

## 1 **Abstract**

### 2 Purpose:

3 The purpose of this study is to characterise the decision-making and self-management  
4 strategies of individuals with Type 1 diabetes (T1D) participating in a 150-mile ultra-endurance  
5 cycling event and inform Healthcare Professionals working in T1D. Participation in ultra-  
6 endurance exercise is becoming increasingly popular in the T1D community and self-  
7 management in this context needs further investigation.

8

### 9 Method:

10 Qualitative, semi-structured interviews were conducted with 12 participants with T1D who took  
11 part in the 'Coast to Coast in a Day' cycling sportive. Event-specific and T1D self-management  
12 strategies in the context of endurance exercise were assessed using the Thematic Network  
13 Approach to analysis.

14

### 15 Results:

16 Participants reported that they took part in the event "as a cyclist rather than a Type 1 diabetic".  
17 A range of self-management strategies to manage glycaemic control were identified, but all  
18 were grounded in experience of a "trial-and-error" approach to determine "successful practice".  
19 Engagement with Healthcare Professionals in preparation for the event was limited due to a  
20 perceived lack of endurance exercise knowledge. Participants reflected that T1D can be  
21 controlled in ultra-endurance events through careful and practised self-management of energy  
22 intake and insulin strategies.

23

### 24 Conclusions:

25 Individuals with T1D are capable of taking part and excelling in ultra-endurance events, but  
26 current Healthcare Professional advice does not match patient ambition and practice, which is  
27 grounded in an identity that is first and foremost as a 'cyclist and person'. Limitations in  
28 participants' "trial-and-error" practices require further understanding from Healthcare

29 Professionals to provide advice around existing knowledge, preparation and self-management  
30 strategies for ultra-endurance exercise.

31

## 32 **Keywords**

33 Type 1 diabetes, ultra-endurance, exercise, cycling, self-management, Healthcare  
34 Professionals, nutrition

35

## 36 **Introduction**

37 Participation in ultra-endurance running and cycling events is becoming increasingly popular  
38 in the Type 1 diabetes (T1D) community.<sup>1</sup> Evidence around how ultra-endurance athletes with  
39 T1D manage their condition and the appropriate guidance necessary for participation in these  
40 events is currently lacking. The evidence suggests that Healthcare Professionals (HCPs) lack  
41 the knowledge and expertise necessary to provide the accurate information needed for  
42 individuals to safely engage in, and self-manage physical activity and exercise (PAE), let alone  
43 ultra-endurance events, within their diabetes regimen.<sup>2-5</sup> The recent consensus statement<sup>6</sup>  
44 and the development of the JDRF PEAK curriculum,<sup>7</sup> are both important initiatives for  
45 educating HCPs about the management of T1D and PAE. However, although it is encouraging  
46 that steps are being taken to increase HCPs' knowledge in this area, there is still a lack of  
47 information addressing behaviour change and individualised, patient-centred advice and  
48 support.<sup>4,8-10</sup> These are important issues to be considered for the successful self-management  
49 of T1D alongside PAE and ultra-endurance events. One explanation for this is an absence of  
50 research relating to decision-making processes and determinants of decision-making, as part  
51 of self-management strategies employed by those with diabetes when participating in PAE and  
52 ultra-endurance events, especially around insulin administration and nutrition.

53

54 Self-management is regarded as *the* cornerstone of care for people with (T1D).<sup>11,12</sup> People  
55 with T1D spend over 10,000 hours per year self-managing their condition, compared with only  
56 3 hours per year interacting with a HCP.<sup>13</sup> Given the self-care responsibility placed on such

57 individuals, it is imperative they receive appropriate diabetes self-management education  
58 (DSME) and skills to be empowered to manage T1D and PAE and ultra-endurance events  
59 effectively.

