

A 150-mile ultra-endurance type 1 diabetes cycling event: qualitative analysis of knowledge, preparation and management strategies

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- 1 Abstract
- 2 Purpose:

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

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9 Method:

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

14

15 Results:

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

23

24 Conclusions:

Individuals with T1D are capable of taking part and excelling in ultra-endurance events, but current Healthcare Professional advice does not match patient ambition and practice, which is grounded in an identity that is first and foremost as a 'cyclist and person'. Limitations in participants' "trial-and-error" practices require further understanding from Healthcare Professionals to provide advice around existing knowledge, preparation and self-management
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.¹ 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 ultra-endurance events, within their diabetes regimen.²⁻⁵ The recent consensus statement ⁶ 43 44 and the development of the JDRF PEAK curriculum,⁷ 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 information addressing behaviour change and individualised, patient-centred advice and 47 support.^{4,8-10} These are important issues to be considered for the successful self-management 48 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).^{11,12} 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.¹³ Given the self-care responsibility placed on such individuals, it is imperative they receive appropriate diabetes self-management education
(DSME) and skills to be empowered to manage T1D and PAE and ultra-endurance events
effectively.

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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 Coast in a Day' is a 150-mile cycling sportive from Seascale (Cumbria, UK) to Whitby (North 76 Yorkshire, UK). Twelve physically active individuals with T1D volunteered to take part in this 77 78 gualitative 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 the research team. Ethical approval was granted by the Leeds Beckett University HREC 83 84 (REC reference 17/LO/0906) and the study followed COREQ (consolidated criteria for

reporting qualitative research) guidelines¹⁴ as recommended for rigorous qualitative
research.¹⁵

87

88 Patient involvement

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

95

96 Study Design

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

101

102 **Questionnaire and Interview**

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

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

4

113 providers.

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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

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

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

event questionnaire and conducted at the finish line to capture immediate reflections. Each
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 Network Approach (TNA).¹⁷ TNA examines connections between emerging themes, which 146 147 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

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

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161 Theme 1: Balancing Act

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

170 Nutrition

Participants were keen to emphasise that food composition and diet were important factors for overall performance and not simply because they had T1D. Primarily, participants' main concern was to try and operate like a cyclist and then accommodate their diabetes, rather than allowing their diabetes to control their cycling. This meant they followed general nutritional guidelines and, therefore, incorporated nutritional principles that could be applied 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 by testing blood glucose levels as and when they could, often using a continuous glucose 188 189 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

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

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

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

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

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

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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 because that means I can ride for however many hours I want to...if I'm trying a new 215 food or a new strategy I'm not too worried if I crash and burn because you know the 216 217 sofa's right there" (Participant 001). 218 Education 219 220 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

and apply the acquired information to their particular exercise regime,

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 to manage their T1D more effectively. Most importantly, a CGM was a valuable decision-244 245 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).

Participants that used CGM reported the superior data versus fingertip blood testing, noting the pattern of glucose values over time is meaningful when deciding nutrition and exercise intensity strategies on the move. Following physical cues and sensations is a practice familiar to people with T1D and in the present study, the ability to make informed decisions when exercise demands increase was valuable₁.

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, your appetite is going to be swayed anyway. So it's more difficult without the CGM 268 269 For all the big events that I do, I'll stick the Dexcom on, just to be sure." (Participant 270 001).

271

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

282

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

285

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

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

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,

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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 regular basis. HCP availability for all individuals may be limited, especially during the current 304 305 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

Sensitivity: Internal

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

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338

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

There has been significant research on the physiological/glycaemic response to endurance
 exercise and T1D,¹⁸ but such evidence is less common in ultra-endurance events,

362 particularly in relation to self-management and T1D based experiential strategies.^{19,20} 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

disposal.⁶ However, current guidance regarding this is lacking and suggests only moderate
reductions. In ultra-endurance events, our participants reported that (exogenous) insulin
intake was reduced to unexpectedly low levels or in some cases, unnecessary. This may
present as counter-intuitive to individuals with T1D who are unaccustomed to ultraendurance exercise and emphasises the need to disseminate such experiential evidence
amongst the T1D community via HCPs. Future research should trial insulin management
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.²¹ 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 adhere to guidelines for T1D management¹⁸ and large inter-individual variations exist around 385 successful exercise management.²² In agreement and in a novel finding to date, our findings 386 387 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

supporting nutrition (fuelling) planning for exercise and training and making potential
adjustments to an individual's insulin regimen as training and exercise progress (based on
the metabolic responses and nutrition requirements for exercise), HCPs advice will centre on
the individual while remaining embedded in current sport and exercise guidelines for training
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 HCPs around PAE.¹⁰ Evidence based recommendations exist for exercise with T1D,²³ but 405 406 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 base. In this subset of the population, empowering the individual to tailor their regimen may 411 412 be considered a more optimal approach.

413

Recent technological advances have improved glycaemic control in T1D²⁴ and the use of a CGM may be essential in providing those living with the condition with more in-depth and 'live' blood glucose feedback to inform decision-making and T1D self-management strategies. While undertaking arduous exercise, those participants who used a CGM found simplifying the decision-making process to be beneficial, supporting recent *in silico* evidence²⁵ of CGM to improve both time spent in euglycaemic concentrations and the patient narrative in free-living conditions.²⁶ Specifically, CGM allowed participants to make

fine adjustments to their event plan and respond to unexpected physiological responses.
Furthermore, the physiological demands of ultra-endurance exercise may mask or alter
individuals' typical physical responses to hypoglycaemia for example, where CGM data can
serve as an additional tool to mark changes in blood glucose concentration and aid decisionmaking. However, while there are major benefits to CGM, not all individuals wish to engage
with the technology and HCPs may need to accommodate individual beliefs, motivation and
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 ²⁷ (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 exercise and the physiological demands of exercise, particularly during ultra-endurance 440 441 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" approach adopted by the present participants, and identified in previous research,³ there is a 448

need to undertake this in safe environments, such as the home, with input from HCPs, inorder 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.

479

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
- 490

491 **Table 1: Participant characteristics**

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

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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496		
497	- People with T1D received little or no ultra-endurance event specific help or advice from HCPs.	
498	- Education relied on a previous self-education approach of trial and error, i.e. nutrition,	
499	exercise and insulin strategy practice alongside engagement with the T1D community.	
500	- Participants who 'best' managed the event were prepared, had previous experience of such events and planned their insulin and nutrition for the day.	
501	- The identity with which the majority of the participants associated themselves was that of a	
502	'cyclist' rather than that of somebody defined by their condition. Participation in ultra-	
503	endurance exercise does not need to be limited by T1D	
	- HCPs focus on the following key messages when engaging with T1D endurance	
504	exercisers may be beneficial to future work:	
505	• be mindful of inter-individual responses and following a 'one size fits all' approach.	
506	 encourage awareness and understanding of individual metabolic responses to exercise 	
507		
508	and training	
509	• provide nutrition (fuelling) planning & education and endurance exercise support based on	
510	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	
511	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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