

Support needs people with diabetes and carers during COVID-19 pandemic

Identifying support needs of people living with diabetes and their carers during the COVID-19 pandemic: insights from a UK survey.

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Executive summary

Background

The coronavirus COVID-19 pandemic has generated unprecedented challenges for people living with diabetes and their carers, parents, and partners. Given the demands placed on resource-limited healthcare teams and organisations dedicated to supporting people living with diabetes, commissioners must act strategically when determining distribution of healthcare provision.

Aims

1. To identify the impact the pandemic has had on people living with diabetes and important others (parents, carers, partners).
2. To capture their opinions on how the information, advice and support they receive could be improved.

Methods

A UK-wide online survey was developed and distributed from April to August 2020 for people living with diabetes and their parents, carers, and partners. The survey was prepared as a collaboration between the NIHR Bristol Biomedical Research Centre, the Diabetes UK South West team and individuals living with diabetes.

Key findings

- 37% of people with diabetes showed that their confidence in taking care of their mental wellbeing had decreased with the start of the pandemic. 34.2% of respondents reported difficulties accessing information and advice for their emotional wellbeing, and 39.4% in obtaining external support to improve their emotional wellbeing.
- Among respondents with diabetes living alone, 41.2% reported not having received any support from outside their household.
- Though respondents expressed a need for more contact from their healthcare team, telephone and video consultations were thought to be acceptable replacements.
- 9.8% of people with diabetes were voluntarily shielding despite not having received a letter instructing them to do so, compared to the 7% of respondents who had received the government letter.
- The pandemic has had variable impact on confidence in self-care across the various aspects of diabetes self-management. The pandemic has had a negative impact perceived ability to correct for low blood glucose for 9.6% of respondents, while confidence in ability to achieve recommended physical activity and to follow a healthy eating pattern had deteriorated for 32% and 29.6% of respondents respectively.
- Following the start of the pandemic, 32.1% of respondents with type 2 diabetes reported an improvement in perceived self-efficacy in selecting the correct foods and 30.5% in healthy weight maintenance, compared to 20.8% and 17.2% among respondents with type 1 diabetes.
- Quality of information, advice and support received from the government and healthcare teams were rated more poorly than other resources (% of respondents giving a rating of poor or very poor: 39% and 37% respectively). Differently, the respondents who were parents, partners or carers found news channels and employers as the resources that provided the poorest quality of information, advice and support (% of respondents giving a rating of poor or very poor: 34% and 41% respectively).

Discussion

The coronavirus COVID-19 pandemic has had a notable negative impact on the perceived self-efficacy of people living with diabetes on their ability to manage their condition, and on the confidence that their parents, carers and partners have in supporting them adequately. However, there are several steps that could be taken to meet the needs of these individuals. Health commissioners can prioritise increased contact between healthcare teams and their patients when patients express a need. They can provide opportunities to access support for mental health and wellbeing and equip important others with the knowledge and tools to confidently assist the person living with diabetes.

Abbreviations

T1DM = Type 1 diabetes mellitus

T2DM = Type 2 diabetes mellitus

Key definitions

Important others = parents, carers and partners of people living with diabetes.

Recommendations

The recommendations presented below address the needs expressed by respondents where commissioners may prioritise and action changes in care provision.

Increasing contact with healthcare teams

- Commissioners could work towards facilitating contact between healthcare teams and people living with diabetes. Many respondents reported having received no contact at all from their team since the start of the pandemic, or only a generalised text message.
- Increased contact can be via telephone or video consultation. Few respondents specifically requested face-to-face appointments, and those whose care was switched to these alternative delivery approaches responded positively to the change.
- There is a need to address inequalities in the contact received with healthcare teams. Switch to remote care was localised, which may have contributed to the disparity of feedback received in relation to support from the healthcare team.

Type of information and support to provide

- Anxiety and stress were reported to contribute to a decrease in perceived self-efficacy in diabetes self-management and reduced motivation to continue. It is essential that mental health and wellbeing of people living with diabetes is addressed.
- There is a very strong request for clearer, more consistent, and tailored guidance and support. Healthcare teams could aim to ensure that their patients are aware of their individual risk (considering age, glucose control and other co-morbidities) to facilitate self-management.
- There is a need for more guidance on the steps to take if someone has diabetes and has COVID-19 symptoms. Where the individual with diabetes is shielding, the parent, carer or partner should be aware of the relative risk of being in physical contact with the individual shielding in cases of diabetes complications (e.g. hypoglycaemic episodes). This could include information about appropriate PPE and emphasising handwashing.
- Telephone and virtual consultations should provide tailored guidance on strategies to achieve physical activity and dietary recommendations for continued weight management. Remote access to weight management services might be particularly valuable. Novel approaches to support patients achieve long-term weight goals (loss or maintenance) remotely should be considered.
- Given that some individuals reported improvements in diabetes self-management confidence, facilitating access to monitored peer support offers opportunities for knowledge exchange and how to adapt to the changing circumstances.
- Remote diabetes training is important for parents, carers and partners of people living with diabetes. Increasing their understanding of diabetes, its management, and the steps to take if the person they care for falls ill will empower these individuals to provide better support.

Prioritisation

- Greater support needs to be made available for people with diabetes and who are living alone.
- Healthcare teams must continue to prioritise individuals who have recently been diagnosed, those familiarising themselves with a new type of medication, and those whose condition is progressing. It is essential that factors identified to contribute to elevated vulnerability to severe COVID-19 (e.g. poor blood glucose control, co-morbidity) are addressed as promptly as possible.

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- Though resumption of pre-pandemic activity is an unrealistic target at this stage, demonstrating patients that their care team is available if support (via e-mail, telephone call or text) is needed may be particularly beneficial for mental health and wellbeing, and subsequently diabetes self-management.

1. Background

The need to prioritise COVID-19 patients from the start of the coronavirus COVID-19 pandemic in March 2020 has caused extensive disruption in the healthcare provision available. For people living with diabetes, this has included the cancellation of routine check-up appointments (e.g. HbA1c and retinopathy checks), diabetes education sessions, and hospital services for non-urgent care. Additionally, support systems such as face-to-face peer support had to be suspended and digitally delivered solutions had to be accelerated.

Nationally imposed restrictions to control the spread of COVID-19, resulted in societal changes in everyday life and widespread uncertainty. Individuals with diabetes faced unprecedented challenges to diabetes self-management, which stresses the importance of a healthy and balanced lifestyle. Further, at the start of the pandemic the vulnerability to COVID-19 disease for people living with diabetes was unclear. There were multiple reports of increased risk of severe disease if people living with diabetes contracted COVID-19, but only some individuals were deemed as “extremely vulnerable” and instructed by the government to shield.

Following the initial wave of the pandemic, health policymakers and healthcare teams have been working towards shifting care provision to telephone and virtual consultations. Face-to-face appointments were also restarting, enabling patients to access delayed care. However, as cases started to rise again, lockdown restrictions were imposed again, and a new influx of COVID-19 related hospitalisations is taking place. It is essential to learn from the first wave to mitigate the impact of future disruption.

Aims

2. To understand the impact of the COVID-19 pandemic on diabetes self-management.
3. To identify where and what improvements need to be made in the information, advice and support provided to individuals with diabetes and their carers, parents, and partners.
4. To develop a set of recommendations for consideration in current care and future waves of COVID-19.

The following research questions were posed:

1. What impact has the COVID-19 pandemic had on the confidence people with diabetes have on their self-management, and that of their important others to support them in this task?
2. What resources are people with diabetes and important others using to obtain information, advice and support regarding physical distancing and diabetes self-management?
3. What are the opinions of people with diabetes and their important others regarding the information, advice and support received during COVID-19?
4. In what ways do people with diabetes and their carers think the help they receive during the pandemic could be improved?
5. Are there any differences in support needs between people who have different types of diabetes?
6. Are there differences in support needs between people who live alone and those who are living with others during the pandemic?

3. Methods

A mixed-methods survey was developed in collaboration with the Diabetes UK South West Team. The survey comprised the following sections to answer the research questions:

- Demographic characteristics (includes questions related to COVID-19).

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- Confidence in diabetes self-management pre- and post-start of the national lockdown.
- Impact of diabetes appointment cancellations in both primary and secondary care.
- Sources used for information/advice/support during the pandemic
- Opinions on information/advice/support received.
- Support from personal networks.

The first draft of the survey was reviewed by members of the NIHR Bristol Biomedical Research Centre (BRC) diabetes Patient and Public Involvement group to ensure suitability of the language, inclusivity in regards to scenarios respondents may find themselves in, and appropriateness of the questions. Following adjustments, the survey was distributed online between the 24th of April 2020 and the 31st of August 2020 via the networks of the NIHR Bristol BRC, the University of Bristol, and Diabetes UK. Means of dissemination included research portals, social media, university website, e-mail contacts and monthly newsletters. Responses were completely anonymous. See Supplementary file 1 for a copy of the survey and Participant Information Sheet.

Analysis of data

Summary statistics show participant responses to the survey questions. Results are presented for all participants with diabetes and by the main diabetes type (type 1 or type 2). Results specific to other types of diabetes can be found in the supplementary material (Supplementary file 2) but given the small number of respondents, the data was not presented graphically to avoid skewing interpretation. The category “All participants with diabetes” also includes respondents with another type of diabetes. Questions on diabetes management were measured from 0 (could not do at all) to 10 (certain could do). Questions referred to confidence in diabetes self-management before the pandemic and at the point of completing the survey. Differences between the two scores were calculated and participants were grouped by whether their scores decreased, stayed the same or increased.

Open-ended survey questions were presented when the option “Other” was selected for a multiple-choice question, or when there was need for free-form feedback from the respondent. The first 15 responses of all open-ended items were reviewed independently by two members of the team to generate an initial codebook for each item. The codebook was malleable, and code names could be altered to fit with the data. Open-ended questions in response to “Other” were categorised by a single researcher in the team and examined with the principal investigator. Where deemed more appropriate, a response was sorted into the pre-existing options (*e.g.* “*leaving the house only for exercise*” was classified as “adhering to physical/social distancing guidelines”). Qualitative data collected in the form of open-ended questions (*i.e.* free-form feedback) were analysed by two researchers in the team, and themes emerging from each question were agreed following discussion with the principal investigator.

4. Findings

All quantitative data can be seen in Supplementary file 2. Further details on qualitative data can be seen in the Appendix. Below is an outline of key findings and initial interpretations.

4.1. People living with diabetes

4.1.1. Demographic characteristics.

A total of 773 people living with diabetes responded to the survey. Responses came from across the UK, though the majority were from South East (25%), South West (18.4%) and Scotland (11.5%). See Figure 1 for a spatial representation of origin of responses.

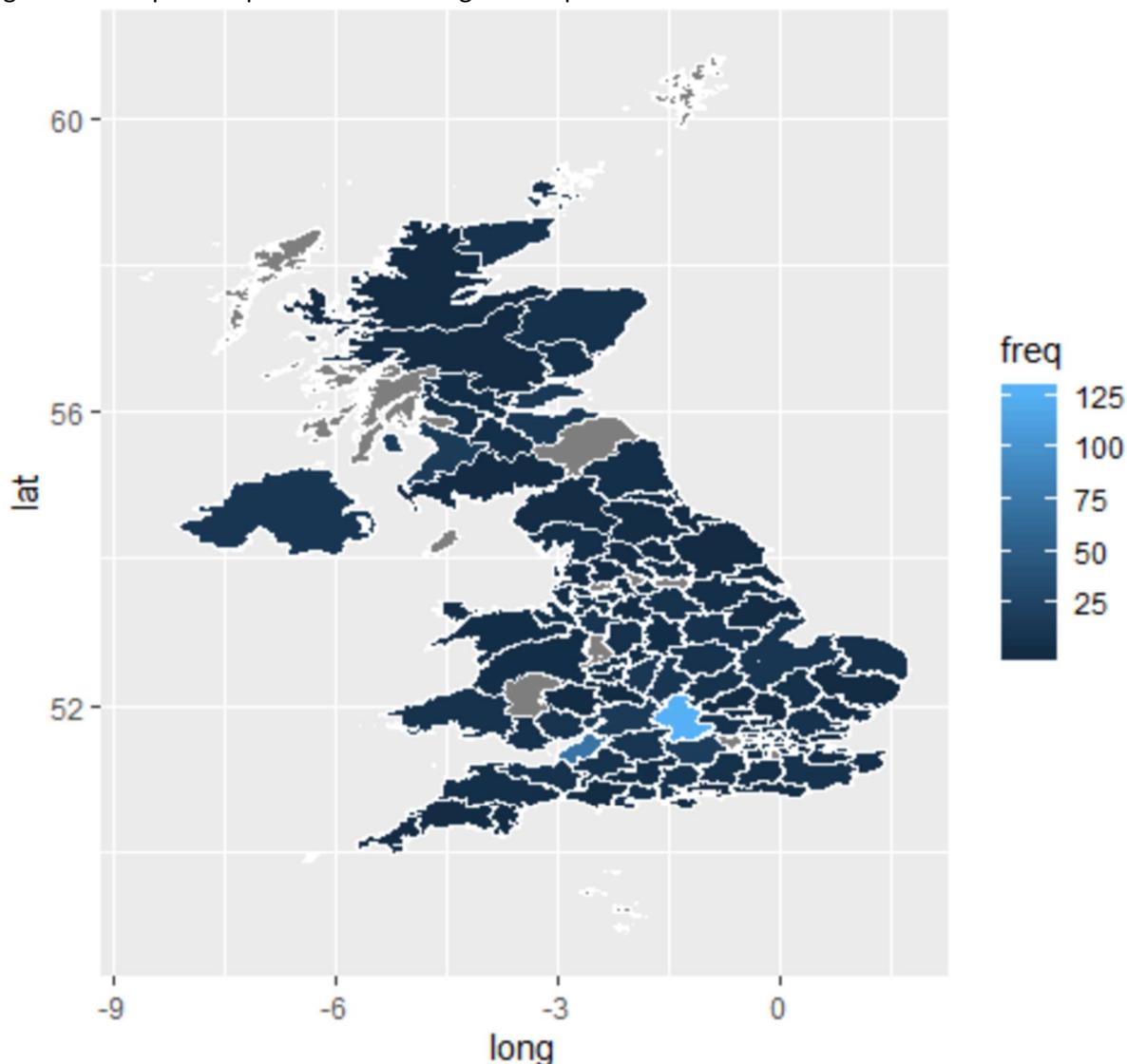


Figure 1. Pictorial representation of distribution of responses. Grey: no responses from the postcode area.

