DOI: 10.1111/dme.15429

RESEARCH ARTICLE

Care Delivery



The top 10 priorities in adults living with type 1 diabetes in Ireland and the United Kingdom – A James Lind Alliance priority setting partnership

Christine Newman ^{1,2,3} Suzannah Kinsella ⁴ Peter Rooney ¹ Jake Bromley ⁵
Rachel Connor ⁶ Kate Gajewska ⁷ Sinead Hannan ⁸ Richard I. G. Holt ⁹
Julia Hubbard ⁶ Columb Kavangh ⁵ Jinty Moffett ⁵ Anna Morris ¹⁰
Hilary Nathan ⁶ Nick Oliver ¹¹ 💿 John R. Petrie ¹² 💿 Michael Skarlatos ¹³
David Treanor ⁵ Pauline Williams ⁵ Fidelma P. Dunne ^{1,2,3}

¹Institute for Clinical Trials, College of Medicine, Nursing and Health Sciences, University of Galway, Galway, Ireland

²Irish Collaborative Clinical Trial Network in Diabetes, University of Galway, Galway, Ireland

³Galway University Hospital, Galway, Ireland

⁴James Lind Alliance, National Institute for Health Research Evaluation, Trials and Studies Coordinating Centre, University of Southampton, Southampton, UK

⁵Diabetes Collaborative Clinical Trials Network Public and Patient Involvement Department, University of Galway, Galway, Ireland

⁶Breakthrough T1D (Formerly Juvenile Diabetes Research Foundation), London, UK

⁷Diabetes Ireland, Northwood Business Campus, Dublin, Ireland

⁸Southern Trust, Health and Social Care, Craigavon, UK

⁹Human Development and Health, Faculty of Medicine, University of Southampton, Southampton, UK

¹⁰Diabetes UK, London, UK

¹¹Imperial College London, London, UK

¹²School of Health and Wellbeing, College of Medical, Veterinary and Life Sciences, University of Glasgow, Glasgow, UK

¹³Leicester Diabetes Centre, Leicester, UK

Correspondence

Christine Newman, Institute for Clinical Trials, College of Medicine, Nursing and Health Sciences, University of Galway, Galway, Ireland. Email: cnewman@universityofgalway.ie

Funding information Health Research Board

Abstract

Aims: To undertake a Priority Setting Partnership (PSP), identifying the most important unanswered questions in type 1 diabetes in Ireland and the United Kingdom and to compare these to priorities identified in a 2011 PSP.

Methods: A steering committee (including eight individuals with lived experience/charity representatives and six clinicians) designed a survey which asked stakeholders to list three questions about type 1 diabetes. This was disseminated through social media, direct email contact, and printed posters. Following analysis, a second survey asked participants to rank these priorities in order of importance. The top questions were then carried forward to an online, 2 days final workshop where the final top 10 were ranked.

This is an open access article under the terms of the Creative Commons Attribution-NonCommercial-NoDerivs License, which permits use and distribution in any medium, provided the original work is properly cited, the use is non-commercial and no modifications or adaptations are made. © 2024 The Author(s). *Diabetic Medicine* published by John Wiley & Sons Ltd on behalf of Diabetes UK.

Results: There were 1050 responses (64% female, 78% adults living with type 1 diabetes, 9% healthcare professionals, 9% family members) to the first survey and 2937 individual questions were submitted. Sixty-five summary questions were submitted into a second survey, completed by 497 individuals (76% adults living with type 1 diabetes, 9% healthcare professionals, and 11% family members). Nineteen questions from the interim survey progressed to a final workshop, which identified the top 10 priorities through group discussion. As in 2011, there was emphasis on psychological health, diabetes-related complications, and hypoglycaemia. New themes prioritised included artificial intelligence and women's health.

Conclusions: The research priorities, which have been identified using a robust and proven methodology, highlight the key concerns of those living with type 1 diabetes, their families and representatives, as well as clinicians in Ireland and the UK.

KEYWORDS

priorities, research, type 1 diabetes

1 | INTRODUCTION

Nearly 280,000 people live with type 1 diabetes in Ireland and the United Kingdom $(UK)^{1-3}$ and rates of type 1 diabetes are increasing worldwide.⁴ While an ever increasing number of studies are under way to investigate complications and management options in type 1 diabetes, the research does not always reflect the priorities of people living with type 1 diabetes or those closest to them.^{5,6}

The James Lind Alliance (JLA) was established in 2004 as a non-profit organisation to bridge the gap between researchers, funders, and people with lived experience of health-related conditions⁷ by bringing them together as equal partners to identify questions through publicly circulated surveys, and then to prioritise those considered to be unanswered via further surveys and workshops. The prioritised questions for research are then disseminated through various routes and highlighted to research funders.

In 2011, a UK-based PSP conducted in the area of type 1 diabetes identified the top 10 priorities for research.⁸⁻¹⁰ Since then, many of these priorities have been studied and the top three questions listed – concerning the use of continuous glucose monitoring (CGM) and hybrid closed loop (HCL) therapy – have been incorporated into routine clinical practice.^{11–13} A "refresh" PSP was established to review and update the unanswered priorities in adults living with type 1 diabetes. This differed from the original protocol as it included adults and clinicians living in Ireland and brought together the Diabetes Collaborative Clinical Trials Network (based at the University of Galway, Ireland), Diabetes Ireland,

What's new?