60

61 Therefore, the primary purpose of this study was to investigate diabetes self-management  
62 amongst athletes with T1D participating in a 150-mile cycling event and to augment the  
63 evidence base around DSME and ultra-endurance exercise for both HCPs and those with  
64 T1D. Using an inductive research approach The study aimed to: (i) conduct an in-depth  
65 investigation of individuals' attitudes, beliefs and decision-making practices in relation to the  
66 management of T1D during ultra-endurance cycling to generate end user based data for the  
67 purpose of informing HCPs and future research; (ii) examine the management strategies  
68 individuals adopted, and on what basis these were decided, when taking part in such an event,  
69 and (iii) inform the knowledge base of HCPs and DSME strategies to improve individuals' self-  
70 management of T1D for ultra-endurance events.

71

## 72 **Materials and Methods**

### 73 ***Participants***

74 A purposive sampling approach was adopted to recruit adults with T1D who had signed up  
75 to the 'Coast to Coast in a Day' cycling event, which took place in June 2017. The 'Coast to  
76 Coast in a Day' is a 150-mile cycling sportive from Seascale (Cumbria, UK) to Whitby (North  
77 Yorkshire, UK). Twelve physically active individuals with T1D volunteered to take part in this  
78 qualitative study and provided written, informed consent. Mean age (range), age at  
79 diagnosis and time since diagnosis of T1D and insulin regimens are presented in table 1.  
80 The event involved cycling a designated route on open roads that incorporated 4500m of  
81 total ascent and required navigating to five intermediate checkpoints with food stations.  
82 Participants undertook preparations for the event and the event itself without direction from  
83 the research team. Ethical approval was granted by the Leeds Beckett University HREC  
84 (REC reference 17/LO/0906) and the study followed COREQ (consolidated criteria for

85 reporting qualitative research) guidelines<sup>14</sup> as recommended for rigorous qualitative  
86 research.<sup>15</sup>

87

### 88 ***Patient involvement***

89 A T1D patient and a T1D consultant, both with previous experience of taking part in this and  
90 similar ultra-endurance events, were involved in the study design, in line with Public and  
91 Patient Involvement. Discussions with these individuals highlighted a lack of advice and  
92 direct experiential evidence from individuals with T1D taking part in ultra-endurance events.  
93 Participants received results from the study through an electronic report and a summary of  
94 the key findings.

95

### 96 ***Study Design***

97 An inductive research process was chosen to explore the approaches used by individuals  
98 and generate theoretical themes relevant to T1D self-management for ultra-endurance  
99 events. As such a qualitative investigation of practice was conducted using a short  
100 questionnaire and semi-structured interview, which were analysed by thematic analysis.

101

### 102 ***Questionnaire and Interview***

103 Four weeks prior to the event, participants completed a self-report questionnaire by email  
104 requesting details of their medical history and signs and symptoms of non-diabetes related  
105 cardiovascular and pulmonary disease, as per the American College of Sports Medicine  
106 guidelines for exercise participation.<sup>16</sup>

107

108 One week prior to the event, participants completed a short, two-part questionnaire by email.  
109 The questionnaire was designed to collect information relating to 4 themes; background  
110 information to participants' T1D; strategies to manage their condition in the immediate build-  
111 up to the event, during the event itself and the 24-hour period post-event; participants'  
112 habitual and historical physical activity and access to and use of T1D support by care

113 providers.

114

115 The primary focus of the questionnaires was to collate information relating to participants'  
116 intended T1D management plan for the 'Coast to Coast in a Day' event. Open ended  
117 questions focused on the pre-event, during event and post-event strategies participants  
118 intended to utilise to maintain ideal blood glucose management. Guidance was given in  
119 regard to the broad details that participants were asked to provide, i.e. nutrition timing and  
120 types of foods to be consumed, adjustments made to basal and bolus insulin doses and  
121 allowances for the varying exercise intensities throughout the event, but participants were  
122 asked to provide as much subjective detail as they wished.

