Changing the narrative around obesity in the UK: a survey of people with obesity and healthcare professionals from the ACTION-IO study

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ABSTRACT

Objectives To investigate the perceptions, attitudes, behaviours and potential barriers to effective obesity care in the UK using data collected from people with obesity (PwO) and healthcare professionals (HCPs) in the Awareness, Care, and Treatment In Obesity maNagement–International Observation (ACTION-IO) study.

Design UK’s PwO (body mass index of ≥30kg/m2 based on self-reported height and weight) and HCPs who manage patients with obesity completed an online survey.

Results In the UK, 1500 PwO and 306 HCPs completed the survey. Among the 47% of PwO who discussed weight with an HCP in the past 5 years, it took a mean of 9 years from the start of their struggles with weight until a discussion occurred. HCPs reported that PwO initiated 35% of weight-related discussions; PwO reported that they initiated 47% of discussions. Most PwO (85%) assumed full responsibility for their own weight loss. The perception of obesity-related comorbidities was cited by 76% of HCPs as a top criterion for initiating weight management conversations. The perception of lack of interest (72%) and motivation (61%) in losing weight was reported as top reasons by HCPs for not discussing weight with a patient. Sixty-five per cent of PwO liked their HCP bringing up weight during appointments. PwO reported complex and varied emotions following a weight loss conversation with an HCP including supported (36%), hopeful (31%), motivated (23%) and embarrassed (17%). Follow-up appointments were scheduled for 19% of PwO after a weight discussion despite 62% wanting follow-up.

Conclusions The current narrative around obesity requires a paradigm shift in the UK to address the delay between PwO struggling with their weight and discussing weight with their HCP. Perceptions of lack of patient interest and motivation in weight management must be challenged along with the blame culture of individual responsibility that is prevalent throughout society. While PwO may welcome weight-related conversations with an HCP, they evoke complex feelings, demonstrating the need for sensitivity and respect in these conversations.

BACKGROUND

The causes of obesity are complex and multifaceted, encompassing biological, genetic, environmental, economic, social and psychological factors. The chronic and relapsing nature of obesity is associated with many serious physical and psychological comorbidities, reduced quality of life and increased healthcare costs. The WHO has recognised obesity as a disease, and the National Institute for Health and Care Excellence provides guidance on its assessment and treatment. Strengths include the scientific rigour in the study design and implementation. The large number of UK respondents and the ability to directly compare the UK data to the equivalent global dataset is an additional strength. Limitations of this study include possible response bias from the population sampled and recall bias.

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Strengths and limitations of this study

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► The large number of UK respondents and the ability to directly compare the UK data to the equivalent global dataset is an additional strength.
► Limitations of this study include possible response bias from the population sampled and recall bias.

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estimated to reach £49.9 billion per year.\textsuperscript{11} The significant increase in the prevalence of obesity has not been matched by a proportionate expansion of continuing education on the biological basis and clinical management of obesity and training provision for healthcare professionals (HCPs), irrespective of their discipline.\textsuperscript{12} Moreover, little effort has been made to address weight stigma and societal effects of weight bias, which continue to be experienced in a consistently negative way by those who have excess weight or obesity. Current evidence demonstrates that weight stigma is widespread in the UK,\textsuperscript{13} that weight stigma is experienced in many settings\textsuperscript{14 15} and that experience of stigma is associated with negative psychosocial outcomes, increased eating, reduced engagement with physical activity and weight gain.\textsuperscript{16}

The variability of causal pathways of weight gain is inherently unsuited to a ‘one size fits all’ treatment approach.\textsuperscript{1} There is a range of existing guidance to support practice and care throughout the obesity care pathway in the UK.\textsuperscript{9 17} However, the extent and range of the provision of weight management services is inconsistent and geographically dependent.\textsuperscript{18} The obesity care pathway has an important role within the whole systems approach to tackling obesity, as outlined in the Foresight’s report,\textsuperscript{1} and endorsed in the Department of Health and Social Care’s (DHSC) Call to Action\textsuperscript{19} and the Public Health England’s paper on a whole systems approach to obesity.\textsuperscript{20} The DHSC clinical policy outlines a tiered system of obesity care with a focus on public health and community advice in tier 1; primary care, community interventions and pharmacotherapy in tier 2; multi-disciplinary weight management service in tier 3 and secondary care and bariatric surgery in tier 4.\textsuperscript{21}