- The priorities of those conducting research do not always match the priorities of those living with type 1 diabetes.
- A Priority Setting Partnership was conducted in type 1 diabetes in 2011 to identify the most important unanswered questions, however, there have been significant changes in the field of diabetes management.
- This study identified the top 10 unanswered questions in type 1 diabetes in adults living in Ireland and the United Kingdom.
- New themes prioritised as "top 10" included the use of artificial intelligence, the provision of holistic care, access to newer forms of therapy including stem cell transplantation, and women's health.
- These priorities will help funders and researchers address the issues that are most important to those living with type 1 diabetes, their families and representatives, as well as clinicians.

and Breakthrough T1D (formerly the Juvenile Diabetes Research Foundation) and Diabetes UK. Although the UK and Ireland have different health systems, they share several similarities including free healthcare and medications for adults living with type 1 diabetes

DIABETIC

delivered via the National Health Service and the longterm illness scheme, respectively.

2 **METHODS**

We adhered to established JLA methodology to complete this PSP.¹⁴

2.1 Step 1 – Establishing the steering group and defining the scope

The PSP was conducted by a steering group, composed of people living with diabetes, clinicians and representatives from diabetes charities. As this was a refresh PSP, two members of the previous PSP (JRP and RC) joined the steering group to ensure their valuable experience was incorporated into the process. The individual charity representatives (KG and AM) were nominated by their charities which in turn contacted people living with type 1 diabetes who had acted as representatives in other projects. All interested participants met with CN and PR, who explained the nature of the project and likely time commitments. Participants were chosen based on their gender, geographical location, age, and duration of lived experience to ensure a wide range of experience was represented. The composition of the steering group was approved by an impartial JLA adviser (SK), who also chaired all steering group meetings. The steering group comprised six clinical representatives (four endocrinologists, one consultant clinical psychologist, and one senior dietitian); four adults living with type 1 diabetes; one parent of adult children living with type 1 diabetes and three charity groups. Ten members were from the UK and four were from Ireland. The steering group had an equal gender representation and met 13 times before the final workshop on 16th and 17th May 2024 and twice after the final workshop. All meetings were held virtually using videoconferencing software. During the earlier steering group meetings, the scope and outline of the PSP were decided and are detailed in Table 1. A copy of the completed protocol, including steering group make-up, can be found on the JLA website: https://www.jla.nihr.ac.uk/news-and-publications/ documents.htm?postid=33630.

2.2 Step 2 – Establishing uncertainties

The initial step of this PSP was to develop and promote a primary survey which asked adults living with type 1 diabetes, their families/carers and healthcare professionals to list three questions they would like to see answered TABLE 1 Terms of reference and scope of PSP.

Questions about the following were included	Questions about the following were excluded
• Adults over the age of 18, their families, carers and friends	 Paediatric care in type 1 diabetes Questions or priorities
• Cause, prevention,	without a UK or Irish focu

diagnosis (including misdiagnosis), screening, precipitating factors, treatment and management of type 1 diabetes and its complications

- Other conditions type 1 diabetes
- · Physical, social, cultural, economic and psychological aspect
- · Information, education and service improvement
- commonly associated with

- or relevance Questions or priorities
- about other forms of diabetes including MODY, type 2 diabetes and gestational diabetes, type 1 diabetes in pregnancy (due to recent completion of a PSP in the area of diabetes in pregnancy), cystic fibrosis related diabetes etc.

about type 1 diabetes. The survey was piloted on 22 healthcare professionals and people living with type 1 diabetes for ease of use and acceptability. The survey was available in English and ran from June 6th to September 6th, 2023. It was promoted through social media networks, emails to professionals and printed posters in diabetes clinics and general practice offices throughout Ireland and the UK. To ensure a diverse range of voices were included, we also ran a phoneline for 2h each week for individuals with visual impairment or who preferred spoken to written English, emailed organisations working with under-represented patient groups and contacted professional networks.

Questions, alongside some basic demographic details, including data on age, gender, and income were submitted via QuestionPro® (licence held by the University of Galway). Regular interim analyses were conducted to evaluate the demographic make-up of participants: this allowed us to increase efforts within certain demographics by targeted interventions; for example, we attempted to contact local leaders within certain ethnic groups and specifically promoted the survey in social media groups and locations for those populations. In the survey, all participants were provided with an explanation of how their data and information would be used and participants gave consent before completing the survey.

Based on the response rate of 1100 questions from 583 individuals in the 2011 PSP, we aimed to reach 3000 questions (based on the inclusion of Ireland, the rising prevalence of type 1 diabetes and the increased use of social media).

2.3 | Step 3 – Data processing and verifying uncertainties

Once the survey closed all data were downloaded. A random sample of 200 questions were reviewed by the information specialist and grouped into summary questions. Using QuestionPro software, questions containing specific keywords were tagged and automatically grouped together (via a text categorisation and tagging facility) for ease of review; for example, hundreds of questions containing the words "cure," "triggers" and "cause" were automatically grouped together. The information specialist (CN) manually reviewed each individual question under these headings and formulated indicative summary questions into a PICO (population, intervention, comparison and outcome) structure. The steering group (split into three sub-groups composed equally of healthcare professionals, people with lived experience and charity representatives) then reviewed each indicative summary question alongside the original individual submissions and the details of the individual submitting the question (e.g., family member, healthcare professional) to maintain integrity and minimise individual bias and misinterpretation.

The steering sub-groups were free to edit the summary questions provided each member was in agreement and that they remained faithful to the meaning of the original survey submission. Importantly, many submissions contained multiple questions within the same text box or asked questions which touched on more than one theme. In such instances, the questions were mapped on to all relevant areas to ensure full representation. The steering group also reviewed any questions deemed out of scope by the information specialist (Table 1).

Once the steering group was satisfied, the information specialist checked each summary question against national (Ireland and the UK) and international guidelines, PubMed and the Cochrane database for systematic reviews published from 2020 onwards. We also searched the same sources and the PROSPERO international prospective register of systematic reviews for ongoing but incomplete systematic reviews. Questions which could be considered comprehensively answered were not carried forward to the next stage of the process.

