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“If I control diabetes, I may live a healthier life for many years”:

Perceptions of the changing nature of diabetes and its treatment over time among people with type 2 diabetes and healthcare professionals

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ECONOMIST IMPACT

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Contents

Executive summary

The management of type 2 diabetes usually begins with lifestyle changes to improve people's diet and increase their physical activity. Type 2 diabetes is a condition that changes over time, meaning that most people will eventually require oral and injectable medications, including insulin. People with type 2 diabetes can feel anxious about these treatments, which can contribute to delaying starting these treatments once clinically indicated, leading to complications and poorer outcomes.[1-6]

Healthcare professionals (HCPs) play an important role in informing, supporting and empowering people with type 2 diabetes to feel comfortable with changes to their diabetes treatment.[1-3, 7-9] To do so they need to understand the perspectives of people with type 2 diabetes and have the necessary tools to support them.

This project was designed to explore perceptions of the changing nature of diabetes and its treatment over time among people with type 2 diabetes and healthcare professionals (HCPs).

The centrepiece of this project is a survey of 405 people with type 2 diabetes and 408 HCPs (specialist doctors, primary care doctors and diabetes nurses where available) in eight countries: Brazil, China, Germany, India, Russia, Saudi Arabia, Turkey and the US

By surveying both people with type 2 diabetes and HCPs, we sought to gain an understanding of whether and where there are differences in their views. The survey was followed by a series of interviews with a range of experts to explore the findings of the survey and contribute to identifying actionable change.

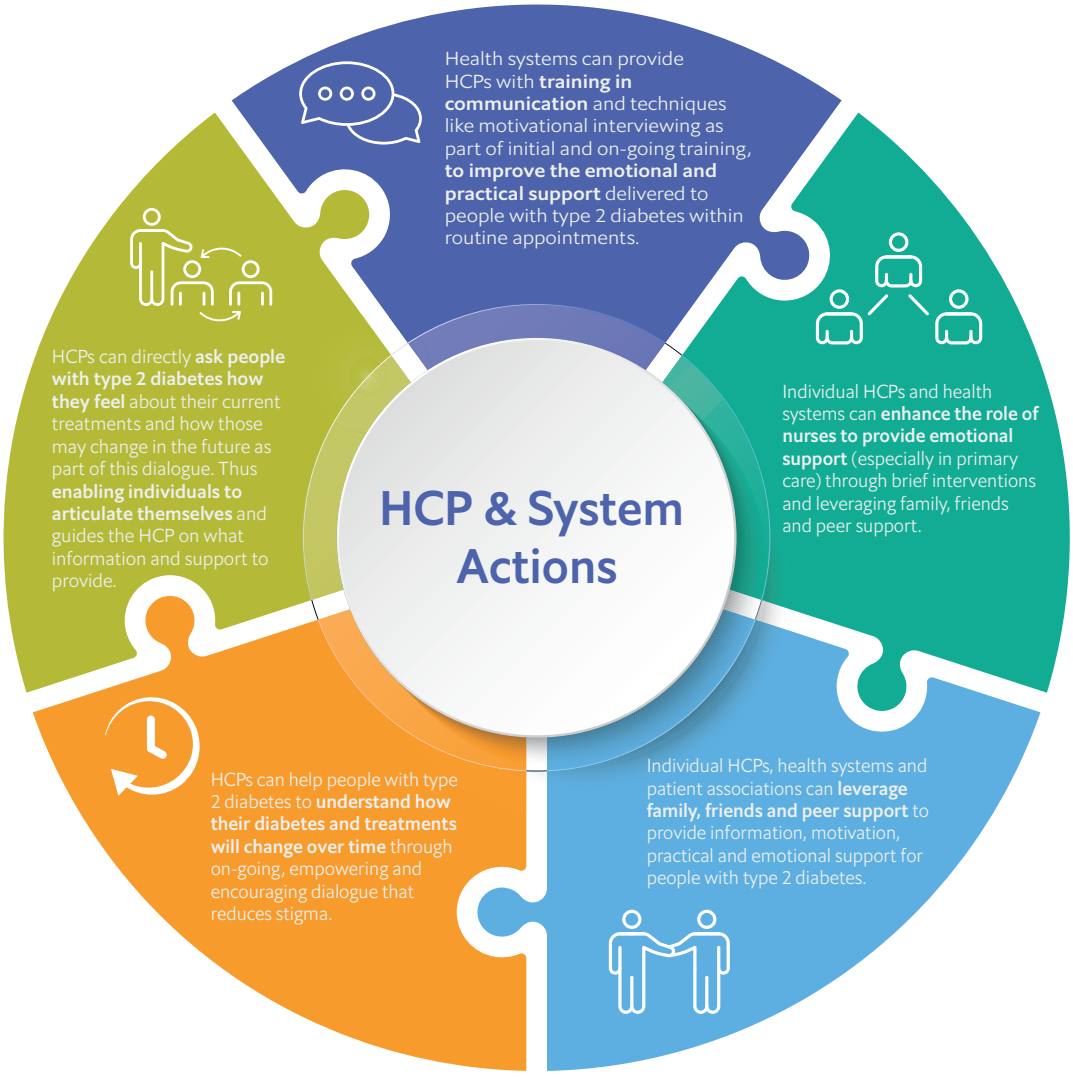
The key findings of this project are:

- The progressive nature of type 2 diabetes can be a powerful motivator for people to avoid or delay complications.
- There is scope for more initial and on-going training in communication for HCPs, to improve their ability to understand and motivate people with type 2 diabetes.
- HCPs may overestimate negative attitudes to certain treatments and even exacerbate those feelings if treatments are used as a "threat".
- Emotional support for people with type 2 diabetes is lacking, with limited time the main barrier to delivering this care.
- Nurses are seen as an important part of the multidisciplinary team and can be particularly effective at providing emotional support to people with type 2 diabetes.
- Family and friends are important contributors to the motivation of people with type 2 diabetes, but it can be challenging for HCPs to reach or engage them.
- Peer support groups can be a useful source of support for people with type 2 diabetes.

This report presents the findings of this research project, which have been summarised into key policy and practice take aways.

Policy and practice take aways

Here we have synthesised the findings of this project into key actions that health systems and healthcare professionals can take to address the issues identified. These actions fall within two broad categories of communication and support. These categories are interlinked as **communication** is both a facilitator of providing support and a **support** mechanism.



About this project

"**If I control diabetes, I may live a healthier life for many years": Perceptions of the changing nature of diabetes and its treatment over time among people with type 2 diabetes and healthcare professionals** is a report by the Economist Intelligence Unit. The report reflects the findings of a survey of over 800 people with diabetes and healthcare professional in 8 countries, and interviews with experts. The programme is sponsored by Sanofi. The EIU research team comprised Elly Vaughan and Jordan Lee.

The Economist Intelligence Unit would like to thank all participants in the survey and the interviewees who generously offered their time and insights.

The findings and views expressed in this report are those of the EIU and do not necessarily reflect the views of survey respondents, interviewees or the project sponsor.

The quote used in our title is from a survey respondent.

Introduction

In 2019 an estimated 463 million adults globally had diabetes, a figure that is set to rise by 51% to 700 million people in 2045.[10] The global cost of managing diabetes was estimated at $1,123bn ($ID), again rising to $1,308bn in 2045.[10] An estimated 75% of all diabetes related costs are due to preventable complications.[11] As such, there is a clear health, social and economic case that can be made for improving the management of diabetes.

"Untreated diabetes is the leading cause of many complications, well-controlled diabetes is the leading cause of nothing."

WH Polonsky[15]

Type 2 diabetes management usually begins with trying to improve people's diet and increase their physical activity. Managing type 2 diabetes using diet and physical exercise alone can be difficult as it involves changing long-held daily habits and can feel relentless, with rewards that are not always immediately apparent.[12] Over time most people with type 2 diabetes will require different treatments for their diabetes, such as oral medications, injectable drugs, including insulin.

People with type 2 diabetes report fear and anxiety about starting oral or injectable medication, including insulin.[1-3] This fear is of the treatment itself and what they perceive this change in treatment says about their current and future health.[3-5] However, these attitudes can change over time, with people with type 2 diabetes reporting that these treatments were not as bad as they had thought they would be ahead of starting treatment.[1, 3] There is evidence that glycaemic control is suboptimal in many people with type 2 diabetes, with this fear of medication and insulin, and the attitudes of healthcare professionals, potentially contributing to delays of up to three years in starting these treatments.[2, 6] Such delays can lead to complications and poor outcomes for people with type 2 diabetes.

Healthcare professionals (HCPs) play an important role in informing, supporting and empowering people with type 2 diabetes to feel comfortable with changes to their diabetes treatment.[1-3, 7-9] To do so, HCPs need to understand the perspectives of people with type 2 diabetes and have the necessary tools to support them.

Methods

Survey

We used an online platform to survey a total of 405 people with type 2 diabetes and 408 HCPs (specialist doctors, primary care doctors and diabetes nurses where available) evenly distributed across eight countries: Brazil, China, Germany, India, Russia, Saudi Arabia, Turkey and the US. The countries were selected to represent a variety of regions, income levels and type 2 diabetes demographics—in some countries numbers are already high and steadily rising, whereas in others rates are currently lower but rising at a faster/greater rate (Table 1).

Screening questions were used to gather demographic data about respondents and ensure their eligibility. Questions were mainly quantitative, with the option to leave additional qualitative remarks for some questions.

