapping back
- Staying quiet and hoping the conversation moves on
- Conforming to social norms (such as eating food they do not want to eat)
- Taking a break from social media



SHORT TERM IMPACTS OF STIGMA ARE PRIMARILY ANNOYANCE AND FRUSTRATION



Q. As a result of the negative views and attitudes you've experienced regarding diabetes, to what extent have you felt...? N=417 (answer: at least sometimes)

IN THE LONG-TERM, STIGMA CAN IMPACT PEOPLE'S LIFE CHOICES

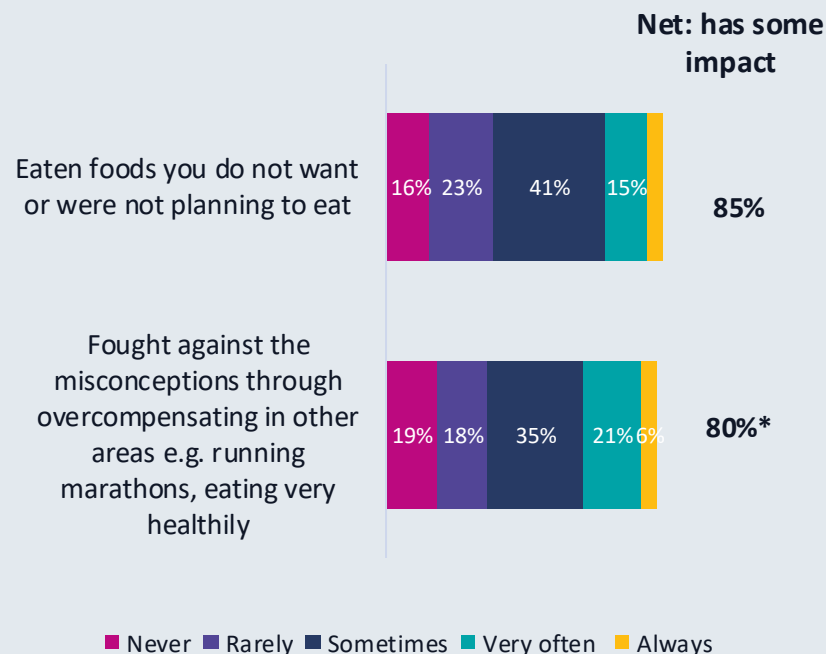
EATING FOODS THEY WEREN'T PLANNING TO EAT

Some report feeling peer pressure from others to eat certain foods at social events, or feel they should eat certain foods at the risk of disrespecting hosts. 85% have eaten foods they did not want to eat or were not planning to eat and this can be at the expense of their health, long-term and short-term.

OVERCOMPENSATING

Many try to fight against misconceptions, particularly around diabetes being brought on by an unhealthy lifestyle. 80% have overcompensated in other areas of their lives, such as running marathons or eating very healthy, such as all natural and organic foods. Black African people are more likely to have done this (87%) compared to South Asian people (74%).

IMPACT OF NEGATIVE VIEWS AND ATTITUDES



Q. As a result of the negative views and attitudes you've experienced regarding diabetes, to what extent have you...? n=417



CASE STUDY: SHAZ

Shaz a Black African woman in her 30s. She sometimes avoids social gatherings where food is involved because she feels like she doesn't want the pressure of eating certain dishes or ingredients. Now and again when she feels like she's missing out, she does attend these events but experiences a lot of peer pressure from others to eat food she doesn't want to. Not only is this emotionally draining, she said she often 'succumbs', resulting in a lot of physical pain and discomfort afterwards.