2.4 | Step 4 – Interim priority setting

Following steering group review and evidence checking, 65 indicative summary questions were included in the interim survey. This survey was again conducted on the QuestionPro software and distributed via the same media as before; however, participants of the first survey who gave their consent and contact details were emailed directly to complete the second survey. In this survey, participants were asked to select up to 10 questions from the 65 questions which they felt were important for research to answer. They were then asked to rank these questions from 1 to 10. This survey ran from 6th March to 2nd May 2024. At this time, individuals completing the survey were asked to register their interest in participating in the final workshop to define the top 10 priorities.

During the analysis of this survey, we reviewed the ranking results from the total population as a whole, healthcare professionals, people living with diabetes and their carers, ethnic minorities (excluding healthcare professionals), those who identified as being on a lower income and male participants (excluding healthcare professionals) to compare the priorities and answers from different subgroup and to ensure that under-represented voices carried equal weight. Each of the 65 summary questions was then assigned a numeric score (lower score equated to a higher rank) according to its ranking by each of the six groups. The scores for each of the groups were combined and then divided by six to obtain an average score. This ensured that if a question was ranked very highly by one specific group, the question had a greater chance of progressing to the final PSP survey. The 19 questions with the lowest average scores were brought through to the final PSP workshop (Data S1).

2.5 | Step 5 – Final priority setting

The final workshop took place over 2 days (May 16th to 17th 2024) via an online video platform. In order to establish a diverse and representative panel, we reviewed the demographic details of all individuals who registered interest in attending the final PSP workshop when completing the interim survey. Where deficits in diversity and expertise either by profession or lived experience were identified targeted invitations and advertisements were issued to ensure fair representation at the final workshop: e.g., personal invitations to healthcare workers from under-represented groups, group emails to healthcare workers in areas with high proportions of ethnic minorities and contacting specific social media groups. Participants were asked to complete a conflict-of-interest form (see above) and all healthcare professionals were active in clinical practice.

The final workshop was led by the JLA adviser and three other JLA moderators were present to facilitate four small group discussions. Four non-participating observers were also present. A welfare officer was available for any individual who required personal or additional emotional support during the workshop.

During the first sub-group session, each participant identified their highest and lowest priority and gave a brief

explanation of why they ranked the question in that way. The JLA facilitator kept a record of how each question was ranked and placed each question in either a "high", "middle" or "low" priority category.

In the second session, the sub-groups remained the same, and the group reviewed the questions using visual aids and ranked the questions in the "high" and "middle" categories to create a top 10. At the end of Day 1, the rankings from each sub-group were combined to create an overall ranking.

At the start of Day 2, these results were shared with the entire group and new sub-groups were formed. These groups reviewed the priorities and debated the order of questions to create a top 10 list. The results of each of the sub-groups were again combined to form the final top ranking and top 10 (Data S4).

2.6 | Ethics

The UK Health Research Authority decision aid identified no need for research ethics approval.

3 | RESULTS

The outline of the total process can be found in Figure 1. The final top 10 priorities as determined by the final workshop and their ranking according to individual demographic groups in the interim ranking survey are outlined in Table 2.

3.1 | Initial survey

The initial survey received 13,387 initial views. 1050 individuals completed at least one question box and the average number of questions was 2.9. Nearly 70% of respondents completed three or more of the question boxes and many question boxes contained more than one question. 3601 individual questions were submitted (including 137 questions which were eliminated for containing "yes", "no", "n/a" or "see above"), leaving 3464 questions that were individually reviewed. The ethnic and demographic breakdown of survey respondents is outlined in Table 3 and further details are available in Data S2.

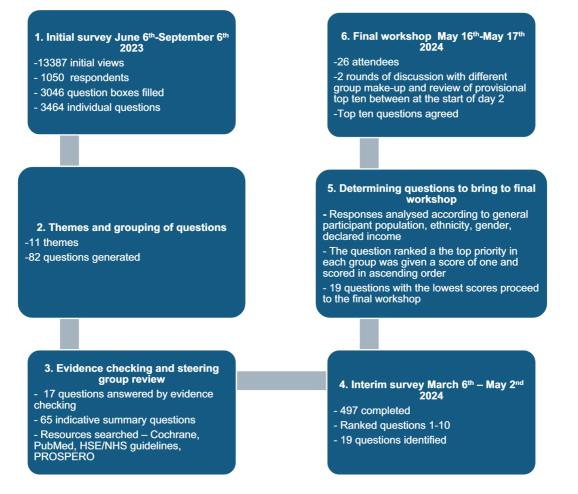


FIGURE 1 Outline of the PSP process.

TABLE 2	Top ten priorities for research from the final workshop and their original overall and subgroup scoring from the interim
survey.	

		Ranking in interim survey					
Final ranking from workshop	Question	Overall rating	НСР	Adults with lived experience	Ethnic minority participants	Male participants	Participants with lower incomes
1	Can the use of artificial intelligence or fasting acting insulins help achieve fully closed loop insulin delivery?	1	2	1	8	1	1
2	Is time in range a better predictor of diabetes management and complications compared to HbA1c (an average reading of blood sugar over a 3-month period)?	13	8	13	29	7	12
3	What impact do hormonal phases such as the perimenstrual period and menopause play in glycaemic management and what treatments are most effective for managing glucose levels around these times?	18	4	5	39	62	6
4	What interventions are the most effective for reducing diabetes related distress and burnout?	9	57	9	4	46	9
5	What are the long-term implications of frequent hypoglycaemia on physical and mental health?	6	5	6	3	5	5
6	What impact does type 1 diabetes (including frequent low blood sugar) have on memory and cognition in older adults?	2	9	3	2	4	2
7	How can healthcare professionals better take into account the physical, psychological and social aspects of type 1 diabetes in clinics?	8	1	8	25	24	8
8	How can access to potential therapies like stem cell therapy, transplants and medications that modify the immune systems be improved so that everyone with type 1 diabetes can be guaranteed access?	3	52	2	1	3	4
9	Why do some people with type 1 diabetes become insulin resistant and does resistance increase with the number of years a person has diabetes and if so, why?	11	31	10	21	6	11
10	Can technology assist to accurately count carbohydrates without having to weigh or measure all foods and drink?	10	3	12	40	9	10