The survey was developed based on a brief literature review to identify key themes relating to the overall topic of people with type 2 diabetes and HCPs' perceptions of how diabetes and its management changes over time (see Table 2). Each survey contained 12 questions, the questions in the people with type 2 diabetes and HCP surveys were designed to mirror each other to enable direct comparison of their responses. Two of the 12 questions were asked to a subset of people with type 2 diabetes respondents—those receiving oral medication, injectable GLP-1-receptor agonist or insulin. These questions related to their attitudes to these treatments before and after starting them. Equivalent questions were asked in the HCP survey. The themes covered in the survey are summarised in Table 2, please see Appendix 1 for the full questionnaires.

Table 1: Survey country characteristics

	Age-adjusted comparative prevalence of diabetes, %			Income level (World Bank)	Region (World Bank)
	2010	2045	2010-2045		
Brazil	6.4	12.7	6.3	Upper middle income	Latin America & Caribbean
China	4.2	10.8	6.6	Upper middle income	East Asia & Pacific
Germany	8.9	12.6	3.7	High income	Europe & Central Asia
India	7.8	11.5	3.7	Lower middle income	South Asia
Russia	7.6	7.3	-0.3	Upper middle income	Europe & Central Asia
Saudi Arabia	16.8	17.8	1	High income	Middle East & North Africa
Turkey	8	13.1	5.1	Upper middle income	Europe & Central Asia
US	10.3	12.8	2.5	High income	North America

Sources: IDF Diabetes Atlas,[10] World Bank[13]

Table 2: Themes covered in the survey of people with type 2 diabetes and HCPs

Theme	People with type 2 diabetes	HCPs
About you	Time since diabetes diagnosis	Professional category (specialist doctor, primary care doctor or nurse)
	Treatments received immediately after your diagnosis and now	
Discussion of and attitudes towards the changing nature of diabetes over time	Has your healthcare team discussed with you that diabetes is a chronic condition that may require different treatments over time?	Do you discuss with your patients that diabetes is a chronic condition that may require different treatments over time?
	Attitudes to statements about the changing nature of diabetes (same options as HCPs)	Attitudes to statements about the changing nature of diabetes (same options as HCPs)
	How the changing nature of diabetes impacts on motivation to control their diabetes	How the changing nature of diabetes impacts on patients' motivation to control their diabetes
Emotional support for people with type 2 diabetes	Rating the emotional support received	Rating their ability to deliver emotional support
Motivations to control diabetes	Motivations to control their diabetes (e.g. to be healthier overall)	Patients' motivations to control their diabetes (e.g. to be healthier overall)
	Motivational factors (e.g. encouragement from family/friends	Patients' motivational factors (e.g. encouragement from family/friends
Attitudes to starting oral medication, injectable GLP-1-receptor agonist or insulin (questions only asked to people with type 2 diabetes who stated they were currently receiving these treatment(s))	Attitudes to starting this treatment ahead of time	Patient attitudes to starting this treatment ahead of time
	Attitudes after starting this treatment	Patient attitudes after starting this treatment
		What factors affect how quickly you commence medication/insulin once clinically indicated (e.g. patient resistance)

Interviews

We interviewed a number of internationally renowned experts to gain their perspective on the survey findings and their practical ideas to address the issues raised in the survey findings. We sought a range of perspectives: HCPs—physicians and nurses, systems researchers, civil society group representatives, diabetes education. We also sought insights from people with specific expertise in diabetes and NCDs more broadly.

- Ms Olivia Barata Cavalcanti (PhD), Director of Science and Programmes at the World Obesity Federation.
- Professor Andrew Boulton, President of the International Diabetes Federation, Consultant Physician (Diabetes) at the Manchester University NHS Foundation Trust and Professor of Medicine, University of Manchester.
- Manjusha Chatterjee, Capacity Development Manager at the NCD Alliance.
- Professor Angus Forbes, Professor of Diabetes Nursing, FEND Chair of Clinical Diabetes Nursing at King's College London.
- Dr Kremlin Wickramasinghe, Technical Officer at the World Health Organization Regional Office for Europe.

Overview of survey respondents

Survey respondents comprised 408 HCPs and 405 people with type 2 diabetes evenly distributed across: Brazil, China, Germany, India, Russia, Saudi Arabia, Turkey and the US.

People with type 2 diabetes—demographics

To be eligible to take part in the survey, respondents had to indicate that they had type 2 diabetes (from a range of conditions). Most respondents received their diagnosis two or more years ago—48% 2-6 years ago and 46% between 7 or more years ago, only 6% of our sample was diagnosed within the last year (Figure 1).

People with type 2 diabetes—treatments received

People with type 2 diabetes included in the sample currently receive a range of treatments, indicating that this sample is well placed to answer questions about attitudes to changing treatments over time (Figure 2). The US was an outlier in terms of treatments received at diagnosis, with only 63% receiving healthy eating advice compared to the average of 84%. It was also at the lower end in terms of the proportion of patients receiving physical activity advice at 45%—compared to the average of 65%—but Russia (41%) and China (42%) were even lower. In Saudi Arabia 100% of respondents indicated receiving healthy eating and physical exercise advice. Respondents indicated all treatments received, so may receive a combination of multiple simultaneous treatments.

Figure 1: Time since diagnosis among respondents with type 2 diabetes

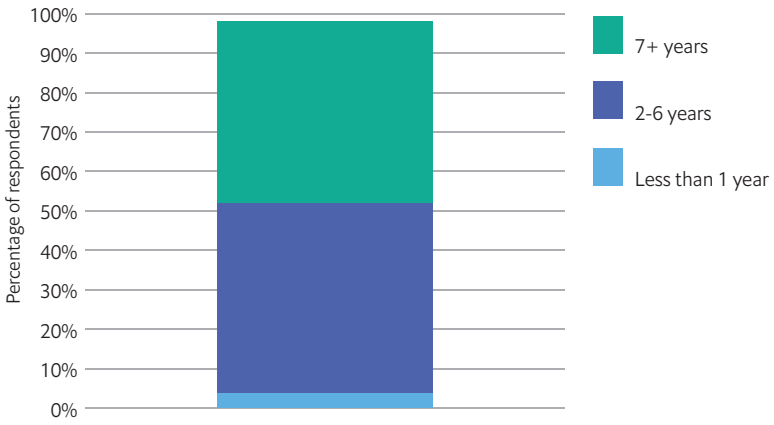
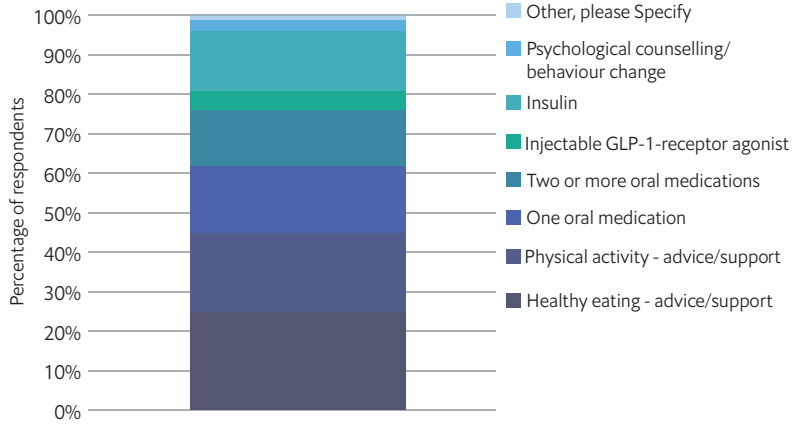


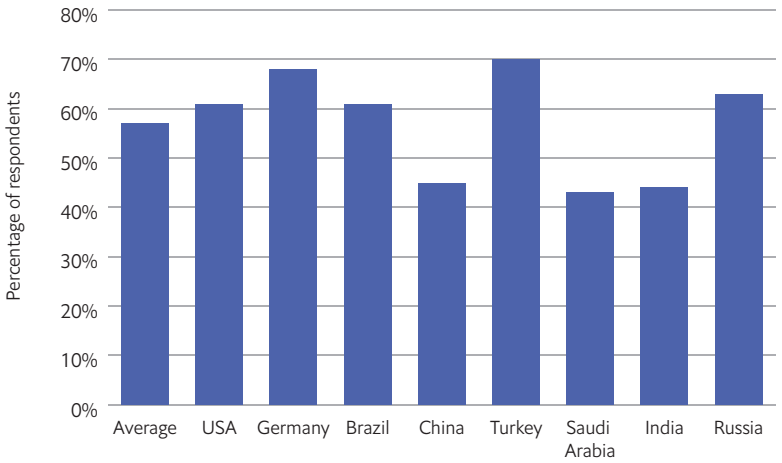
Figure 2: Treatments that respondents with type 2 diabetes currently receive



People with type 2 diabetes—those on oral medication

An average of 57% received one oral medication at diagnosis (Figure 3)—the highest rates were in Turkey (70%) and Germany (68%). Those who reported being demotivated by the changing nature of their diabetes were more likely to receive oral medication as an initial treatment. Two or more oral medications were only prescribed initially to 36% of respondents. Those who reported being demotivated were more likely to now receive two or more oral medications—this may indicate that these individuals are more demotivated because their condition is more acute, regardless of time since diagnosis. Injectable GLP-receptor agonists were only initially prescribed to 13% of respondents.