About two thirds of respondents were female (67.1%), with a mean age of 47.9 (SD=14.5) years, and of white British ethnicity (90.1%). In terms of diabetes type, 69.2% were living with type 1 diabetes mellitus (T1DM), 28.5% with type 2 diabetes mellitus (T2DM), and 2.3% had another type of diabetes. The discrepancy in mean age of respondents with T1DM and T2DM was 12.5 years (44.4 T1DM, 56.5 T2DM).

Most respondents were not living alone (84.1%), nor had their living circumstances changed due to the pandemic (88.9%). 80.6% of respondents reported not having experienced symptoms of COVID-19, 9.1% reported having experienced symptoms, 0.3% had tested positive to COVID-19, and 10% were not sure. Symptoms reported were cough, shortness of breath, and fever. Though the majority

of respondents were adhering to the physical distancing guidelines in place at the time of their response (66.8%), 7% had received a letter instructing them to shield, and 9.8% were voluntarily shielding despite not having received a letter (Figure 2).

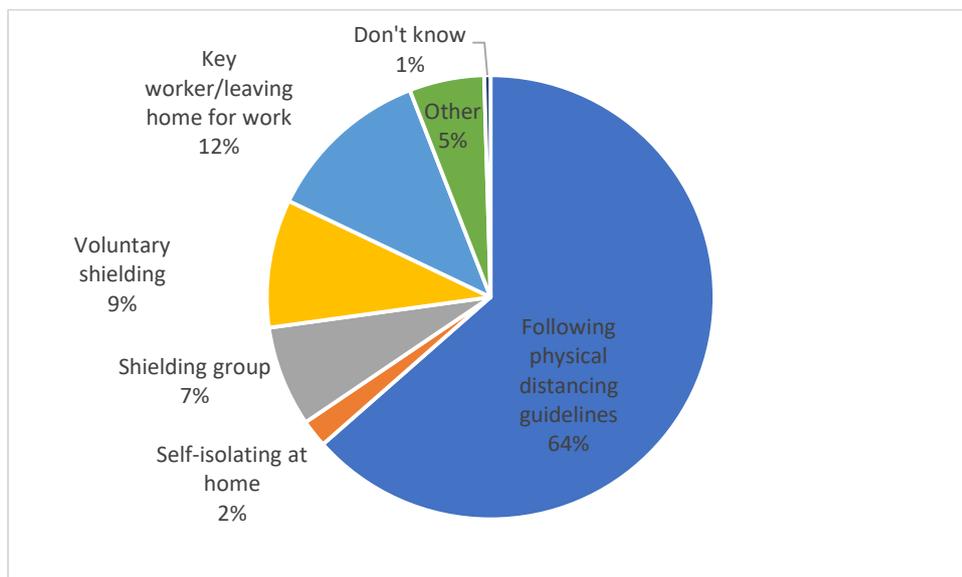


Figure 2: Physical distancing measures taken by respondents

4.1.2. Confidence in Diabetes self-management

Glucose monitoring (checking and correcting for spikes) and examination of feet remained largely unaffected by the pandemic. Changes were more noticeable in the lifestyle component of diabetes management (e.g. adhering to physical activity recommendations and keeping a healthy weight) though for some the pandemic generated an increased confidence in diabetes self-management (Figure 3).

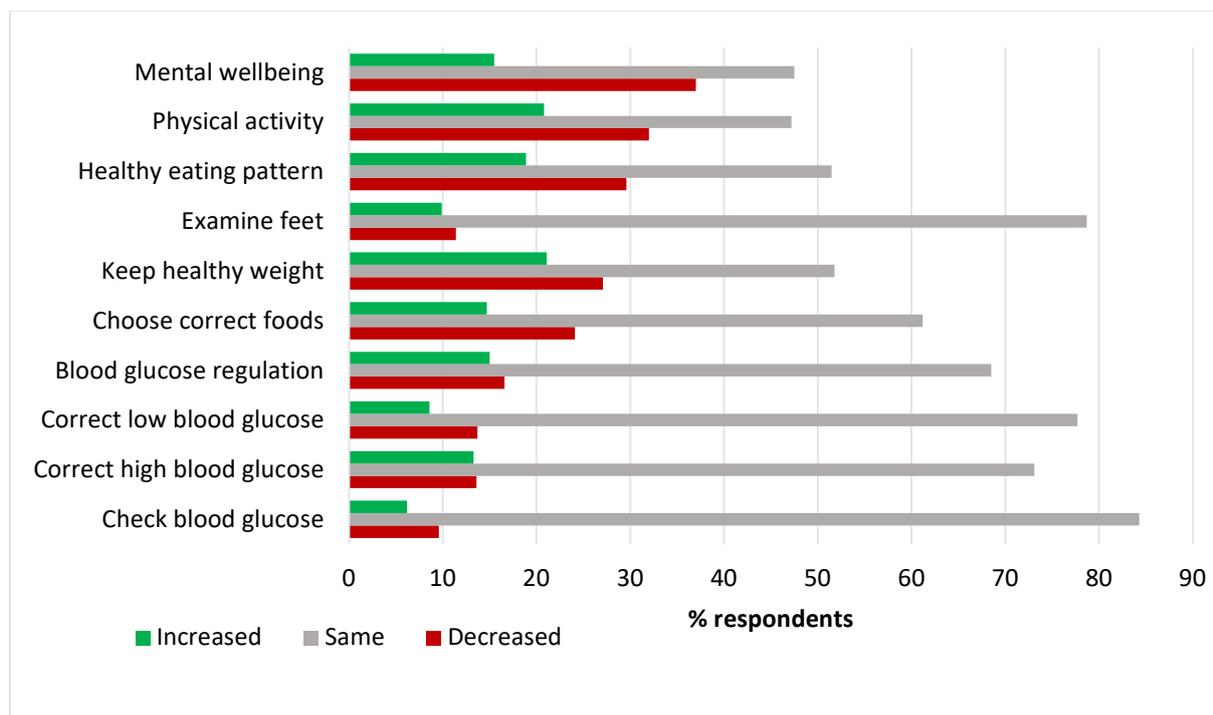


Figure 3: Changes in reported confidence in diabetes self-management caused by the start of the pandemic.

Differences between diabetes types were observed. A decrease in perceived self-efficacy in selecting the correct foods was reported by 32.1% of people with T2DM, compared to only 20.8% in people with T1DM. Further, over a quarter of both respondents with T1DM and T2DM indicated an impoverished confidence in healthy weight maintenance, but among respondents with T2DM another 30.5% reported increased confidence compared to only 17.2% of respondents with T1DM (Figure 4). A similar pattern was found for confidence in sustaining a healthy dietary pattern (improvements in T2DM 25% while in T1DM 16.8%). Our survey does not enable us to untangle the factors that may be contributing to this difference. However, the lifestyle changes generated by the pandemic seem to have improved some individuals’ ability to pay attention to their diabetes management and adopt healthier habits:

“I actually my diabetes management has been better as a result of the pandemic. Having appointments cancelled has made me pay much closer attention to things, as I haven’t had my regular three month appointments due to the pandemic.” (T1DM, 27 years).

“I found it did go off to start with but is better now that before due to more stable and regular days.” (T1DM, 39 years)

“The start of the pandemic coincided with an overdue review, which identified a significant worsening of HaB1c. I was started on new med, given a blood test monitor and am in frequent contact with my diabetic nurse. Since lockdown I have been eating healthier meals, few take always lots of fresh food. But exercise has diminished as my gym is shut. It was coincidental that the approach to managing my diabetes came at the same time as lockdown” (T2DM, 53 years)

“My self management is much improved. I have had the time to focus on my diabetes. Exercise more & learn about better foods & nutrition. I wanted to get in the best possible health in case I contracted

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the virus especially with having a lung condition too. Over 90 days I have reduced my A1c from 71 to 50. With hard work. No support from diabetes team which has been a struggle. I haven't had an appointment in 16 months because of their cancellations. I've had the Libre for 1 year & never had a consultation. Every thing I've done I've had to do myself. Low carb, no alcohol, limited caffeine & exercise. I have not had the support before or after that I needed. A struggle but I've done it. Lost 1 stone from 10.5 to 9.5. Mental health has suffered throughout; before & after.” (T1DM, 46 years)

“New low calorie recipes” (T2DM, 66 years)

These findings suggest that for some individuals the pandemic generated an opportunity for greater self-reliance and a shift away from being a passive recipient of care.

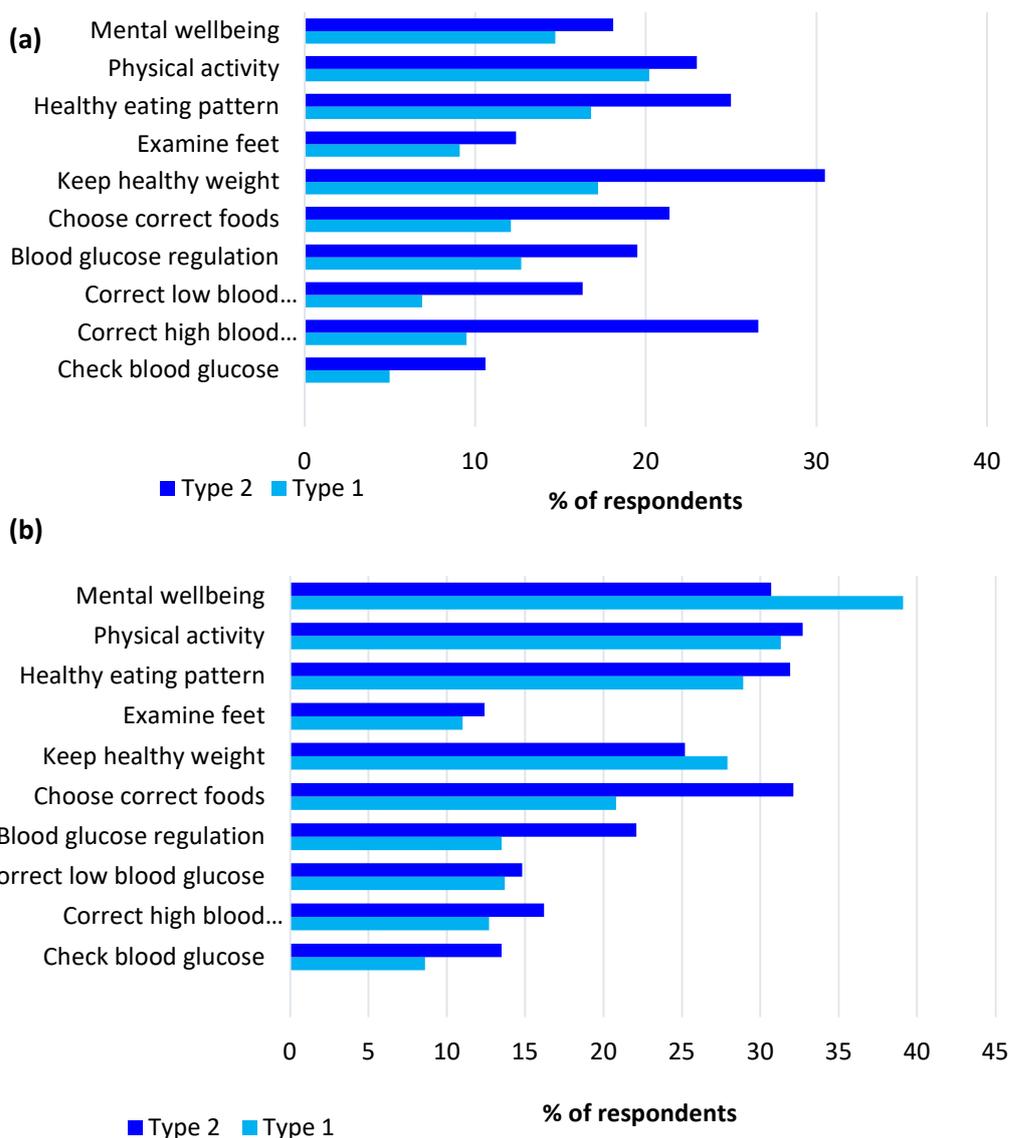


Figure 4: Comparison between diabetes types in % of respondents who reported (a) an increase and (b) a decrease in confidence in diabetes self-management due to the coronavirus COVID-19 pandemic.

Long-term impact. 37% of people with diabetes reported a decrease in their ability to take care of their mental health and wellbeing, almost 39.1% in people with T1DM. As the UK enters a second wave of coronavirus COVID-19, the prolonged negative effect of the pandemic on mental health may

eventually start impacting ability to self-manage. Both acute and diabetes-related stress, as well as decreased perceived self-efficacy have been associated with poorer glycaemic control¹⁻³. It may additionally accentuate the elevated comorbidity between diabetes and mental health⁴.

Helping people resume diabetes self-management confidence can be achieved via a mixture of actions, according to respondents with diabetes. Free text responses to these questions were categorised into the following (themes presented in order of frequency of mention):

- Clearer guidance on individual risk for better decision making.
- No changes in diabetes management required.
- Improvement of mental health support available to reduce stress
- Adjustments to current self-managements, especially given the change in lifestyle.
- Support from external others. This includes family and friends, adherence to physical distancing guidelines by others, greater choice in living arrangements, and help in household tasks and childcare.
- Ability to return to pre-pandemic lifestyle or the availability of a vaccine.
- Increased access to:
 - a. Healthcare team
 - b. Opportunities for physical activity
 - c. Appropriate food
- Continuous blood glucose monitoring.
- Reminders in relation to medication.

Additional changes from social environment were also proposed, including greater adherence to physical distancing requirements from others, greater availability of choice in living arrangements, ability to meet friends and family, and meeting with others who have diabetes for face-to-face peer support. See Appendix A for further details.