These questions were then reviewed for scope, grouped into themes and translated to 82 indicative summary questions. The breakdown of questions included cause and aetiology (28%), cure (19%), treatment and prevention (18%), long-term outcomes and complications (11%), questions regarding sexual health and fertility (5%), service access (5%), psychological queries (4%), weight management (4%), assessment and initial diagnosis (2%), the impact of Covid-19 on type 1 diabetes (2%) and communication and education (1%). After evidence checking, 17 questions were removed as considered answered and 65 questions proceeded to the interim survey phase (Data S3).

3.2 | Interim survey

The interim survey ran for 8 weeks and received 497 replies. In total, 22% of initial respondents agreed to be contacted for the interim survey and among this cohort

Initial surveyInterim surveyTotal number of participants1050497Gender (%)3429Male3429Female6469Prefer not to say<11Non-binary<11Other10Location (%)848Scotland4817Wales24Scotland4817Wales24Northern Ireland35Rep of Ireland1623Other23Ethnicity (%)7387Welsh22Black/Black British/Asian Irish22Black/Black British/Asian Irish22Black/Black British/Black Irish11Mixed and multiple ethnic12groups707Other12Unknown2270Parent/guardian46Family member (non-parent)55Member of a diabetes11organisation33Other3839Hospital doctor3839Hospital doctor3839Hospital doctor3832Community nurse40Podiatrist44GP32Community nurse40Podiatrist44GP30Income	interim surveys.		
Gender (%) Male 34 29 Female 64 69 Prefer not to say <1 1 Non-binary <1 1 Other 1 0 Location (%) 8 48 England 28 48 Scotland 48 17 Wales 2 4 Northern Ireland 3 5 Rep of Ireland 16 23 Other 2 3 Ethnicity (%) White/British/Irish/Scottish/ 73 87 Weish 2 1 1 Asian/Asian British/Asian Irish 2 2 Black/Black British/Black Irish 1 1 Mixed and multiple ethnic 1 2 groups 0 7 7 Other 1 2 1 An adut living with type 1 78 76 diabetes 1 1 1 HCP 9 9 9 Parent/guardian 4 6 <			
Male 34 29 Female 64 69 Prefer not to say <1	Total number of participants	1050	497
Female 64 69 Prefer not to say <1	Gender (%)		
Prefer not to say <1	Male	34	29
Non-binary <1	Female	64	69
Other 1 0 Location (%) England 28 48 Scotland 48 17 Wales 2 4 Northern Ireland 3 5 Rep of Ireland 16 23 Other 2 3 Ethnicity (%) White/British/Irish/Scottish/ 73 87 Welsh 7 87 Welsh Asian/Asian British/Asian Irish 2 2 Black/Black British/Black Irish 1 1 Mixed and multiple ethnic 1 2 groups 0 7 Other 1 2 Hoknown 22 7 Participant type (%) 7 76 An adult living with type 1 78 76 diabetes 1 1 7 HCP 9 9 9 Parent/guardian 4 6 5 organisation 3 3 1	Prefer not to say	<1	1
Location (%) England 28 48 Scotland 48 17 Wales 2 4 Northern Ireland 3 5 Rep of Ireland 16 23 Other 2 3 Ethnicity (%) White/British/Irish/Scottish/ 73 87 Welsh 2 2 Black/Black British/Asian Irish 2 2 Black/Black British/Black Irish 1 1 Mixed and multiple ethnic 1 2 groups 0 7 76 1 2 Other 1 2 7 7 Participant type (%) 7 76 1 2 An adult living with type 1 78 76 1 2 HCP 9 9 9 9 Parent/guardian 4 6 5 10 10 Other 3 3 3 1 1 Opanisation 0 0	Non-binary	<1	1
England 28 48 Scotland 48 17 Wales 2 4 Northern Ireland 3 5 Rep of Ireland 16 23 Other 2 3 Ethnicity (%) White/British/Irish/Scottish/ 73 87 Welsh 2 2 Asian/Asian British/Asian Irish 2 2 Black/Black British/Black Irish 1 1 Mixed and multiple ethnic 1 2 groups 7 7 Other 1 2 Hokybant type (%) 7 7 An adult living with type 1 78 76 diabetes 1 1 HCP 9 9 Parent/guardian 4 6 Family member (non-parent) 5 5 Member of a diabetes 1 1 organisation 1 20 Other 3 3 3 Healthcare professional breakdown (%) 15 15 Institian <td>Other</td> <td>1</td> <td>0</td>	Other	1	0
Scotland 48 17 Wales 2 4 Northern Ireland 3 5 Rep of Ireland 16 23 Other 2 3 Ethnicity (%) White/British/Irish/Scottish/ 73 87 Welsh 2 2 Black/Black British/Asian Irish 2 2 Black/Black British/Black Irish 1 1 1 Mixed and multiple ethnic 1 2 1 Other 1 2 1 Other 1 2 1 Mixed and multiple ethnic 1 2 1 Other 1 2 1 An adult living with type 1 78 76 diabetes 1 1 1 HCP 9 9 9 Parent/guardian 4 6 Family member (non-parent) 5 5 Member of a diabetes 1 1 organisation 3	Location (%)		
Wales 2 4 Northern Ireland 3 5 Rep of Ireland 16 23 Other 2 3 Ethnicity (%) White/British/Irish/Scottish/ 73 87 White/British/Irish/Scottish/ 73 87 Welsh 1 1 Asian/Asian British/Asian Irish 2 2 Black/Black British/Black Irish 1 1 Mixed and multiple ethnic 1 2 groups 70 70 Other 1 2 Horown 22 7 Participant type (%) 78 76 An adult living with type 1 78 76 diabetes 1 1 HCP 9 9 Parent/guardian 4 6 Family member (non-parent) 5 5 Member of a diabetes 1 1 organisation 20 20 Phospital nurse 16 15 Dietitian 24 20 Psychologist	England	28	48