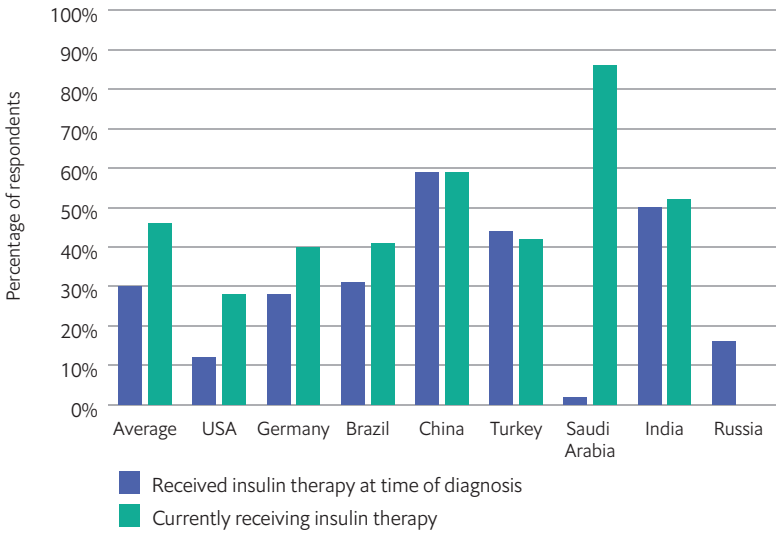
Figure 3: People with type 2 diabetes (PWT2DM) receiving one oral medication immediately after diagnosis



People with type 2 diabetes—those on insulin

Insulin was initially prescribed to an average of 30% of respondents, with Saudi Arabia (2%) and China (59%) as outliers (Figure 4). When asked about what treatments they currently receive, this figure increased to 46% receiving insulin. The biggest difference was in Saudi Arabia where only 2% of respondents indicated that they received insulin at the time of diagnosis but 86% indicated that they now did. This may reflect overall treatment approaches at the time of diagnosis, with 43% receiving one oral medication (the lowest proportion in the included countries) and 100% of respondents indicated that they received diet and/or physical activity advice at the time of diagnosis (the highest proportion in the included countries).

Figure 4: Treatments received by PWT2DM



People with type 2 diabetes—those receiving psychological counselling

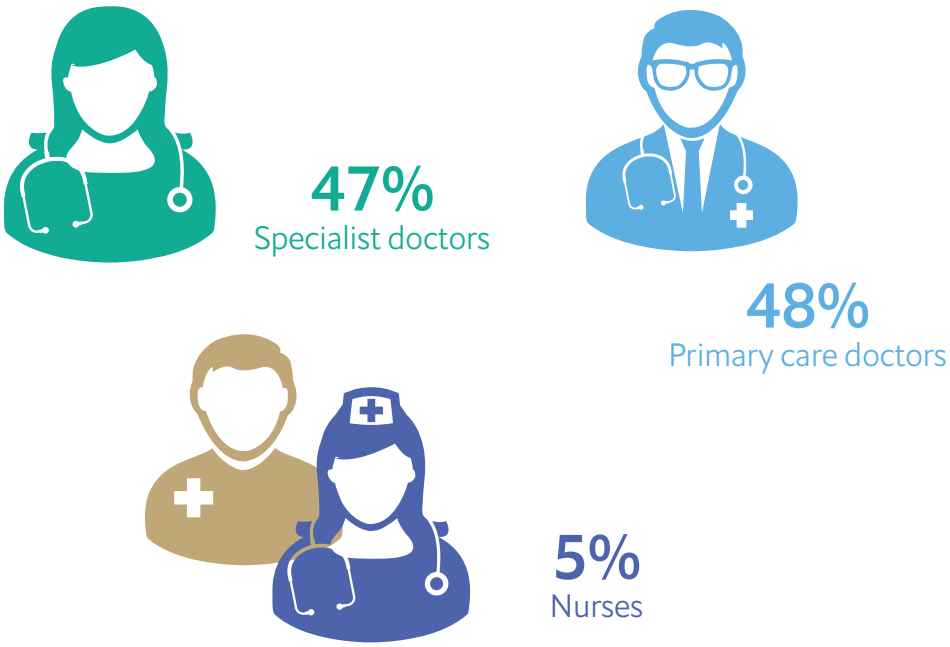
Only 11% of people with type 2 diabetes stated that they received psychological counselling or behaviour change interventions—it may be that these elements are incorporated into their overall management. In India 20% of respondents reported receiving this treatment whereas none of our Saudi Arabian respondents reported receiving psychological counselling.

Healthcare professionals

The HCP sample was mainly made up of specialist doctors (47%) and primary care doctors (48%, Figure 5). Diabetes specialist nurses made up a smaller proportion of respondents (5%) because they are only present in India, Germany and the US. The small sample size for nurses means that our findings are indicative and we cannot draw broad conclusions about the attitudes of this group.

All respondents had to indicate that they were directly responsible for the care of people with diabetes (among a range of conditions) to be eligible to take part in the survey.

Figure 5: HCP survey respondent overview



Survey Findings

Most people with type 2 diabetes report having discussed with their healthcare team how diabetes changes over time and it motivates them to manage their diabetes to delay its progress

The majority of people with type 2 diabetes reported that **their healthcare team had discussed the progressive/changing nature of diabetes with them** (67%, Figure 6). Overall countries ranged between 63% and 84% of respondents reporting having had this discussion, with Russia the outlier at 39%. In Saudi Arabia and India no respondents reported not having had this conversation at all. By contrast, 96-100% of HCPs reported having this conversation to some extent across all specialities, **suggesting there may be a disconnect between patients' and HCPs' perceptions of these conversations**.

The changing nature of diabetes over time motivates people with type 2 diabetes to manage their diabetes to delay its progress (72%) and HCPs agree (73%, Figure 7). **Those who are motivated by the progressive nature of diabetes—e.g. wanting to prevent complications or changing treatments—were more likely to have talked it through with their healthcare team** (77%, Figure 8) compared to those who were neither motivated nor demotivated (43%) and those who feel demotivated by the progressive nature of their diabetes (33%).

Figure 6: Proportion of PWT2DM and HCPs who report having discussed how diabetes will change over time

Figure 7: PWT2DM are motivated to slow the progression of their diabetes

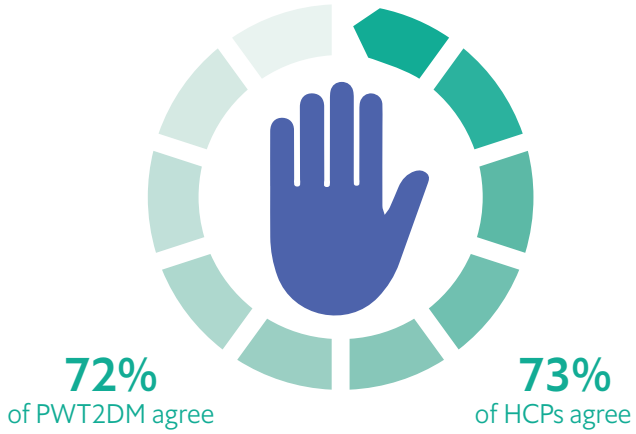
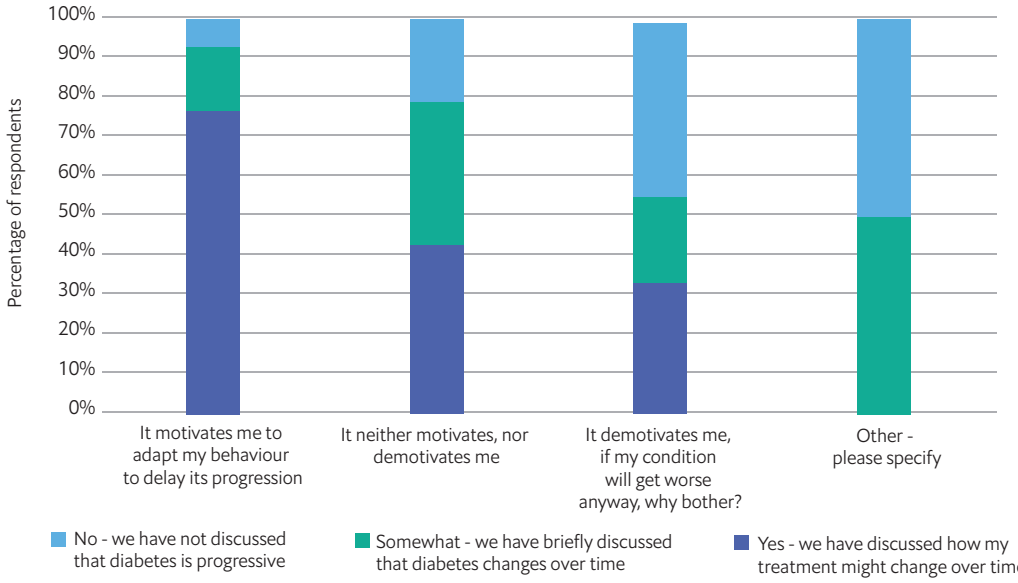


Figure 8: the impact of discussing how diabetes changes over time on the motivations of PWT2DM to control their diabetes

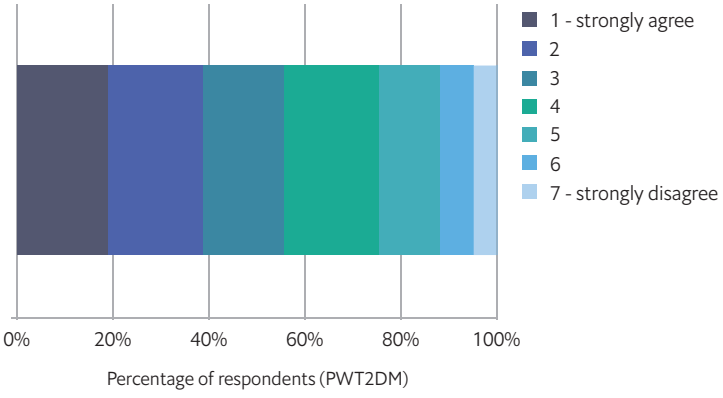


HCPs who discuss how diabetes and its treatments change over time to some extent with their patients are more likely to view the progressive nature of diabetes as a motivator for their patients. Whereas those who don't have that discussion are ambivalent about this statement.