Despite its wide global prevalence, obesity remains poorly understood by the general public and HCPs, and this contributes to the high levels of stigma associated with obesity.\textsuperscript{22} Society is continually informed through intense media coverage that obesity is simple and easily manipulated.\textsuperscript{23} This attitude contributes to greater perceptions of individual responsibility, contrary to evidence that suggests that many factors outside a person’s control influence obesity.\textsuperscript{22 23} To improve the quality and accessibility of obesity care, a better understanding of the disease and the gaps between current and optimal obesity management strategies is required. The Awareness, Care, and Treatment In Obesity maNagement–International Observation (ACTION-IO) study assessed the perceptions, attitudes and behaviours of PwO and HCPs.\textsuperscript{24} The global dataset revealed a need to increase understanding of obesity and improve education concerning its aetiology. The aim of this subanalysis was to identify the perceptions, attitudes, behaviours and potential barriers to effective obesity care in the UK.

**METHODS**

**Study design and participants**

The ACTION-IO study was a cross-sectional, non-interventional study that collected data via an online survey in Australia, Chile, Israel, Italy, Japan, Mexico, Saudi Arabia, South Korea, Spain, the UK and the United Arab Emirates. The full methods for the ACTION-IO study have been reported previously.\textsuperscript{24} Eligible PwO in the UK were 18 years or older, with a current BMI of at least 30 kg/m\textsuperscript{2} based on self-reported height and weight. The PwO sample was targeted for demographic representativeness based on gender, age, income, race/ethnicity and region. Therefore, PwO were excluded if they declined to provide any of these variables. Respondents were also excluded for non-obesity reasons, for high BMI or for dramatic weight loss, that is, if they were pregnant, participated in intense fitness or body building programmes, or had significant, unintentional weight loss in the past 6 months. Eligible UK’s HCPs were in practice for 2 years or more, with at least 70% of their time spent in direct patient care, and who had seen 100 or more patients in the past month, at least 10 of whom had a BMI of at least 30 kg/m\textsuperscript{2}. HCPs specialising in general, plastic or bariatric surgery were excluded. Respondents were recruited via online panel companies (via email) to whom they had given permission to be contacted for research purposes, and completed the survey in English. All respondents provided electronic informed consent prior to initiation of the screening questions and survey. Preceding participation, PwO were only informed of the purpose of the study, and were blinded to the specific study goals.

**Survey development and procedures**

The study was designed by an international steering committee of obesity experts (representing primary care, endocrinology and psychology, and including three medical doctors employed by Novo Nordisk), with support from KJT Group (Honeoye Falls, New York, USA), and based on the ACTION US and Canada questionnaires.\textsuperscript{20 26} KJT Group managed the acquisition and analysis of data; UK responses were collected between September 2018 and October 2018. Questionnaire items were carefully phrased and presented in identical order for each respondent. Items in a list were displayed in alphabetical, categorical, chronological or random order as relevant for each response. Respondents accessed the survey using a unique web link, details regarding the digital fingerprinting system used to assess unique site visitors has been previously described.\textsuperscript{24} To prevent duplicate survey entries, unique site visitors were recorded via a user ID that was passed along the unique web link that respondents used to access the site. The system checked every respondent entering the survey against previous user IDs logged in its database. Respondents who began the survey and suspended were able to re-enter the survey while it was still open and finish the survey where they left off. Respondents who had already received a terminal status (complete, over-quota or terminate) were blocked from re-entering the survey. Following closure of the survey, no users were able to gain access. The user ID and data of suspended respondents were stored until the
### Table 1  Sample demographics and characteristics