SOME HIDE DIABETES FROM OTHERS AND AVOID MEDICAL APPOINTMENTS

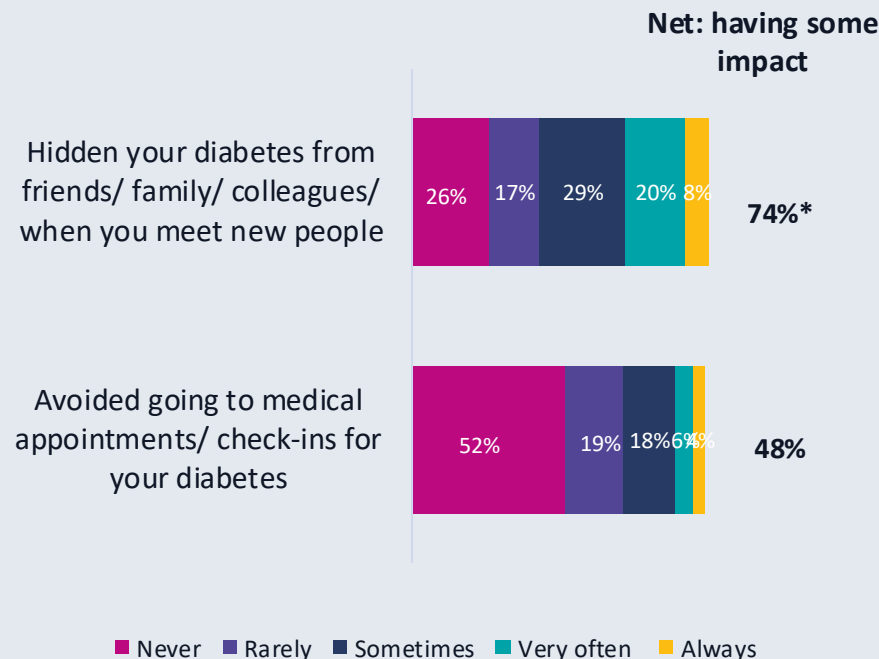
HIDING THEIR DIABETES

Nearly three quarters have hidden their diabetes from others such as friends, family, colleagues and new people due to stigma. This can be a result of pressure from family members, or a decision made by the individual based on perceived stigma. Some are hesitant about telling employers due to perceived discrimination based on previous negative experiences. Black African people are more likely to have done this (83%).

AVOIDING MEDICAL APPOINTMENTS

Nearly half have avoided going to medical appointments for their diabetes because of feeling judged, dismissive, or othered. Furthermore, some do go to medical appointments but avoid being completely transparent with healthcare professionals, omitting and distorting information around diet and exercise to avoid any criticism.

IMPACT OF NEGATIVE VIEWS AND ATTITUDES



Q. As a result of the negative views and attitudes you've experienced regarding diabetes, to what extent have you...? n=417

**Nearly
HALF** have
avoided going to
medical
appointments

“

'A lot of the judgement or the anxiety about being diabetic came from the healthcare professionals, and I don't know if that's the tactic they do to scare people into some kind of action. But I think for me, it had the opposite of, kind of just keeping me numb to everything.'

**BLACK CARIBBEAN,
FEMALE, TYPE 2, 45-49
YEARS**

STIGMA CAN LEAD TO FEELINGS OF HELPLESSNESS, AS WELL AS STRENGTH

UNABLE TO COPE

63% say they have, at times, felt like giving up and unable to cope as a result of negative attitudes and behaviours they have encountered. South Asian people are more likely to say this (71%).

FUELS RESILIENCY

However, there are also numerous stories of hope and positivity. Many individuals have turned these negative experiences into opportunities for growth, feeling stronger, more resilient, and better equipped to support others facing similar challenges. Some also share that they have become more empathetic and understanding as a person overall.

63%

say they have felt like giving up and been unable to cope



Q: As a result of the negative views and attitudes you've experienced regarding diabetes, to what extent have you...? P: 430

STIGMA CAN LEAD TO FEELINGS OF HELPLESSNESS, AS WELL AS STRENGTH



FOR MANY, THE UPSET OF EXPERIENCING STIGMA IS LONG-LASTING

For Nadine, her Type 2 diabetes diagnosis in her 30s came as a shock to her, as did the stigma she experienced from healthcare professionals. Whilst trying to make healthier lifestyle choices, she was dismissed when she mentioned smoothies and was told by doctors they were unhealthy as crushing up fruit will release more sugar.

Whilst Nadine was pregnant, she felt both guilt and anxiety from her doctors who berated her about the risks to her baby and the importance for her to lose weight. When Nadine had a miscarriage, she felt blamed by her doctors as it was attributed to her diabetes and for not taking medication.

Nadine still feels the effects of her experiences with doctors, as their judgemental attitudes have made her less willing to be open about her diabetes with healthcare professionals. It has also caused long-lasting doubts on her self-confidence and her own ability to manage her diabetes.



