



Research Paper

Disparate healthcare experiences of people living with overweight or obesity in England

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ABSTRACT

Background: Ensuring that patients have high quality, equitable experiences in healthcare is a high priority in the UK. As such, identifying and addressing areas where patient experiences are unsatisfactory and inequitable is of high priority, and has been included as part of the National Health Service (NHS) England equity objectives.

Methods: The healthcare experiences of people who identified as living with overweight or obesity were gathered from freely available websites using the Patient Experience Platform (PEP). PEP was used to gather and analyse all comments from NHS UK, Google, Facebook and Twitter that related to care experiences of people who identified as living with overweight or obesity across all NHS Acute and Specialist Trusts and all general practitioners (GPs) in England from 01/01/2018 to 31/12/2020. These healthcare experiences were analysed to provide care quality metrics, a comparison of care across regions of England, and to explore associations between behavioural clusters of personality attributes, values and sentiment with care quality metrics.

Findings: Perceptions of the quality of care were significantly lower for people who identified as living with overweight or obesity compared to people who didn't identify as living with overweight or obesity across all regions for 'Effective Treatment' and 'Emotional Support'. The perceived quality of care metrics can be predicted by the behavioral clusters, where for instance, the experiences of people who identified as living with overweight or obesity in the negative behavioral cluster have a lower overall perceived quality of care score. Themes arising from the data also highlighted that barriers quality care experienced by people who identified as living with obesity include the speed of access, effective treatment, and emotional support, with stigmatising healthcare experiences are reported.

Interpretation: The findings of this study provide insights into the experiences reported via freely available websites, of people who self-identified as living with overweight or obesity in healthcare in England. These insights demonstrate that the perceived quality of care was lower for people who identified as living with overweight or obesity compared to the general population, and that there is regional variation in care quality. The study has also shown that patient experiences differ based on personality attributes, values and sentiment, highlighting the need for patient-centred care and personalised approaches. These findings hold important considerations for healthcare and policy makers aiming to address healthcare inequity.

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1. Introduction

In response to the prevalence of overweight or obesity in England, there has been increased public health focus, and calls for improved access to services. Indeed, NHS England has stated as part of the long-term plan that there will be targeted support and access to

services for people with a body mass index of 30 kg/m² and above [1]. However, there is a need to consider, and based on previous research evidence [2], improve the experiences that people living with overweight or obesity have in healthcare environments.

The experiences of patients in healthcare settings is of key importance given that they have an impact on likely future use, patient-practitioner relationships and overall quality of care [2,3,19]. Issues related to access and quality of appropriate healthcare has been noted in relation to weight management and obesity [4]. Reducing

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Research in context

Evidence before this study

Research evidence has highlighted the importance of experiences of healthcare on satisfaction, future use and health outcomes. Indeed, research has reported that people living with obesity experience stigma in healthcare and are in some instances, unable to access healthcare support.

Added value of this study

To our knowledge, this is the first study to provide insights into the perceived quality of care experiences of people who identified as living with overweight or obesity in England, to compare these across regions of England and to the general population, and to provide insights about these healthcare experiences.

Implications of all the available evidence

These insights provide indications of the regions, domains of care and personality attributes of patients, which can be used to direct improvements in healthcare by services and policy-makers. These findings could also be used to develop person-centred care and support for people who report inequitable healthcare experiences.

as relevant using the keywords, were then manually checked by the authors for accuracy. Ethical clearance was not sought as all comments were freely available in the public domain. Any identifiable information (i.e. names, age) were removed.

Quality of healthcare All relevant comments were automatically scored using a custom-built AI model to identify which of eight internationally recognised healthcare-quality domains [10]; (1) fast access to reliable health advice, (2) clear information, communication and support for self-care (3) effective treatment delivered by trusted professionals (4) emotional support, empathy and respect (5) continuity of care and smooth transitions (6) involvement of, and support for family and carers (7) involvement in decisions and respect for preferences (8) attention to physical and environmental needs (see supplementary materials for description) they concern, and the sentiment of the reference(s) to each individual domain. The domains were not exclusive; a comment could relate to none, some or all. Comments were only deemed relevant if they reported first-hand experience of care, and were from a patient or carer. A score of 1 or 5 relates to a strongly negative or effusive response, with a score of 2 or 4 being negative or positive, and 3 being neutral. Typically, the overall score for a review is given by the user alongside their comment. Where scores are not provided, for example with tweets, PEP's custom model, that has been trained on the millions of user-scored comments-which has a high degree of accuracy (+90%) - automatically scored them.

