

# Digitalising diabetes support groups in response to the coronavirus COVID-19 outbreak: a collaborative initiative

**Peer support groups are groups of people who share something in common and use their experiences to help each other. As the pandemic persists and health care teams are adjusting to the changing circumstances, facilitating access to peer support groups that can hold meetings via a digital platform can provide a unique source of additional help for diabetes self-management and mental wellbeing.**

## Diabetes care and COVID-19

The rapid spread of coronavirus COVID-19 worldwide has generated major disruptions in health care provision for diabetes diagnosis and treatment. Government-enforced stringent physical distancing measures and an NHS-wide COVID-19 prioritisation have resulted in the cancellation of routine check-up appointments, diabetes education sessions, and hospital services for non-urgent care. Health care teams have found themselves having to accelerate plans to increase remote disease monitoring and self-management, which can exacerbate inequalities in access to care.<sup>1</sup> Advice and recommendations have been provided based on a continuously evolving understanding of the pathogenesis and clinical manifestations of severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) in the context of diabetes and its comorbidities.

Early research already suggested that diabetes was a risk factor for severe COVID-19 outcomes.<sup>2</sup> This resulted in people with diabetes being considered as a 'clinically vulnerable' group. Individuals with certain comorbidities were instructed to shield as they were deemed to be 'clinically extremely vulnerable'. Accumulating evidence, however, is demonstrating that vulnerability to severe COVID-19 is highly variant among people with diabetes. Risk of in-hospital COVID-19 mortality is elevated in those individuals with

type 1 compared to type 2 diabetes mellitus (odds ratios 2.86 and 1.80 respectively), and modulated by factors such as sex, age, socioeconomic status and ethnicity.<sup>3</sup> More recently, the presence of obesity and poor glucose control have been identified to play a key role in individual response to COVID-19.<sup>3,4</sup> These latter findings have resulted in the International Diabetes Federation and health care teams emphasising the importance of glycaemic control. However, uncertainty around individual risk and pressure to succeed in self-management within a highly irregular social context, can add to the psychological burden linked with everyday diabetes management.

## Diabetes self-management during COVID-19

The introduction of lockdown by the government at the end of March 2020 has led to people with diabetes facing unprecedented challenges for diabetes self-management. Home confinement for prolonged time can result in boredom, which can facilitate increased energy intake.<sup>5</sup> Elevated anxiety and sleep disruptions in response to COVID-19<sup>6,7</sup> may trigger overconsumption of rewarding foods that are normally high in sugar.<sup>8,9</sup> Stockpiling when the lockdown was announced and restrictions on movement interfered with the food supply chain and access to certain foods.<sup>10</sup> Simultaneously, due to temporary closure of sporting facilities, suspension of group exercise activities, working from home and the initial limitations on outdoor exercise, people have had to find alternative approaches to adhere to physical activity recommendations. Difficulties in accessing medication and cancellation of follow-up appointments mean that monitoring and treating glycaemic spikes may have become more difficult. As the first lockdown was eased, people were asked to return to work and school when individual risk to severe COVID-19 was uncertain, augmenting diabetes

related stress that, in turn, can further interfere with glucose control.<sup>11</sup>

The need to adapt to changing circumstances, without the continued support from health care teams, is therefore posing a significant strain on the mental wellbeing of people living with diabetes. An ongoing survey distributed by the NIHR Bristol Biomedical Research Centre<sup>12</sup> is showing that around 37% of respondents with diabetes (n=773) view the guidance and support received by health care teams during COVID-19 to be of poor quality. A large majority of respondents have not had contact from their health care teams. Cancellations of appointments have left patients *'in limbo not knowing what to do'*. Some have taken the changes in health care availability as an opportunity *'to spend more time working on [their] control'*. Others report having *'given up on self-management'*, while others are managing but as a temporary measure and with elevated feelings of isolation. Family members are also unsure whether it is safe to intervene when a shielding individual is experiencing a hypoglycaemic episode and needs assistance. Although the majority express confidence in their diabetes self-management, 37.2% have indicated that their ability to take care of their mental wellbeing has been negatively affected by the pandemic.