4.1.3. Impact of cancellations of appointments

51.9% of respondents had had at least one diabetes appointment cancelled or cancelled their appointments in the period from the 24th of April to the 31st of August (53.5% T1DM, 50.5% T2DM, 72.2% other type of diabetes). The impact of cancelled appointments as perceived by respondents was the following (themes presented in order of frequency of mention):

- Changes in medical management:
 - Uncertainty over glucose control: Respondents did not know their glucose control, struggled to interpret the information, and lacked confidence in the actions they needed to take to improve glucose control.
 - Difficulties in switching treatment and receiving adequate support in the process.
 - Switch to remote medical care (*e.g.* phone calls and e-mails)
 - Delayed or cancelled referrals to other services (for management of diabetes-related medical complications).
- No impact on day-to-day management:
 - Adapted to circumstances to improve self-management.
 - Delayed appointments but no impact on diabetes self-management
- Reduced support and advice regarding self-management or risk
- Strain on mental health and confidence in self-management.

See Appendix B for further details.

4.1.4. Sources used for guidance, advice and general support

As expected, news channels were the most frequently used sources for guidance on physical distancing measures, followed by Diabetes UK website, the public health and government webpages corresponding to each nation, and other NHS websites (percentage of respondents reporting on using them were: 72.5%, 59.9%, 50.1% and 50.1% respectively; See Figure 5). 33.9% of respondents reported relying on their healthcare team for guidance on physical distancing. Diabetes UK appears to be the most frequently used source for guidance on diabetes self-management, followed by the healthcare team and the NHS website (percentage of respondents reporting on using them were: 48.7%, 29% and 21.5% respectively). Discrepancies between diabetes types were primarily on the reliance on Diabetes UK and the guidance provided by Public Health sites for physical distancing, and the reliance on healthcare team and peer support groups for guidance on diabetes self-management. (See Figures 5 and 6).

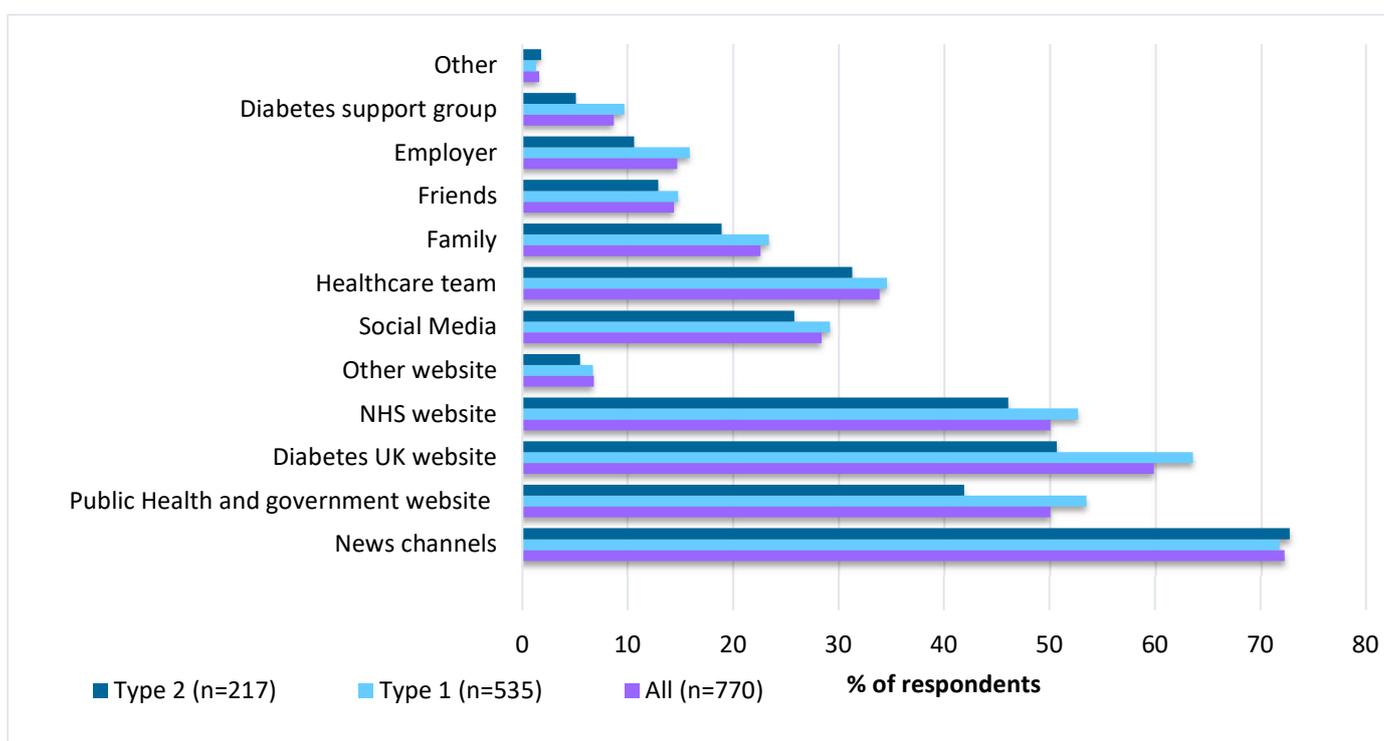


Figure 5. Percentage of respondents who indicated using a particular source for guidance on physical distancing measures. Data are presented an overall and split by diabetes type.

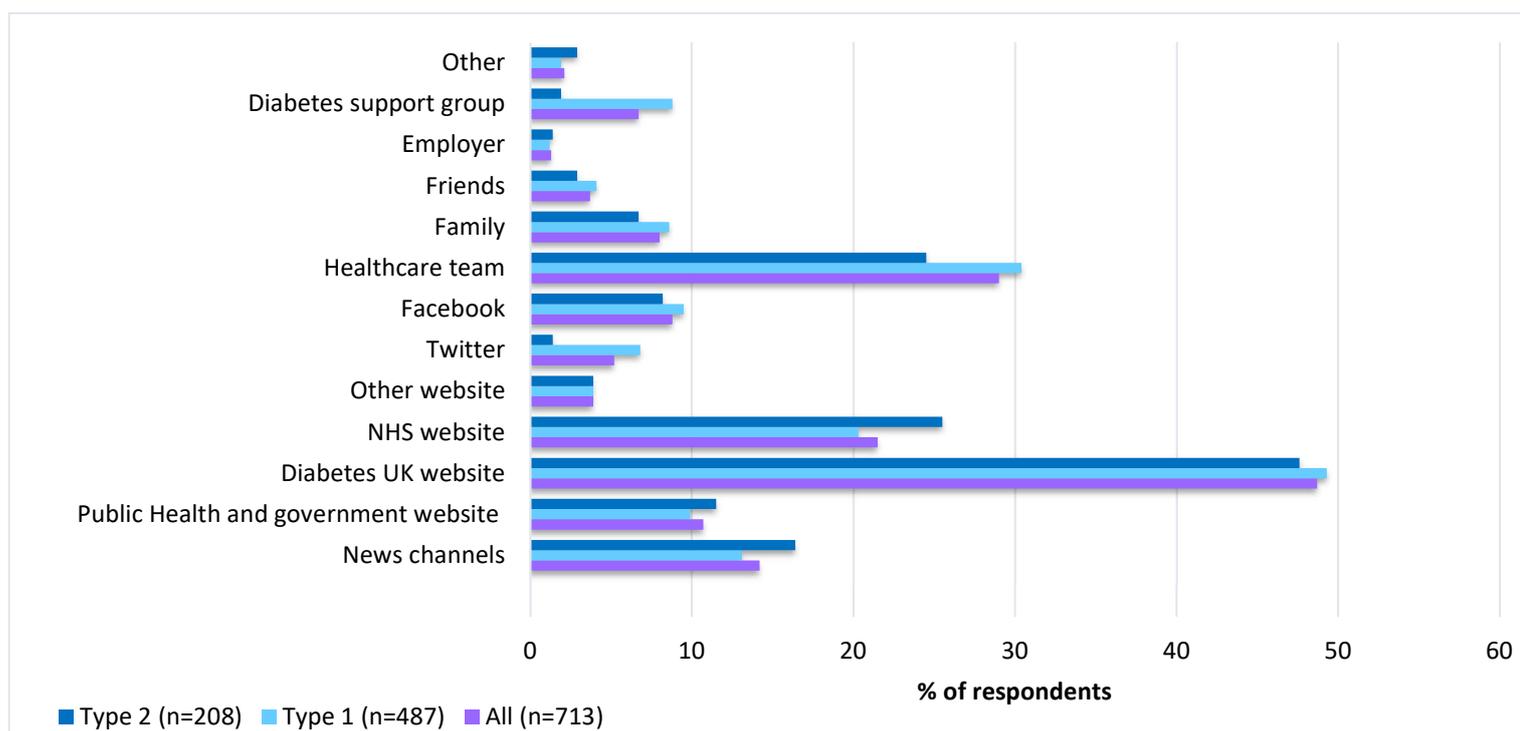


Figure 6. Percentage of respondents who indicated using a particular source for guidance on diabetes self-management. Data are presented as an overall and split by diabetes type.

4.1.5. Sources used for emotional support

Overall, friends and family appear to be the primary sources for emotional support (51% and 68.9% respectively). However, a greater proportion of respondents with T1DM received emotional support from their friends (54%) compared to respondents with T2DM (43.9%). Reliance on social media communities (e.g. Facebook or Twitter groups) and healthcare teams was relatively similar (10.3% and 12.5% respectively). See Figure 7.

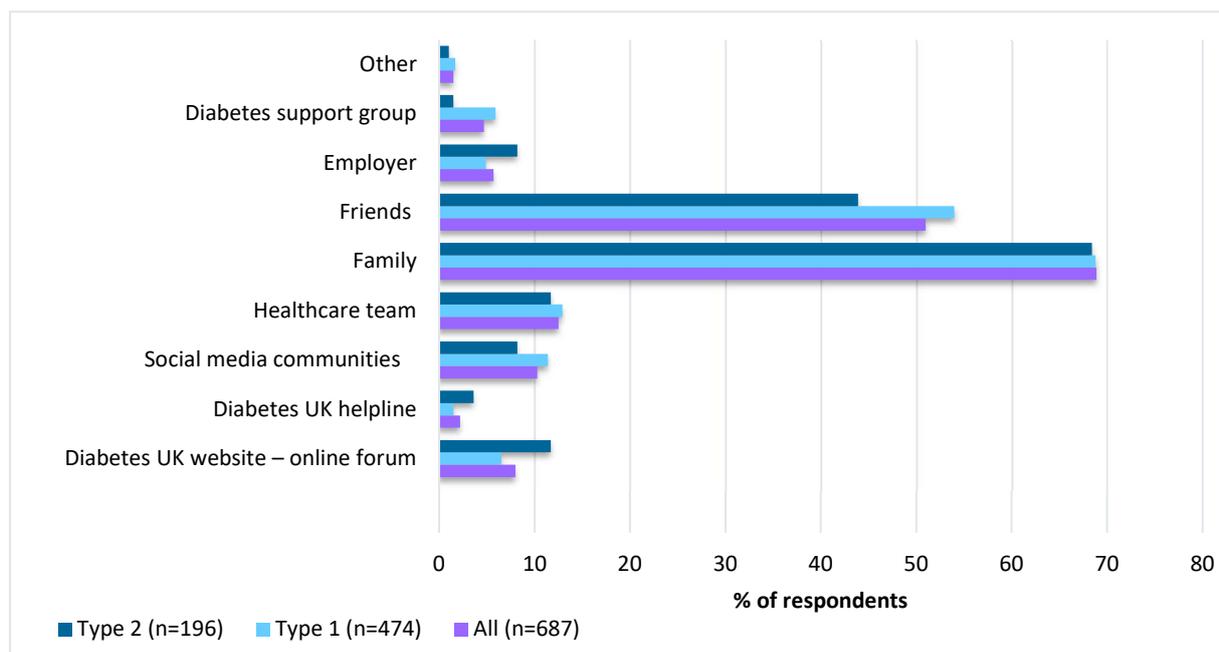


Figure 7. Percentage of respondents who indicated using a particular source for emotional support. Data are presented as an overall and split by diabetes type.

Among those living alone, 41.2% of respondents were not receiving support from outside their household. Of those who did, support was primarily received from the family (68.7%), friends (67.2%), neighbours (28.4%) or other (4.5%). Additionally, a greater percentage of individuals living alone reported a decrease in their perceived ability to correct for high blood sugar (23.3% vs 11.9% living with others) and to meet physical activity recommendations (46.2% vs 29.5% living with others). However, those individuals living alone without outside support were more likely to report improvements in perceived self-efficacy across several domains compared to those who were receiving outside support. In terms of mental health, more respondents receiving outside reports reported an increase in their confidence to look after their well-being (see Figure 8), but there were no differences in those who reported an impoverishment in this field (for both: 40%). Please note that the small number of respondents living alone signifies that these findings should be interpreted with caution.

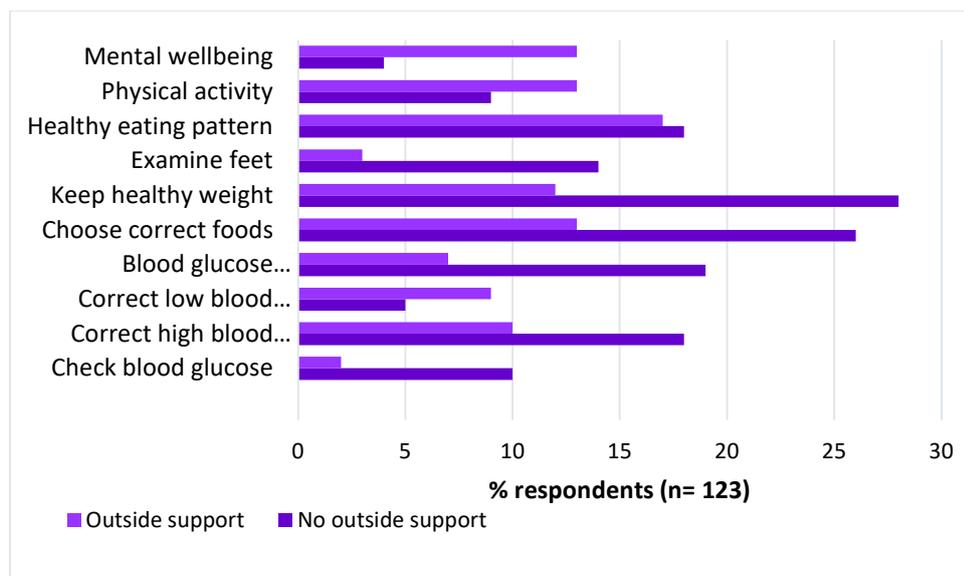


Figure 8: Confidence in diabetes self-management among respondents who reported living alone.