| Recruitment and qualification* | UK’s PwO (n=1500) | HCPs (n=306) |
|-------------------------------|--------------------|--------------|
| Total survey invitations sent | 69676              | 2508         |
| Respondents                   | 9786               | 886          |
| Respondents who completed screening questions | 9779       | 737          |
| Respondents who qualified     | 2146               | 387          |
| Respondents who qualified and completed validated survey | 1500 | 306          |
| Age, years (range)            | 55.7 (19–88)       | 48.9 (28–68) |
| Gender, n (%)                 |                    |              |
| Male                          | 687 (45.8%)        | 225 (73.5%)  |
| Female                        | 811 (54.1%)        | 81 (26.5%)   |
| Other                         | 2 (0.1%)           | –            |
| BMI classification, n (%)     |                    |              |
| Respondents†                  | 1500 (100%)        | 236 (77.1%)  |
| Underweight or healthy range (<25 kg/m²) | –          | 152 (64.4%)  |
| Overweight (25–29.9 kg/m²)    | –                  | 72 (30.5%)   |
| Obesity Class I (30–34.9 kg/m²) | 883 (56.2%)  | 7 (3.0%)     |
| Obesity Class II (35–39.9 kg/m²) | 333 (22.4%) | 2 (0.9%)     |
| Obesity Class III (≥40 kg/m²)  | 284 (18.1%)        | 3 (1.3%)     |
| Number of comorbidities, n (%)|                    |              |
| 0                             | 264 (16.9%)        | –            |
| 1                             | 360 (25.0%)        | –            |
| 2                             | 330 (22.2%)        | –            |
| 3                             | 257 (16.0%)        | –            |
| ≥4                            | 289 (20.0%)        | –            |
| HCP category, n (%)           |                    | 306 (100%)   |
| PCP                           | –                  | 156 (51.0%)  |
| SCP                           | –                  | 150 (49.1%)  |
| Endocrinologist               | –                  | 43 (14.1%)   |
| Cardiologist                  | –                  | 51 (16.7%)   |
| Obstetrician-gynaecologist    | –                  | 16 (5.2%)    |
| Other                         | –                  | 40 (13.1%)   |
| Obesity specialist,‡ n (%)    |                    |              |
| Yes                           | –                  | 162 (52.9%)  |
| No                            | –                  | 144 (47.1%)  |

All ‘n’ sizes for PwO are from unweighted data. Demographic percentages (age and gender) are also from unweighted data. All non-demographic percentage results are for PwO weighted data. HCP data were not weighted; therefore, n sizes and percentages are all unweighted data.

*Participation rate (those who completed the screener) was 99.9% for PwO and 84.7% for HCPs; completion rate was 100% for PwO and 85.8% for HCPs.

†Disclosure of height and weight was optional for HCPs. The percentages for the BMI categories were calculated using the number of respondents to this question as the denominator.

‡A physician who meets at least one of the following criteria: at least 50% of their patients are seen for obesity/weight management; or has advanced/formal training in treatment of obesity/weight management beyond medical school; or considers themselves to be an expert in obesity/weight loss management or works in an obesity service clinic.

BMI, body mass index; HCP, healthcare professional; PCP, primary care professional; PwO, people with obesity; SCP, secondary care professional.
survey was closed and were then eliminated from the data analysis. The study was conducted in accordance with the Guidelines for Good Pharmacoepidemiology Practices.27

To ensure representativeness to the general population, the final PwO sample was weighted to demographic targets within each country for age, gender, income, race/ethnicity and region. The HCP data were not weighted. Only data from those who completed the survey were included in the analyses.

Patient and public involvement
No patients or members of the public were involved in the design or conduct of the study. A patient representative was involved in the analysis and interpretation of the UK data and is an author on this article. She was also involved in disseminating these findings to a wider audience.

RESULTS
Demographics
A total of 69676 PwO and 2508 HCPs, in the UK, were invited. The response rate to the survey was 14% (9786/69676) for PwO and 35% (886/2508) for HCPs, as expected for this type of study and in line with the target sample size.24 Of those who completed the screening questions, the eligibility rate was 22% (2146/9779) for PwO and 53% (387/737) for HCPs. The final UK sample for the ACTION-IO survey was 1500 PwO and 306 HCPs, of whom 156 were primary care professionals (PCPs) and 150 were secondary care professionals (SCPs) (table 1). Some differences were observed in the survey outcomes between PCPs and SCPs, which will be reported in full at a later date.