## Peer support groups for continued support during COVID-19

Peer support can be defined as the advice and support that people who have lived a similar experience can provide to each other. Online peer support communities, such as Facebook groups and online forums, offer the opportunity to receive immediate guidance and informal health advice on specific issues. Composed of a smaller number of members, peer support groups meet regularly for more in-depth discussions, thus enabling the development of a rapport. With the development of trust, members gain

increased confidence in sharing personal experiences and address topics beyond the practical challenges of diabetes management. Although the evidence of the benefits of peer support for diabetes management remains primarily anecdotal, recent research has shown that it can improve clinical, behavioural, and psychosocial outcomes.<sup>13</sup>

Given the interrupted care and storm of challenges that people living with diabetes are still experiencing because of the COVID-19 pandemic, peer support groups may hence be extremely valuable. However, peer support groups are traditionally face-to-face and current physical distancing restrictions require a shift towards technology-mediated group meetings. Diabetes UK, which has over 300 volunteer-led diabetes support groups across the United Kingdom, has already seen some of its groups independently transition to alternative means for continued mutual support. This includes the adoption of Zoom, WhatsApp and Skype. Yet, as health care teams are increasingly recognising, there are challenges to technology-assisted adult diabetes care and the development of digital support for people with diabetes must be user-oriented.<sup>14,15</sup>

### Digitalising diabetes peer support groups

Based on calls for support from people with diabetes across the UK, the NIHR Bristol Biomedical Research Centre (University Hospitals of Bristol and Weston NHS Foundation Trust and University of Bristol) partnered with the Diabetes UK South West Team to re-activate and evaluate peer support group meetings using a digital platform. The project, funded by the Elizabeth Blackwell Institute, aims to adopt a user-led approach, and generate material to overcome the challenge where unfamiliarity with technology is a barrier to access.

During April 2020, people living with type 1 and type 2 diabetes aged 18 years or over were invited to take part in focus group discussions via a secure cloud-based software platform. All participants were sent out instructions and a short video to guide them when joining. Three focus groups were run successfully, lasting approximately 75 minutes each. Overall, 16 people with diabetes took part, aged 18 to

65 years and with varying familiarity with virtual meetings. Several topics were discussed:

- What are the expected benefits of peer support groups during the COVID-19 pandemic?
- What are the initial thoughts when told about the possibility to meet regularly with other people with diabetes using a digital platform?
- How might the structure of peer support groups be different if online? And should there be different rules?
- What is the role of facilitators if meetings are online?
- How can we encourage people with diabetes who are less familiar with technology to take part?
- What platform should be used? Are there concerns regarding privacy of these platforms?
- What kind of support would people need to get started? And in what format should it be provided?

The information generated from the discussion was then grouped to develop two sets of written guidelines, one for people who wanted to join a peer support group and one for those who were keen on setting up and facilitating peer support groups. There was consensus that the groups should be able to independently decide the objective and structure of the group, with an external entity to provide guidelines and support when needed. Participants valued the possibility of talking with others who have diabetes and can therefore emphasise more with their personal situation. The added anonymity of communicating via a digital platform was seen as an opportunity to facilitate 'sharing' of personal experiences and express emotional distress – an identified problem in existing formats of virtual consultations.<sup>14</sup>

Short videos are being developed, tailored to the needs for peer support group meetings and the target population. The videos additionally address common technological difficulties people may encounter.

### Feasibility of digital peer support groups

The usefulness of peer support group meetings run via digital platforms will be assessed in conjunction with the Diabetes UK South West Team. Acceptability, access, feasibility, and

impact on wellbeing of digital peer support groups will be evaluated by asking peer support groups members to complete a short survey at the end of every meeting. The survey captures participants' experience with online meetings, ease of access to the meetings and identified benefits/barriers to the online format of meetings. We will additionally monitor attendance to the meetings (total number of participants) to examine engagement over time.

Diabetes UK has developed a training module for people who want to run peer support groups using digital platforms (volunteer facilitators). The training consists of a half-day online training, plus pre-work accessed via the online training platform Moodle. It is designed by Diabetes UK to address diabetes-related topics (e.g. healthy eating and diabetes, and the impact diabetes can have on your mental wellbeing) and characteristics specific to digital meetings that need to be taken into account (e.g. safeguarding, ensuring confidentiality, encouraging participation). This training is offered to anyone who wants to volunteer to set up a new group or wants assistance in shifting their existing group to online meetings. Following training, volunteers receive help in setting up and recruiting members if needed. Facilitators are additionally encouraged to seek help from the Diabetes UK local volunteer team if they encounter difficulties or need further advice.

