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Prioritising Action on Diabetes in Greater Manchester

Working in collaboration with:

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1.0 Rationale

The Greater Manchester Rule of Halves analysis[1] indicated that diabetes may be under-diagnosed in adults under 40 years of age. Where diabetes was diagnosed, those under 40 were also less likely to receive appropriate care and achieve HbA1c treatment targets when compared with older age groups.

In this study, we aimed to explore the following questions among a population of adults under 40 living with diabetes in Greater Manchester:

- Can we identify sub-groups of people sharing specific perspectives towards health, wellbeing and living with diabetes?
- Do these perspectives create specific barriers to and opportunities for successful diabetes prevention; diabetes diagnosis, care and management, as well as overall health and wellbeing?

Ultimately, this study may inform the design of future community-based initiatives that are sensitive to the different perspectives on diabetes care.

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[1] The Rule of Halves is a theoretical framework used in the Cities Changing Diabetes program to describe the burden of diabetes and the unmet clinical needs along the diabetes treatment pathway. The framework dates back to a published paper by Hart in 1992 (Hart, "Rule of Halves.").

2.0 Methods

The Applied Research Collaboration for Greater Manchester (ARC-GM) delivered this Urban Diabetes Priority Assessment using the Cities Changing Diabetes (2018) protocol, which forms part of a wider global mixed methods approach (Napier et al, 2017). This study was approved by the North-West - Greater Manchester Central Research Ethics Committee (REC reference: 21/NW/0030), HRA and Health and Care Research Wales (HCRW).

2.1. Recruitment

Data for this study were collected in three parts from a cohort of people under 40 years old living with diabetes that were recruited from the Greater Manchester area between June-December 2021. Recruitment was via general practices; the NHS supported research register 'Help BEAT Diabetes' (Research for the Future), as well as through local community engagement and social media.

In an advert for our study we invited those interested to sign up in order to receive an initial screening. Once they had completed the screening and were deemed eligible[2], participants were provided with a link to our online data collection tool which had been customised by the research team for the purposes of this study (Pruneddu, Qsortware).

Note that the research method implemented in this study calls for between 40 to 50 participants for specific statistical and data analytical reasons, as well as for a diverse and varied demographic makeup of participants. The priority here is to ensure breadth of experience in order to be able to capture a varity of distinct points of views.

2.2. Data Collection and Analysis

Once participants had logged into the online data collection platform, they were first asked to complete an online demographic survey to capture information on socioeconomic status, housing, employment, health insurance, any long-term conditions, diabetes complications, as well as height and weight.

Participants were then instructed to carry out a statement sorting exercise ('Q-sort') to assess their perspectives on various aspects of living with diabetes. The 64 statements used in our study represented a broad range of social and cultural factors relevant to health, well-being and living with diabetes, and had been synthesised from participant interviews in prior Cities Changing Diabetes studies. Participants were instructed to place statements, based on their personal level of agreement or disagreement, into a grid pattern with a fixed number of options along a 'very strongly agree' and 'very strongly disagree' continuum. The grid pattern required prioritising certain statements over others and thus sharpened personal points of views for comparison in our research study.

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[2] Eligibility criteria were: adults between 18 and up to the age of 42, with an existing Type-2 diabetes diagnosis.

Once all participants had finalised their statement sorting exercises, a method-specific statistical analysis was applied to detect similarities in sorting patterns between participants. We used Zabala's 'qmethod' analysis package, run in R (Zabala, 2014), to extract 'factors', or sub-groups of participants, with similar sorting patterns and hence shared personal viewpoints. The analysis indicated that the statistically ideal factor number was five. Although two of the factors (or sub-groups) only had two and three participants associated with them respectively, all statistical significance criteria for those sub-groups were met (i.e., they were sufficiently distinct in their points of views from the other sub-groups to warrant being maintained)[3].

After the initial data collection phase, via the sorting exercise, was finished and first results had been obtained, participants were invited to take part in either a focus group or individual interview (conducted remotely). Topic guides were developed by the core research team based on the study protocol and covered the journey to diagnosis, diabetes management, and participants' lived experiences of living with diabetes in Greater Manchester.