Sentiment and personality A subsection of data with 200 or more words were analysed using Scaled insights behavioural artificial intelligence software. Each patient experience comment was processed to derive sentiment and personality scores. An AI model [11] fine-tuned for sentiment analysis was used to estimate the sentiment of each comment on a scale of 1 to 5; Personality scores were obtained using proprietary software by Scaled insights. The software takes as input a language sample and produces 114 personality features. Following this, features were used as input into the multiple machine learning models, which were used in two settings: unsupervised (clustering) and supervised (classification or regression). We also investigated to what extent features obtained from a language sample are predictive of the 8 internationally recognised domains of healthcare.

2.1. Statistical analysis

To explore differences between regions based on the perceived quality of care for overweight or obesity compared to not overweight or obesity, independent *t*-tests with Bonferroni-Holm correction were conducted. To examine whether personality features predicted quality of care, the means of clusters were compared using Welch's unequal variances *t*-test. For all tests, α was set at 0.05.

2.2. Role of funding source

Novo Nordisk funded the research referred to in this article and has funded the article's production and the open access article charge. The funding source had no role in the conceptualisation of the study, its analyses and interpretation and had no influence over the design and content of this article. The research was conceived and designed by the lead author, who has full editorial control and responsibility over this article. The full data set was accessed by SWF, ML, AG and MK, who made the decision to submit the article for publication.

3. Results

3.1. Descriptives

In total, 256,067 patient comments were identified. Of these, 5675 comments were retrieved that were deemed relevant (450 about

inequalities in access to healthcare has been a focus for the National Health Service in the England, with actions to reduce the impact of negative experiences, prejudice or discrimination and a lack of awareness of how to access to healthcare reduce healthcare seeking behaviours. To improve access for all, NHS England [5] published an improving access for all resource for general practice providers and commissioners.

In a review of thirty studies published between 1990 and 2010, exploring the perceptions and experiences of people living with obesity of healthcare provision, and healthcare professionals' views of care for people living with obesity highlighted that several factors influence access and quality of care such as stigma in healthcare [6]. Indeed, there is evidence that healthcare professionals spend less time in appointments with people living with overweight or obesity [2,19].

Experiences of weight stigma in healthcare can lead to avoidance of future healthcare, lower trust in healthcare professionals, reduced quality of care and lead to health disparities [7,20]. It is also well-known that experiences of weight stigma and discrimination are associated with physical and mental health concerns such as lowered self-esteem, depression, and increased cardio-metabolic risk factors [8].

This study aimed to explore the healthcare experiences of people living with overweight or obesity in UK.

2. Methods

The Patient Experience Platform (PEP) leverages the abundant volume of patient feedback available on social media to identify risks to the quality of care that is delivered in primary and secondary care settings in a robust and proven methodology [9]. For the purposes of this study, PEP was used to gather and analyse all comments from NHS UK, Google, Facebook and Twitter that related to care experiences of people who identified as living with overweight or obesity across all NHS Acute and Specialist Trusts and all GPs in England from 01/01/2018 to 31/12/2020. All comments were freely available in the public domain. Of these collected comments, a selective set of keywords and associated conditions were used to identify relevant comments posted by people living with overweight or obesity (see supplementary materials). A subset of comments that were flagged