FOR SOME, THE IMPACT OF STIGMA CAN SPARK POSITIVE CHANGE

Keiron was diagnosed with Type 1 diabetes when he was 2 years old, and has grown up experiencing stigma firsthand, which was often linked to racism. Keiron recalls when he was a teenager and he had a hypo on the bus home from college. Rather than helping him, other children made jokes about “the monkey having a fit”.

For Keiron, the frustration of others’ views on diabetes pushed him to rebel, choosing to eat whatever sweets he wanted to since other kids could. However, this mismanagement has now resulted in blindness in one eye for Keiron.

Yet his experience with stigma also marked a key point for Keiron. Empowered by his mum and supported by a school mentor, Keiron began to manage his diabetes and ignore stigma from others. He is now managing his diabetes happily, and has been able to pass his learnings on to his son to help him manage his own diabetes.

1

2

3

4

5

6





5 SUGGESTIONS FOR SUPPORT



TRAINING FOR HEALTHCARE PROFESSIONALS

A MORE NUANCED APPROACH

People from South Asian, Black Caribbean and Black African backgrounds want healthcare professionals to take the time to understand them as individuals. They value information and support that goes beyond general information about diabetes or generalisations about their cultural background, emphasising a more nuanced and personalised approach.

TRAINING ON CULTURAL DIFFERENCES

Although healthcare professionals should avoid making assumptions based on cultural background and how this may impact someone's lifestyle, they should be aware of any nuances, enabling them to provide more personalised support tailored to cultural background if necessary.

HUMANISING INTERACTIONS

Soft skills matter and people with diabetes want to be listened to, not talked at, and certainly not judged or criticised. Jargon and scientific terms should also be avoided and sensitivity at diagnosis is particularly important.



56%

would like education for HCPs in the way diabetes affects people differently. This comes out top of all support options. This is higher amongst Black African people (64%).

'It's very, very prevalent in in our community unfortunately. Here in the migration to the UK, not much has been done to be able to provide support for my community. And the reason for that is because of the fact that 1) we don't count, 2) they don't have enough knowledge and 3) they don't really care to know.'

BLACK AFRICAN, MALE, TYPE 2, 55-59 YEARS

INFORMATION TO SUPPORT AND EDUCATE OTHERS

INFORMATION FOR RELATIVES

Many discuss the impact a diabetes diagnosis can have on relatives, particularly close friends and family. A diagnosis can instill fear and anxiety amongst relatives, and inaccurate advice and information is often provided, leading to confusion for both the loved one and person diagnosed. Over half would like information for relatives on how to best support someone with diabetes.

TAKING AWAY THE BURDEN OF EDUCATING OTHERS

Over half would like information that can be shared with others to avoid having to educate them, such as short graphics or Q&As. Myth-busting was seen as particularly valuable to mitigate against the plethora of misinformation. Key myths to address include:

- Type 1 and Type 2 diabetes are the same
- Cake or too much sugar gives you diabetes
- You can't live a 'normal' life with diabetes
- There is a diabetes 'look'
- You get diabetes because you're lazy
- The experience of diabetes is the same for everyone and can be managed in the same way

56%

would like information for relatives on how to best support someone with diabetes. This is higher amongst Black Caribbean (61%) and Black African (60%) people than South Asian people (41%)

53%

would like information that can be shared with others to take away the burden of educating others. This is higher amongst Black African people (62%) compared to Black Caribbean (50%) and South Asian people (47%)



CULTURALLY SPECIFIC SUPPORT IS IMPORTANT FOR MANY

TAILORED BASED FOOD ADVICE

Over half would like food advice for diabetes that is tailored towards traditional cuisines and ingredients. Many feel that information provided is often generic and caters to a western diet and this information would not only make it easier for individuals to adopt sustainable, healthy eating habits but foster more trust and understanding between them and their healthcare professional.

PEER SUPPORT FROM OTHERS WITH A SIMILAR BACKGROUND

Many individuals expressed a desire for emotional support from peers in managing life with diabetes and the stigma associated with it. Nearly half would find it particularly valuable to receive this support from others of a similar cultural background, as they often face similar challenges in navigating the condition, particularly around food and cultural and religious norms, and share a common understanding. Suggestions included support groups and coffee mornings.