Pre-consultation and initiation of weight management discussion
People with obesity
Only about half (47%) of all PwO had discussed excess weight or losing weight with an HCP in the past 5 years. It took a median of 6 years and mean of 9 years (range: 0.0–56.0 years; IQR: 13 years) between the time when PwO said that they first started struggling with excess weight or obesity and when they first had a weight management conversation with an HCP (figure 1A). In comparison, globally it took a median of 3 years and a mean of 6 years (range: 0.0–68.0 years; IQR: 8 years (figure 1A)).24 Forty-seven per cent of PwO who discussed weight with an HCP reported that they initiated the conversation themselves. When PwO were asked to name the top five reasons why they may not discuss weight management with their HCP, the most common reason was the belief that it was their own responsibility to manage their weight (51% of PwO) (figure 1B). Indeed, when asked whether they agreed with the statement ‘my weight loss is completely my responsibility’, 85% of PwO agreed with the statement. Thirty-four per cent of PwO said that they were motivated to lose weight, and 36% provided a neutral response (neither agreed nor disagreed that they were motivated). Only 4% of PwO reported an indifference to losing weight as a reason for not discussing managing their weight with an HCP. Sixty-five per cent of PwO who previously had a weight conversation with their HCP liked that their HCP discussed their weight with them, and 58% who did not previously had a conversation would have liked their HCP to bring up weight during their appointments. Most PwO (81%) believed that obesity has a large impact on overall health, similar to other chronic diseases such as diabetes (82%), stroke (88%), cancer (82%) or chronic obstructive pulmonary disease (COPD; 84%). The internet was cited as a source of information used by 31% of PwO for managing weight (figure 2A). Other sources of information were reported as family and friends (27%), weight loss programmes (26%), information from an HCP (25%) and media (books/magazines: 21%, television programmes: 20%) (figure 2A).

Healthcare professionals
Those HCPs who discussed weight with their patients reported that 35% of the time the patient initiated the conversation. Compared with PwO (85%), a smaller proportion of HCPs (33%) placed the responsibility for weight loss on PwO. Only 13% of HCPs thought that their patients were motivated to lose weight, and 42% provided a neutral response (neither agreed nor disagreed that their patients were motivated). The most commonly selected reason for not discussing weight management with a patient (selected by 72% of HCPs) was the perception that the patient was not interested in losing weight, and 61% of HCPs selected lack of patient motivation (figure 1C). Other reasons provided for not discussing obesity with a patient were that the appointments were not long enough and that they felt rushed (selected by 68% of HCPs), and that more important health issues/concerns were an impediment to discussing obesity with a patient (selected by 58% of HCPs). In addition, almost one-third of HCPs (31%) reported that the good health of a patient and the absence of weight-related comorbidities would be a reason for not discussing weight management. The most important criterion for initiating weight management conversations with a patient was the presence of obesity-related comorbidities, cited by 76% of HCPs. Only 68% of the UK’s HCPs (vs 76% of global HCPs)24 recognised the impact of obesity on health, and it was rated as less serious than diabetes, cancer, stroke or COPD by 40%, 65%, 62% and 43% of the UK’s HCPs, respectively.

Consultation
People with obesity
Eighty-one per cent of the PwO who had discussed weight with an HCP had had a discussion with a PCP, 42% with a nurse, 18% with a dietitian/nutritionist and 17% with a diabetes educator. PwO reported a complex mixture of feelings following a weight loss conversation with an HCP (figure 2B). PwO cited a combination of feelings
such as supported 36%, hopeful 31%, motivated 23%, embarrassed 17%, indifferent 16%, discouraged 11%, relieved 10%, blamed 10%, rushed 10%, offended 4% and confused 4% (figure 2B).

Healthcare professionals
Fifty-nine per cent of HCPs reported that they were extremely or very comfortable discussing weight, 30% were neither comfortable nor uncomfortable and 11% were a little or not at all comfortable discussing weight. On average, HCPs reported that they spent 10 min interacting with their patients when discussing weight (range: 1–20 min).

Consultation outcomes and follow-up
People with obesity
Among the 47% of PwO who had discussed their weight with an HCP in the past 5 years, 49% reported that they had been diagnosed with obesity in the past by an HCP (24% of all PwO, figure 3). Only 19% of PwO who had discussed their weight with an HCP had a follow-up appointment scheduled (9% of all PwO) (figure 3). However, 62% of PwO would have liked a follow-up appointment and 96% reported attending or planning to attend a follow-up appointment if scheduled. The most frequent methods for managing weight tried by PwO were general improvements in eating habits/reducing calories (reported by 61% of PwO) and general increases in physical activity (55%), which were reported at a greater frequency than by global PwO (51% and 39% for general eating habits and physical activity, respectively; ACTION-IO study steering committee, personal communication). Bariatric surgery and behavioural therapy referral rates were reported in small numbers by the UK’s PwO (1% and 2%, respectively). Visits to a nutritionist/dietician and obesity specialist were reported less frequently by the UK’s PwO than global PwO (nutritionist/dietician: 11% UK, 24% global; obesity specialist: 2% UK, 9% global; ACTION-IO study steering committee, personal communication).