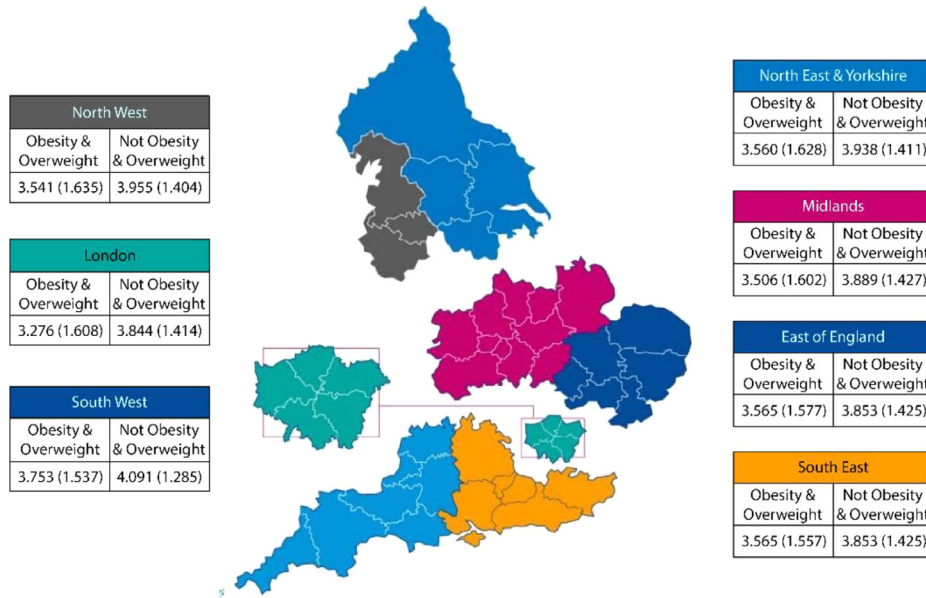


Fig. 1. Regional map of the overall recommend scores. Regional map (England) of the overall recommend scores (mean and standard deviation) for people who identified as living with overweight and overweight or obesity compared to people who did not (1 to 5 rating, with 5 being the best possible rating).

overweight or obesity, and 5225 about associated health conditions). The sources of the comments were from nhs.uk ($N = 4423$), Google ($N = 593$), Facebook ($N = 371$) and Twitter ($N = 288$).

3.2. Regional comparison of patient experience scores

Overall patient experience scores (1–5) were calculated for people who identified as living with overweight or obesity and overweight for each NHS region in England and compared to the regional ratings for the general population. This comparison indicates that people who identified as living with overweight or obesity have uniformly poorer care experiences than the general population (see Fig. 1, all results significant, $\alpha = 0.05$).

Aspects of care that had the lowest patient experience scores were ‘Effective Treatment’ and ‘Emotional support’ and thus, are in need of

improvement. In each region (Fig. 2), the ‘Effective Treatment’ and ‘Emotional Support’ for people who identified as living with overweight or obesity is, with the exception of ‘Emotional Support’ in the East region ($p = 0.03$, The p -value for this test is less than 0.05, it is not less than the much lower significance threshold of 0.0083 calculated using the Bonferroni-Holm correction to account for the increased likelihood of Type I and II errors arising from multiple tests), significantly lower people who did not. Whilst the ‘Fast Access’ scores were lower in every region for people who identified as living with overweight or obesity, none of these differences were statistically significant ($p > 0.05$).

We also investigated how patient experience varied in Primary Care (all GPs in England) and Secondary Care (all hospitals in England) settings. Overall care experience for people living with overweight or obesity is better performing in Secondary (3.221 (Std Dev:

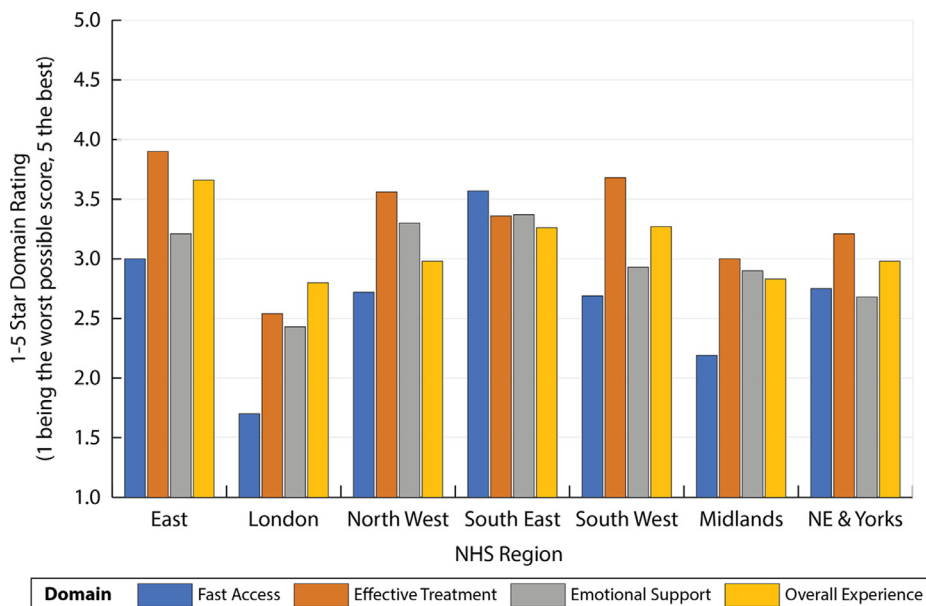


Fig. 2. Regional variation in patient experiences. Mean of ratings (1 worst, 5 best) in different health care domains divided by NHS Region.