53%

would like tailored food advice around traditional food. This is higher amongst Black African people (62%) compared to Black Caribbean (45%) and South Asian people (49%)

45%

would like links to other people living with diabetes from a similar background

44%

would like support navigating different cultural/ religious norms e.g. around food

“

'Maybe a WhatsApp group or where you meet locally and discuss recipes would be really helpful because unfortunately with the Hindu Gujarati family a lot of the traditional types of food don't help diabetes in any way. So chapatis, rice, potatoes... Maybe come up with different dishes and teach them that you don't necessarily need to stick with the traditional ones, but try to vary that and therefore introduce that into the family diet.'
SOUTH ASIAN, MALE, TYPE 1, 50-54 YEARS

DIABETES UK IS A TRUSTED SOURCE OF INFORMATION

NEARLY THREE QUARTERS WOULD TRUST DIABETES UK FOR CULTURALLY SPECIFIC SUPPORT

After healthcare professionals and the NHS website, 71% would trust Diabetes UK as a source for information about diabetes related to their cultural background. Healthcare professionals and the NHS website are more likely to be trusted by Black African groups (80% and 83%) than Black Caribbean (62% and 66%) and South Asian people (62% and 66%).

COMMUNITY-FIRST SUPPORT

For some, community-first support is extremely important. Where possible, support for people with diabetes needs to be led by people from within the community. People in supporting roles should have deep cultural understanding and not simply be someone that 'looks like them'.



'Diabetes UK is another big one out there as well. I feel like talking to other people who have been in the situation is very good. It's really good that these websites have these forums where the general public can come and talk and get information from like-minded people and people who have lived experiences as well.'

SOUTH ASIAN, MALE, TYPE 1, 35-39 YEARS

TRUSTED SOURCES FOR DIABETES INFORMATION RELATING TO CULTURAL BACKGROUND



Q. Which, if any, of the following sources would you trust for information about diabetes related to your cultural background? n=417

THE MEDIA CAN PLAY A KEY ROLE IN CHANGING THE DIABETES NARRATIVE

MORE VISIBILITY OF PEOPLE THRIVING

The media can play a pivotal role in reshaping the narrative around diabetes by showcasing stories of individuals thriving while managing the condition. This representation is especially important for people from Global Majority groups, who are often surrounded by fears and anxiety from family and the wider community, and where misconceptions around future health complications are pervasive. Highlighting positive outcomes of people from Global Majority groups can inspire hope and optimism, not only for those living with diabetes but also for their families, encouraging a more forward-looking and empowered perspective on the future.

MORE ACCURATE REPRESENTATIONS OF LIVING WITH DIABETES

Over half would like more accurate representations of people living with diabetes in the media. This includes how it is to live with diabetes on a day-to-day basis. For example, you do not have to avoid eating traditional foods entirely, you can still play sports and drive, sometimes you may have a hypo and it's not due to mismanagement. Communicating these messages was seen to foster a greater understanding and empathy around living with diabetes.

52%

would like more accurate representations of people living with diabetes in the media

“

'CBeebies did a whole bedtime story on diabetes quite recently and there was a book that they read by an actor with diabetes. He's reading it and he's got this little teddy bear with a glucose monitor on it.....have watched that and really it would have like meant something, they would have felt that representation.'

SOUTH ASIAN, FEMALE, TYPE 1, 40-44 YEARS



WORKPLACE SUPPORT COULD BE BENEFICIAL

AWARENESS COURSES FOR MANAGERS AND EMPLOYEES

Providing an educational course for all staff members to raise awareness and knowledge of what diabetes is and how it is managed, and debunk common myths, could lead to a more inclusive workplace. Some compared this to existing mental health courses and resources at work. However, it is acknowledged that it may not be feasible to offer courses for every health condition.

MORE TRAINING FOR MANAGERS ON HOW TO SUPPORT EMPLOYEES WITHIN THE WORKPLACE

Those who have been subjected to unsupportive managers and inflexible workplace policies recommend training for managers on how to support people living with diabetes.