Northern Ireland 3 5 Rep of Ireland 16 23 Other 2 3 Ethnicity (%) White/British/Irish/Scottish/ 73 87 Welsh 2 2 Asian/Asian British/Asian Irish 2 2 Black/Black British/Black Irish 1 1 Mixed and multiple ethnic 1 2 groups 0 2 7 Participant type (%) 1 2 1 An adult living with type 1 78 76 1 diabetes 1 1 1 HCP 9 9 9 Parent/guardian 4 6 6 Family member (non-parent) 5 5 1 organisation 1 1 1 Other 3 3 1 Hospital doctor 38 39 1 Hospital nurse 16 15 1 Dietitian 24	Scotland	48	17
Rep of Ireland 16 23 Other 2 3 Ethnicity (%) ************************************	Wales	2	4
Other23Ethnicity (%)White/British/Irish/Scottish/7387Welsh	Northern Ireland	3	5
Ethnicity (%)87White/British/Irish/Scottish/7387Welsh12Asian/Asian British/Asian Irish22Black/Black British/Black Irish11Mixed and multiple ethnic12groups12Other12Unknown227Participant type (%)7876An adult living with type 17876diabetes11HCP99Parent/guardian46Family member (non-parent)55Member of a diabetes11organisation12Other33Healthcare professional breakdown (%)15Hospital doctor3839Hospital nurse1615Dietitian2420Psychologist515Community nurse40Podiatrist44GP32Renal physician32Community based consultant0Other30Income under living wage (%)4Yes106No8586Prefer not to answer34	Rep of Ireland	16	23
White/British/Irish/Scottish/ Welsh7387Asian/Asian British/Asian Irish22Black/Black British/Black Irish11Mixed and multiple ethnic12groups72Other12Unknown227Participant type (%)7876An adult living with type 17876diabetes11HCP99Parent/guardian46Family member (non-parent)55Member of a diabetes11organisation33Healthcare professional breakdown (%)1515Dietitian2420Psychologist515Community nurse40Podiatrist44GP32Renal physician32Community based consultant02Other30Income under living wage (%)6Yes106No8586Prefer not to answer34	Other	2	3
WelshAsian/Asian British/Asian Irish2Black/Black British/Black Irish1Mixed and multiple ethnic1groups2Other127Participant type (%)78An adult living with type 178An adult living with type 178Parent/guardian46Family member (non-parent)5Member of a diabetes111organisation1Other3Healthcare professional breakdown (%)15Hospital doctor389161515Community nurse4021Podiatrist444GP323Community based consultant002Other393939393106No8586Prefer not to answer334	Ethnicity (%)		
Black/Black British/Black Irish11Mixed and multiple ethnic12groups12Other12Unknown227Participant type (%)7876An adult living with type 17876diabetes79HCP99Parent/guardian46Family member (non-parent)55Member of a diabetes11organisation11Other33Healthcare professional breakdown (%)15Hospital doctor3839Hospital nurse1615Dietitian2420Psychologist515Community nurse40Podiatrist44GP32Renal physician32Community based consultant0Other30Income under living wage (%)4Yes106No8586Prefer not to answer34		73	87
Mixed and multiple ethnic groups12Other12Unknown227Participant type (%)7876An adult living with type 17876diabetes79HCP99Parent/guardian46Family member (non-parent)55Member of a diabetes11organisation11Other33Healthcare professional breakdown (%)15Hospital doctor3839Hospital nurse1615Dietitian2420Psychologist515Community nurse40Podiatrist44GP32Renal physician32Community based consultant02Other30Income under living wage (%)8586Prefer not to answer34	Asian/Asian British/Asian Irish	2	2
groups 1 2 Other 1 2 Unknown 22 7 Participant type (%) 78 76 An adult living with type 1 78 76 diabetes 7 9 HCP 9 9 Parent/guardian 4 6 Family member (non-parent) 5 5 Member of a diabetes 1 1 organisation 1 1 Other 3 3 Healthcare professional breakdown (%) 15 15 Hospital nurse 16 15 Dietitian 24 20 Psychologist 5 15 Community nurse 4 4 GP 3 2 Renal physician 3 2 Other 3 0 Income under living wage (%) 2 Yes 10 6 No 85 86 Prefer not to answer 3 4	Black/Black British/Black Irish	1	1
Unknown227Participant type (%)An adult living with type 17876An adult living with type 17876diabetes79HCP99Parent/guardian46Family member (non-parent)55Member of a diabetes11organisation11Other33Healthcare professional breakdown (%)15Hospital doctor3839Hospital nurse1615Dietitian2420Psychologist515Community nurse44GP32Renal physician32Community based consultant02Other30Income under living wage (%)6Yes106No8586Prefer not to answer34	-	1	2
Participant type (%)7876An adult living with type 17876diabetes17876HCP99Parent/guardian46Family member (non-parent)55Member of a diabetes11organisation11Other33Healthcare professional breakdown (%)1615Hospital doctor3839Hospital nurse1615Dietitian2420Psychologist515Community nurse44GP32Renal physician32Other30Income under living wage (%)6No8586Prefer not to answer34	Other	1	2