Diabetes is seen by people with type 2 diabetes and healthcare professionals as a condition that progresses over time, yet the need for medication/insulin is also seen as a reflection of individuals not managing their diabetes well.

Most people with type 2 diabetes (people with type 2 diabetes) agreed that **the progression of type 2 diabetes is a natural process that they cannot stop (except early on), but only slow down through their behaviour** (56%—Figure

Figure 9: Progression of type 2 diabetes is a natural process which I cannot stop or reverse (except early on), but only slow down through my behaviour



9). Although, 25% disagreed with this statement and 20% indicated that they neither agreed nor disagreed. There were no significant differences in the responses of people receiving different types of treatments for their diabetes. Patients in China and India were more likely to agree that the progression of diabetes was something that they cannot stop or reverse (except early on), but only slow through their behaviour. Across countries, those who had not discussed the progressive nature of diabetes are less likely to agree with this statement, suggesting that **a conversation about the changing nature of diabetes is a helpful primer for overall understanding of the condition**.

Healthcare professionals (HCPs) also agreed that **the progression of type 2 diabetes is a natural process that patients cannot stop (except early on), but only slow down through their behaviour** (average 58%). Brazil, Germany, Russia and the US responses were fairly evenly distributed across agreement and disagreement. Whereas HCPs in China, India and Turkey were far more likely to agree, with Saudi Arabia the outlier with 94% agreeing. This mirrors the findings among people with type 2 diabetes. Agreement rates were generally consistent, even among those HCPs who do not discuss that diabetes is progressive—**so why are some HCPs not having that discussion if they think that the condition progresses irrespective of their patients' actions?**

Generally people with type 2 diabetes agree that **taking more oral medication or insulin is part of the progression of diabetes** (57%, Figure 10), as did HCPs (56%). Patients in Saudi Arabia were most likely to agree with this statement and none of the respondents in Saudi Arabia disagreed with it. Patients in Russia were least likely to agree (31%), which reflects our finding that Russian respondents were less likely to have discussed how their condition and treatment

Figure 10: Taking more and/or stronger oral medication or insulin is a natural part of the progression of diabetes

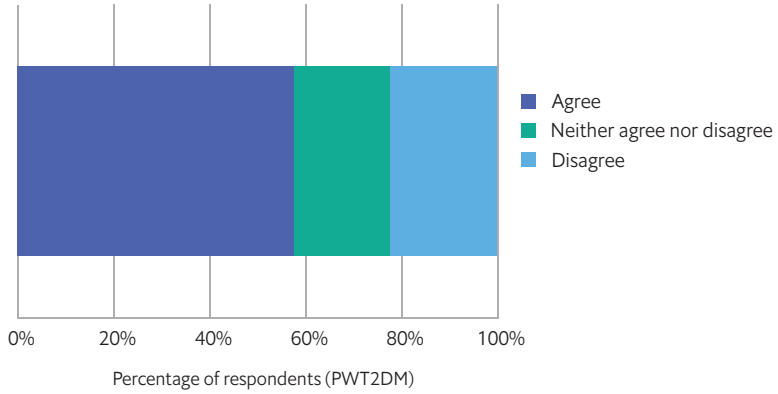
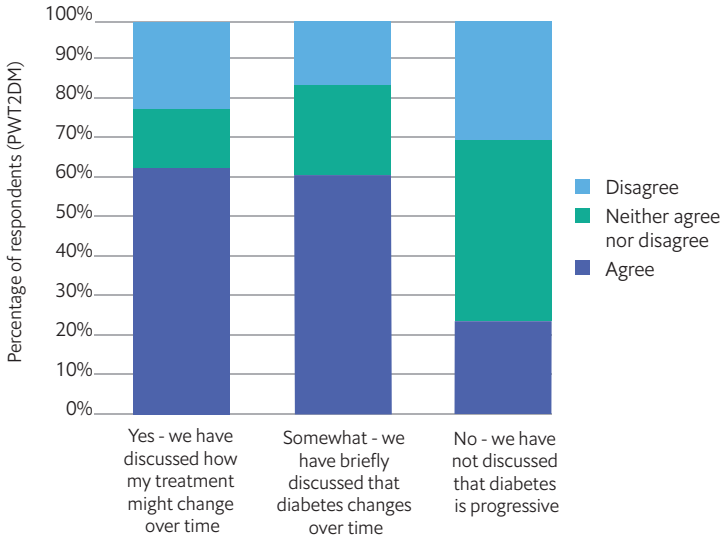


Figure 11: The impact of discussing how diabetes changes over time on whether PwT2DM agree that taking more and/or stronger oral medication, or insulin, is a natural part of the progression of diabetes



needs will change over time. **People who have discussed how diabetes changes over time to at least some extent are far more likely to agree that treatment will change over time** (discussed it 62%, somewhat discussed 61%, not discussed 24%, Figure 11).

Similarly, people with type 2 diabetes and HCPs agreed that over time their bodies may **struggle to produce enough insulin**, meaning that they will need to take insulin (68% of people with type 2 diabetes, 73% of HCPs) and that the reversal of T2DM is only possible early on (49% of people with type 2 diabetes, 50% of HCPs). All respondents in Saudi Arabia agreed with this statement—this may reflect that all respondents indicated having discussed to some degree the changing nature of diabetes over time. **People with type 2 diabetes who have discussed how diabetes changes over time to at least some extent are more likely to agree that over time their bodies may struggle to produce enough insulin, suggesting better understanding of the changing nature of their condition** (discussed 75%, somewhat discussed 64%, not discussed 35%).

Yet both people with type 2 diabetes and HCPs also agreed that the need to take medication or insulin is a sign that patients have not managed their diabetes well (54% of people with type 2 diabetes, 51% of HCPs). In the US only 25% of people with type 2 diabetes agreed. By contrast all respondents in Saudi Arabia agreed with this statement, which may reflect that all respondents in Saudi Arabia indicated having discussed to some degree the changing nature of diabetes over time. Therefore people with type 2 diabetes in Saudi Arabia may take greater personal responsibility for their changing condition.

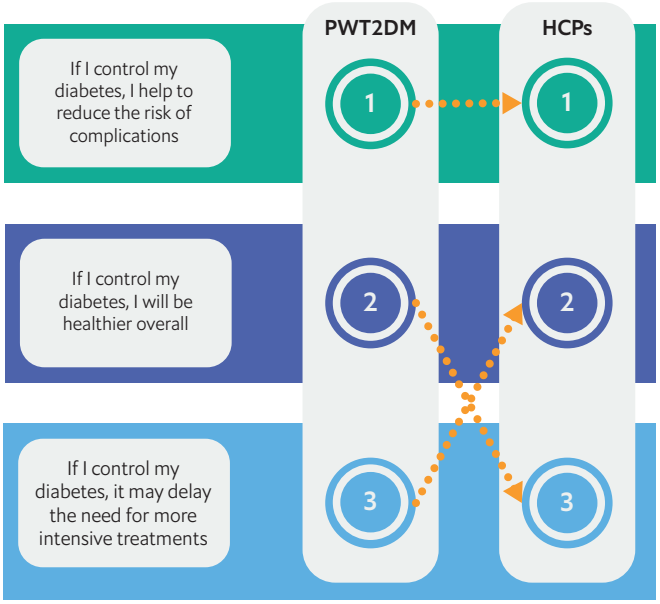
The changing nature of diabetes can be a positive motivator for people with type 2 diabetes to manage their diabetes and healthcare professionals generally have a good understanding about what motivates their patients to try to manage their diabetes.

Overall the changing nature of diabetes is a motivator for people with type 2 diabetes, the exception being in Saudi Arabia where the majority felt that it neither motivated nor demotivated them (63%). Across the surveyed countries a very low proportion of respondents indicated that it was a demotivating factor (average 2%). **People who had talked about the changing nature of diabetes with their healthcare team are much more likely to say the progressive nature motivates them, e.g. because they want to slow down the progression of their condition, prevent complications etc (discussed 83%, somewhat discussed 54%, not discussed 44%).**

We asked two questions relating to what motivates people with type 2 diabetes to manage their condition. The responses of people with type 2 diabetes and HCPs were broadly similar.

Across the countries surveyed, **people with type 2 diabetes ranked their top motivations as reducing complications**, improving their health overall and delaying the need for more intensive treatment (Figure 12). Healthcare professionals ranked their patients' motivations delaying the need for more intensive treatments above improving overall health.

Figure 12: What motivates you to try to control your diabetes? (weighted average rank 1 [highest] - 4 [lowest])



When looking at motivational factors, **people with type 2 diabetes ranked their commitment to their health as their number one motivating factor**, followed by the encouragement of their family and friends (Figure 13). Ranked third and fourth were their healthcare team informing them about the complications that could arise from not controlling their diabetes and the encouragement of their healthcare team. Reminders via an app/text message etc were ranked lowest as a motivator to control their diabetes by people with type 2 diabetes. There were no significant differences in what patients reported as their motivations depending on whether they had discussed the progressive nature of diabetes with their healthcare team or not.