1.433)) care than in Primary care (2.853 (Std Dev: 1.372)) settings. This remains true across the care principals, where perceived quality of fast access, effective treatment and emotional support is reported as poorer in the Primary Care system than in Secondary care.

3.3. Clustering

Of the 256,067 comments, those that were over 200 words were shared with Scaled Insights ($n = 618$ with relevant keyword, $n = 1448$ with associated condition, and $n = 107$ with both relevant keyword and associated condition).

The personality features were used as input to a clustering algorithm (k -means) in order to separate survey participants into groups. As the k -means algorithm requires to specify the number of clusters, we first experimented with different values of k (between 2 and 20). We used two heuristics (sum of squared distance and an elbow plot, and degree of separation between clusters and a silhouette plot) to evaluate which k value resulted in most coherent and disparate clusters. According to both heuristics, two clusters resulted in the best differentiation: the first cluster with 870 patients and second with 1303 patients (see Fig. 3 for a visualisation of the clusters).

Table 1 lists the 10 most differentiating features and the cluster centroid values. The first cluster had a 3.585 average sentiment score (Std Dev: 1.154) and higher values for persuasive, trust, social skills, driven, Dutifulness, workhorse and happiness, while the second cluster had a 1.997 average sentiment score (Std Dev: 0.796) and higher values for depression, insecure and cold. From here on in, the second cluster is referred to as the negative cluster, and the first cluster as the positive cluster.

The study investigated whether the two clusters had differed in their experiences of healthcare (Table 2). The positive cluster consistently had a higher average rating across all the perceived quality domains. Across all the perceived quality domains, the difference in means between the positive and negative clusters was statistically significant ($p < 0.05$).

Throughout the experiences reported by people living with overweight or obesity is instances of weight stigma and discrimination.

Table 1.
Cluster centroids for the ten features with greatest absolute value differences between clusters.

Feature	Positive cluster		Negative cluster	
	Mean	Std Dev	Mean	Std Dev
Persuasive	0.693	0.191	0.339	0.173
Facet_trust	0.644	0.200	0.291	0.169
Social_skills	0.548	0.240	0.218	0.119
Depression	0.477	0.172	0.778	0.136
Power_driven	0.616	0.218	0.324	0.185
Dutiful	0.728	0.137	0.453	0.147
Workhorse	0.773	0.199	0.508	0.190
Insecure	0.497	0.258	0.754	0.183
Cold	0.363	0.198	0.601	0.190
Happiness	0.381	0.163	0.147	0.088

*All scores are within (0, 1) range with the exception of sentiment score which uses [1–5] values.

These experiences reflect: disrespectful experiences where people are treated with a lack of dignity; a lack of empathy and compassion in the care people received; and that people did not receive care or that it was delayed, please see the supplementary materials. In many instances, people living with overweight or obesity discussed interactions with healthcare professionals as well as others working in the healthcare environment (e.g. reception staff). Many people reported that they had rude, derogatory and disrespectful interactions, where people feel they are not treated with dignity. For instance,

“Shocking Experience - This surgery and Doctor are a joke. The staff are rude. Consistent problems with my prescription. I'm busy and want to use an online pharmacy. Doctor keeps insisting i use local one. Then ring me leaving a rude message saying, “I need to be consistent in who i want to use”. I was consistent. You was not. On one appointment with the doctor. I'm very distressed and pleading for some help on my weight issues. The doctors response to this was to take a cake out of his drawer and say “Look, that's been there for 3 days and I have not eaten it”. I then got a 10 min lecture on will power and how he was such a driven person and had risen from poor