123

124 Self-reported details of current insulin and blood glucose monitoring/regimen were captured,  
125 including basal:bolus doses and timings and use of management strategies, e.g.  
126 carbohydrate counting. In addition, the questionnaire addressed the participants access to  
127 T1D support through primary and non-government based care providers, and what  
128 improvements, if any, they felt would enhance their self-management and ultra-endurance  
129 education in the future. PAE and T1D support data was collected using open ended style  
130 questions to allow participants to provide their own responses and subjective thoughts to  
131 minimise researcher bias. These were followed up in the post-event interview.

132

133 Finally, shortly after completion of the cycling event, a 30-minute interview was conducted  
134 with the participants to assess their self-management strategies. A qualitative methodology  
135 was adopted to provide a greater, and often unique, insight into the views and experiences  
136 of the participants, increasingly called for in the literature.<sup>15</sup>

137

138 A semi-structured interview approach was chosen as the primary method for data collection  
139 to allow participants to explore their experiences of the event and T1D management. The  
140 semi-structured interview was partially informed by the participants' responses to the pre-

141 event questionnaire and conducted at the finish line to capture immediate reflections. Each  
142 interview lasted approximately 30 minutes and was recorded with participants' consent.

143

#### 144 ***Data Analysis***

145 The data from the interviews were transcribed and analysed according to the Thematic  
146 Network Approach (TNA).<sup>17</sup> TNA examines connections between emerging themes, which  
147 are grouped and graphically represented according to basic, organising and global themes.  
148 Data from the interviews was coded into these classes of themes and a thematic network  
149 produced, providing an illustrative summary of the relationships between the main themes.  
150 At least two researchers were involved in this process, reducing interpretation bias; no  
151 software was used. Research participants verified the themes as a means of establishing  
152 the reliability of the research findings.

153

#### 154 **Results**

155 All participants in the study completed the 150-mile ride, with finishing times between 10  
156 hours and 16 hours. The findings from an analysis of the post-event interviews revealed  
157 three global themes: 1) Balancing act [5], 2) Self-reliance and 3) Person first, Type 1  
158 second. See Figure 1 for the thematic networks illustrating the interconnectivity of the global,  
159 organising and basic themes.

160

#### 161 ***Theme 1: Balancing Act***

162 A key theme to emerge was how much participants had to think about and balance their  
163 nutrition and insulin regimen to manage their T1D. Participants continually had to weigh up  
164 the advantages and disadvantages of different decisions and how these could affect their  
165 T1D and performance within the context of a long-distance cycling event, which in itself was  
166 naturally changing. All participants' nutrition and insulin regimens were different and unique  
167 to them. However, the goal remained the same, to make their diabetes work for them and  
168 successfully complete the event.

169

170 *Nutrition*

171 Participants were keen to emphasise that food composition and diet were important factors  
172 for overall performance and not simply because they had T1D. Primarily, participants' main  
173 concern was to try and operate like a cyclist and then accommodate their diabetes, rather  
174 than allowing their diabetes to control their cycling. This meant they followed general  
175 nutritional guidelines and, therefore, incorporated nutritional principles that could be applied  
176 by any individual taking part in a long-distance cycling event,

177

178 "I'm a cyclist first and a diabetic second. So, I will use normal nutritional  
179 principles...the biology that sits behind it, regardless of being diabetic or not. I  
180 suppose it's easier to do that and then factor in the diabetes, rather than try and  
181 make the nutrition work for blood sugars" (Participant 010).

182

183 *Strategy*

184 Most participants started the event with a plan for how they were going to manage their T1D  
185 pre-, during and to a lesser extent, post-event. Throughout the event participants accepted  
186 that their T1D control might be sub-optimal due to the exercise. However, this was less of a  
187 consideration than their overall cycling performance. Participants largely managed their T1D  
188 by testing blood glucose levels as and when they could, often using a continuous glucose  
189 monitor (CGM), eating and drinking regularly and only taking insulin when required. The  
190 administration of insulin was also reported to be less than expected due to the physical  
191 demands of the exercise,

192

193 "I was expecting to have a little bit of insulin at each of the food stations, but as  
194 turned out I only had a bit of insulin at the first food station and then I ate absolutely  
195 loads throughout the day but didn't take any more insulin for the whole ride which  
196 kind of surprised me a bit. But I think with doing blood tests I expected to be able to

197 manage that and work out what I would need as I went along” (Participant 014).