Thematic coding in NVivo12 and a rapid analysis using rapid assessment procedure (RAP) sheets (Taylor et al, 2018; Vindrola-Padros et al, 2020) were used to analyse transcribed interviews and focus groups to provide an in-depth understanding of the issues that underpinned the statement sorting and factor analyses. Linking this to the demographic data collected provides a comprehensive overview of the findings of the Q-sort exercise.

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[3] Because Q-methodology is concerned with identifiying statistically distinct points of views among a poplution it is acceptable, and indeed unsurprising, that we might obtain very small sub-groups from a larger sample. In fact, there are many excellent studies that feature sub-groups with just one participant. Researcher judgement also plays a role, and in our case we held a series of meetings with the core research team as well as experienced statisticans and Q-methodologists to ensure the results were methodologically and statistically correct.

3.0 Findings

43 people aged 18-40 completed the demographic survey and Q sort activity. A demographic summary of participants is presented in Table 1.

Table 1: Summary of participants (n = 43)

Participant characteristic		
Age (years)	Mean	35.3
	Standard Deviation	4.35
Sex	Male	67.4%
	Female	32.6%
Body Mass Index (n=41)	Healthy weight (BMI 18.5 – 24.9)	12.2%
	Overweight (BMI 25 – 29.9)	7.3%
	Obese (BMI 30 – 39.9)	41.5%
	Severely obese (BMI over 40)	39.0%
Ethnicity	White	74.4%
	Asian/Asian British	20.9%
	Black/African/Caribbean/Black British	2.3%
	Multiple Ethnic Groups	2.3%
Household income (£)	<£30k	46.5%
	>£30k	53.5%

Of the 43 participating in the Q-sort exercise: 17 people participated in either a focus group discussion or an individual semi-structured interview: Key findings are summarised in Table 2.

The five different ’perspectives’ on living as a younger person with type 2 diabetes in Greater Manchester outlined below illustrate the everyday challenges people face in living with type 2 diabetes and the different abilities and/or capacity they may have to moderate these.

Table 2: Summary of Q-sort factors (participant sub-groups)

Subgroup 1	**Report having the awareness and some ability to manage their diabetes**
'Stressed and calamity coping' Majority female Mean age 34 n=13	Diabetes diagnosis People in this sub-group had some of the highest BMIs across our study but often had not noticed or had ignored onset of diabetes; they experienced challenges engaging with their diagnosis in the early stages. This group highlighted other life demands, including stress, work and childcare and noted they often put others' needs before their own. *"I don't know how long I was diabetic for, I wouldn't be surprised if I've been diabetic for at least a couple of years before my diagnosis. Now it's one of those cases where you realise signs were there but they weren't as prominent" (30-year old Male 51F1)* *'We were in the middle of organising my sister's wedding and…I just felt like…I kept going to the toilet and I thought, why do I keep needing a wee and I was tired going up the stairs. I was tired, and I kept needing a wee and I thought it was all the nerves from my sister's wedding 'cause she was stressing us out.' (39-year old Female 00F1)* Service support Despite challenges at diagnosis, people suggested that they had good awareness and ability to manage their diabetes and a desire to 'turn things around', but felt they had insufficient support. Advice received was felt to be contradictory and 'prescribed' diabetes management courses were not useful as they were tailored to older people; this meant most did not attend further after one or two sessions. People noted medications side effects that were difficult to tolerate given their lifestyles and commitments. *"I went on a course when I was first diagnosed, but they don't take into consideration people's age, because I was on this course with, like, people my nana and grandad's age. So, like, even though it was nice and, you know, we're all in the same boat, they're not really in the same boat because they're slowing down whereas I'm just starting my life really and I've got a long way to go." (28-year old Female 32F1)* Lifestyle/self-management issues Self-described 'food addiction' was common in this group. People felt poorly educated about the benefits of being healthy before becoming overweight or diabetic. Demanding lives were noted as leading to increased reliance on takeaway food: there was a theme that the demands of family/dependants can make it harder to do better in relation to 'good health'. Respondents also noted a lack of employer support (e.g. breaks at work) particularly in the healthcare sector. *"I mean, we both are very busy. He is a [job title] and we just swapping in between the meetings, so one is taking care of the baby while my husband is in the meeting, if I am in the meeting he's taking care of the baby, and sometimes we both end up around seven, eight o'clock pm to finish our everyday work, and then we both are so much tired and we decide, let's order from outside […] But honestly, we are so much tired at the end of the day that we don't think about it." (32-year old Female 31F1)* *"When we're stuck at hospitals for hours, queuing outside, they have what they call welfare vehicles. And it's where the staff can quickly go over and get a brew and get something to eat. So if you want something to eat it's either a Mars bar, a Snickers or a bag of crisps."(36-year old Male 45F1)*