4.1.6. Ease of access to information, advice, and support

Access to information and guidance around emotional wellbeing and how to manage diabetes if experiencing symptoms was reported to be particularly difficult (rating of difficult or very difficult: 34.2% and 34.4% respectively). The greatest difference between diabetes types was in the ability to access information and guidance on diabetes management if showing symptoms (rating of difficult or very difficult: 31.6% among T1DM and 42.5% among T2DM).

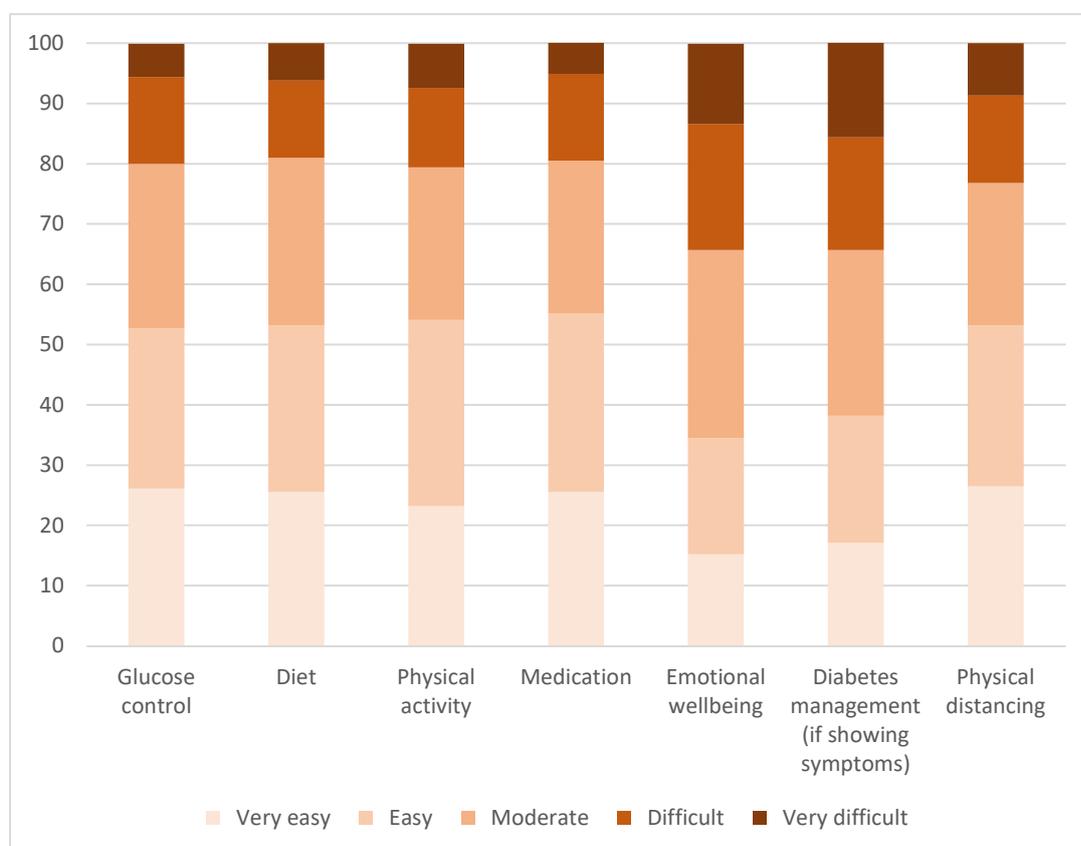


Figure 9. Reported ease of access to information/advice on different aspects of diabetes self-management and physical distancing guidelines.

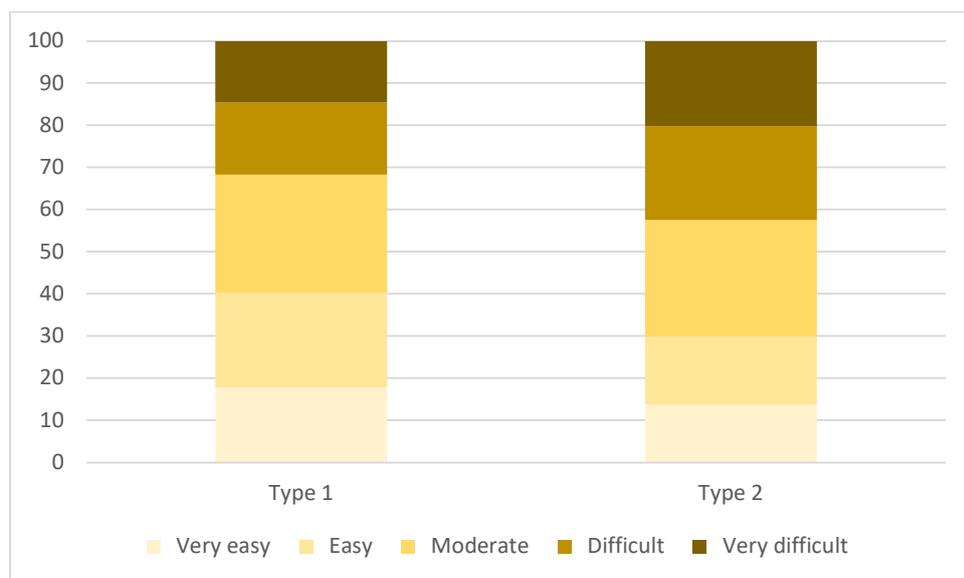


Figure 10. Ease of access to information/advice regarding diabetes management in case of COVID-19 symptoms according to diabetes type.

Access to support was globally more difficult than access to information and advice, but again support for emotional wellbeing and diabetes management if showing symptoms were rated as being more difficult to obtain than other categories (rating of difficult or very difficult: 39.4% and 37.7% respectively, Figure 11).

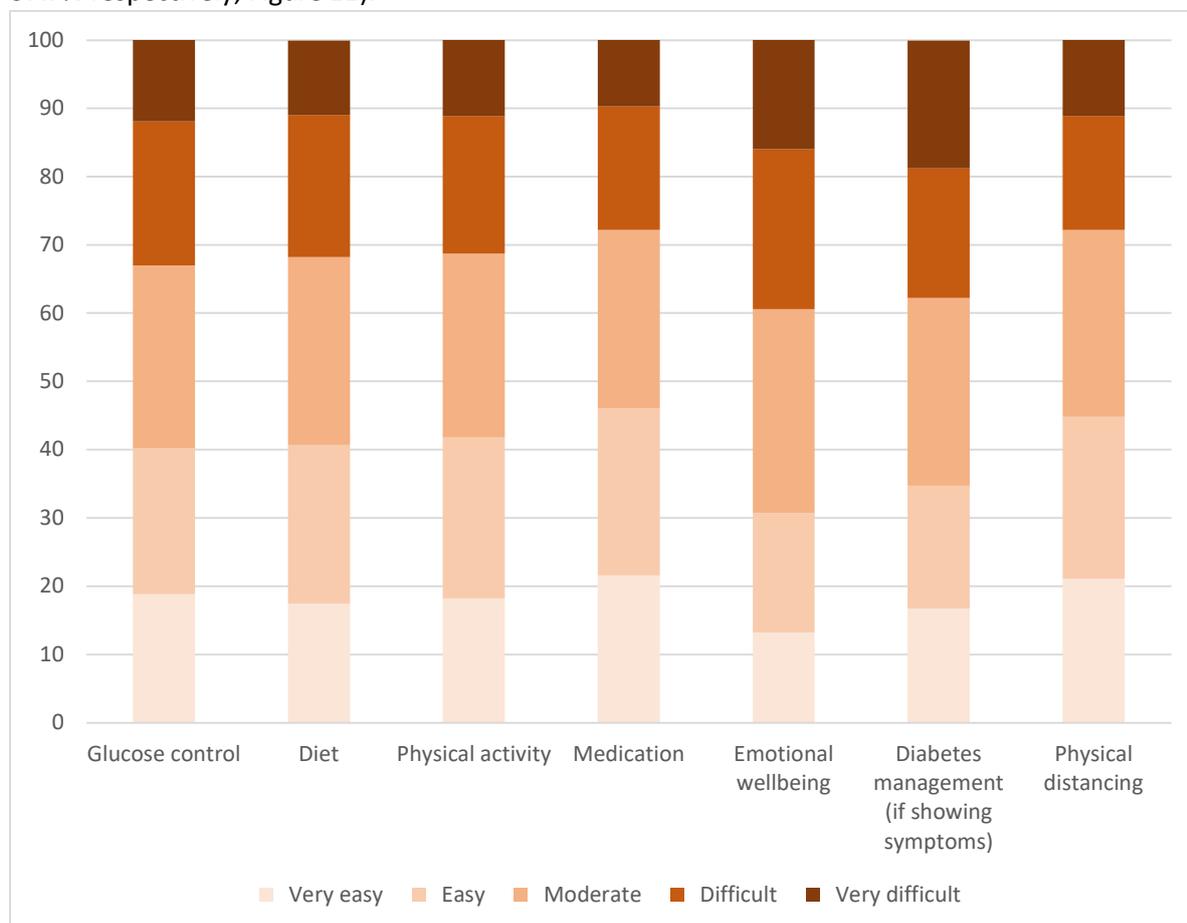


Figure 11. Rated difficulty in accessing support regarding various aspects of diabetes self-management and adhering to physical distancing guidelines.

In this case, discrepancies were clear between diabetes types. Access to support for glucose control was rated as more difficult by people with T2DM, with 42.5% of people with T2DM reporting difficult or very difficult access compared to 28.9% of respondents with T1DM (Figure 12). This could be attributed to differential care between the two types of diabetes, where glucose self-monitoring tools are part of standard care for T1DM but not T2DM. Patients with T2DM rely on follow-up HbA1c check-ups, many of which were cancelled.

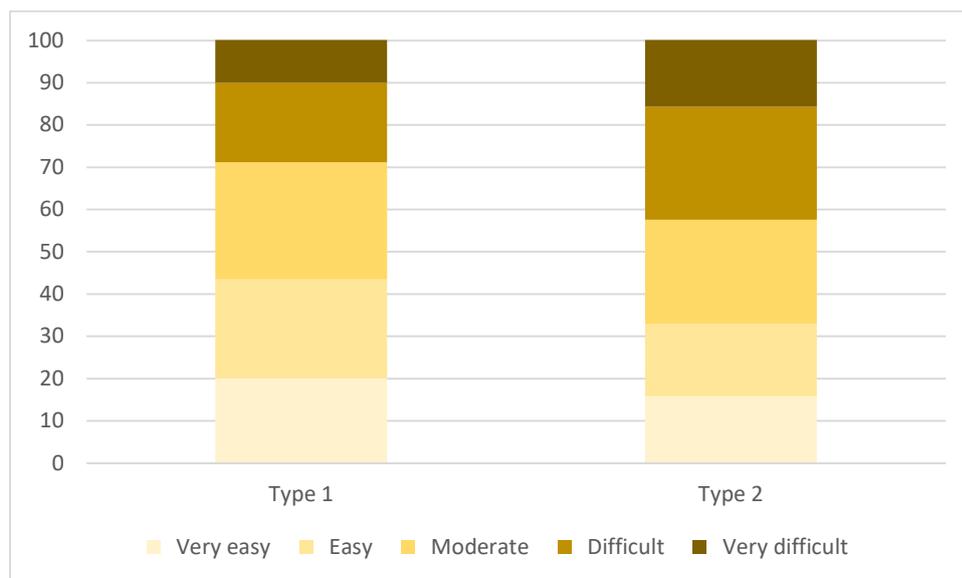


Figure 12. Ease of access to support regarding glucose control according to diabetes type.

4.1.7. Perceived quality of information/advice/support from various resources

39% of respondents rated the information/advice/support received from government as poor or very poor, with scores being poorer from T1DM respondents (41.8%) compared to T2DM (31.7%; Figure 13). Perceived quality from healthcare teams was similar, at 37% of respondents considering it as poor or very poor, though in this case ratings were poorer from T2DM respondents (43.2%) compared to T1DM respondents (35.2%). Resources valued more highly were Diabetes UK, friends and family.

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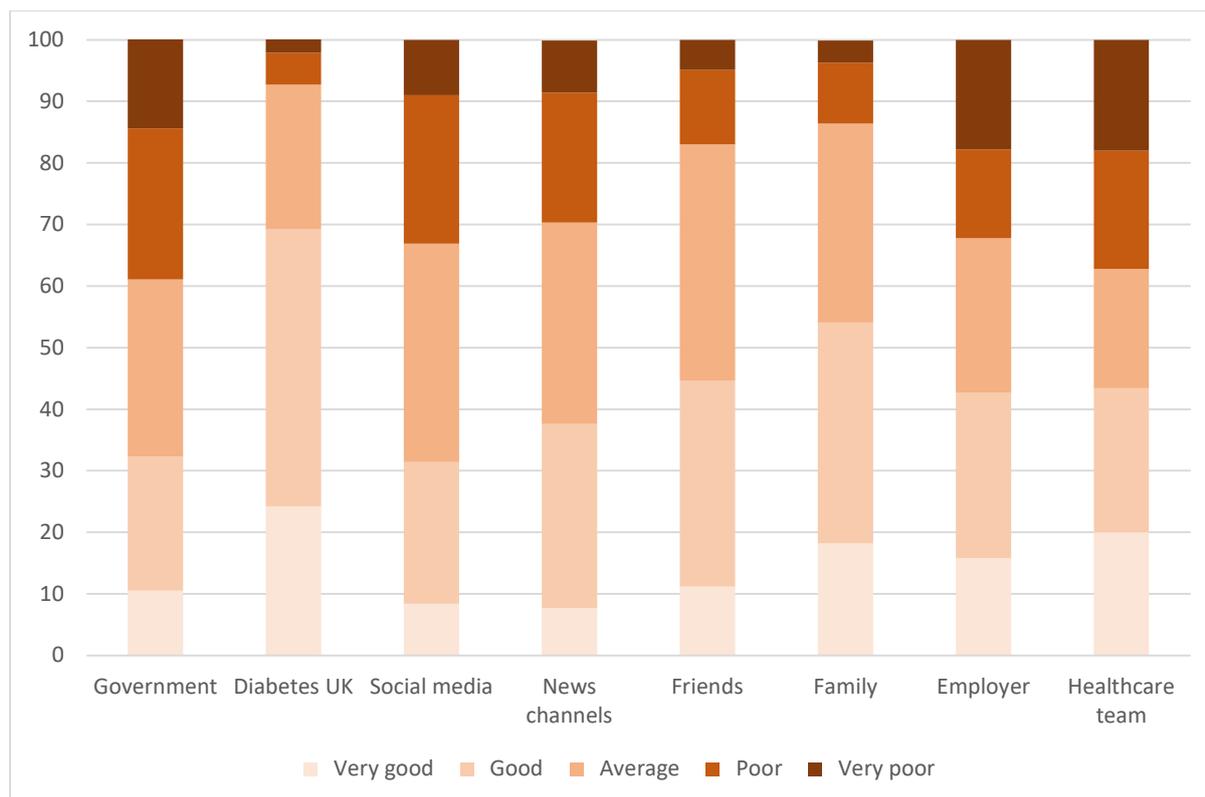


Figure 13. Reported quality of information, advice and support received from various resources.