198

199 Post-event, participants closely monitored blood glucose levels to be sure how their T1D

200 would respond. Following their post-event meal and just before bed, they adjusted their

201 insulin if they thought it was required. Nocturnal hypos were a main concern.

202

### 203 ***Theme 2: Self-reliance***

204 An important theme was that participants were responsible for self-managing their T1D and

205 developing their own event strategy, with minimal input from others, especially HCPs.

206 Participants largely relied on experience, education and technology to control their T1D and

207 achieve their event goals.

208

#### 209 *Experience*

210 All participants stated that they adopted a “trial and error” approach for managing their T1D

211 and ultra-endurance exercise. Repeatedly trialling different strategies meant that participants

212 had become experienced in managing their own T1D,

213

214 “If I want to try new things out I tend to do a lot of that on the turbo trainer at home

215 because that means I can ride for however many hours I want to...if I’m trying a new

216 food or a new strategy I’m not too worried if I crash and burn because you know the

217 sofa’s right there” (Participant 001).

218

#### 219 *Education*

220 Participants were clear that they were largely responsible for educating themselves around

221 T1D and PAE. They relied on obtaining information from anywhere it was available,

222 including books, social media and their T1D peers. The onus was on them to understand

223 and apply the acquired information to their particular exercise regime,

224

225 “But a lot of it (information), you have to go out there and find it for yourself. I know a  
226 lot of people struggle, especially with the conflicting information out there. I think it’s  
227 just a case of a lot of trial and error and you’ve got to have a bit of sense about  
228 yourself to be able to work it out for yourself” (Participant 014).

229

230 Although a few participants found their HCPs helpful in providing appropriate advice in  
231 relation to T1D and ultra-endurance events, the majority found that HCPs lacked the  
232 knowledge and expertise to be able to offer specific guidance tailored to them and their  
233 cycling. While some participants acknowledged certain HCPs had sufficient knowledge to  
234 give advice about low levels of PAE, ultra-endurance exercise was beyond their scope:

235

236 “I’ve learned more from social media than I’ve ever learned from any medical  
237 professional. They always tend to be, ‘Oooh, you have to be careful, you shouldn’t let  
238 your bloods do that’. But in the real world...” (Participant 012).

239

#### 240 *Technology*

241 Those that had technology, in particular a CGM, found it difficult to imagine completing the  
242 event without it. For many it was a ‘game changer’, revolutionising their approach to ultra-  
243 endurance events by increasing their self-management, reducing anxiety and enabling them  
244 to manage their T1D more effectively. Most importantly, a CGM was a valuable decision-  
245 making tool providing participants with a means to be able to strategize,

246

247 “There are only two bits of information on there, actually what your blood sugar is  
248 now and then a little bit of a trend line as to where it’s been...if it’s kind of plummeting  
249 down. I’m taking on board both those bits of information and then thinking about,  
250 ‘Well how far’s the next food station? How long have I got?’ Those kind of things”  
251 (Participant 009).

252

253 Participants that used CGM reported the superior data versus fingertip blood testing, noting  
254 the pattern of glucose values over time is meaningful when deciding nutrition and exercise  
255 intensity strategies on the move. Following physical cues and sensations is a practice  
256 familiar to people with T1D and in the present study, the ability to make informed decisions  
257 when exercise demands increase was valuable.

258

259 “bearing in mind that CGM has got a lag. Going with just the number really isn’t  
260 enough – you need to know where you’re heading...