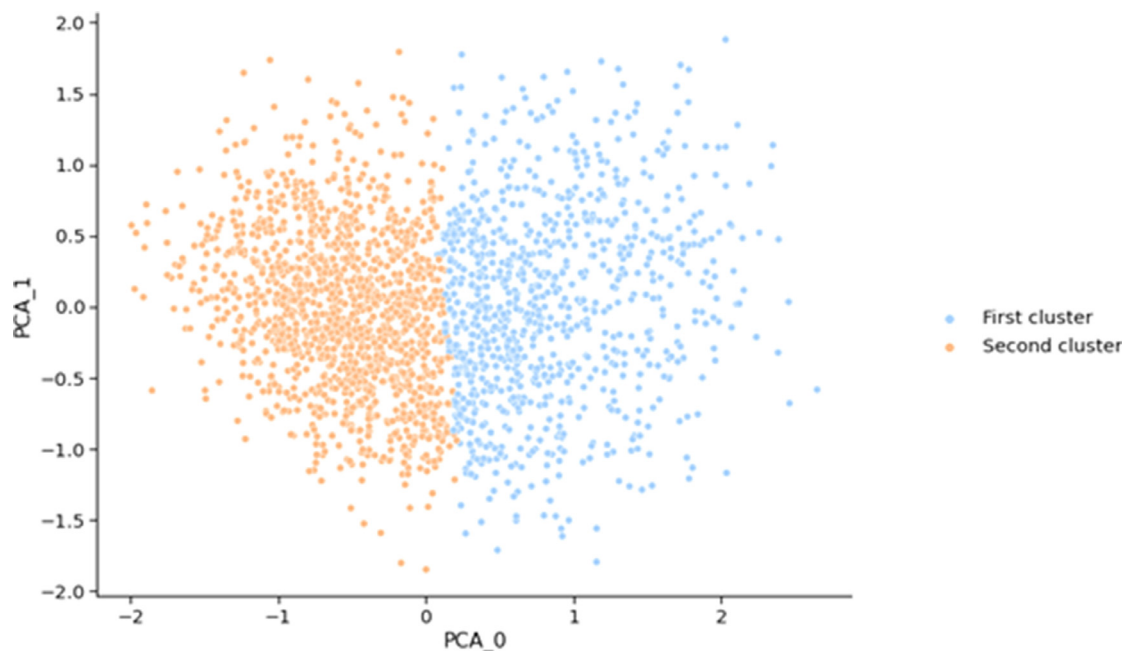


Fig. 3. Visualisation of the personality feature clusters of people living with overweight and obesity reporting their experiences of healthcare using principal component analysis (PCA). Personality features were used as input to a clustering algorithm (k -means) in order to separate the people living with overweight and obesity into groups; orange = positive cluster, blue = negative cluster.

Table 2.
Comparison between clusters of internationally recognised perceived quality domains of healthcare.

Internationally recognised domains of healthcare	Positive cluster	Negative cluster	Test result	P value	CI
Fast access to reliable health advice	3.156	1.785	13.452	< 0.001	(1.171,1.572)
Clear information, communication and support for self-care	3.537	1.662	16.219	< 0.001	(1.648,2.103)
Effective treatment delivered by trusted professionals	4.395	2.224	24.636	< 0.001	(1.998,2.344)
Emotional support, empathy and respect	4.124	2.308	18.898	< 0.001	(1.627,2.005)
Continuity of care and smooth transitions	2.978	2.108	3.511	0.001	(0.375,1.366)
Involvement of, and support for family and carers	3.696	1.923	6.263	< 0.001	(1.210,2.336)
Involvement in decisions and respect for preferences	3.562	1.810	3.952	0.001	(0.841,2.665)
Attention to physical and environmental needs	4.186	2.237	14.518	< 0.001	(1.685,2.213)
Recommend (aggregated, overall score)	4.026	1.989	28.555	< 0.001	(1.897,2.177)

*All values were rounded to three decimal places; Cluster values were in range of 1 to 5, 1 being strongly negative, 5 being strongly positive; CI = Confidence interval.

beginnings and now had his own surgery and all through will power. Thanks for that. Cos it had not occurred to me to not eat the cake.”

“Treated by a disrespectful, arrogant consultant! - compassion cannot be taught at medical school and so arrogance prevails in some doctors' minds...”