Healthcare professionals
On average, HCPs scheduled follow-up appointments with 33% of their patients for obesity and 46% of HCPs said...
that patients kept these follow-up appointments always or most of the time. HCPs most frequently recommended general improvements in eating habits/reducing calories (reported by 61% of HCPs) and general increases in physical activity (65%). Referrals to obesity specialists were recommended less frequently by UK HCPs (12%) compared with the global dataset (23%).

**DISCUSSION**

PwO are faced with biological predispositions, and societal and environmental conditions that contribute to obesity, weight stigma and discrimination. Obesity prevention and management are key health priorities and require a whole systems approach. However, the national response for obesity focuses on individual responsibility regarding nutrition and lack of physical activity. In this study, multiple barriers to effective weight management were identified, which are summarised in figure 4 and discussed below.

**Initiation of weight management discussion with HCPs**

Fewer than half of PwO in the UK (47%) had a discussion with an HCP about their weight in the past 5 years, despite HCPs being the gateway to weight management care in the NHS. Moreover, for the PwO who did have a weight discussion, it took a mean of 9 years after they first started struggling with their weight before having the discussion (compared with 6 years globally). This delay is particularly important as it may create an opportunity for significant obesity-related complications to develop. This long delay may also reflect a higher degree of obesity stigma in the UK and a culture of individual responsibility for obesity. Indeed, a focus on individual responsibility is reflected in UK government policy on obesity. Reducing the time gap by initiating earlier weight management discussions may be an effective strategy for improving obesity treatment and preventing the development of comorbidities.

From the PwO perspective, a delay in seeking help could be linked to the high percentage (85%) of PwO who perceived their weight loss as completely their responsibility. From the HCP perspective, a delay in discussing obesity with a patient could be linked to reported perceptions that the patient was not interested or motivated in losing weight, consistent with previous research. Other impediments to the discussion were HCPs’ views that there were more important health issues to discuss and that a weight management discussion is only required when weight-related comorbidities
are present, as supported by other studies.33 34 Moreover, HCPs in the UK underestimated the effect of obesity on health to a greater extent than the UK’s PwO and global HCPs.24 For PwO, this will likely require a change in the narrative around obesity to lessen focus on individual responsibility, and for HCPs a need to increase the understanding of the health consequences of obesity and the desire of PwO for help and support. The internet, media, and family and friends formed a substantial source of information for PwO for managing weight. We need to change this from personal responsibility to recognising the aetiology of obesity and its implications for PwO.

Consultation
Primary care is the gateway to obesity treatment, and most weight management discussions were held with a primary care physician or nurse. While many PwO welcomed weight discussions with HCPs, they also reported experiencing complex and varied emotions after these discussions. It is important to acknowledge the complexity of the experience for PwO. Studies have previously reported patients feeling that their obesity had been ignored, dismissed, distorted or attributed as the explanation of all their health problems by HCPs.35–37 Negative experiences can contribute to depression, anxiety, low self-esteem and body dissatisfaction.38 39 Dissatisfactory conversations with an HCP may discourage PwO from seeking further weight management help in the future and reinforce feelings of personal responsibility for weight management. The attitudes of health professionals towards obesity and its management have been generally reported to be negative, and knowledge and skills in managing obesity have been noted to be inconsistent.40–45 Even well-intended acts can cause offence and humiliation,46 and PwO often experience their weight in profoundly negative ways as a result of the pervasive stigmatisation of obesity. Patient experiences are valid indications of the strengths and shortcomings of the services they receive.17 It is important to ensure that the narrative around obesity resonates with the lived experiences of those affected by it and encourages patients to engage with an HCP.47 HCPs in turn should aim to provide compassionate care that is free of bias and use supportive communication and language to facilitate successful and meaningful conversations.47

HCPs often have limited time and resources, and lack of time has previously been reported as a barrier to discussing obesity.48 49 More HCPs in the UK (68%) than globally (54%) indicated that the limited appointment time would be a factor in not having a weight loss conversation.24 This may be a reflection of the average primary care consultation time in the UK, which is 10 min and considerably shorter than in many other countries.50 51 Other potential barriers described in the literature have included uncertainty about appropriate language,48 concerns about compromising rapport9 and concerns discussing a potentially upsetting and stigmatising topic.22 50 52 However, in this study, relatively few HCPs reported discomfort with weight discussions.