Subgroup 2	**Lack the skills, finances or support to better manage their diabetes**
'Financially disadvantaged and poorly supported' Majority female Mean age 36 Majority have complications associated with diabetes n=12	Diabetes diagnosis People in this sub-group recognised they had been 'borderline diabetic' for some time before being diagnosed with diabetes. Following diagnosis, they also felt they were then left with limited early support and lack of monitoring. Individuals in this sub-group suggested they seldom shared their diagnosis with friends and family due to fear of being judged and that this could lead to isolation around their health with potentially serious consequences. For example, one person had not confided in their long-term partner that they had been given a diabetes diagnosis more than 9 months ago. *"I haven't told my partner; he doesn't know. I've told my mum but I think it's the same, it's that you feel like people are going to judge you for having it and it's your fault because of the way that you eat." (37-year old Female 40F2)* *"So it's just me and my instincts and intuition that's guiding me more than anything". (38-year old Female 50F2)* Service support Following diagnosis, many in this group felt unsure about the symptoms of their diabetes, and said they lacked clarity and guidance from healthcare providers. They perceived a clinical focus on medication, whilst they would prefer support with diabetes-specific diet. Some said they knew *what* to do but not *how* to do it – their desire to manage their symptoms through lifestyle change ran into the hurdles of every-day life, and support was unavailable or refused by medical providers who wanted to implement a different regime. Diabetes Management courses were perceived as not useful, as they were not tailored to people's needs and age. A lack of options did not prevent people discontinuing key medications, such as metformin, in the event of difficult side effects. *"But there was nothing, it was just like right, well, no potatoes, come off the coke, do more exercise, see you later." (38-year old Female 50F2)* *"In terms of medication, metformin I probably only put up with for about a month or so because it was just the side effects were too much for me to handle […] I spent more time in the bathroom than anywhere else, without going into too much detail. So, I just stopped taking it." (37-year old Female 40F2)* Lifestyle/self-management issues A key point raised here was that it was difficult to eat healthy food at work, and takeaways were a convenient option at home. Healthy eating was deemed resource intensive, in terms of time and money, both being in short supply. People were embarrassed to exercise and felt self-conscious and judged by others. A lack of role models in the media (including television characters) was also noted. *"There's not even one story in there of oh well, I have to live with this. This is what I have to do every day. This is what I have to deal with. And there's no truth in what they're saying on telly or in leaflets. All it is, is a fact sheet. And to me it needs to be more real based." (38-year old Female 50F2).*

Subgroup 3 *'Well-intentioned but not succeeding'* Majority male Mean age 37 Majority diabetes associated complications n=5	**Talk about diabetes management, but struggle to make this work in every-day life** Diabetes diagnosis People in this sub-group had often been diagnosed as 'pre-diabetic' prior to full onset. They often noted that a family history of diabetes meant they had expected a diagnosis sooner or later, and they felt their family history meant the diagnosis was not necessarily all their own fault. However, they did express surprise at being diagnosed at such a young age. A sense of the unavoidability of diabetes made this group hard to target for prevention-efforts. *"I'm not going to completely change my life and suddenly start doing things I don't want to do and change who I am […] We will still have a takeaway once a week 'cause that's our treat" (35-year old Male 29F3)* *"It's my turn sooner or later it would be anyway." (41-year old Male 29F3)* Service support Uneven access to GP services with provision perceived to be worse in inner city areas was a significant problem here. Although participants noted they were proactive in monitoring their own blood sugar and diet and tried to access advice and information, they felt they had a lot of questions, but no one to ask. Peer support was pointed out as a form of desirable support. *"I think that – like I explained about diets – that there's not enough information on how to try and control your blood sugars from what I've been given. And I've seen other diabetics, they've not been really told. A lot of them have had to do their own research. And I think, with how we are technology-wise now, that I'm surprised there's no sort of app or something like that, that can tell you what kind of foods are good, what kind of foods are bad." (36-year old Male 45F1)* *"There must be something separate or there should be for diabetic people." (38-year old Male 24F3)* Lifestyle/self-management issues Crucially, participants noted a lack of time as a barrier to doing 'the right things', and having to balance multiple priorities. People felt that being overweight was more socially acceptable than it has been previously. There was a view across this subgroup that diet is more important than exercise in controlling diabetes. The role of family was seen as being positive in providing motivation to '*do better*'. People in this subgroup were, on the whole, quite optimistic about the future. *"I think a big thing is, because it's quite socially acceptable, I never felt particularly scared. I just wanted to feel better," (35-year old Male 29F3)* *"So, I think it's in moderation, and to be quite sensible with things, and what works for you. If it works, going to the gym and things like that for you, then brilliant, go for it. But, just because, if you're not one that's going to go and try and run a triathlon or a marathon or something, then that doesn't mean you can't do some of the right stuff for yourself." (35-year old Male 29F3).*