There has been reports and guidance for healthcare professionals to start conversations with people living with overweight or obesity about their weight and weight management such as the ‘let’s talk about weight’ guide from Public Health England [12]. However, many people reported that the way that healthcare practitioners communicated about weight and in some instances, began conversations about weight was insensitive and disrespectful. For example,

“Rude interaction with particular doctor - I generally have positive experiences with [name of surgery provider], today being an exception. Went into the surgery for a medication review only to be insulted as soon as I entered the room. The first comment I received from one of the doctors was “have you put on weight? “To which I wasn’t able to reply as I was shocked that they thought it was relevant to the nature of the appointment. At first I ignored this comment thinking nothing of it. As soon as I had sat down he began repeating this comment about how I’m now “excessively overweight” and that I should “exercise more”. He also proceeded to get the scales out to weigh me to then make further criticism towards my weight. I know I’m not exactly the skinniest of people and I’m aware of my size, but I do not see myself as “dangerously overweight”. I’m 20 with diagnosis of depression and anxiety as well as having autism. So for these unnecessary comments to be made when they’re irrelevant to my appointment has upset me and I refuse to see this particular doctor again in the future. There is always a nicer way of phrasing a comment about someone’s weight or any other health issues, but to assume it’s okay to speak to someone this way and not have any damage down psychologically is ridiculous.”

“The doctor I saw I didn’t find particularly welcoming when meeting them. Not a major issue, but not ideal nonetheless, as I felt I was in a pressed for time environment and had to get on with it ASAP ... Then, just as I was about to leave, the doctor said losing some weight might help. I was livid with how insensitively they approached this - almost as an aside at the end. I am 6 feet 4, around 20 stones and have been walking between five and ten miles a day for the last ten years for work. I consider myself big but fit. My knee problems began in my early 20s when I weighed around 12 stones, so weight, or lack of it, had absolutely no bearing on their beginnings. My right knee is absolutely fine, too - despite my weight! Also, how did they know I wasn’t trying to lose weight already? Perhaps if the doctor had approached things in a different way by asking me about my lifestyle choices a little more and in a less abrupt way, I may have welcomed the advice, but not when it was given in the manner it was. I went there for help with my knee and left wishing I hadn’t bothered. I so rarely see the doctor and making the appointment took a real effort as I dislike going so much. I will now carry on with the pain and not progress things any further as I don’t want to see that doctor or visit

the surgery again. It seems you have to be super sensitive about potentially upsetting anyone over their gender, ethnicity sexuality etc. these days, but see a big bloke come in, and you can upset him at will with a badly and ill-timed and researched message about his size. Extremely disappointed with how I was dealt with, and while I have the choice, I will never set foot in there again.”

4. Discussion

The findings of this study demonstrate that overall, there is a lower perceived quality of care that people who identified as living with overweight or obesity receive compared to people who did not. Across all 8 metrics of perceived quality of health care, people who identified as living with overweight or obesity receive a lower level of care. Aspect of perceived quality of care that were particularly low were fast access, effective treatment and emotional support. It was also evident that there is regional variation in perceived quality of care, where the speed of access (fast access) was particularly low in the West Midlands and London, and emotional support was lower compared to other regions in Yorkshire and Humberside and London. The findings of this study have implications for the perceived quality of healthcare that people living with overweight or obesity experience in England. Healthcare policymakers including NHS England should consider and take actions to address the lower level of care that people living with obesity across England experience. Addressing this inequality in care experienced by people living with overweight or obesity is needed to support the principles of that guide the NHS [13].

The use of an innovative artificial intelligence tool has provided advanced insights about patient experiences and has been used to predict perceived quality of care. The findings of the artificial intelligence analysis shows that people in the negative cluster received significantly worse healthcare experiences compared to the positive cluster and thus, the personality attributes and values measured could provide useful insights for healthcare practitioners when understanding the experiences of patients at scale. Many of the metrics of healthcare are very low (below 2 out of 5), and thus their experiences that people living with overweight or obesity have who are in the negative cluster may be more likely to lead to lower levels of engagement, satisfaction and reduced likelihood of future health seeking behaviour. Thus, use of artificial intelligence could also be used by healthcare practitioners to better understand, predict and improve the care that people living with overweight or obesity. Further research that explores the potential use of artificial intelligence to provide insights that support healthcare delivery could offer valuable information for clinicians and healthcare professionals when caring for people living with overweight or obesity, and to consider ways of tailor personalising care.

Themes from the qualitative data also demonstrates that people who identified as living with overweight or obesity have stigmatising and in some instances, pejorative experiences in healthcare.