An adult living with type 17876diabetes99HCP99Parent/guardian46Family member (non-parent)55Member of a diabetes11organisation11Other33Healthcare professional breakdown (%)15Hospital doctor3839Hospital nurse1615Dietitian2420Psychologist515Community nurse40Podiatrist44GP32Renal physician32Community based consultant0Other30Income under living wage (%)6Yes106No8586Prefer not to answer34	Unknown	22	7
diabetes HCP 9 9 Parent/guardian 4 6 Family member (non-parent) 5 5 Member of a diabetes 1 1 organisation Other 3 3 3 Healthcare professional breakdown (%) Hospital doctor 38 39 Hospital nurse 16 15 Dietitian 24 20 Psychologist 5 15 Community nurse 4 0 Podiatrist 4 4 GP 3 2 Renal physician 3 2 Community based consultant 0 2 Other 3 0 Income under living wage (%) Yes 10 6 No 85 86 Prefer not to answer 3 4	Participant type (%)		
Parent/guardian46Family member (non-parent)55Member of a diabetes11organisation11Other33Healthcare professional breakdown (%)13Hospital doctor3839Hospital nurse1615Dietitian2420Psychologist515Community nurse40Podiatrist44GP32Renal physician32Other30Income under living wage (%)4Yes106No8586Prefer not to answer34		78	76
Family member (non-parent)55Member of a diabetes11organisation11Other33Healthcare professional breakdown (%)15Hospital doctor3839Hospital nurse1615Dietitian2420Psychologist515Community nurse40Podiatrist44GP32Renal physician32Community based consultant02Other30Income under living wage (%)4Yes106No8586Prefer not to answer34	НСР	9	9
Member of a diabetes organisation11organisation13Other33Healthcare professional breakdown (%)1Hospital doctor3839Hospital nurse1615Dietitian2420Psychologist515Community nurse40Podiatrist44GP32Renal physician32Community based consultant02Other30Income under living wage (%)6Yes106No8586Prefer not to answer34	Parent/guardian	4	6
Infinite of a materialIorganisation3Other3Healthcare professional breakdown (%)Hospital doctor38Hospital nurse16Dietitian2420Psychologist5515Community nurse4446P32Renal physician32Community based consultant002Other3910106No8586Prefer not to answer34	Family member (non-parent)	5	5
Other33Healthcare professional breakdown (%)Hospital doctor3839Hospital doctor3839Hospital nurse1615Dietitian2420Psychologist515Community nurse40Podiatrist44GP32Renal physician32Community based consultant02Other30Income under living wage (%)Yes10Yes106No8586Prefer not to answer34	Member of a diabetes	1	1
Healthcare professional breakdown (%)Hospital doctor3839Hospital nurse1615Dietitian2420Psychologist515Community nurse40Podiatrist44GP32Renal physician32Community based consultant02Other30Income under living wage (%)4Yes106No8586Prefer not to answer34	organisation		
Hospital doctor3839Hospital nurse1615Dietitian2420Psychologist515Community nurse40Podiatrist44GP32Renal physician32Community based consultant02Other30Income under living wage (%)4Yes106No8586Prefer not to answer34			3
Hospital nurse1615Dietitian2420Psychologist515Community nurse40Podiatrist44GP32Renal physician32Community based consultant02Other30Income under living wage (%)4Yes106No8586Prefer not to answer34	-		
Dietitian2420Psychologist515Community nurse40Podiatrist44GP32Renal physician32Community based consultant02Other30Income under living wage (%)4Yes106No8586Prefer not to answer34	-		
Psychologist515Community nurse40Podiatrist44GP32Renal physician32Community based consultant02Other30Income under living wage (%)4Yes106No8586Prefer not to answer34	-		
Community nurse40Podiatrist44GP32Renal physician32Community based consultant02Other30Income under living wage (%)Yes10Yes106No8586Prefer not to answer34			
Podiatrist44GP32Renal physician32Community based consultant02Other30Income under living wage (%)36Yes106No8586Prefer not to answer34		-	
GP32Renal physician32Community based consultant02Other30Income under living wage (%)7Yes106No8586Prefer not to answer34			
Renal physician32Community based consultant02Other30Income under living wage (%)7Yes106No8586Prefer not to answer34			
Community based consultant02Other30Income under living wage (%)106Yes106No8586Prefer not to answer34			
Other30Income under living wage (%)Yes10No85Prefer not to answer34			
Income under living wage (%)Yes10No85Prefer not to answer34	-		
Yes106No8586Prefer not to answer34		3	0
No8586Prefer not to answer34		10	<i>,</i>
Prefer not to answer 3 4			
	- · -		
	Olibuit	2	+