Subgroup 4 *'Withdrawn and worried'* All male Mean age 35 n=2	**Isolated with concerns about future health** ***We were unable to recruit either of the two individuals in this factor for a focus group or interview. The below is based on the outcomes of the statement sorting procedure and summarises priority statements pertinent to the three focus areas that we charatcerised in depth in the other factors.*** Diabetes diagnosis People in this group found diabetes 'scary' and would have tried to avoid it if they had known more about it before. Service support People were unsure who to trust with their health. They found it hard to learn about their diabetes and did not feel well equipped to take care of themselves. This group felt choices for them were limited and they were very worried about their health. Lifestyle/self-management issues People felt that integration into the community was important, but that it was hard to socialise (because of diabetes) and this increased feelings of loneliness. Support groups were a popular option in theory, but people felt that they did not have the time to attend. The group noted financial limitations to accessing gyms and fitness activities or to buy good quality food.

Subgroup 5 *'Young and stigmatised'* 2 female, 1 male Mean age 33 All complications associated with diabetes n=3	**Feel too young to have diabetes and deny their diabetes complications** <u>Diabetes diagnosis</u> People in this group suggest they found it hard to accept their diabetes diagnosis and so postponed addressing management until they were older and/or there was the onset of complications. There was a sense that their health was not going to be good in the future, yet participants felt they would choose to address their diabetes when they were ready. *"I always put myself off from going to appointments. I don't know why I find it so daunting. Maybe it's because I don't want to hear what I'm going to be told." (30-year old Female 24F5)* *"One of the doctors were like, you can go blind and you can…and I'm like yeah, I'm not going to go blind, I'm not 60 yet." (30-year old Female 24F5)* <u>Service support</u> There was a significant issue around limited trust in health services. A lack of follow-up or monitoring was noted, and the sense of being left alone with a scary yet not immediately threatening diagnosis. It was pointed out that being a younger person with diabetes should mean increased attention by GPs and health care professionals, though feelings of being judged for having diabetes and/ or being overweight were more common. This group also felt medication side effects were difficult to tolerate given their age and lifestyles, and again would discontinue key medications. There was a feeling that younger people did not get as much support as older people. *"I remember I was in Nando's once they were like…that was how bad the smell was. It was like something out of…it was disgusting. And then that put me off, I was like I can't even socialise, I can't go even go out. And especially when I was younger I was like I'm not doing this. So, I stopped taking the injections." (30-year old Female 24F5)* *"'I always think of diabetes as someone in their 50s or 60s becoming diabetic, so if a young person has got diabetes would you not want to work with them more? Would there not be more things in place for them? Would they not have more check-ups?" (30-year old Female 24F5)* <u>Lifestyle/self-management issues</u> People were embarrassed to have diabetes at such a young age, but being busy and having a fast pace of life with long working hours meant it was hard to engage in activities that prioritise health. People said they did not have enough time to exercise or cook healthy meals. Takeaways were used for convenience, despite recognising these were often unhealthy options. People believed that diabetes is reversible, with diet and exercise, but they needed support with this. *"Life was just at such a fast pace for me I just had to take a step back. I've not worked for the last few months but I feel better within myself.[…] I feel I can concentrate on myself. I'm cooking three meals a day at home." (30-year old Female 24F5)* *"I live in [place] now and it's just fried chicken shops and pizza shops. […] I do like salads and grilled, and if I could have that I would." (30-year old Female 24F5)*

4.0 Implications for current and future care delivery

The 'rule of halves' study highlighted potentially poorer service provision and diabetes-related outcomes in those under 40 with a diabetes diagnosis. Using the Q-sort approach we identified five perspectives as a younger person (under 40) with diabetes in Greater Manchester. We are the only city within the global Cities Changing Diabetes project to focus on younger adults as a population, and further exploration with these groups has provided unique insights into the experience of younger adults with type 2 diabetes living in Greater Manchester.