There are several possibilities for the low ratings for the healthcare team. It may be possible that people living with diabetes have higher expectations from the healthcare team compared to other sources. For example, several respondents indicated that they would not anticipate reliable information from social media: *“As expected, particularly on forums & in groups where there was lots of speculation & differing opinions of what the official diabetes information actually meant!”* (42 years, T1DM). It must also be noted that the cancellation of appointments and reduced contact was sudden, possibly without enough time for people living with diabetes to adjust their self-management with confidence. This could have had an important effect on those individuals who had more contact with their team, those individuals who only obtain insight into their glucose control on follow-up HbA1c check-up appointments, or recently diagnosed adults. Indeed, many respondents reported *“Haven’t heard anything from diabetes team since pandemic began.”* (27 years, T1DM).

It must also be noted that opinions regarding the support provided by healthcare teams varied across respondents. While some indicated having little to no contact with their care teams, other reported receiving support when needed (e.g. *“Rang me to check I was ok as check-up delayed. Could ring if I wanted to”* (69 years, type 2)). Differences across regions were also observed, though the number of responses split per region are small (Table 1).

Region/Nation	respondents	Healthcare rating good or very good	%
Scotland	65	26	40.0
Wales	28	13	46.4
East England	45	20	44.4
East Midlands	32	13	40.6

Greater London	47	20	42.6
North East	19	4	21.1
North West	51	21	41.2
Northern Ireland	13	5	38.5
South East	132	68	51.5
South West	114	55	48.3
West Midlands	47	14	29.8

Table 1: Respondents who provided a ‘good’ or ‘very good’ rating to the quality of healthcare they received across England regions, Scotland, and Wales.

4.1.8. Support from personal networks

The support received from personal networks in diabetes self-management (family, friends, contacts) was mainly rated as good or very good (59.9%), and respondents felt that their personal network had an understanding of their current self-management needs (good or very good: 51.4%). There were no major discrepancies between individuals living alone and those living with others, though people living alone showed slightly poorer support.

Overall, support from personal networks remained the same for over half of respondents (53%), and for those of whom support had changed, they primarily reported an increase in support. This did not differ between diabetes type and the support was primarily centred around emotional support, food shopping/preparation and to pick up medication. 28.9% of respondents reported receiving encouragement to adhere to self-management behaviours.

4.1.9. Improvements in information/advice/support

Respondents who had provided ‘poor’ or ‘very poor’ scores on the quality of information and support received, were asked to recommend how it could be improved. The main themes are presented below, with direct quotes presented in Appendix C.

Healthcare team:

- Increased contact in general: many respondents reported not having been contacted at all by their healthcare team throughout the pandemic.
- Increased information on steps to take
- Demonstrating availability if support is needed
- Individualised advice and communication
- Transition to online and telephone across services: this shift was viewed favourably and recommended.

Government:

- Increased specificity: Insufficient details on risk across vulnerability categories and differences between diabetes types.
- Increased honesty and trustworthiness: Less political bias and transparency on the factors underpinning decisions on vulnerability and measures to be taken.
- Increased consistency in messaging: the risk category for people with diabetes was changed several times at the beginning of the pandemic.
- Increased clarity on individual vulnerability to severe COVID-19 and the appropriate measures to be taken.

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- Other

Diabetes UK:

- Increased visibility and access: healthcare teams could direct patients to the Diabetes UK website.
- More active pressure on the government and news coverage
- Greater specificity on risk across vulnerability categories and differences between diabetes types.
- More and/or better information

Note: Some individuals communicated that improvements had been observed over the pandemic. For example: *“The information was much more clear. Particularly as they [Diabetes UK] spoke about T1 and T2 separately - or at least made it clear when it was both types they were referring to. Through DUK I learnt that it is far more about the disruption to diabetic control rather than an impact of COVID on diabetics per se (although being a new virus I guess we don’t really know) so that was useful to understand.”* (43 years, type 1).

Social Media

- Less sensationalism as it augments experienced anxiety.
- Fact-checking and less opinionated

News Channels

- Fact-checking and pressure on politicians
- Greater specificity on risk across vulnerability categories and differences between diabetes types.
- Increased consistency in messaging
- Less sensationalism and bias

Friends and Family

- Less confidence in own knowledge
- Improved understanding of condition and challenges
- Increased contact and emotional support

Employers

- Improved contact and communication
- Individualised advice and support for people living with diabetes
- Improved understanding of diabetes

4.2. Parents, carers, partners of people living with diabetes

Please note the small number of respondents when interpreting the findings presented below.

4.2.1. Demographic characteristics

A total of 79 respondents indicated that they were the parent or carer (n=58), or the partner (n=21) of someone living with diabetes. Respondents came from across the UK, though most were from Scotland (30.4%) or the South West (19%). See Figure 14 for a geographical representation of responses.

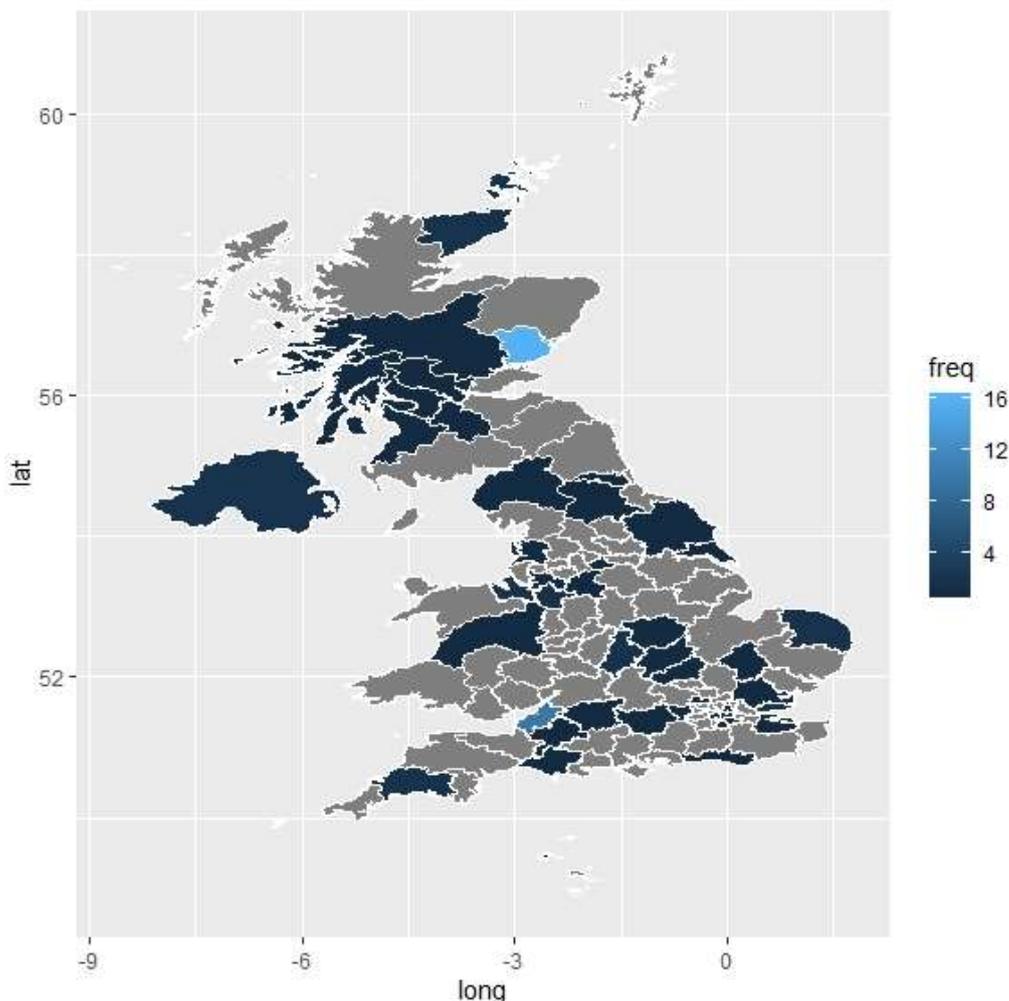


Figure 14: Pictorial representation of distribution of responses. Grey: no responses from the postcode area.

Most respondents were female (91%), with a mean age of 45.2 (SD=10.1) years, and of a white British ethnicity. Most respondents were living with the person with diabetes (91%) and reported no change in the number of people living in the household since the start of the pandemic (94%).

Only 6 respondents had experienced symptoms associated with COVID-19, however none of respondents had been diagnosed. 65% were following the physical distancing guidelines present at the time of survey completion, 24% were key workers or were still leaving the house to work, 3 respondents were self-isolating, 4 had received instructions to shield at the early stages of the pandemic, and 2 were minimising interactions to protect someone in the household.

4.2.2. Confidence in ability to support diabetes self-management

Respondents were asked how confident they were they could help the person living with diabetes in self-management. As was the case for people living with diabetes, most parents/carers/partners were confident that their ability to support the person with diabetes had remained the same regarding support in checking blood glucose levels (87%), correcting for high or low blood glucose (76% and 78% respectively), and examining feet (82%). Confidence had changed more in sustaining good blood glucose regulation, selecting correct foods, keeping a healthy weight, keeping a healthy eating pattern of diabetes self-management, though a very similar number reported an increase in confidence to those who reported a decrease in confidence (Figure 15). Areas where respondents were more likely to report decreased confidence in ability to provide support compared to pre-pandemic confidence were physical activity (27% decrease) and supporting mental wellbeing (26% decrease).

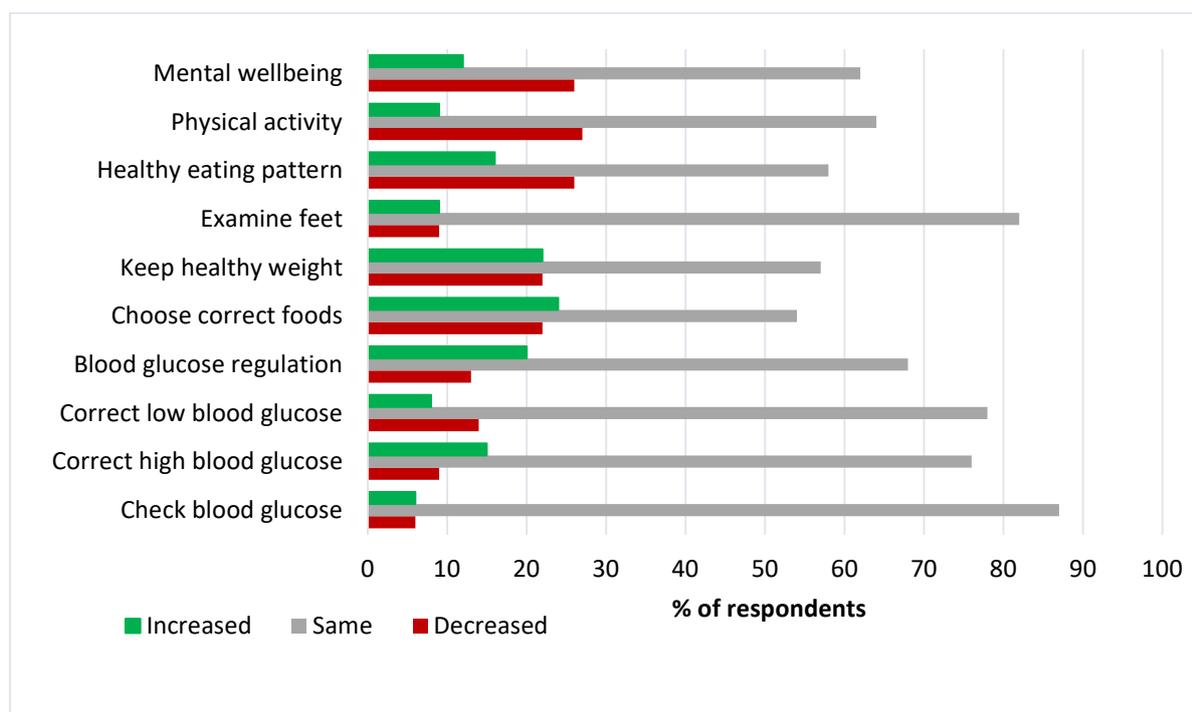


Figure 15: Changes in reported confidence in the ability to support diabetes self-management caused by the start of the pandemic.

Factors that respondents reported would help them improve the support they are able to provide included (see Appendix D for further details):

- Increased support from the healthcare team in terms of:
 - The mental wellbeing of the person with diabetes
 - Own confidence in understanding diabetes and the person’s needs.
 - Diabetes management
 - More contact, preferably face-to-face
- More information and guidance on:
 - Recommended physical activity
 - Diabetes and comorbidities (especially mental health)
 - Risk in relation to COVID-19
 - Use of medical devices
 - Training on how to support the person with diabetes
- Practical help in:

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- Taking annual leave
- Access to outdoor exercise facilities
- Shielding
- Obtaining food
- Reducing stress
- Scaremongering

4.2.3. Sources used for guidance, advice and support

The most frequently used sources for guidance on the social/physical distancing measures to take were news channels, the Diabetes UK website and the NHS website (all: 60% of respondents reported having used those resources; Figure 16). Differently, the resources used for guidance on how to support the individual with diabetes were the Diabetes UK website (49%), followed by the NHS website (35%) and the healthcare team (32%).