261 The joy of the CGM is that you can see the effect and adjust constantly, really, as I’m  
262 going along. It’s much harder for me to do it without CGM. I can associate certain  
263 things with it. If I’m feeling particularly tired all of a sudden, I know I’m going low. If  
264 I’m feeling a little nauseous all of a sudden I know I’m going high. Or if I’m losing  
265 concentration on what I’m doing, or I’m just starting to pedal slower without realising,  
266 I know I’m going low again. So I have certain mental and physical triggers. But  
267 again I think, as I said to you before, if you’ve been eating jelly babies for 12 hours,  
268 your appetite is going to be swayed anyway. So it’s more difficult without the CGM  
269 For all the big events that I do, I’ll stick the Dexcom on, just to be sure.” (Participant  
270 001).

271

272 However, the demands of ultra-endurance exercise may mask certain physical sensations  
273 that are familiar to athletes during day-to-day life or more moderate exercise. This raised the  
274 need to be aware of physical cues and the importance of having a plan around technology  
275 use and interpretation. For example, insulin pumps, where used, were able to replace an  
276 element of decision making and glucose management tasks,

277

278 “So I’ve found that really beneficial, because I think no matter how acutely aware of  
279 what a hypo or hyper feels like when you’re 100km into a race, you’re hot, you’re  
280 sweaty, you’re fatigued. It’s going to be hard to feel those sensations. So I relied on

281 my pump a lot.” (Participant 003).

282

283 However, relying on technology and data from devices such as CGM and having awareness  
284 of, and monitoring physical sensations, is required,

285

286 “It’s not perfect technology, it’s still evolving. Sometimes it’s wildly out. But generally

287 I find... first week, bang on; second week good; third week, hmm; fourth week,

288 anything’s up for grabs. So I get up to a month out of them, but by the third to fourth

289 week I do more finger prick testing, because you don’t trust it, necessarily. And on

290 an event like this... I put a new one in on Thursday, because I want it to be bang on.

291 And it has been.” (Participant 012).

292

293 Similarly, one participant noted being uncomfortable with using technology when it was

294 attached to their body, indicating that CGM technology is a personal choice and operates

295 within the framework of each individual’s self-management,

296

297 “No, I use Accu-Chek Mobile. I just can’t get into having something attached to me

298 on a daily basis, I don’t like the idea, and I certainly think it’s uncomfortable. I had a

299 little blood sugar reader attached to me for a week once, and it was just horrible. I

300 use everything external.” (Participant 008).

301

302 In terms of individualisation, the use of technology such as CGM provides athletes with

303 further and deeper insight to their self-management when engaging with HCPs on a less

304 regular basis. HCP availability for all individuals may be limited, especially during the current

305 Covid-19 pandemic and as such technology can provide a level of detail for individual

306 decision-making,

307

308 “And they’ve [HCPs] got that many things to be doing. If I’m bombarding them with

309 questions all the time, it might be a week before I get a reply on something. So at  
310 that point it becomes easier to read up a little bit and fall back to the old pattern of  
311 test, record, experiment, keep testing..." (Participant 009).

312

313 ***Theme 3: Person first, type 1 second.***

314 The final theme to emerge related to the participants and their 'diabetes identity'. Key issues  
315 related to the importance of the individual and glucose awareness. Both influenced the  
316 participants' approach to self-management and their event strategy.

317

318 *Individual*

319 Participants wanted to be recognised as individuals rather than labelled as a 'type 1  
320 diabetic'. However, individual variation in the presentation of the condition was important to  
321 acknowledge. Participants reported that there is no 'one size fits all' approach for anyone  
322 managing an ultra-endurance event and likewise for those with T1D,

323

324 "I'm conditioned to think if it works for you it might not necessarily work for me. So  
325 you can read and you can listen and you can learn and can watch somebody else's  
326 patterns, but size, shape, effort, intensity, physiology – everybody's different and  
327 every ride's different" (Participant 009).