The responses of people with type 2 diabetes suggest that the healthcare team plays an important role in motivating individuals to control their diabetes—both through "warnings" and "positive encouragement". On average HCPs ranked their role in encouraging their patients to control their diabetes higher than patients did, suggesting that **they may be underestimating the contribution of family/friends in motivating patients**, but agree with patients that reminders via apps/text message were not a significant motivator. The weighted average rank of these motivational factors among people with type 2 diabetes were 1.6, 2.7, 3.2, 3.0, 4.5. Whereas HCP responses were very closely clustered—weighted average rank 2.3, 2.9, 2.6, 2.8, 4.4—so we should be cautious in how much weight we give to individual rankings.

"The healthier I am, the better time I have with my loved ones."

Patient survey respondent

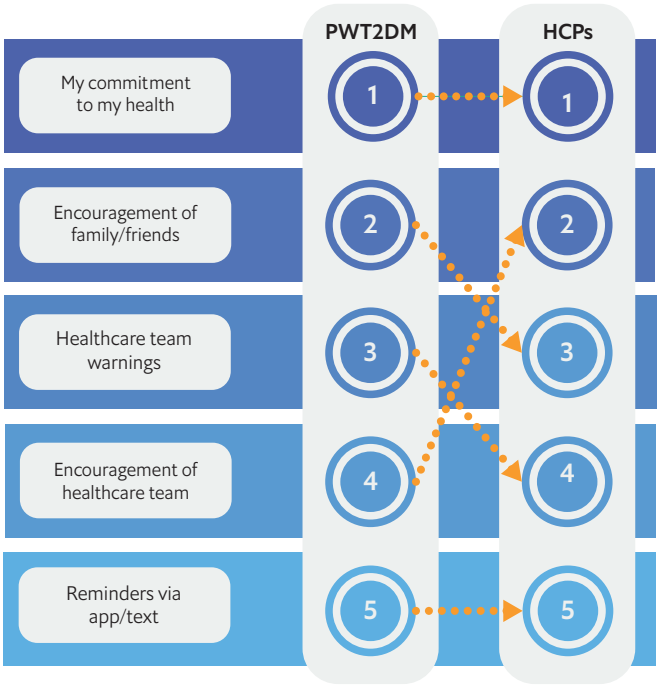
Healthcare professionals may overestimate patients' fear about starting oral or injectable medication (including insulin), but feel that patients will be happy about this treatment after it has started.

We asked two additional questions to those people with type 2 diabetes receiving oral medication, injectable GLP-1-receptor agonist or insulin, relating to their attitudes before and after starting these treatments. Equivalent questions were asked to HCPs about what they thought their patients' attitudes would be.

People with type 2 diabetes view starting treatment with oral or injectable medication (including insulin) primarily as a result of the natural progression of their diabetes (80%—Figure 14). **People who had at least somewhat discussed how diabetes changes over time were more likely to agree that treatment change was due to natural disease progression both at the time of treatment initiation and afterwards.**

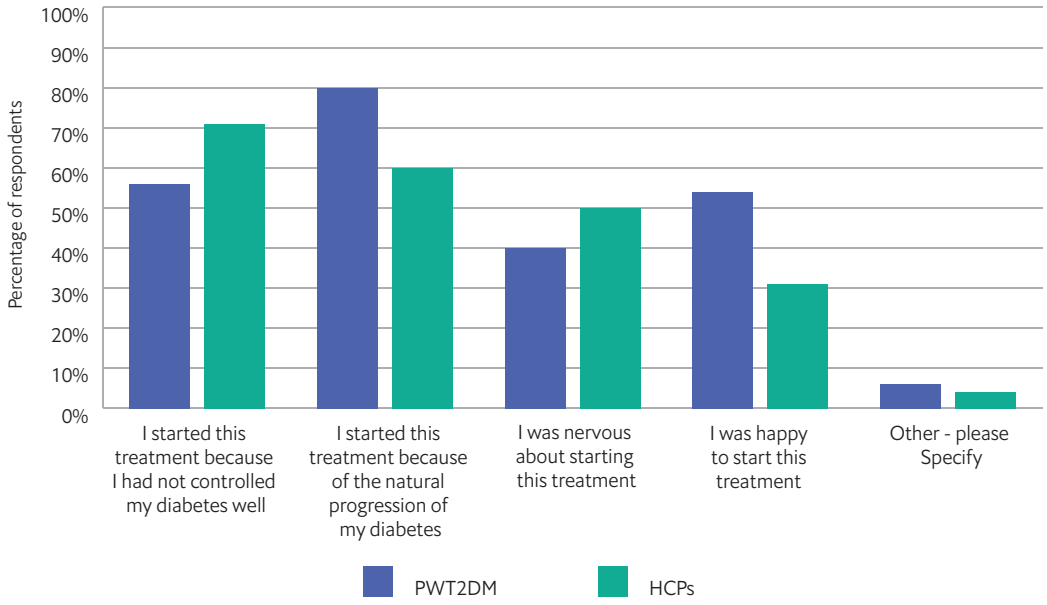
However, over half of people with type 2 diabetes also considered that they started this treatment because they had not managed their diabetes well (Figure 14). Those on insulin were most likely to agree, whereas those receiving psychological counselling were least likely to. This may imply that psychological counselling helps patients to better understand their role in affecting the progression of their diabetes. Because insulin is the last line of therapy, it may also be associated with the "failure" of treatments to date and the individual's ability to manage their diabetes, suggesting a need to consider how the move to insulin therapy is framed by HCPs. Those HCPs that had discussed the changing nature of diabetes to at least some extent were more likely to agree with this statement, but it is worth remembering that this is what they perceive that their patients think.

Figure 13: What factors make you feel more motivated to keep your diabetes under control? (most [1] to least important [5])



Attitudes towards starting treatment also varied, with 54% happy to start this treatment and 40% nervous about doing so (Figure 14). People who had discussed the progressive nature of diabetes to some extent were more likely to agree that they were right to be happy about starting their treatment (discussed 56%, somewhat discussed 61%, not discussed 41%). However a greater proportion of those who had discussed this also reported that

Figure 14: How did you feel when you were told that you needed to start your current treatment (oral medication, Injectable GLP-1-receptor agonist, insulin)? / How do you think patients feel when you tell them that they needed to start on oral medication



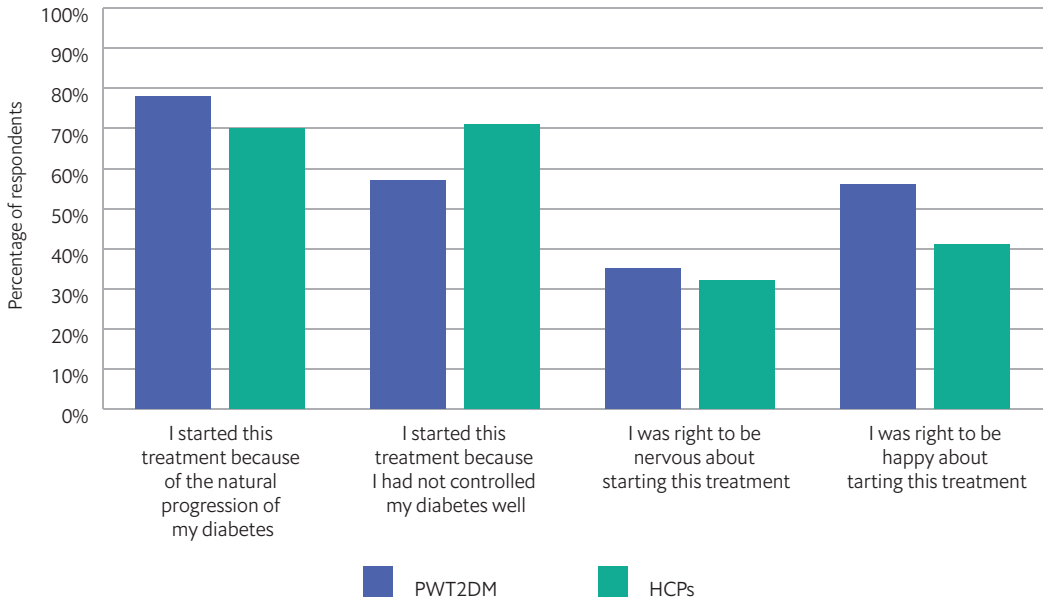
they were right to be nervous about starting their treatment (discussed 39%, somewhat discussed 31%, not discussed 11%), but these numbers were lower overall.

HCPs agreed that many of their patients would perceive that they were starting the treatment due to not managing their diabetes well, but believed that a greater proportion of patients would be nervous about starting treatment (Figure 14). **Therefore HCPs may be overestimating patient fear about starting these treatments.**

When asked about how their patients would feel after starting their treatment, the proportion of HCPs who thought patients would be happy about their treatment rose and the proportion who thought that patients would think they were right to have been nervous fell. Suggesting that HCPs believe that patients will feel more positively about changes in treatment once they have commenced treatment. This reflected the responses of people with type 2 diabetes, but HCPs underestimated patient happiness both at the time of treatment initiation (Figure 14) and a year on (Figure 15).