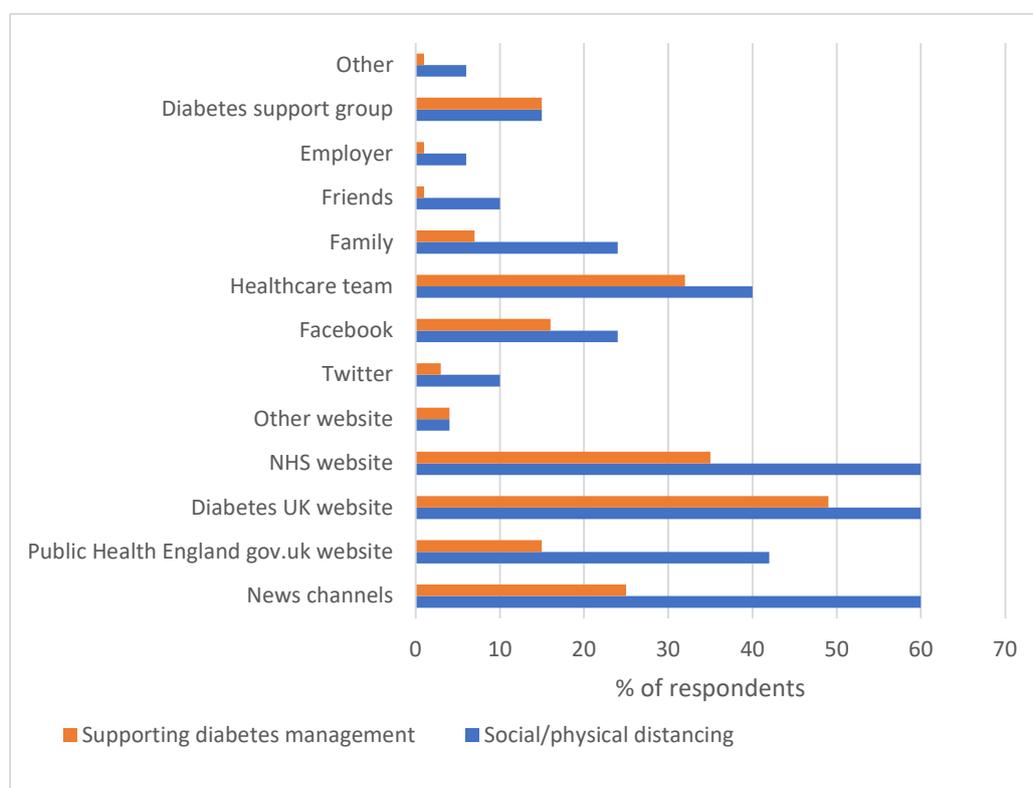


Figure 16. Resources used for guidance and advice in relation to social/physical distancing measures to take and how to support the individual with diabetes in their self-management of the condition.

Differently, **when seeking emotional support**, respondents turned towards family and friends (60% and 36% respectively) more than any other source (Figure 17).

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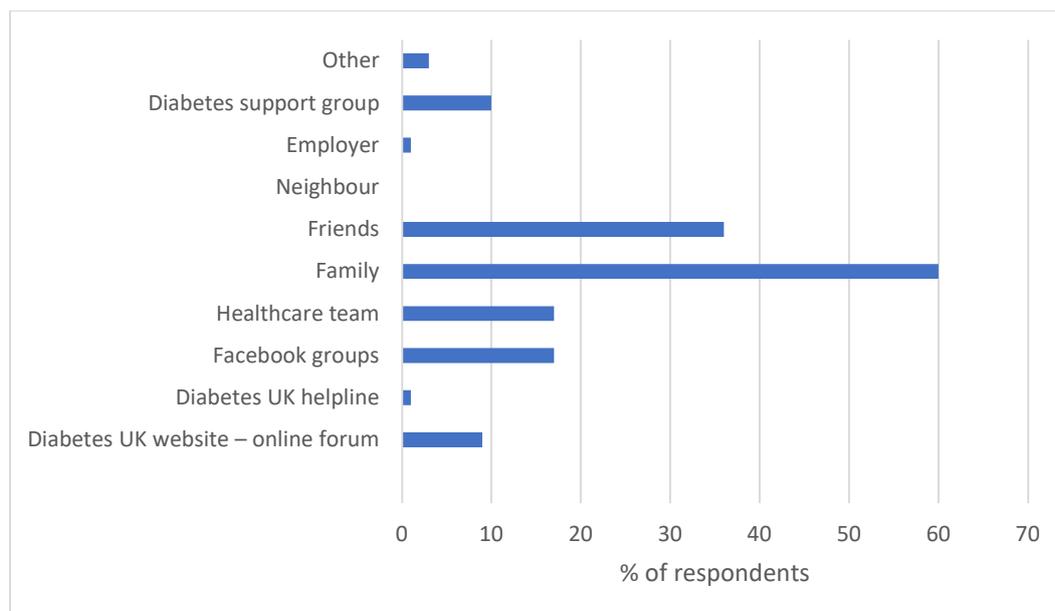


Figure 17. Resources used for own emotional support.

4.2.4. Ease of access to information, advice and support

Parents/carers and partners found it particularly difficult to access information on diabetes management if the person with diabetes is showing symptoms (up to 47% rated ease of access as difficult or very difficult; Figure 18). A similar pattern was observed in relation to ability to access support (Figure 19).

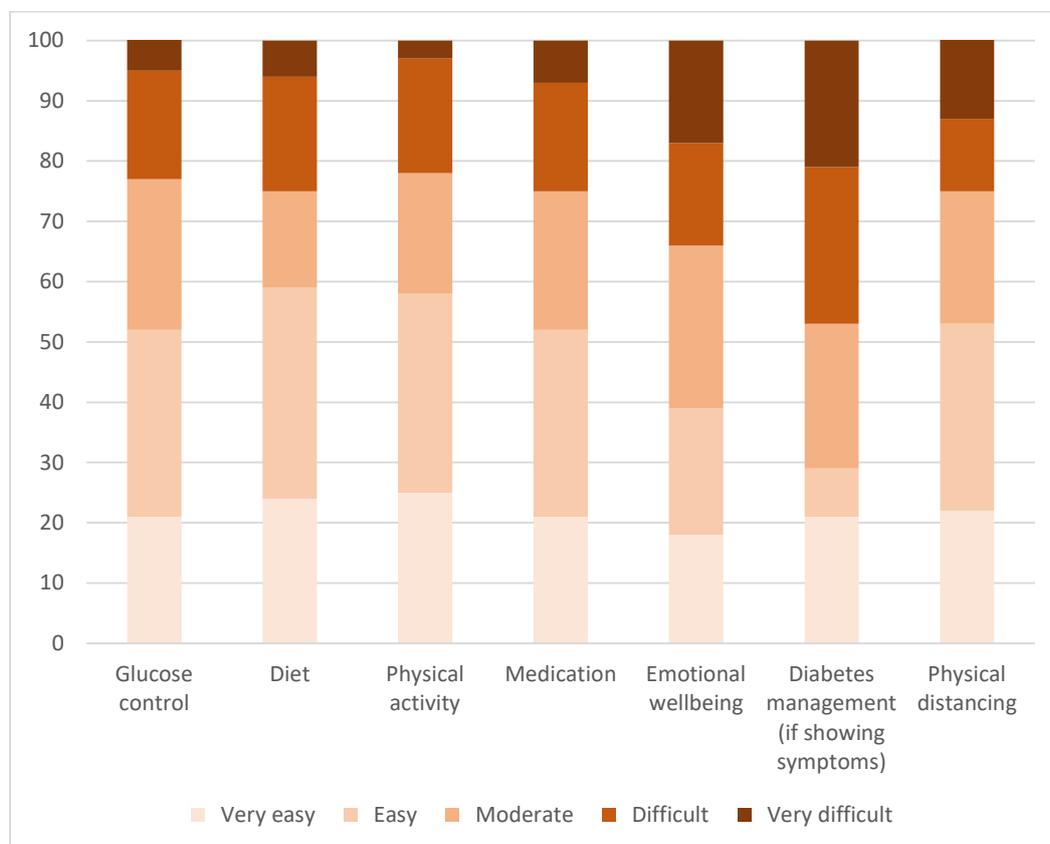


Figure 18. Ease of access to information and advice about different aspects of diabetes management applicable to the person they were helping.

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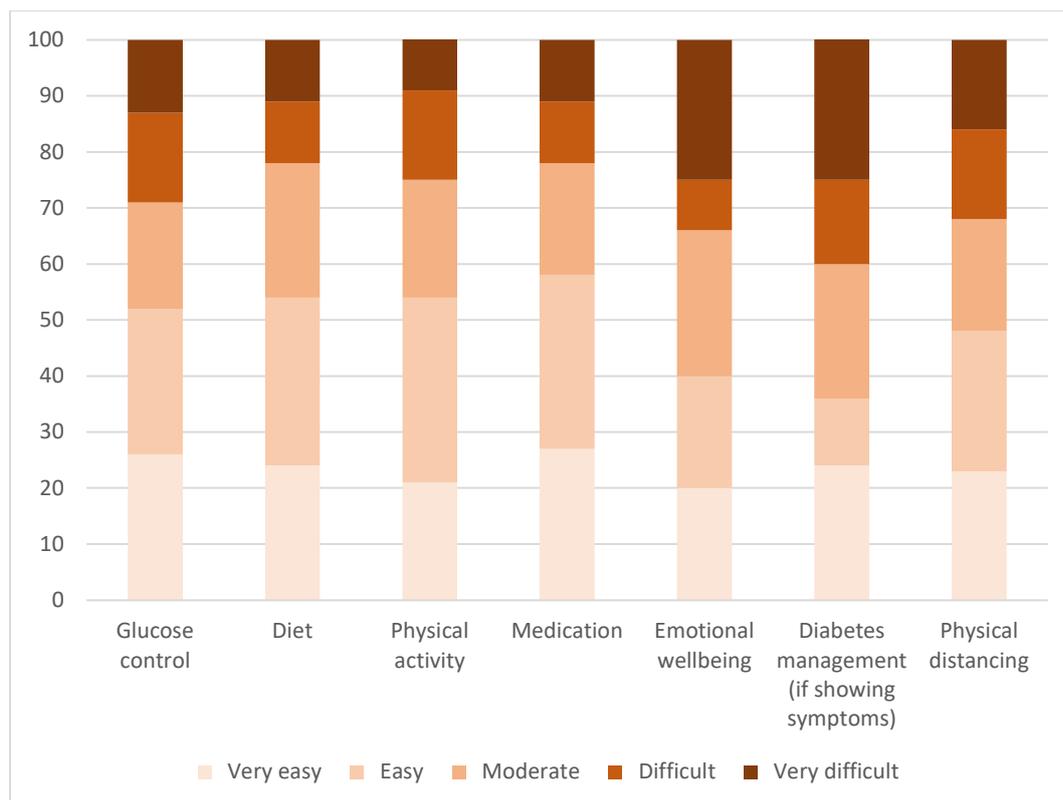


Figure 19. Ease of access to support applicable to the person they were helping.

4.2.5. Perceived quality of information/advice/support from various resources

The employer, government and news channels were the sources considered to provide the poorest level of guidance and support (percentage of respondents giving a rating of poor or very poor quality: 41%, 34% and 33% respectively; Figure 20). Whilst 75% of respondents rated the quality of advice and support provided by Diabetes UK as good or very good, and 60% of respondents giving a similar rating to the healthcare team.

Support needs people with diabetes and carers during COVID-19 pandemic

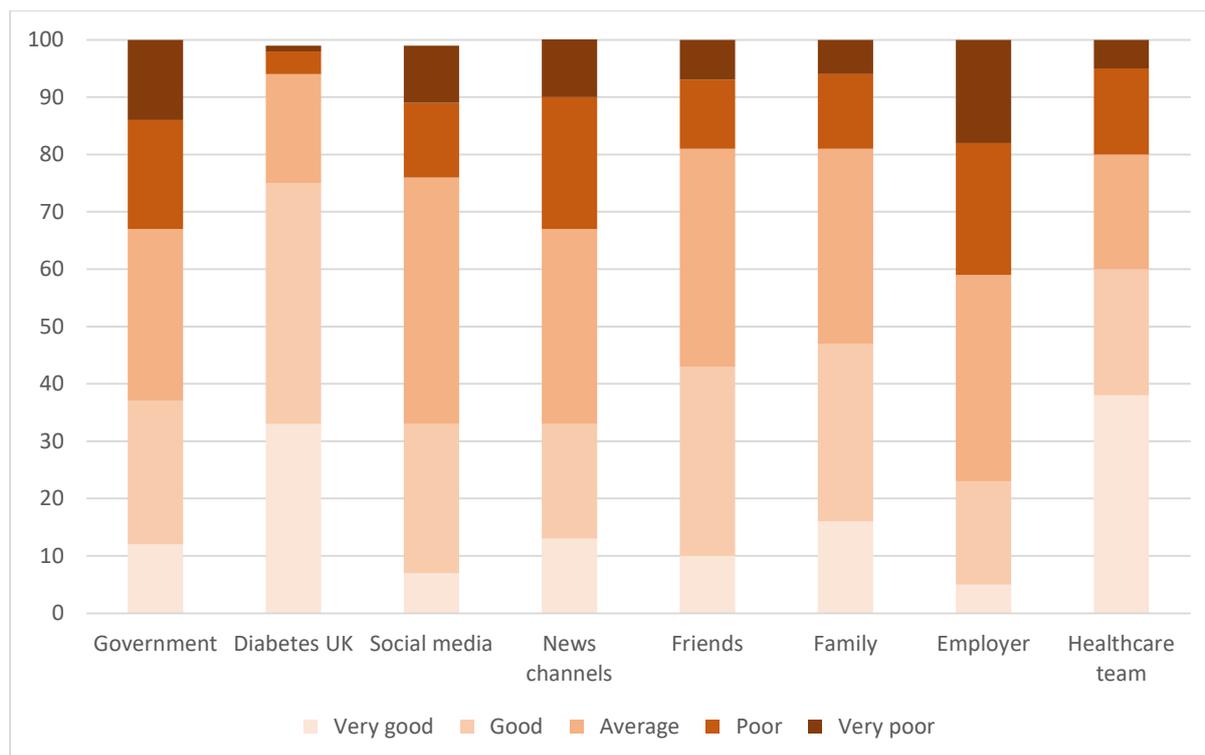


Figure 20. Perceived quality of information, advice and support received to help the respondent support the person living with diabetes.