Consultation outcomes and follow-up
Obesity diagnoses, follow-up appointments and referrals to specialists were infrequently reported by PwO, which could incorrectly reinforce the feeling of individual responsibility. Indeed, methods for managing weight reported by PwO, which relied largely on general improvements in eating habits and physical activity, suggest a lack of knowledge of effective treatment methods and/or a consequence of the availability of therapeutic options (see below).

The data from HCPs on the frequency of follow-up appointments and methods for obesity management largely aligned with the data from PwO. Barriers to effective
weight management cited in the literature have included lack of effective and individualised treatment and/or referral options.40 41 50 53 Weight management services in the UK exist as part of fragmented health and social care systems, which are geographically dependent.49 54 55 The range of services and treatments, including pharmacotherapy and bariatric surgery, is limited in the UK, which may restrict HCPs in what they can offer patients. Indeed, HCPs report insufficient management options and scepticism about their efficacy.56 57 This is further compounded by limited consultation times for the UK’s general practitioners.50 51 The limited availability of weight management services, effective treatments and coherent, joined-up strategies in the UK health system are significant barriers to providing effective obesity care.53

**Strengths and limitations**

Strengths of this study include scientific rigour in the study design (including carefully phrased and ordered questions to prevent biased responses, blinded purpose of the survey for PwO and determination of eligibility by initial screening questions to eradicate bias during recruitment) and implementation (including stratified sampling to provide a representative cohort of the general population and rigorous data analysis). Other strengths include the large number of UK’s PwO and HCP respondents and the ability to directly compare the UK data to the equivalent global dataset. Limitations include the cross-sectional design and reliance on accurate reporting from the PwO and HCP respondents, which could be perceived as recall bias. The self-reported height and weight could underestimate the BMI of the PwO. A higher proportion of HCPs than might be expected self-identified as obesity specialists using the broad criteria specified in table 1. The low response rates could affect sample representativeness and is a known limitation for this type of study. Response bias from the population sampled cannot be ruled out. However, the PwO sample was representative of the demographics of the general population.

**CONCLUSION**

This study demonstrates the need to change the narrative around obesity, with less stigmatising focus on individual responsibility, for the government, commissioners, general public, PwO and HCPs. The findings identified areas that prevent PwO from seeking help and receiving appropriate care. In addition, the attitudes of HCPs prevent them from offering the support PwO require for obesity management. The consultation about weight with an HCP is the gateway to treatment in the NHS and improving the frequency and quality of PwO–HCP conversations is essential. Sufficient time should be given to HCPs to approach the topic of overweight and obesity sensitively and effectively. The current survey did not have high numbers of people with a BMI of over 40 kg/m²; further research is required to understand whether people with higher BMIs have distinct experiences in the management of their obesity.

To conclude, a whole systems approach is required to address and eliminate weight bias and stigmatisation, to change the narrative around obesity in the UK, and to improve provision of NHS services. Educating the whole population, including PwO and HCPs, about the aetiology and psychology of obesity and the interaction with the obesogenic environment should help to ensure that patients access and receive quality care and effective weight treatment and management. Changing the narrative around obesity will allow for a more effective delivery framework for health service providers and greater access to effective treatment pathways and weight management services for PwO.

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**Patient and public involvement** Patients and/or the public were not involved in the design, or conduct, or reporting, or dissemination plans of this research.

**Patient consent for publication** Not required.

**Ethics approval** The National Health Service Health Research Authority (Central Research Ethics Committee, London) advised that ethical approval was not needed in the UK.

**Provenance and peer review** Not commissioned; externally peer reviewed.

**Data availability statement** Data are available upon reasonable request. De-identified participant data will be made available for this article on a specialised SAS data platform. Datasets from Novo Nordisk will be available permanently after completion of data analysis. Access to data can be made through a request...
requesting access to data. Data use is subject to approval by the independent review board.

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