328

329 *Glucose Awareness*

330 Participants felt strongly that their T1D should not be the focus of the event. Importantly,  
331 many had a sense of what was happening physiologically because they were 'in-tune' with  
332 their T1D and how they were feeling. While many felt they could achieve better control, they  
333 did not want their T1D to be 'all consuming',

334

335 "I don't want my life to be just chasing a line. I know some people get quite good  
336 lines, but it just seems that all they think about is micro-dosing all the time. I don't

337 really want to get in that position if I can help it, but I'd obviously like to get better  
338 control than I have at the moment" (Participant 002).

339

340

## 341 **Discussion**

342 This is the first study to capture the reflections and self-management strategies adopted by  
343 individuals with T1D taking part in an ultra-endurance cycling event. We highlight a possible  
344 lack of advice for these individuals, but that this does not necessarily preclude participation  
345 in ultra-endurance events. Three common themes were reported during experiences of the  
346 'Coast to Coast in a Day' cycling sportive: '*balancing*' exercise performance and T1D; the  
347 '*self-reliance*' both as a participant in the event and in general as an individual with T1D and  
348 identifying as a '*person first, type 1 second*'. The identification of these qualitative  
349 experiential descriptors is a novel contribution to the T1D literature to date. Importantly,  
350 HCPs may use this evidence to support those with T1D wishing to take part in ultra-  
351 endurance events and other arduous exercise. Based on this data, obtained directly from  
352 individuals with T1D, advice should be to trial nutrition and insulin strategies to support  
353 exercise pre-event, but that reductions in insulin and maintaining adequate energy intake  
354 during an event are likely required and need to be individualised. Furthermore, in order to  
355 support individuals with T1D in achieving ultra-endurance exercise goals, it is necessary,  
356 from the perspective of such individuals, for HCPs to receive further education and training  
357 around endurance exercise and diabetes management.

358

## 359 ***Insulin and Nutrition Management***

360 There has been significant research on the physiological/glycaemic response to endurance  
361 exercise and T1D,<sup>18</sup> but such evidence is less common in ultra-endurance events,  
362 particularly in relation to self-management and T1D based experiential strategies.<sup>19,20</sup> Those  
363 with T1D are, for example, advised to make some reductions in basal and bolus insulin  
364 doses or pump rates to account for the muscle contraction induced increase in glucose

365 disposal.<sup>6</sup> However, current guidance regarding this is lacking and suggests only moderate  
366 reductions. In ultra-endurance events, our participants reported that (exogenous) insulin  
367 intake was reduced to unexpectedly low levels or in some cases, unnecessary. This may  
368 present as counter-intuitive to individuals with T1D who are unaccustomed to ultra-  
369 endurance exercise and emphasises the need to disseminate such experiential evidence  
370 amongst the T1D community via HCPs. Future research should trial insulin management  
371 strategies during ultra-endurance events in those with T1D.

372

373 The idea of “avoiding hypos at all costs” emerged in the current study. Alongside insulin  
374 management, event nutrition was planned to maintain high blood glucose concentrations  
375 and avoid hypoglycaemic episodes. The severity of such episodes is well-established and a  
376 primary concern in those with T1D.<sup>21</sup> In line with the key theme of “being a person/cyclist  
377 first” to emerge from the data, participants commonly reported trying to adhere to general  
378 sports/exercise nutrition guidelines, rather than specific T1D advice from HCPs. We did not  
379 directly measure energy intake during the event, but although reported individual intakes  
380 varied, these were often motivated by non-T1D based targets. Significantly, every T1D  
381 participant in the study completed the 150-mile ride, emphasising that different strategies  
382 focusing on the needs of the individual can be deemed ‘successful’. However, this may not  
383 apply to participants exercising at ‘race-pace’ intensities due to the increased physiological  
384 demands of such efforts. Recent evidence suggests athletes with T1D do not routinely  
385 adhere to guidelines for T1D management<sup>18</sup> and large inter-individual variations exist around  
386 successful exercise management.<sup>22</sup> In agreement and in a novel finding to date, our findings  
387 report that individuals undertaking ultra-endurance events do not rely on HCP engagement  
388 in training and competition and instead require significant self-reliance to hone T1D  
389 regimens for the level of exercise required. With this in mind, HCPs should focus on key  
390 messages when engaging with T1D endurance exercisers, being mindful of inter-individual  
391 responses and not following a ‘one size fits all’ approach. By encouraging awareness and  
392 understanding of one’s own metabolic responses to exercise and training, providing and