4.2.6. Reported own role in helping someone with diabetes

80% of respondents indicated that they had a good to very good understanding of the person's current diabetes self-management needs. Support was provided primarily for food shopping/preparation, emotional support, prompting self-management behaviours and picking up medication (Figure 21).

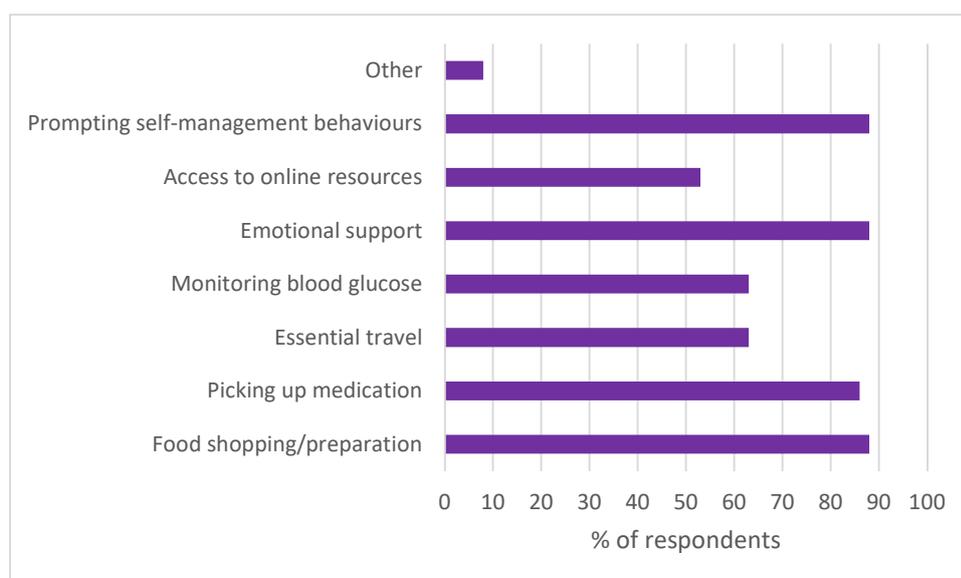


Figure 21. Different types of support provided by respondents to the people they were caring for.

4.2.7. Improvements in information/advice/support

Respondents who had provided 'poor' or 'very poor' scores on the quality of information and support received, were asked to recommend how it could be improved. The main themes are presented below, with direct quotes presented in Appendix 2E.

Healthcare

- More contact, even if remote
- Greater availability
- More specific information

Government

- Guidance that is more specific according to type of diabetes and level of vulnerability.
- Guidance and support that is specific to children and their parents
- Clearer and more consistent information
- Policy and assistance that is suitable
- Greater trustworthiness

Diabetes UK

- Separation of advice for adults and children
- More pressure on the government
- Greater and more simply presented information for parents

Employer

- They should be better informed
- More detailed advice and support
- Monitor adherence to guidance

Family and Friends

- Less advice based on own opinion
- Adherence to social/physical distancing guidelines
- Greater awareness of the condition and challenges

News channels

- Improved research
- Increased trustworthiness and reporting of sources
- Greater discussion of risk
- Less sensationalism

5. Considerations

Interpretation of findings needs to be conducted in the light of some methodological limitations. The survey was distributed online, via professional networks, patient portals of research groups, and relevant organisations (e.g. Diabetes UK). This limits participation by individuals who are less engaged, with both their healthcare teams and existing support networks, or are unable to access or are less familiar with technology. Ethnic minorities and males were underrepresented in the survey despite the use of a wide variety of steps taken to raise awareness of the survey across these groups. This is important the higher prevalence of diabetes in ethnic minority communities⁵. The number of respondents who were parents, carers or partners of someone living with diabetes was also very small. A survey has now been launched specifically for families living with children and young adults with diabetes.

Despite its limitations, the survey offers valuable insight in how people living with diabetes and their important others have been impacted by the coronavirus COVID-19 pandemic. It reveals feasible actions that can be taken to improve care provision. It also reflects growing evidence that government-imposed restrictions have had varied effects on people's activity and dietary habits^{6,7}, and the strain

that the pandemic has had on mental health and wellbeing⁷⁻⁹. Finally, it emphasises the value that organisations such as Diabetes UK have when the diabetes healthcare teams are resource limited.

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Appendices: Examples from open-ended qualitative responses.

Appendix A: Needed support to facilitate resumption of diabetes self-management confidence according to individuals living with diabetes.

Our qualitative analysis of this open question resulted in the following response categories:

- **Clearer guidance on risk for better decision-making**

“Preparation guides for how to manage sugar levels if you get corona - virus. Also guidelines on how to stay vigilant as a diabetic when carrying out daily activities as we are a higher risk group.” – 23, type 1 diabetes

- **No change in diabetes management required**

- **Improvement of mental health support available to reduce stress**

“My blood sugars have been more erratic due to the stress and worry for myself and my family, and they have been harder to keep under control.” – 31, type 1 diabetes

- **Adjustments to current self-management**

“Dietary changes! Being less busy and at home more has meant a diet which is not so good for people with diabetes!” – 47, type 1 diabetes

- **Support from external others:**

- **Family and friends**
- **Adherence to physical distancing by others**
- **More choice on living arrangements**
- **Help in household tasks and childcare**

“We need a ‘vulnerable hour’ at least 3 times a week we can feel confident going out where there will be only other vulnerable people/their carers/essential workers and 2m+ distance will ALWAYS be respected” – 23, type 1 diabetes

“Lack of help with childcare means difficulty in exercising and more strain at home, so sugars for harder to look after.” – 35, type 1 diabetes

- **Ability to go back to normal or availability of a vaccine**

“Once things get back to normal and I can get back to my routine” – 55, type 2 diabetes

- **Increased access to:**

- **Healthcare**
- **Appropriate food**
- **Opportunities for physical activity**

“Support from diabetes team” – multiple respondents

“Access to online delivery slots to get a range of food in!” – 36, other type of diabetes

“Lockdown limited exercise which I rely on to control sugar levels. Readjustment of insulin due to me a exercise is not straight forward” – 28, type 1 diabetes

- **Blood glucose monitoring**

“Getting CGM on prescription” – 46, type 1 diabetes

- **Medication**

“Reminders about changing insulin doses (via pump) in response to lower levels of physical activity.” – 54, type 1 diabetes

Appendix B: Impact of cancellation of appointments

Our qualitative analysis of this open question resulted in the following response categories:

- **Changes in medical management:**

- **Uncertainty over glucose control.**

“It came when I was trialling Flash and CBG methods of control, and feeling very insecure because I have lost hypo symptoms. My self-confidence has plunged, and lack of follow-up hasn't helped. The clinic cancelled appointments and I didn't know who else to consult.” – 72, type 1 diabetes

“I'm okay for the time being but I've had issues because my GP has cancelled my repeat prescription for blood testing strips.” – 28, type 1 diabetes

“I have pretty much given up on self-management. I don't know where I am in terms of my Hba1c so don't know where I need to be heading.” – 61, type 1 diabetes

“I'm newly diagnosed 7 months aged 28 and need regular check ins to understand my diagnosis and levels better with a consultant but they are too busy and have spoke once for 5 minutes.” – 28, type 1 diabetes

- **Difficulties switching treatment, or patient-led decisions to alter doses.**

“Started on a Libre trial the first couple of weeks of lockdown. Have had no guidance or training on its use, how to interpret readings etc.” – 45, type 1 diabetes

“I was due to move onto pump therapy due to uncontrollable highs and weight gain, this has now been cancelled indefinitely and it has really affected my confidence and ability to feel safe with the condition.” – 23, type 1 diabetes

“Started using insulin just before lockdown. I'm finding it worrying and have gained weight.” – 67, type 2 diabetes

- **Switch to remote medical care**

“I have always been given advice, emails, and phone numbers for contact in an emergency, and have had a video appointment, this has helped” – 69, type 1 diabetes

“It has made me a bit anxious but I have an amazing diabetic team who are always on the other end of the phone or I can drop them an email if I'm worried” – 24, other type of diabetes

- **Delayed or cancelled referrals to other services (for management of diabetes-related medical complications).**

“It has made me worried about my eyesight as it has noticeably got worse and my retinopathy appointment has been repeatedly cancelled (even before COVID)” – 33, type 2 diabetes

“Considerable- had to cancel an eye appointment to evaluate a possible issue with retinopathy.

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Knowing the way in which this progresses, having no one to talk to or any tests is very scary” – 23, type 1 diabetes

- **No impact:**
 - **Adapted to circumstances to improve self-management.**
 - **Delayed appointments but no impact on diabetes self-management**

“None; just have to wait a bit longer for clinic/podiatry appointments” – 61, type 1 diabetes

“I have had to trial and error many things, which in a way has enabled me to learn different things. However, if I slip with self-management it is incredibly difficult to get back up with no support or understanding from those around me.” – 21, type 1 diabetes

“I didn’t cancel the clinic has stopped all appointments and services. I have had to learn to cope and have read more and joined a Facebook diabetes support group, run by other diabetics” – 60, type 2 diabetes

- **Reduced support and advice regarding self-management or risk**

“Understandable, but a shame as it delays answers to questions with my treatment” – 48, type 1 diabetes

“I was due a diabetes review at beginning of lockdown, it was cancelled and I cannot find words to say how scared I was without the support of the NHS, and blood tests to help monitor my diabetes. However, the NHS is brilliant, and I had an appt with the nurse at my GP surgery 3 days ago, so feeling much better now.” – 56, type 1 diabetes

“Really not sure what I am doing as, was diagnosed just before lockdown and have not spoken to anyone at my health centre since.” – 65, type 2 diabetes

“Not having the opportunity to discuss changes in insulin dosages and get advice on other changes I could make has meant that I have struggled to keep my sugar levels in range, despite making changes at my own discretion.” – 29, type 1 diabetes

- **Strain on mental health and confidence in self-management.**

“I have given up. I just pretend I do not have diabetes.” – 61, type 2 diabetes

“I feel like I’m on my own” – 53, type 2 diabetes

“Although I don’t feel less able to self-manage, I have sometimes felt less motivated to manage my diabetes well. A result of general anxiety and poor sleep.” – 54, type 1 diabetes

“Have no confidence at all. Levels are unmanageable no matter what I eat. Never seen a diabetic nurse!” – 47, type 2 diabetes

“Mentally I am finding it difficult to control my eating” – 66, type 2 diabetes

“Struggling a lot more and scared to ask team for help.” – 26, type 1 diabetes

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“Increased anxiety knowing if my background retinopathy is worsening and possible treatment being delayed. Not able to have HbA1c checked therefore do not know if I am meeting preconception target for family planning. Stress at delays in being able to get blood glucose testing strips therefore having to reduce the frequency of blood testing compared to my normal.” – 29, type 1 diabetes

“Mental health has gone downhill as I have been shielding blood levels have been up and down.” – 23, type 1 diabetes

Appendix C: Respondents’ opinions on how to improve information and support provided to people living with diabetes.

Healthcare team

- **Increased contact in general**

“I’ve not heard from them once and I haven’t had an appointment since August. I’m a type 1 trying to conceive. It’s not good enough” – 39, type 1 diabetes

“I have not received any information at all from my diabetes health care team” – 52, type 2 diabetes

“Focuses on sick day rules, so in that good but other concerns that were there before pandemic not really heard by health team” – 46, type 1 diabetes

- **Increased information on steps to take**

“MY SURGERY WERE NOT VERY HELPFUL REGARDING MY SHIELDING QUERY” – 49, type 1 diabetes

“Inform patients of what services are operating and how to book.” – 56, type 1 diabetes

“I’ve had no communication from healthcare team about what I should/shouldn’t be doing” – 29, type 1 diabetes

“When I had a hypo and was very mixed up and no one in the family intervened because of us being distanced inside the home. They kept an eye on me and I didn’t lose consciousness or falter but it would have been better if I’d been able to sit down and not completely mess up what I was doing.” – additional comment sent via e-mail, type 1 diabetes

- **Demonstrating availability if support is needed**

“Would be good to hear more of “please contact us if there is a problem” rather than always “stay away from the surgery.” – 47, type 1 diabetes

“Although I have contacted my diabetic nurse several times, the only reply I have received is a text message suggesting I go to diabetes UK website” – 64, type 2 diabetes

“I was told to go to a hospital, which is a fair distance from home, to collect a meter. Yet when I arrived, they didn’t have any. Bad communication.” – 56, type 1 diabetes

- **Individualised advice and communication**

“But in general I felt official guidance distinctly lacking for T1 & my team probably weren’t allowed to elaborate further regardless of their opinion on it.” – 42, type 1 diabetes

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"I was contacted via a generic email to say my team could be contacted but that they were v busy at this time. I do feel that a quick phone call or more personal email would have been good at some point over the last few months." – 50, type 1 diabetes

"Not had any contact however it appears shielding criteria varies by area - I have T1D and Rheumatoid Arthritis, was not told to shield by GP however Rheumatology Consultant believed I should have been identified to shield." – 49, type 1 diabetes

- **Transition to online and telephone across services**

"More expansion of online data availability (only some tests results uploaded), better synchronisation between GP and clinic data services, rapid adoption of telemedicine (video consult) services instead of clinic visits." – 62, type 1 diabetes

"Improve access to diabetes team by telephone" – 63, type 2 diabetes

Government:

- **Increased specificity: Insufficient details on risk across vulnerability categories and differences between diabetes types.**

"Information about diabetics was likely to be confusing - particularly as they rarely differentiate between T1 and T2 and its sometimes not obvious whether we should be lumped together." – 43, type 1 diabetes

- **Increased honesty and trustworthiness: Less political bias and transparency on the factors underpinning decisions on vulnerability and measures to be taken.**

"The government communications are untrustworthy and tainted by a constant wish to portray everything they do as right. I don't trust them." – 65, type 2 diabetes

"It should be easier to find detailed information and it would be better if it came across as completely open and trustworthy." – 61, type 1 diabetes

- **Increased consistency in messaging**

"Changing risk category of Diabetes since the beginning. Caused lots of confusion." – 36, type 1 diabetes