The content of discussions during the focus groups was relayed to the Diabetes UK South West Team during the design of training. The guidelines and video support created from this research project will be available alongside the training programme. In the upcoming months, the Diabetes UK South West Team will provide training to facilitators of local groups with an interest in shifting to online platforms, and individuals who would like to set up new groups. The evaluation process will be carried out via coordination with these individuals, supervised by the Diabetes UK South West Team.

The peer support group facilitators will contact group members to inform them of the research project. Involvement in the peer support

group will not be contingent on participation in the research project. As such, the evaluation process will take place at a group level (keeping a record of number of attendees in each meeting), and individual level (survey). Individuals looking for a peer support group may decide to join the group but not provide feedback.

Data collected from this small-scale initiative will be used by Diabetes UK to evaluate this format of peer support group meetings and make any necessary adjustments to the training module before offering the training UK-wide. It will aid to identify technology issues that people may encounter and for which we need to provide additional guidance. We expect it will also provide a blueprint on how an initiative to address an urgent need can be launched and further developed through the collaboration between researchers and the third sector.

### Benefits beyond COVID-19

Within the timeframe of the pandemic, technology-mediated peer support groups enable their members to receive and provide continued support for everyday diabetes management. The structure and function of the group is determined by their members. This therefore accommodates for the variable support needs of individual people living with diabetes. Being digital, this novel format of peer support groups is equally accessible regardless of individual risk of severe COVID-19 outcomes. These groups are also not dependent on changes in prioritisation of NHS services, as assistance in setting up or joining a group is provided by Diabetes UK.

This initiative yields benefits beyond the pandemic, emphasising its long-term value. Many people still prefer face-to-face meetings for peer support and will revert to this traditional format when possible. However, digital peer support group meetings can overcome barriers to joining face-to-face meetings. These include distance, transportation, mobility, caring responsibilities, schedule, and social anxiety. The added sense of anonymity generated by the online format may also be a useful alternative through which individuals can find a 'safe space' to share personal issues

and emotional distress. Hence, this format of peer support group meetings should be available as an option even when circumstances permit face-to-face meetings.

### Scaling up: what challenges do we face?

Access remains an issue. Despite the proliferation of digital interventions as a cost-effective approach to augment access to health care services, usability by under-served and disadvantaged groups is limited.<sup>16</sup> Peer support groups as a source of guidance and support may overcome obstacles encountered by one-size-fits-all digital interventions and advice (e.g. education, culture). At present, however, it cannot address financial barriers (e.g. access to a suitable computer and internet connection). Although physical distancing regulations imposed to address COVID-19 have heightened technology uptake in older age groups, we still struggle to engage with more isolated older adults, who are also the ones that may benefit the most from joining peer support groups. Additionally, we need to increase our efforts to provide training and guidance in other languages. In this manner, communities where English is not the first language, will also be able to benefit from this form of support.

Further cross-sector collaboration is essential to increase the visibility and access to these types of initiatives. Health care services can increase awareness of the peer support group programme by providing patients with the contact details of their local Diabetes UK office ([https://www.diabetes.org.uk/get\\_involved/volunteer/contact-us](https://www.diabetes.org.uk/get_involved/volunteer/contact-us)), via text message or through a notification in their patient portal. As health care provision is resumed, either in-person or via a digital platform, practitioners may be particularly well placed to identify individuals who can benefit from the programme. Future development of an integrated screening and referral system with health care commissioners may streamline the process of guiding people with diabetes to groups that may be best suited for their needs.

If there is an exponential rise in interest in peer support groups, partnerships among organisations and/

or additional resources may be needed. The focus group discussions revealed that online meetings should not exceed eight members to permit meaningful participation from all. Each group should have a facilitator to organise and lead group meetings, with the assistance of a co-facilitator. Mentors involved in the Brigstowe Diabetes Peer Support project (<https://www.brigstowe.org/diabetes/>), who have had to transition to alternative formats of one-to-one mentorship (e.g. WhatsApp and Zoom), have stressed the confidence required to volunteer as a facilitator especially if the meetings are online. Providing additional external support can encourage more people with diverse backgrounds and varying levels of technology literacy to volunteer as facilitators.

In the long run, peer support groups that meet via digital platforms may be a cost-effective and accessible source of additional support for people living with diabetes, that is resilient to inequalities or changes in accessibility to health care services. Effective coordination between researchers, relevant charities, and health care teams can ensure that the programme is accessible, user oriented, and appropriately monitored.

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