Those people with type 2 diabetes who were either 'motivated' or 'neither motivated nor demotivated' by the progressive nature of diabetes were more likely to state that they were happy to start this treatment (54% each) than people who were demotivated (38%)—this pattern remained constant at the time of treatment initiation and to the present day. **Those who were 'motivated' or 'neither motivated nor demotivated' were also less**

Figure 15: Since starting your current treatment, how have those initial feelings changed? / How do you think patients' initial attitudes to their treatment change over the first year of using oral medication, injectable GLP-1-receptor agonist or insulin?



likely to agree that they were nervous about starting treatment (41% and 37%) compared to those who were 'demotivated' (50%). This difference grew when describing how they currently felt about this treatment. People who were 'demotivated' were more likely to agree that they were right to be nervous about starting this treatment (63%) compared to those who were 'motivated' (39%) or 'neither motivated nor demotivated' (18%). This may suggest a more negative attitude or experience among these people with type 2 diabetes.

People who were on oral or injectable medication (including insulin) were fairly stable in their responses when asked about their attitude to starting these treatments and their attitude now.

Some HCPs may delay prescribing medication and/or insulin because of their patients' desire to continue managing their condition with diet and exercise

We also asked HCPs about what factors influence how quickly they begin medication/insulin once clinically indicated (Figure 16). The most common answer was the patient's desire to continue managing their condition with diet and exercise (44%). Patient resistance to taking medication (19%) and their negative perceptions of insulin specifically (13%) also influenced HCPs' decision-making. Some HCPs felt that the patient's perception of what starting medication means e.g. leading to further treatment (8%) and how it reflects on their condition e.g. indicative of worsening health (7%) influenced their decision-

making. Negative patient perceptions of oral medication (5%) and the cost of medication or insulin (both 2%) were not significant factors influencing HCPs' decision and timing of medication/insulin initiation.

"I was mentally ready to treat my diabetes."

Patient survey respondent

Half of people with type 2 diabetes rate the emotional support they receive as sufficient, with those who have discussed the changing nature of diabetes more likely to feel emotionally supported than those who have not

Just over half of people with type 2 diabetes surveyed rated the emotional support they received from their medical team as sufficient (average 58% rating 1-3). Healthcare professionals rated themselves as adequately trained to provide emotional support to their T2DM patients (62%).

"I will live longer and be able to watch my grandchildren grow up."

Patient survey respondent

There was a fairly even distribution across countries. The greatest proportion of people with type 2 diabetes indicating that they did not receive the emotional support they needed from their healthcare team was in Russia and Saudi Arabia. Overall the emotional support was rated most adequate by Indian respondents. This may reflect the larger proportion of Indian patients receiving psychological counselling (20% versus 11% average). **Those people with type 2 diabetes receiving psychological counselling were the least likely to say that they receive the emotional support that they need** (12%, versus average of 21%). This could indicate a greater need for psychological support amongst this group.

People who have discussed the changing nature of diabetes to some degree are more likely to feel emotionally supported—having had this conversation could be a sign of a generally supportive medical team (Figure 17). Those who are motivated by the progressive nature of diabetes are more likely to report receiving adequate emotional support, those neither motivated nor demotivated report middling satisfaction and those who are not motivated report the lowest overall satisfaction.

Generally HCPs judged that they had sufficient time to provide emotional support (55%), had the resources they needed (63%) and can refer their patients to specialist emotional support (79%).

Figure 16: Most people with type 2 diabetes begin with diet and exercise interventions, do any of the following influence how quickly you commence medication/insulin therapy when it is clinically indicated?

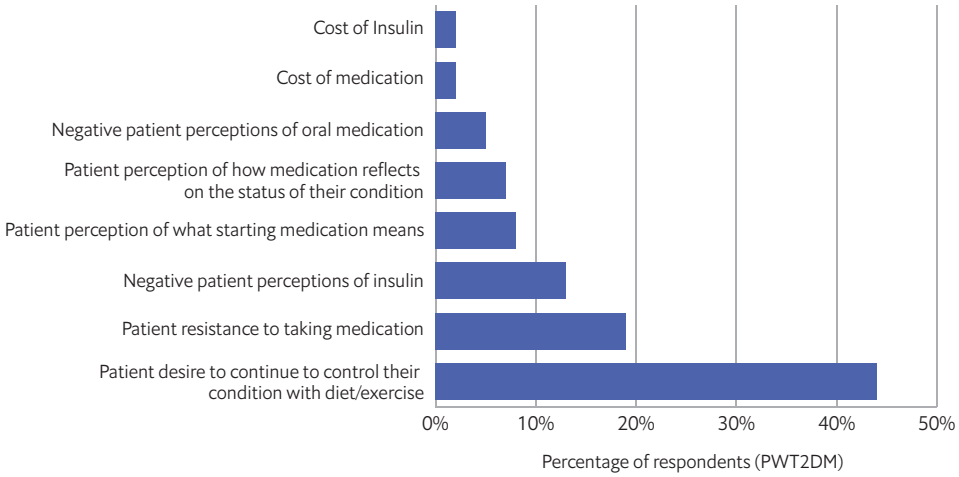
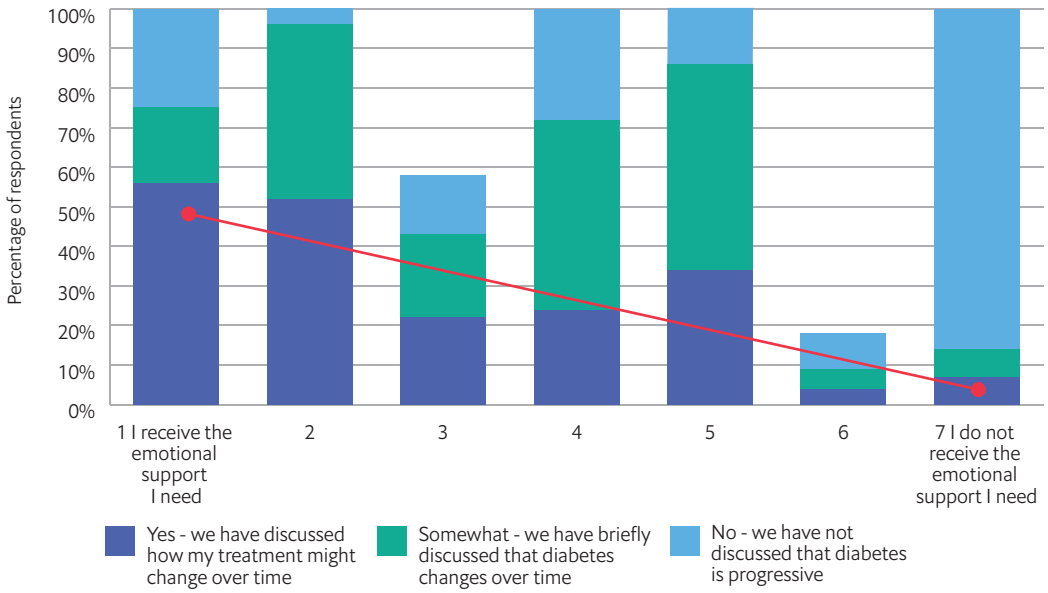


Figure 17: How would you rate the emotional support given to you by your healthcare team?



Interviewee insights

"We must not go for fear arousal."

Professor Andrew Boulton

As part of this project, we also spoke to several experts across diabetes and NCDs, representing a range of views from doctors and nurses to patient perspectives. During these interviews we discussed the findings of our survey to capture the reaction of our interviewees and gathered their practical ideas to address the issues raised in the survey findings.

Understanding the stigma around T2DM and its impact

People with type 2 diabetes have to "psychologically transition" to having a chronic health condition, according to Angus Forbes. This is why it is important that HCPs communicate to people with type 2 diabetes that it is a long-term, chronic condition that may change over time. In building an effective relationship between the person with type 2 diabetes and HCPs, Olivia Barata Cavalcanti stressed the need for a high level of trust, with Professor Forbes highlighting the role of continuity of care in building that trust. Andrew Boulton emphasised communicating that "we can help them and they can help themselves".

Interviewees described the importance of HCPs understanding how highly stigmatised type 2 diabetes is, with generally negative portrayals and perceptions of people with type 2 diabetes in the media and society. This leads to many people with type 2 diabetes feeling a sense of failure and shame—both at the time of diagnosis and as the condition progresses—which impacts on their understanding of the condition and their motivation.

Manjusha Chatterjee described speaking to people with various NCDs who reported HCPs being a source of stigma and discrimination themselves. This was primarily, she says, due to a lack of empathy, training and understanding that left some people with NCDs feeling "unserved at the point of service".

"I'll have to put you on insulin"—the villain enters the room! No wonder patients are terrified of insulin.

Professor Angus Forbes

Motivating people with type 2 diabetes—avoiding threats and focusing on overall health

Interviewees described motivating people with type 2 diabetes by focusing on maintaining good overall health and steering away from scare tactics.

Sometimes HCPs can describe treatments almost like a threat, so if the person doesn't control their diabetes then the HCP will have to prescribe a different treatment. Professors Forbes and Boulton agreed that fear is not a good motivator because type 2 diabetes changes over time, requiring different treatments. How can an HCP talk about the benefits of a new treatment that was used as a "threat" years before?

"We live in a symptom driven society—dealing with a condition that may have no symptoms so no perceived benefit of taking the treatment."