Response to diagnosis

From the sub-groups identified, we saw differential responses to a diabetes diagnosis. One group (mainly women) appeared to have their diagnosis sub-subsumed into wider demands of working and caring and it seemed their health was not viewed as a priority given these competing demands. In other groups, the diagnosis followed a recognised period of 'pre-diabetes' and was potentially considered, to some degree, inevitable. Others noted a feeling of shock, fear and lack of acceptance following their diagnosis.

Implications to consider:

- Can young people identified as 'pre-diabetic' or at high risk of future diabetes be better supported locally to prevent progression to more a full diagnosis?

- Can we better support younger adults immediately after diagnosis to address some of the issues raised across these groups?

Service support

Across most groups there were issues raised with medication and this treatment was not popular with participants. In general, support from health services was perceived as limited - it is unclear if this was impact on by COVID-19 and reduced access to primary care services.

Implications to consider:

- How can young adults with diabetes be better supported by health services to manage their diabetes following diagnosis?

- What do current services offer and are there opportunities to shape these further in the support of younger adults (especially as these patients may have less regular GP contact)?

Lifestyle/self-management issues

People across all groups reported many barriers to lifestyle improvements that might ameliorate diabetes risks. Time and 'busy lifestyles' were consistent barriers – with pressures coming from work, social and family commitments as well as desires to progress in personal issues such as housing. There was a gender split, with men largely citing family responsabilities as their motivation to 'do better', while women largely experienced these responsibilities as limiting their ability to do better. Reliance on takeaways was noted in multiple groups. Eating healthily was considered expensive by some and hard to fit into existing lifestyle patterns.

Some groups had undertaken courses to support self-management but did not feel this was tailored to their age and living situations.

Implications to consider

- What lifestyle advice is offered to younger adults with a diagnosis of diabetes?

- How can this be improved further for this particular group to ensure relevance, appeal and impact?

- Are their tools used in other areas of the UK can could be explored for Greater Manchester?

In this report we have highlighted a number of insights, which demand further exploration and action to address the growing problem of type 2 diabetes in younger adults and to change the future of this population. Despite their younger age, this population already had very high BMIs – over 80% of participants we have this data on were classed as obese (BMI over 30) or severely obese (BMI over 40) – which adds urgency to this. The five different 'perspectives' on living as a younger person with type 2 diabetes in Greater Manchester we have identified illustrate the everyday challenges people face in living with type 2 diabetes and the different abilities and/or capacity they may have to moderate these. This suggests that different people may require different approaches to help them avoid, delay onset or live well with type 2 diabetes.

Our findings will also be disseminated via peer-reviewed publication:

- People living with diabetes at a younger age *want* to be healthier, fitter, and more engaged in their own care. They are frequently scared of the future and worry about their health problems which they do see coming down the line. However, "life gets in the way"– young families and early or mid-career work pressures make it difficult for them to focus on themselves, and because there are no or few targeted programs that take their particular circumstances into account they are finding it hard to prioritise their diabetes care.

- We saw an interesting parallel in the ability of different subgroups to participate in the interview part of our research, with all participants in subgroup 3 keen and able to make time for this and no one in subgroup 4 able to do the same. This may be seen as a further reflection of our findings above, regarding the specific circumstances, barriers to and opportunities for successful diabetes management in this polulation.

- Younger people with diabetes are not just individual patients – GPs and care providers should take into account the presence of children and partners in households. Suggested and necessary ‘lifestyle modification’ is harder to achieve when a person living with diabetes has to manage not just one, but several persons who are affected by such modification.

- There may be a lack of type 2 diabetes prevention and management intervention tailored to an older population. The condition is already heavily stigmatised and younger people may suffer disproportionately more from this.

- Listening to and hearing the stories of participants provides a unique opportunity to understand and contextualise the issues raised in The Greater Manchester Rule of Halves analysis. The perspectives shared here are not often communicated between participants and their healthcare providers, which creates an immediate opportunity for change and improvement.

5.0 References

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