CLEARER WORKPLACE POLICIES

Some workplaces lack clarity regarding their policies on diabetes management and taking time off for medical appointments. Providing clearer guidance to employees could help address this issue.



48%

would like education for employers debunking myths and how to best support

“

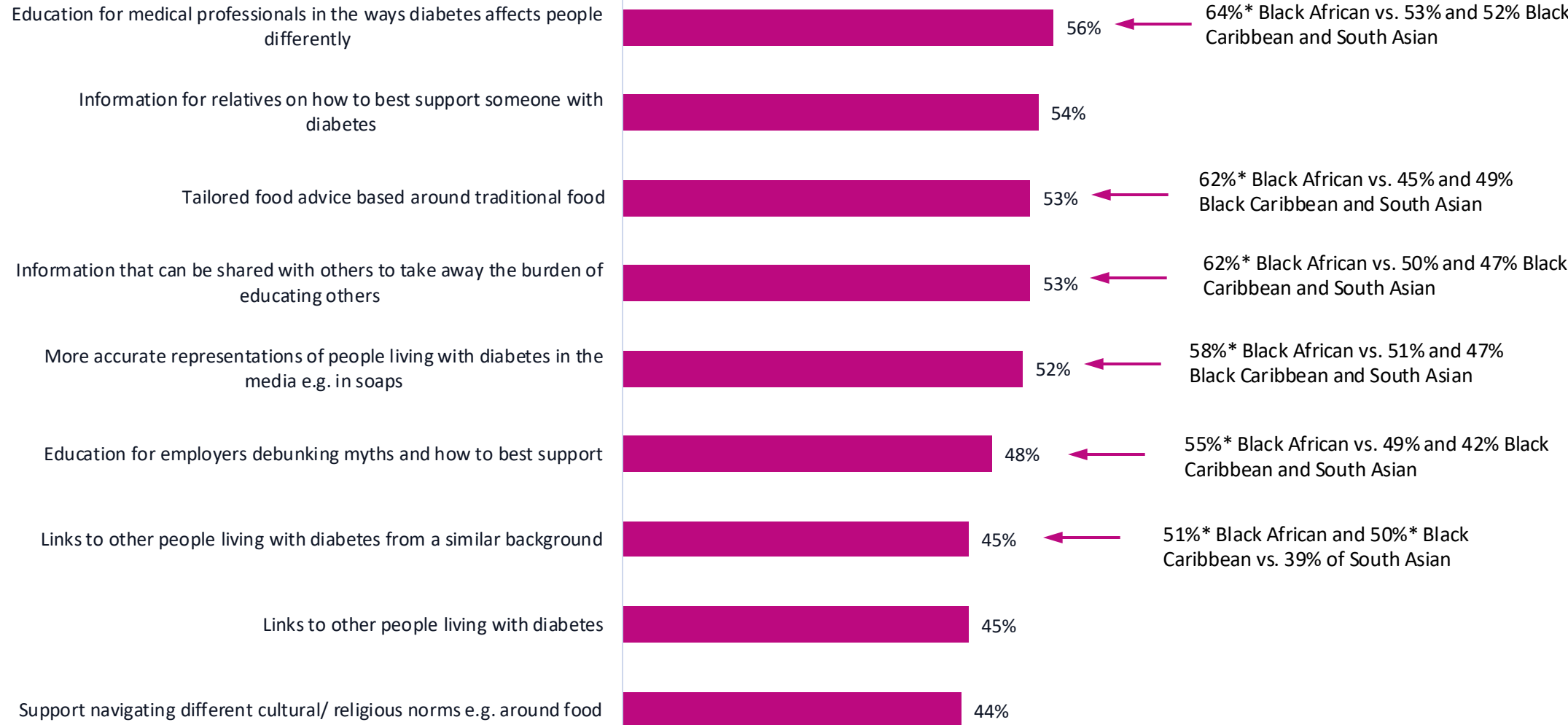
'I've seen free manager courses that people can do, like mental health first aid courses. ...I feel if there's more information, that can only be good because if it gets up into the management, it's only going to trickle down and be good for the whole workplace.'