TABLE 3 Demographic details of respondents to initial and interim surveys.

the response rate was 62%. The demographic profiles of the participants in the interim survey closely matched the initial survey (Table 3). However, when the responses of the six sub-groups of respondents (healthcare professionals, people living with diabetes and their carers, ethnic minorities, men and those who identified as being on a lower income) were reviewed, we noted some differences between groups. Only four out of 10 priorities overlapped between healthcare professionals and those with lived experience. Topics rated important by those with lived experience but ranked lower by healthcare professionals included the use of other hormones, including glucagon, somatostatin, and amylin in the management of type 1 diabetes, access to stem cell therapy and immunotherapy, long-term outcomes compared to individuals who do not live with type 1 diabetes and insulin resistance. Those with lived experience and those who reported a lower income had almost identical priority rankings. When the replies from those self-identifying as being from an ethnic minority were compared to replies from the general population, only four out of 10 priorities overlapped; individuals from ethnic minorities placed less emphasis on discussing psychological and social issues at clinics, long-term outcomes compared to individuals who do not live with type 1 diabetes, accessing carbohydrate counting technologies, and insulin resistance. A full outline of the different responses to all 65 indicative summary questions can be found in Data S1.

3.3 | Final workshop and top 10

The final workshop was held virtually with 27 participants. Healthcare professionals accounted for 14 members of the panel professionals (two dietitians, two advanced diabetes nurse practitioners, two podiatrists, one general practice nurse, five endocrinologists (four adults and one paediatric), one psychologist, and one mental health nurse who is also trained as a behavioural scientist). The remaining 13 participants were people living with type 1 diabetes and their family members. Fifteen members of the final workshop were female (56%), 11 were men (41%), and one member identified as non-binary. Two members (7.4%) were from black or minority ethnic groups. Three members of the steering group also sat on the final workshop panel. The JLA facilitators ensured that all participants had the opportunity to express their opinion and gave a clear explanation that all workshop participants were experts either by training or by experience.

The top 10 priorities (Table 2) highlighted the changes that have occurred in diabetes care. The top ranking priority, "can the use of artificial intelligence

or fasting acting insulins help achieve fully closed loop insulin delivery?" was the top priority for four out of the six sub-groups in the interim survey and was consistently in the top 10. There was also a focus on the use of technology to assess the carbohydrate content of food visually without the need for weighing food portions. The complications of type 1 diabetes which featured in the top 10 included utilising time in range to predict complications, improving perimenstrual and reproductive health, reducing the implications of hypoglycaemia on physical and mental health and cognition, and the impact, causes, and treatment of insulin resistance. From a psychological perspective, the priorities included focusing on effective methods for reducing diabetes distress and burnout and methods that can be employed by healthcare professionals to adopt a more holistic approach to patient care. Finally, the priority ranked at number eight identified the need for broader access to less commonly used therapies like immunotherapy and stem cell therapy to ensure equity of care.

4 | DISCUSSION

This was a refresh PSP led by the Diabetes Collaborative Clinical Trials Network and the James Lind Alliance, updating the 10 priorities outlined in 2011⁹ and is one of only four refresh JLA PSPs to date. In 2011, there was a focus on the use and safety of insulin pumps, continuous glucose monitors and closed loop therapy. In 2024, these topics have expanded to include: the use of artificial intelligence in insulin delivery technology; the use of newer technologies to identify foods and accurately count carbohydrate; and access to advanced forms of therapy including stem cell transplants and immunotherapy. Other topics included in the 2024 top 10 which did not feature in the 2011 top 10 are the impact of hormonal changes, menstruation, and menopause on glycaemic management and the impact of type 1 diabetes on cognition in older adults. Important themes that carried through from 2011 include: the impact and the prevention of hypoglycaemia; the psychological burden of living with type 1 diabetes; and for healthcare professionals, the importance of a person-centered approach during clinical interactions.

This refresh PSP adds to some of the other work being done in type 1 diabetes in similar formats. A Canadian group recently adopted a modified-JLA approach to determine the most important unanswered questions in exercise in type 1 diabetes.¹⁵ There was notable overlap between this exercise-specific PSP and our PSP, specifically the importance of hypoglycaemia avoidance; three questions mention hypoglycaemia and two other questions reference glucose stability post-exercise, reflecting the enormity of the impact hypoglycaemia on those living with type 1 diabetes.

An Australian study published earlier this year surveyed 300 adults living with type 1 diabetes to identify the unanswered research priorities.¹⁶ While we found limited overlap with our top 10 priorities (the impact of diabetes on mental health and improving access to diabetes therapies were the only similarities), two additional questions, namely questions on triggers and the financial impact of type 1 diabetes featured on our interim survey but did not rank within the top 19. Other important topics featuring in the Australian study (including updates on cure and the latest diabetes research and informing the public about diabetes) were all submitted in our survey responses but deemed out of scope by the JLA process although these are undoubtedly important aspects of diabetes management that warrant further investigation.

A UK-based exercise which also adopted a modified JLA approach sought to determine the priorities for target behaviour using a consensus method.¹⁷ A survey of adults living with type 1 diabetes and healthcare professionals generated 79 behaviours. While this was a different type of exercise, with a focus on behaviour change rather than research, the top two priorities for healthcare professionals were firstly to "engage in collaborative treatment goal setting with patients" and "provide consultations that empower and motivate service users" which thematically overlap with priority number seven "How can healthcare professionals better take into account the physical, psychological, and social aspects of type 1 diabetes in clinics" from our PSP.

This process had a number of strengths. First, it followed the well-defined JLA process for determining priorities and significant efforts were made to ensure that the steering group and survey respondents represented a wide range of stakeholders and demonstrated balance from a gender, ethnic, and social deprivation viewpoint. The survey was promoted through multiple channels and options were made available for those with visual impairment or those uncomfortable with written English. A further strength is that the majority of responses (87%) came from adults living with type 1 diabetes and their families in each survey. It is widely accepted that healthcare professionals and those with lived experience have different priorities and others have suggested that the focus of research priorities should be on those with lived experience, without the need for consensus from healthcare professionals.¹⁶ While this concept warrants further review, it is reassuring to note that in this PSP, eight out of the final 10 were included in the top 10 of the interim ranking for those living with type 1 diabetes, and the other two priorities ranked at numbers 12 and 13.