Empirical evidence has demonstrated that healthcare professionals hold stigmatising attitudes towards people living with obesity, with weight stigma and discrimination in healthcare reported as a common experience [3]. The current findings provide further insight and evidence of these experiences, which may impact future health seeking behaviour. These findings support an All-Party Parliamentary Group on Obesity report that indicated only 26% of people living with obesity reported being treated with dignity and respect by healthcare professionals when seeking advice or treatment for obesity, and that 42% did not feel comfortable talking to their GP about obesity [14]. Moreover, experiences reported by people living with obesity highlight the inappropriate and often insensitive ways that healthcare practitioners start conversations about weight with people living with obesity, which can impact the patient-practitioner relationship and as this study shows, impact patient engagement, satisfaction and likely future healthcare seeking behaviours. The findings of this study suggest that people living with overweight or obesity may have disrespectful, stigmatising experiences. These experiences are not in line with the NHS values, and thus, there is a need for improved patient care in healthcare settings [13].

The current study data suggests that there are regional differences in perceived quality of care provided and that certain elements of care (e.g. fast access) are particularly low for people living with overweight or obesity. The methods used by the study by sampling data based on keyword use may mean that the regional variations in care may reflect the methods used. Previous evidence that has highlighted the pervasiveness of weight stigma in the UK [15], and indeed, evidenced by the accounts of weight stigma in the current study, may mean have led to the low perceived quality of care. This holds important implications for healthcare in improving the patient satisfaction and perceptions of care as this may impact current and future engagement in healthcare. Future research should tease out the impact of weight stigma experiences on perceived quality of care provided, and the role of weight bias internalisation.

This study is not without its limitations. First, that the study only assesses patient comments from open-access websites and social media, and therefore these comments (i.e. a convenience sample of publicly available sources) may not represent all experiences of people living with overweight or obesity. As such, the data captured in this study reflects comments from people living with overweight or obesity who were comfortable posting their feedback on publicly available sites. Future research that captures the experiences of a wider representation of people living with overweight or obesity might provide further insights, and may thus, improve the generalizability of the findings. Second, the data represents patient experiences in 2018–2020, which includes the period of time during the coronavirus (COVID-19) pandemic where access to and delivery of services has been affected. Recent empirical evidence has demonstrated the impact of the restrictions and lockdowns as a result of the pandemic on people living with obesity [16], which may have impacted the experiences of people living with obesity during this time. Third, patient comments analysed in this study were based a pre-defined list of words (see supplementary materials), and thus, may not reflect the healthcare experiences of all people living with overweight or obesity. Likewise, the pre-defined list of words may mean that comments retrieved may be more likely to fall into positive or negative experiences. Fourth, whilst some sites prevent repeat posting from users, usernames were checked to avoid undue influence, and from the authors' experience patients posting on multiple sites is rare, we cannot guarantee that a subset of the comments are not, in effect, repeated. Finally, we are unable to consider the difference in experience of demographic differences such as age, gender and ethnicity, which may provide further insights given the reported differences in healthcare experiences. Understanding the differences that people living with overweight or obesity experience based on demographic differences may, as seen in previous research exploring

weight stigma in other settings such as more stigmatising perceptions of women living with obesity compared to men living with obesity [17,18], demonstrate that there are further inequalities experienced by people living with overweight or obesity.

In sum, this study has provided insights about the experiences of people who identified as living with overweight or obesity in healthcare settings in England. The importance of understanding patient experiences is key to improving services. These findings should be considered by healthcare professionals and policymakers, to identify opportunities to improve the perceived quality of care that people living with overweight or obesity experience in line with the general population. The current study suggests that people who identified as living with overweight or obesity have in many instances negative experiences in the perceived quality of care and interactions with healthcare professionals.

Author contribution

SWF conceived the study and was responsible for the oversight of the study. MK and AG were responsible for the data analysis. All authors contributed to data interpretation, and the writing of the manuscript. All authors contributed to critical revision of the manuscript and gave final approval.

Declaration of Competing Interest

SWF and MK are employed by Scaled Insights. ML and AG are employed by Patient Experience Platform. SWF reports research grants from Johnson and Johnson, research grants from Novo Nordisk, and personal fees to support attendance at meetings from Novo Nordisk, outside of the submitted work.

Data sharing

Data collected for this study is collected as part of the Patient Experience Platform and is not available to be shared. Any query can be directed to the corresponding author via email.

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