"Now the information appears to be more open to interpretation. – 50, type 1 diabetes

- **Increased clarity on vulnerability and measures to be taken.**

"Needs more clarity for people like me who are "vulnerable" but have not received the NHS letter" – 52, type 2 diabetes

"More clearer information on diabetes as we are at higher risk with over 25%of deaths being diabetic so more clearer info on what we should be doing" – 32, type 1 diabetes

- **Other**

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“Too little information given out too late for people to act on” – 33, type 1 diabetes

Diabetes UK

- **Increased visibility and access**

“I need to look on their site more often, it was only by chance I found them” – 80, type 2 diabetes

“Perhaps they should encourage diabetic advisers to suggest use of Diabetes UK and why.” – 62, type 1 diabetes

- **More active pressure on the government and news coverage**

“Petition the govt to confirm if we are high risk or shielded and what measures to take to keep us safe” – 35, type 1 diabetes

“Support diabetics. We are at very high risk we shouldn't be working. Every time I turn on the TV someone with asthma is telling me how much at risk they are, when in reality diabetics are at much greater risk. Please make us visible on TV and fight for our rights to shield.” – 39, type 1 diabetes

- **Increased specificity**

“Most of the dietary advice seems more geared to type 1 and doesn't help me to lower my type 2 blood glucose” – 61, type 2 diabetes

“Weighted heavily to T2 and old school diabetes management. Skewed by the headline that diabetes patients are more likely to die - but this is due to heavy incursions of T2 where the body is out and out failing in the >70 population, and this is not addressed.” – 35, type 1 diabetes

- **More and/or better information**

“It all looks very bland and because government took so long to talk about Covid risk for diabetics they offered nothing beyond. They should adopt the precautionary principle for the people who look to them” – 65, type 2 diabetes

“The advice that I read stated simply that following the guidance for other people is best and also that there were a lot of unknowns e.g. what risk to pre-diabetics. Clearly finding out what ought to be done would be better than not knowing.” – 32, type 1 diabetes

“The guidance I have seen from Diabetes UK has only repeated the Government information” – 54, type 1 diabetes

Social Media

- **Less sensationalism**

“Too [much] negativity and criticism which may be warranted but is equally tiresome” – 37, type 1 diabetes

“Sometimes stressful and scary” – 34, type 2 diabetes

- **Fact-checking and less opinionated**

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“More opinionated than factual. Not the best source of information at a glance.” – 19, type 1 diabetes

“Fake news and anti-vac messaging to be removed promptly” – 36, type 1 diabetes

“Often people give their own advice.” – 55, type 1 diabetes

News Channels

- **Fact-checking and pressure on politicians**

“Journalist questions are very superficial and about finding a story - few really take their mission to find the truth for the benefit of the public seriously” – 65, type 2 diabetes

“More challenge of government when information is inconsistent or ambiguous” – 48, type 1 diabetes

- **Increased specificity**

“Explain what the relevance of vulnerability to C-19 is in relation to what types of diabetics (type 1 or 2), those with complications etc, not just say 'diabetics'” – 47, type 1 diabetes

- **Increased consistency**

“Uses shielding and vulnerable interchangeably so no idea where I stand.” – 39, type 1 diabetes

“News can have different people who have different opinions which is difficult if you need facts.” – 29, type 1 diabetes

- **Less sensationalism and bias**

“They over emphasise the negatives and cause fear or anxiety.” – 77, type 2 diabetes

“Not good at providing objective advice, needs to be more focused” – 63, type 2 diabetes

“Seems to be very government biased” – 60, type 2 diabetes

“Report on facts and NOT what is going to attract audiences. Leave politics behind whilst we all do our best.” – 56, type 1 diabetes

Friends and Family

- **Less confidence in own knowledge**

“Too many people think they know more than they actually do!” – 61, type 2 diabetes

*“They all have a friend whose sister had diabetes and think they are experts
Different friends have different biases” – 41, type 1 diabetes*

Support needs people with diabetes and carers during COVID-19 pandemic

- **Increased understanding of condition and challenges**

“Unless you have an illness and keep being told about having a underlying illness is harmful during this time, you just don't understand. Plus everyone is dealing with other issues at the time.” – 47, type 2 diabetes

“Friends are a very important source of general support but they may not understand the particular challenges of coping with T1 diabetes” – 64, type 1 diabetes

“Better understanding of personal circumstances” – 63, type 2 diabetes

- **Increased contact and emotional support**

“I would like my family to be more involved, but they regard me as ‘the expert’.” – 54, type 1 diabetes

“No emotional support.” – 29, type 1 diabetes

Employers

- **Improved contact and communication**

“My employer is being ultra-cautious so aren't recommending anything. I would like them to tell me their guidelines for returning to work and when - but they haven't yet. OTOH they're not saying I have to return as yet.” – 53, type 1 diabetes

“No contact from manager at this time and waiting for information has made this time more stressful.” – 47, type 2 diabetes

- **Individualised advice for people living with diabetes**

“No specific policy for diabetics. Only general advice for people more vulnerable.” – 26, type 1 diabetes

“Got told I had to return to work, no discussion about how worried that made me. Had to email my Dr to ask if this was the case” – 52, type 1 diabetes

- **Improved understanding of diabetes**

“They struggle to get it” – 60, other type of diabetes

“They would be sympathetic if I raised diabetes-related issues, but my immediate managers have no personal experience or knowledge of Type 1 diabetes. It would be good if they were a little better informed, particularly, now, about the increased risks posed to people with diabetes by Covid-19.” – 54, type 1 diabetes

Appendix D: Factors that help respondents improve the support they provide to people living with diabetes

- **Increased support from the healthcare team in terms of:**

- **The mental wellbeing of the person with diabetes**

“We need more support from Diabetic Team because they haven’t got in touch since the start of the pandemic. My son is struggling with his mental and physical health (superstitious rituals, stress regarding future, insulin requirements vary depending how he feels and how your body responds to environment and diet and I am struggling to keep his glucose levels within normal range).” – 36, parent or carer of someone with diabetes

- **Own confidence in understanding diabetes and the person’s needs.**

“Was only diagnosed in the middle of the pandemic and even though there was support we were literally flying blind with the diagnosis. I still don't think I know everything. They threw so much information at me in 2 days it was very difficult to get my head around.” – 37, parent or carer of someone with diabetes

- **Diabetes management**

“More regular contact with paediatric diabetes team. I think they’ve done their best within the limitations of social distancing etc but my son was only diagnosed on 31 October 2019 so we’re still finding our feet with all this. He’s also autistic, which brings its own challenges.” – 40, parent or carer of someone with diabetes

- **More contact, preferably face-to-face**

“Sadly, I don’t think that anything could have improved the support other than seeing the person face to face which helps with their mental wellbeing. Regular telephone contact or video calling helped greatly.” – 31, parent or carer of someone with diabetes

“Contact from the GP - a shielding letter so that stress of employers needing official paperwork could be alleviated on both parties” – 49, partner of someone with diabetes

- **More information and guidance on:**

- **Recommended physical activity**

- **Diabetes**

- **Risk in relation to COVID-19**

- **Use of medical devices**

- **Training on how to support the person with diabetes**

“Online training for learning more about type 1 diabetes inc diet, how to work out calculations to change meter settings to reduce blood sugar and what to look out for with feet” – 43, parent or carer of someone with diabetes

“Which exercises can I do with my diabetic kid inside to help them stabilize their blood sugar. Not moving a lot results in too high blood sugar levels that are difficult to correct.” – 36, parent or carer of someone with diabetes

“Ability hasn’t changed but acceptance of help by a teenager & young adult is more problematic.” – 43, parent or carer of someone with diabetes

“What would help further is partners to be offered a course on Type 1 Diabetes. For further understanding from professionals. Currently there are none offered.” – 30, partner of someone with diabetes

Support needs people with diabetes and carers during COVID-19 pandemic

“Better understanding of mental health problems people have with long term conditions like diabetes and how to support someone struggling with diabetes management due to poor mental Health, it’s a bit of a vicious cycle” – 33, partner of someone with diabetes

“Better at calculating insulin and correct levels. Better at carb counting” – 24, partner of someone with diabetes

- **Practical help in:**
 - **Taking annual leave**
 - **Access to outdoor exercise facilities**
 - **Shielding**
 - **Obtaining food**
 - **Reducing stress**

“My work required me to be at work throughout the lockdown. With no NHS key worker status and my husband not being on the list to shield it has been exceptionally hard for me to cope with doing all the shopping, working, having all stress and worries with no support.” – 43, partner of someone with diabetes

“Also initially getting food for coeliac diet was hard and this was worrying” – 50, parent or carer of someone with diabetes

“There is very little support for uni students that have had to return home. We have no idea where appointments will be sent. “ – 52, parent or carer of someone with diabetes

“Easier access to monthly repeat medication via GP and pharmacy” – 55, parent or carer of someone with diabetes

- **Scaremongering**

“LESS ALARMIST ARTICLES ON TV” – 59, partner of someone with diabetes

Appendix E: Respondents’ opinions on how to improve information and support provided to people living with diabetes.

Healthcare

- **More contact**

“More support and general contact! Regularly phone calls to check how we are coping and definitely more insight into being aware” – 45, parent or carer of someone with diabetes

“Have been brilliant. And understanding. Maybe more video calls” – 37, parent or carer of someone with diabetes

“Health care team made no attempt to contact us throughout. We had to contact them repeatedly and it was only at our request that we got a HbA1c check and an updated healthcare plan for school but we were told that this plan did not need amended to reflect the impact of Covid.” – 45, parent or carer of someone with diabetes

- **Greater availability**

“Not heard anything from them and when called didn’t return calls” – 49, parent or carer of someone with diabetes

Support needs people with diabetes and carers during COVID-19 pandemic

"[The healthcare team] Don't have time" – 43, partner of someone with diabetes

- **More specific information**

"Clearer guidelines for teenagers with type 1" – 43, parent or carer of someone with diabetes

Government

- **Guidance that is more specific according to type of diabetes and level of vulnerability.**

"Not differentiate between type 1 and type 2. The Confusion between the vulnerable group and shielding group," – 43, parent or carer of someone with diabetes

"They cannot give specific advice to those who are in the high-risk category." – 42, partner of someone with diabetes

- **Guidance and support that is specific to children and their parents**

"More specific guidance and info for children/teens with type 1 diabetes. The same guidance sometimes referred to adults with diabetes, sometimes referred to people with diabetes, sometimes referred to people eligible for the flu vaccine and sometimes referred to adults eligible for the flu vaccine. Half the time my daughter was in these groups (a person with diabetes eligible for the flu vaccine) and half the time she didn't (a teenager, not an adult) which makes following the guidance difficult." – 44, parent or carer of someone with diabetes

"More clear on support for parents with children with diabetes, there has been no specific rules" – 42, parent or carer of someone with diabetes

- **Clearer and more consistent information**

"Frequently complex or unclear - should be simple and explicit" – 24, partner of someone with diabetes

"UK government poor/mixed messages" – 42, parent or carer of someone with diabetes

- **Policy and assistance that is suitable**

"Clearer guidance for patients & employers - issuing of more shielding letters" – 49, partner of someone with diabetes

"Food parcels are generic & not ideal for those on special diet plans." – 42, partner of someone with diabetes

"Provide general statement regarding the resumption of out-patient services and reassurance over the availability of insulin." – 52, parent or carer of someone with diabetes

- **Greater trustworthiness**

"More info relating to children/ people with diabetes- however there is also the issue of whether we trust info from this source" – 50, parent or carer of someone with diabetes

Diabetes UK

- **Separation of advice for adults and children**

"Information may be helpful to be separated into adults and children with diabetes and Covid." – 39, parent or carer of someone with diabetes

“Clearer guidelines for teenagers with type 1” – 43, parent or carer of someone with diabetes

- **More pressure on the government**

“Pressing for more specific info from government would help.” – 44, parent or carer of someone with diabetes

- **Greater and more simply presented information for parents**

“More clear for parents with children with diabetes” – 42, parent or carer of someone with diabetes

“More info on returning to school and work for people with diabetes and safety” – 50, parent or carer of someone with diabetes

“Make it simpler to navigate and use words that are easier to understand. Some of the jargon is overwhelming” – 37, parent or carer of someone with diabetes

Employer

- **Better informed**

“Clearer guidance for them from relevant sources” – 49, partner of someone with diabetes

“Laypeople often have generally poor understanding of diabetes - also increased HR/occupational health access and advice” – 24, partner of someone with diabetes

- **More detailed advice and support**

“Only advice was to use masks, keep distance from others (which is not possible in small working environments) and wash hands.” – 36, parent or carer of someone with diabetes

“More support for carers” – 45, parent or carer of someone with diabetes

“Often have to be the one to ask or initiate finding out information instead of being kept up to date without encouragement” – 20, partner of someone with diabetes

- **Monitoring adherence to guidance**

“My employer carried out risk assessment and advised home working husband employer has made no adjustments- inconsistent since we both work for public sector.” – 39, parent or carer of someone with diabetes

Family and Friends

- **Less advice based on own opinion**

“Not always helpful to talk to people who have their own personal feelings/opinions” – 45, parent or carer of someone with diabetes

“Not often fully informed” – 70, partner of someone with diabetes

- **Adherence to social/physical distancing guidelines**

“Friends do not seem to be up to date and aware with the current news and changes around the virus, nor do they bother to social distance or care about staying safe.” – 20, partner of someone with diabetes

- **Greater awareness of the condition and challenges**

Support needs people with diabetes and carers during COVID-19 pandemic

“Friends have no understanding about diabetes type 1. Therefore more awareness e.g Tele adverts etc” – 30, partner of someone with diabetes

“more understanding this is a serious thing” – 42, parent or carer of someone with diabetes

News channels

- **Improved research**

“Better research” – 40, parent or carer of someone with diabetes

- **Increased trustworthiness and reporting of sources**

“I do not trust they tell the complete truth.” – 36, parent or carer of someone with diabetes

“Stating sources” – 24, partner of someone with diabetes

- **Greater discussion of risk**

“Clearer guidelines for teenagers with type 1” – 43, parent or carer of someone with diabetes

“More diabetes and covid-19 risk discussed” – 31, parent or carer of someone with diabetes

- **Less scaremongering**

“I think the media went for too many scare tactics in reporting” – 45, parent or carer of someone with diabetes