Professor Andrew Boulton

Ms Barata Cavalcanti is an expert on obesity, which share similarities with type 2 diabetes in terms of how it is managed initially through diet and physical activity, then medication. Lifestyle modifications—such as changes to diet and physical activity—are difficult to implement and maintain long term. As Ms Barata Cavalcanti put it, obesity is "a complex disease with a treatment that can feel frustrating". The challenge of motivation is long-term and on-going. Professor Boulton feels that generally diabetes is not taken seriously enough, especially as diabetes often has few symptoms that can be dismissed by people with the condition, which can make it difficult to communicate the benefits of treatments before symptoms worsen and complications set in.

Developing "systemic understanding" of people's lives and the support systems they can draw on

Living with diabetes can be frustrating for the person with diabetes and for the healthcare professionals supporting them. Professor Forbes argues that to support people with type 2 diabetes long-term, HCPs need to develop a "systemic understanding" of the factors around people with diabetes that impact on their overall health. Both Ms Barata Cavalcanti and Ms Chatterjee also described the "responsibility" falling mainly on the individual, ignoring the need for an enabling environment that supports people in following a healthy diet and undertaking physical activity, for example.

Interviewees felt that family/friends were underutilised motivators and supporters of people with type 2 diabetes, which echoes the survey findings. Although HCPs do not come into direct contact with family/friends, interviewees suggested that during consultations HCPs can discuss family history, who the person goes to for support, etc. Living with type 2 diabetes entails lifestyle changes that impact on all members of a household. Professor Forbes and Kremlin Wickramasinghe both agreed that family are important, especially as family members are also at risk of developing diabetes—so it is important to engage them from a preventive health perspective.

Another aspect of this systemic understanding relates to the resources that HCPs can tap into to help to support people with diabetes. Ms Barata Cavalcanti and Professor Forbes cited examples of community-based projects that can offer support, with Ms Chatterjee also suggesting that people with type 2 diabetes and other NCDs can serve as community health workers—utilising their expertise and lived experience.

Developing HCP communication skills—to explain, understand and motivate

Our interviewees shared various insightful tips for communicating with people with type 2 diabetes about the condition, its changing nature and how that means treatments change over time too.

The main strategy was inform people with diabetes about the bodily processes that are taking place and how those change over time. Doing so increases their understanding of why current treatments may no longer be effective, what different treatments do and why they are needed. In this context HCPs can explain the damage that diabetes can do, without fear-mongering and reducing the person's negative perceptions of certain treatments. Ms Barata Cavalcanti suggested being overt about sharing the evidence, to further avoid any stigma or blame.

People with type 2 diabetes are a highly diverse group of people, both globally and within individual countries. Therefore identifying individuals' motivational factors and finding a way to tap into those is a key challenge for HCPs. Professor Forbes and Dr Wickramasinghe both stressed the need to improve initial and on-going training for HCPs in communication and techniques such as motivational interviewing. In obesity, Ms Barata Cavalcanti described a new focus on "non-scale wins"—identifying outcomes that are highly relevant to the individual and cover "their health beyond their health condition". In obesity there is a specific strategy for conversations between HCPs and people with obesity, that promotes empathy, effective communication, understanding and goal-setting:[14]

- **Ask** for permission to discuss weight and explore readiness
- **Assess** obesity related risks and 'root causes' of obesity
- **Advise** on health risks and treatment options
- **Agree** on health outcomes and behavioural goals
- **Assist** in accessing appropriate resources and providers

The survey findings suggested that HCPs may be overestimating the fear of people with diabetes about changing treatments. Ms Barata Cavalcanti suggested that HCPs first need to unpack that fear—what is this person afraid of and why, to avoid inaccurate assumptions and create an environment that is informative and supportive. Dr Wickramasinghe also expressed some scepticism about whether such conversations are taking place, emphasising that they should be taking place every time there is a change to the individual's treatment plan.

The diabetes multidisciplinary team—creating time and space with nurses

Interviewees emphasised the need for a multidisciplinary team to manage the health of people with type 2 diabetes—both in primary and secondary care. Nurses were seen as central to the make-up of this team.

Time is a perennial challenge in healthcare—how to cover everything that you need to in the limited time available within a routine appointment. Interviewees suggested that nurse appointments (either with diabetes specialist or practice nurses) are often longer, creating the opportunity to discuss how the

individual feels about their diabetes and overall health, the challenges they face and devising a plan to address those. Professor Boulton has found that people with diabetes are often more comfortable in reaching out to diabetes nurses and nurse educators, making them "arguably the most important members of the team". But it is important to note that specially trained diabetes nurses are not available in all countries.

"Time limits can limit the discussion."

Dr Olivia Barata Cavalcanti

The frequency of appointments is also an issue, with Professor Forbes and Professor Boulton both highlighting that a lot can happen in a year between check-ups. Interviewees suggested a role for shorter, but more regular appointments with nurses as a potential solution.

Indeed, Ms Barata Cavalcanti argues that if there isn't time to address motivational and emotional factors in general diabetes appointments, there may be a case for scheduling specific sessions. This was echoed by Dr Wickramasinghe, who pointed out that people with type 2 diabetes can be presented with a lot of information during their appointments, making it difficult to take it all in.

Ms Chatterjee—who works with civil society alliances in low and middle income countries—highlighted that for many people in these countries, the cost of basic healthcare can be "so catastrophically high that seeking professional psychological support becomes a distant dream".

Leveraging peer support groups to reduce stigma, share and learn

Peer support was an unexpected topic that interviewees raised as a potentially underutilised resource for people with type 2 diabetes. Such social learning models can be useful for people with diabetes to learn that they are not the only ones with the condition, to counter stigma, share experiences and develop their own understanding of the condition. Professor Forbes felt that it was important that there is continuity between groups and clinical care, so both can reinforce each other and better support the person with type 2 diabetes. He also stressed that not all people would respond to such a group setting, so it is not a universal solution.

Dr Wickramasinghe pointed out that the evidence for the effectiveness for these kinds of groups is mixed, which may limit their implementation, especially if they are compared to drugs etc. He suggested that there is a need to think about how we measure and assess the effectiveness of these interventions.

Discussion

The aim of this project was to understand the attitudes of people with type 2 diabetes about how their diabetes and treatments may change over time, with equivalent questions asked of HCPs to explore their perceptions of patients' attitudes.

Overall we didn't see big differences in many of the data slices. We observed some differences in responses by country, but the biggest difference was generally between those people with type 2 diabetes who had discussed the changing nature of diabetes to some extent and those who had not.

People who have discussed the changing nature of diabetes to some degree were more likely to feel motivated by this to prevent complications, etc, and to feel more emotionally supported. This suggests that it is **important to have a conversation around the progressive nature of the condition as this can be a powerful motivator for patients**. We observed a difference in the proportion of people with type 2 diabetes and HCPs who reported having had this conversation, suggesting that this communication may not be as impactful or clear for people with type 2 diabetes as HCPs perceive it to be. Our interviewees agreed that there is scope for **more initial and on-going training in communication for HCPs**, to ensure that these conversations are effective.

It is important that all parties (people with type 2 diabetes and HCPs) **acknowledge the changing nature of diabetes over time in order to leverage it as a motivation for people with type 2 diabetes**. Those people with type 2 diabetes who had discussed the changing nature of diabetes were also much more likely to rate the emotional support they received as adequate, suggesting that this discussion could be indicative of a diabetes management approach that pays attention to emotional and behavioural aspects. Our interviewees agreed, highlighting the importance of HCPs—particularly nurses—in providing emotional support as part of their routine diabetes care.

Only just over **half of respondents rated the emotional support they received as adequate** and those who reported receiving psychological counselling were less likely to rate their emotional support as adequate. This suggests a potentially large unmet need, which our interviewees agreed with. Although HCPs generally felt they had the resources to emotionally support patients and could refer them on, **only half felt that they had enough time to emotionally support their patients**—a

sentiment echoed by interviewees. Training for HCPs in communication and motivation was identified by interviewees as an area for development, to enable HCPs to better support people with type 2 diabetes.

The motivations and motivating factors for people with type 2 diabetes were similar across all subgroups in the sample, suggesting that these are fairly universal. Overall HCP responses were similar to those of people with type 2 diabetes, but **HCPs may be underestimating the role of family/friends in the motivation of people with type 2 diabetes**. Interviewees felt that family/friends are an important part of the support structures around people with diabetes, but did acknowledge the difficulties of engaging with them. **Peer support groups can help to keep people motivated** and increase the ecosystem of people that can support them, our interviewees suggested.

Although some people with type 2 diabetes were nervous about starting new treatments, overall HCPs overestimated patient fear about changing treatments before and after starting treatment. Interviewees suggested that HCPs should try to elicit their patients' feelings about starting new treatments in order to then address them, but avoid assuming what those emotions are. **HCPs can feed negative attitudes to certain treatments if they are used as a "threat"** to try to motivate people with diabetes to comply with other treatments.

HCPs ranked the delaying of more intensive treatments higher as a motivating factor than people with type 2 diabetes did. They predicted that patients will be fearful about starting a new treatment and will consider that they were "right to be nervous" a year on. HCPs also consistently underestimated that people with type 2 diabetes will be happy with this treatment at its initiation and a year on. These findings suggest that **HCPs may overestimate negative and underestimate positive attitudes to treatment changes in their patients**. These perceptions of attitudes may also feed into HCPs delaying prescribing oral and injectable medication, including insulin, once clinically indicated. HCPs wanted to respect their patients' wishes to continue with diet/exercise. However, if they are generally overestimating negative patient attitudes, then this perception may also be inaccurate.