SOUTH ASIAN, MALE, TYPE 1, 35-39 YEARS

IN SUMMARY

USEFUL SUPPORT TO ADDRESS THE IMPACT OF STIGMA

INCREASING
USEFULNESS



Q. Would the following be useful in supporting you relating to the negative attitudes and actions you have experienced? n=417 (answers: probably, very probably, definitely)



SUMMARY AND RECOMMENDATIONS



SUMMARY



1

STEREOTYPES AND MISCONCEPTIONS ARE MORE PREVALENT WITHIN GLOBAL MAJORITY GROUPS

People from Global Majority groups living with diabetes are more likely to have come across more myths and misconceptions than those in the general population living with diabetes, and they have come across a greater number of myths and misconceptions. Misconceptions are wide-ranging but those commonly encountered are that diabetes is a result of belonging to a particular ethnic group and/or a result of eating traditional foods, which are considered high in carbs and sugar.

2

STIGMA OR NEGATIVE EXPERIENCES ARE COMMON AND OFTEN OCCUR CLOSE TO HOME

Very few overtly admit to experiencing 'stigma' but digging below the surface negative experiences are common. Negative experiences often occur around food and these comments and judgements usually come from close and extended family members, and wider community members, at mealtimes and social gatherings. Comments around food also come from colleagues at lunchtimes.

3

STIGMA ALSO COMES FROM FURTHER AFIELD FROM HEALTHCARE PROFESSIONALS

Healthcare professionals sometimes make assumptions based on ethnicity, for example, around the food they eat or knowing others with the condition. They can also be judgemental, dismissive and critical, leading to mistrust between the person with diabetes and the healthcare professional. This has led nearly half to miss appointments, and some purposefully withhold information from their clinician.

4

BLACK CARIBBEAN AND BLACK AFRICAN PEOPLE TEND TO EXPERIENCE MORE STIGMA AND WOULD FIND A GREATER NUMBER OF SUPPORT OPTIONS USEFUL

Black Caribbean and Black African people report a significantly greater number of negative experiences compared to South Asian people and are more likely to hide their diabetes and overcompensate in other areas of their lives. When it comes to support options, they would like a range of different support options to support them with stigma experienced – more so than South Asian people.

5

DIABETES UK IS A TRUSTED SOURCE OF DIABETES INFORMATION

For many, culturally specific tailored support would be welcomed. Nearly three quarters would trust a health charity such as Diabetes UK to provide this.



RECOMMENDATIONS FOR SUPPORT

CULTURALLY TAILORED SUPPORT FOR PEOPLE LIVING WITH DIABETES	TRAINING AND SUPPORT FOR HEALTHCARE PROFESSIONALS	INFORMATION FOR FRIENDS, FAMILY AND COLLEAGUES	RAISING AWARENESS OF DIABETES
<ul style="list-style-type: none"> Provide tailored resources such as diet advice, top tips for navigating mealtimes and social gatherings, and how to deal with the emotional impact of stigma. Peer support for people of the same cultural background, such as coffee mornings and peer support groups, could be useful. This should be underpinned by healthcare professions and/or Diabetes UK to enhance people's trust. Diabetes UK should consider community-led support. People in supporting roles should have a deep cultural understanding and not simply be someone that 'looks like them'. <p><i>All three groups would benefit from support, however, Black Caribbean and Black African people are priority audiences.</i></p>	<p>Develop an awareness and understanding around:</p> <ul style="list-style-type: none"> Not making assumptions based on someone's cultural background. But, having an awareness of how this may impact someone's experiences. Different belief systems people may be straddling and to not be dismissive, but work in alignment with these. Respectful and mindful interactions, particularly at time of diagnosis, such as avoiding jargon and scientific terms. <p>Access to resources:</p> <ul style="list-style-type: none"> Tailored support, such as diet advice and ingredients, that professionals can access and distribute if required. 	<p>Develop resources around topics such as:</p> <ul style="list-style-type: none"> The impact of diabetes on day-to-day life and the future (to dispel any fear) How to support loved ones/colleagues – what to say and avoid/what may be helpful The differences between Type 1 and Type 2 	<p>Any communications about diabetes to the general public should focus on changing the narrative around diabetes. Show people from Global Majority backgrounds thriving or living a 'normal' life with diabetes to dispel the fear around diabetes and future health outcomes.</p>