393 supporting nutrition (fuelling) planning for exercise and training and making potential  
394 adjustments to an individual's insulin regimen as training and exercise progress (based on  
395 the metabolic responses and nutrition requirements for exercise), HCPs advice will centre on  
396 the individual while remaining embedded in current sport and exercise guidelines for training  
397 and nutrition support.

398

### 399 ***Diabetes Identity and Approach***

400 An important theme to emerge is that participants see themselves as cyclists or competitors  
401 rather than diabetes patients. This may be borne out of a need to establish their own  
402 strategies based on a range of educational, experiential and medical input. The knowledge  
403 and input of HCPs around ultra-endurance, or even 'normal', exercise was reported as a  
404 possible limiting factor, which reinforces previous research on the lack of guidance from  
405 HCPs around PAE.<sup>10</sup> Evidence based recommendations exist for exercise with T1D,<sup>23</sup> but  
406 the dissemination of relevant advice is not apparent in this subset of athletes. Furthermore,  
407 the recommendations outlined are broad spectrum and require and recommend  
408 individualisation. The current study supports this, as to date there is scant evidence  
409 identifying the lived experience of individuals with T1D in ultra-endurance events. As such  
410 the experience of these participants may inform appropriate guidance and HCPs knowledge  
411 base. In this subset of the population, empowering the individual to tailor their regimen may  
412 be considered a more optimal approach.

413

414 Recent technological advances have improved glycaemic control in T1D<sup>24</sup> and the use of a  
415 CGM may be essential in providing those living with the condition with more in-depth and  
416 'live' blood glucose feedback to inform decision-making and T1D self-management  
417 strategies. While undertaking arduous exercise, those participants who used a CGM found  
418 simplifying the decision-making process to be beneficial, supporting recent *in silico*  
419 evidence<sup>25</sup> of CGM to improve both time spent in euglycaemic concentrations and the  
420 patient narrative in free-living conditions.<sup>26</sup> Specifically, CGM allowed participants to make

421 fine adjustments to their event plan and respond to unexpected physiological responses.  
422 Furthermore, the physiological demands of ultra-endurance exercise may mask or alter  
423 individuals' typical physical responses to hypoglycaemia for example, where CGM data can  
424 serve as an additional tool to mark changes in blood glucose concentration and aid decision-  
425 making. However, while there are major benefits to CGM, not all individuals wish to engage  
426 with the technology and HCPs may need to accommodate individual beliefs, motivation and  
427 desire to engage with more traditional testing or [e.g. glycaemia] symptom monitoring.

428

### 429 ***Future recommendations***

430 It would be beneficial for the whole T1D community, including those with T1D, peers, HCPs  
431 and researchers to work from an appropriately informed evidence base. HCPs current  
432 knowledge and awareness of ultra-endurance exercise appears to be lacking based on the  
433 lived experience of the participants in such events. Recognition of the gap between HCP  
434 knowledge and T1D practice exists, but this does not apply exclusively to all HCPs. Useful  
435 education frameworks and resources exist, such as EXTOD <sup>27</sup> (Exercise for Type 1  
436 Diabetes), which allow HCPs to engage in a network of T1D education specifically for  
437 exercise practice. Future work should focus on, not only rigorous research of participants'  
438 self-management approaches and experiences of ultra-endurance events, but the real-world  
439 application of such information. Furthermore, educating HCPs around T1D strategies for  
440 exercise and the physiological demands of exercise, particularly during ultra-endurance  
441 events, will be helpful in enabling those with T1D patients to be prepared in undertaking the  
442 challenges that the non-diabetic population are taking to in increasing numbers. Based on  
443 our data, it is apparent that individuals with T1D are going to take part in ultra-endurance  
444 events anyway, as evidenced by the 'cyclist first' identity, so the scientific approach should  
445 provide safe guidelines and boundaries within which those with T1D can operate. In line with  
446 this, better resources could be provided for those with T1D to supplement word-of-mouth  
447 and peer advice, rather than the other way round. Whilst we understand the "trial and error"  
448 approach adopted by the present participants, and identified in previous research,<sup>3</sup> there is a