Conclusions

Diabetes is a long-term and chronic condition that changes over time. It is important that healthcare providers discuss this with people with type 2 diabetes to aid their understanding of the condition, how it changes over time, and how and why treatments may need to change. This understanding can motivate people to follow their treatment plan and improve their health. A range of communication and motivational techniques are available to support healthcare professionals in these discussions. Crucially, it is important to have a dialogue between people with type 2 diabetes and HCPs that is open, mutually respectful and productive.

Appendix 1: Survey questionnaire

Patient survey

Screening questions:

1. Have you been diagnosed with any of the following health conditions? [select all that apply]
   a. Arthritis
   b. Asthma
   c. Chronic Obstructive Pulmonary Disease (COPD)
   d. Diabetes
   e. Epilepsy
   f. Heart Disease
   g. Kidney Disease
   h. Overweight and Obesity
2. When did you receive your diabetes diagnosis?
   a. 0-1 years
   b. 2-6 years
   c. 7-10 years
   d. 10-15 years
   e. e15+ years
3. What treatment did you receive immediately after your diagnosis? [select all that apply]
   a. Healthy eating—advice/support
   b. Physical activity—advice/support
   c. One oral medication
   d. Two or more oral medications
   e. Injectable GLP-1-receptor agonist
   f. Insulin
   g. Psychological counselling/behaviour change
   h. Other, please specify
4. What treatment are you currently receiving for your diabetes? [select all that apply]
   a. Healthy eating—advice/support
   b. Physical activity—advice/support
   c. One oral medication
   d. Two or more oral medications
   e. Injectable GLP-1-receptor agonist
   f. Insulin
   g. Psychological counselling/behaviour change
   h. Other, please specify

Main survey:

5. type 2 diabetes is a chronic and progressive condition, meaning that over time you will require different and more intensive treatments, such as oral medication or insulin. Is this something that your healthcare team has talked through with you? [select one]
   a. Yes—we have discussed how my treatment might change over time
   b. Somewhat—we have briefly discussed that diabetes changes over time
   c. No—we have not discussed that diabetes is progressive
6. Please rate how much you agree with the following statements: [for each option agree, neither agree nor disagree, disagree—7 point likert scale]
   a. Progression of type 2 diabetes is a natural process which I cannot stop or reverse, but only slow down through my behaviour.
   b. Taking more and/or stronger oral medication or insulin is a natural part of the progression of diabetes.
   c. Over time my body may struggle to produce enough insulin, meaning that I will need to take insulin.
   d. The need to take medication or insulin is a sign that I have not managed my diabetes well.
   e. Reversal of diabetes type 2 is only possible very early on.
7. How does the progressive nature of diabetes impact your motivation to control your diabetes? [choose the one that applies most]
   a. It motivates me to adapt my behaviour to delay its progression
   b. It neither motivates, nor demotivates me
   c. It demotivates me, if my condition will get worse anyway, why bother?
   d. Other—please specify [short textual answer]
8. How would you rate the emotional support you receive from your medical team to help you to manage your diabetes?

I receive the emotional support I need—I do not receive the emotional support I need [7 point likert scale]

9. What motivates you to try to control your diabetes? [rank in order of importance]
   a. If I control my diabetes, I will be healthier overall.
   b. If I control my diabetes, I help to reduce the risk of complications such as eye and blood circulation problems.
   c. If I control my diabetes better today, it may delay the need for more intensive treatments, such as insulin.
   d. I do not feel motivated to control my diabetes.
   e. Other
10. What factors make you feel more motivated to keep your diabetes under control? [rank in order of importance]
    a. My own commitment to my health
    b. The encouragement of my family/ friends
    c. The encouragement of my healthcare team
    d. My healthcare team telling me the bad things that will happen if I do not control my diabetes (e.g. complications)

e. Reminders via an app/text message etc

Additional questions for respondents selecting options c) to f) on question 4, i.e. those receiving oral medication, injectable GLP-1-receptor agonist or insulin only

11. How did you feel when you were told that you needed to start your current treatment (oral medication, injectable GLP-1-receptor agonist, insulin)? [for each option agree, neither agree nor disagree, disagree—7 point likert scale]
    a. I started this treatment because of the natural progression of my diabetes
    b. I started this treatment because I had not controlled my diabetes well
    c. I was nervous about starting this treatment
    d. I was happy to start this treatment
    e. None of the above, please specify [short textual answer]
12. Since starting your current treatment, how have those initial feelings changed? [for each option agree, neither agree nor disagree, disagree—7 point likert scale]
    a. I started this treatment because of the natural progression of my diabetes
    b. I started this treatment because I had not controlled my diabetes well
    c. I was right to be nervous about starting this treatment
    d. I was right to be happy about starting this treatment
    e. None of the above, please specify [short textual answer]

HCP survey

Screening questions:

1. Which of these best describes your role: [select one]
    a. Specialist doctor (e.g. cardiologist, diabetologist, endocrinologist, rheumatologist)
    b. Primary care doctor (GP)
    c. Nurse
    d. Other
2. Do you directly manage the care of people with any of these conditions? [select all that apply]
    a. Asthma
    b. Diabetes
    c. Thyroid Disease
    d. Arthritis
    e. Obesity
    f. Pituitary Gland
    g. Hypertension
    h. Lipid Disorders
    i. Allergic rhinitis
3. Which of these treatments do you initiate, prescribe or refer to a specialist to initiate for patients? [select all that apply)
    a. Healthy eating—advice/support
    b. Physical activity—advice/support
    c. One oral medication
    d. Two or more oral medications
    e. Injectable GLP-1-receptor agonists
    f. Insulin

g. Psychological counselling/behaviour change

h. Other

Main survey:

4. type 2 diabetes is a progressive condition, meaning that over time your patients will require different and more intensive treatments, such as medication and insulin. Is this something that you talk through with your patients? [select one]
   a. Yes—we discuss how treatment will change over time
   b. Somewhat—briefly discuss that diabetes changes over time
   c. No—we do not discuss that diabetes is progressive
5. Please rate how much you agree with the following statements: [for each option agree, neither agree nor disagree, disagree—7 point likert scale]
   a. Progression of type 2 diabetes is a natural process which patients cannot stop or reverse, but only slow down through their behaviour.
   b. Taking more and/or stronger oral medication or insulin is a natural part of the progression of diabetes.
   c. Over time the body may struggle to produce enough insulin, meaning that my patients will need to take insulin.
   d. The need to take medication or insulin is a sign that patients have not managed their diabetes well.
6. Reversal of diabetes type 2 is only possible very early on. How do you think the progressive nature of diabetes impacts on your patients' motivation to control their diabetes? [choose the one that applies most]
   a. It motivates them to control their condition to delay its progression
   b. It neither motivates, nor demotivates them
   c. It demotivates them, if their condition will get worse anyway, why bother?
   d. Other
7. Please rate how much you agree with the following statements about the emotional support that people with type 2 diabetes receive: [for each option agree, neither agree nor disagree, disagree—7 point likert scale]
   a. I am trained to provide emotional support to my patients with type 2 diabetes
   b. I have sufficient time to provide emotional support to my patients with type 2 diabetes
   c. I have the resources (e.g. patient information/education) I need to provide emotional support to my patients with type 2 diabetes
   d. I am able to refer my patients with type 2 diabetes to specialist emotional support as needed
8. What do you think motivates your patients to try to control their diabetes? [rank in order of importance]
   a. "If I control my diabetes, I will be healthier overall."
   b. "If I control my diabetes, I help to reduce the risk of complications such as eye and blood circulation problems."
   c. "If I control my diabetes better today, it may delay the need for more intensive treatments."

d. "I am not motivated to control my diabetes."

e. Other

9. What factors do you think make your patients feel more motivated to keep their diabetes under control? [rank in order of importance]
   a. Their own commitment to their health
   b. The encouragement of family/friends
   c. The encouragement of their healthcare team (including me)
   d. Their healthcare team telling them the bad things that will happen if they do not control their diabetes (e.g. complications)
   e. Reminders (e.g. via an app/text message etc)
10. Most people with type 2 diabetes begin with diet and exercise interventions, do any of the following influence how quickly you commence medication/ insulin therapy when it is clinically indicated? [please rank from most to least influential]
   a. Patient resistance to taking medication of any kind
   b. Patient desire to continue to control their condition with diet/exercise
   c. Negative patient perceptions of oral medication
   d. Negative patient perceptions of insulin
   e. Cost of medication
   f. Costs of Insulin
   g. Patient perception of how medication reflects on the status of their condition (e.g. worsening health)
   h. Patient perception of what starting medication means (e.g. increasing levels of intervention/treatment)
11. How do you think patients feel when you tell them that they needed to start on oral medication, injectable GLP-1-receptor agonist or insulin? [for each option agree, neither agree nor disagree, disagree—7 point likert scale]
   a. "I started this treatment because of the natural progression of my diabetes"
   b. "I started this treatment because I had not controlled my diabetes well"
   c. "I was nervous about starting this treatment"
   d. "I was happy to start this treatment"
   e. None of the above, please specify [short textual answer]
12. How do you think patients' initial attitudes to their treatment change over the first year of using oral medication, injectable GLP-1-receptor agonist or insulin? [for each option agree, neither agree nor disagree, disagree—7 point likert scale]
   a. "I started this treatment because of the natural progression of my diabetes"
   b. "I started this treatment because I had not controlled my diabetes well"
   c. "I was right to be nervous about starting this treatment"
   d. "I was right to be happy about starting this treatment"
   e. None of the above, please specify [short textual answer]

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