449 need to undertake this in safe environments, such as the home, with input from HCPs, in  
450 order to reduce the vast boundaries within which this approach is currently practised.

451

## 452 **Conclusion**

453 Individuals with T1D are capable of taking part and excelling in ultra-endurance events, but  
454 current HCP advice does not match patient ambition and practice, which is grounded in an  
455 identity that is first and foremost as a 'cyclist and person'. Therefore, individuals with T1D  
456 are undertaking ultra-endurance events based more on "trial and error" and peer education  
457 strategies, which provide a large amount of information to inform exercise and nutrition  
458 strategies for T1D management in such events. Despite this, individuals with T1D completed  
459 an arduous 150-mile cycling event based on a similar "balancing act" of insulin requirement,  
460 exercise intensity and nutritional intake. The need for input from HCPs was a key reflection  
461 of participants and future work should look to establish this in practice.

462

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466

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470

## 471 **Declaration of Interest**

472 The authors declare that they have no competing interests.

473

## 474 **Contributions**

475 AK, NK and AP prepared the manuscript. AK and NK conducted data analysis. AK and NK  
476 designed the study. AK was responsible for study organisation. AK, NK and KP were

477 responsible for data collection. All authors reviewed and edited the manuscript. AK is the  
478 guarantor of this work.

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480 ***Availability of data and material***

481 The datasets used and/or analysed during the current study are available from the  
482 corresponding author on reasonable request.

483

484 **List of Abbreviations**

485 CGM            Continuous Glucose Monitor

486 HCP            Healthcare Professionals

487 PAE            Physical Activity and Exercise

488 T1D            Type 1 Diabetes

489 TNA            Thematic Network Analysis

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491 **Table 1: Participant characteristics**

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Gender	
Male:Female	3:9
Age (years)	41.3 years (23 – 57)
Length of T1D diagnosis (years)	23.0 (12 – 42)
Time since diagnosis (years)	18.3 (5 – 34)
Insulin regimen MDI:CSII	5:7

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492 Mean (range) data for participant age, length of T1D diagnosis and time since T1D diagnosis.

493 Totals for male/female participants and multiple daily injection/continuous subcutaneous insulin

494 infusion (MDI/CSII) insulin regimens. No participants reported a biphasic MDI regimen.

495 **Key Points:**

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- People with T1D received little or no ultra-endurance event specific help or advice from HCPs.
  - Education relied on a previous self-education approach of trial and error, i.e. nutrition, exercise and insulin strategy practice alongside engagement with the T1D community.
  - Participants who 'best' managed the event were prepared, had previous experience of such events and planned their insulin and nutrition for the day.
  - The identity with which the majority of the participants associated themselves was that of a 'cyclist' rather than that of somebody defined by their condition. Participation in ultra-endurance exercise does not need to be limited by T1D
  - **HCPs focus on the following key messages when engaging with T1D endurance exercisers may be beneficial to future work:**
    - o be mindful of inter-individual responses and following a 'one size fits all' approach.
    - o encourage awareness and understanding of individual metabolic responses to exercise and training
    - o provide nutrition (fuelling) planning & education and endurance exercise support based on current sport and exercise guidelines for training and nutrition.
    - o be aware of the need to make potential adjustments to an individual's insulin regimen as training and [event] exercise progress is made

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518 **Figure 1 Title**

519 Thematic network of participant responses to a semi-structured interview following the 150-  
520 mile cycling event.

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523 **References**

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