Despite this, we also identified some limitations. The surveys were available in English only which may have limited the range of respondents and therefore may not be applicable to everybody living with type 1 diabetes in the UK and Ireland.¹⁸ Although the steering group was balanced based on gender, it was exclusively made up of individuals from white Irish and UK backgrounds. Despite multiple targeted efforts to engage respondents from ethnic minority groups this population was under-represented at both survey stages and also in the make-up of the final workshop panel, which moreover had a slightly higher proportion of healthcare professionals than those with lived experience. Although all JLA facilitators are highly trained, a sense of powerimbalance can occur when clinicians and those with lived experience are grouped together in projects like these.¹⁹ Steps taken to mitigate any potential distress and to create a safe psychological space included the use of multiple facilitators, the request to obtain any special requests or details of additional needs and the provision of pastoral support. Additional efforts, including an improved understanding of the needs of individual communities, cultural sensitivity and appropriateness and providing reassurance around research relevance are required to encourage participation from underrepresented groups to ensure the priorities generated reflect the entire community.²⁰

Finally, although another media for survey completion was offered (telephone line), the predominant use of social media and online platforms to promote the survey may have disadvantaged individuals exposed to digital poverty and reduced engagement.²¹

5 | CONCLUSION

This JLA refresh PSP poses exciting challenges for research to address a new top 10 set of prioritised key questions. The rigorous process followed has highlighted the ongoing need for enhanced research and treatments in the areas of hypoglycaemia prevention and treatment, holistic care, and psychological health and the need to harness advancements in technology including artificial intelligence to improve outcomes for people living with type 1 diabetes. The publishing of this top 10 priority should serve to motivate researchers and direct funders towards the most pressing unanswered questions in type 1 diabetes.

ACKNOWLEDGEMENTS

We wish to acknowledge and thank the thousands of adults living with type 1 diabetes, their carers and families and the healthcare professionals who completed the surveys, and also the Public and Patient Involvement pillar of the University of Galway for providing pastoral care to participants during the final workshop. This Priority Setting Partnership was funded through the Public and Patient Involvement section of the Diabetes Collaborative Clinical Trial Network which was funded by a grant from the Health Research Board of Ireland. Open access funding provided by IReL.

FUNDING INFORMATION

Funding for this work was made possible by a grant from the Health Research Board.

CONFLICT OF INTEREST STATEMENT

SH, PW, PR, DT, and CK have no conflicts of interest to declare. CN has received fees for lecturing from Boehringer-Ingelheim, Novo Nordisk and Sanofi and also a sub-principal investigator on a study funded by MERCK. RIGH has received fees for lecturing from Boehringer-Ingelheim, EASD, Eli Lilly, Encore, Liberum, Novo Nordisk, and ROVI and funding for conference attendance from Novo Nordisk and Eli Lilly. JM lay is a member of Diabetes UK; is currently vice chair Lay and Health Care Professional forum; was previously a member of the Grant Advisory Panel and Diabetes Research Steering Group and has reviewed Joint British Diabetes Societies guidelines and Royal College of Physicians, Diabetes Care Accreditation Programme pilots; currently acts as a reviewer for the Steve Morgan Foundation Type 1 Diabetes Grand Challenge and sits on the Diabetes in Pregnancy Working Group. FPD is Director of the National Clinical Trial Network (CTN) in Diabetes funded by the Irish Health Research Board (HRB). She is Director of the Institute of Clinical Trials at the University of Galway. In both of these roles, she is associated with Pharma and MedTech engaged in clinical trials in Diabetes. Her research work over the last 20 years has received financial and in-kind contributions from Novo Nordisk, Sanofi, Merck, and Menerini. In addition, she has received peerreviewed funding from HRB and EU. NO has received research support from Dexcom, Medtronic, and Roche Diabetes, has participated in advisory groups for Dexcom, Medtronic, and Roche Diabetes, and has received fees for speaking from Sanofi, Astra Zeneca, Dexcom, Tandem, and Roche Diabetes. JB has acted as a member of the JDRF Scientific Advisory Council (2018–2023) acting as a lay-member and vice-chair (which often required me to chair on occasions where the chair was conflicted), and through the Type 1 Diabetes Grand Challenge Root Causes funding panel (2023–2024) acting as a lay-member. SK is a JLA adviser and freelance social researcher and has no conflicts of interest to declare. AM is an employee of Diabetes UK. KG is an employee of Diabetes Ireland, a charity which is supported by diabetes-related companies



in Ireland, but does not offer any research funding calls and has no scientific grants. RC, JH, and HN are all employees of Breakthrough T1D (formerly the Juvenile Diabetes Research Foundation). JRP has received personal fees from Merck KGaA, non-financial support from Merck KGaA, personal fees from Novo Nordisk, personal fees from IQVIA, grants from Janssen, personal fees from Biocon, non-financial support from Astra Zeneca, personal fees from ACI Clinical; Chairperson Diabetes UK Research Steering Group 6 (Prevention of Complications). MS has received speaker fees from Eli Lilly and since the completion of the final workshop has accepted a position as a medical education associate with Abbott.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

ORCID

Christine Newman b https://orcid. org/0000-0002-6712-3668 Richard I. G. Holt b https://orcid. org/0000-0001-8911-6744 Nick Oliver b https://orcid.org/0000-0003-3525-3633 John R. Petrie b https://orcid.org/0000-0002-4894-9819

REFERENCES

- 1. Gajewska KA, Biesma R, Sreenan S, Bennett K. Prevalence and incidence of type 1 diabetes in Ireland: a retrospective cross-sectional study using a national pharmacy claims data from 2016. *BMJ Open*. 2020;10(4):e032916.
- 2. Group NS-SD. Scottish Daibetes Survey 2021. NHS; 2021.
- 3. NHS Digital. *National Diabetes Audit 2021–22, Type 1 Diabetes.* NHS Digital; 2022.
- 4. Mobasseri M, Shirmohammadi M, Amiri T, Vahed N, Hosseini Fard H, Ghojazadeh M. Prevalence and incidence of type 1 diabetes in the world: a systematic review and meta-analysis. *Health Promot Perspect*. 2020;10(2):98-115.
- Liang R, Long J, Zheng Q, et al. Current landscape of type 1 diabetes mellitus-related interventional clinical trials registered on ClinicalTrials.gov: a cross-sectional study. *Acta Diabetol.* 2021;58(6):723-733.
- 6. Crowe S, Fenton M, Hall M, Cowan K, Chalmers I. Erratum to: Patients', clinicians' and the research communities' priorities for treatment research: there is an important mismatch. *Res Involv Engagem.* 2015;1:14.
- 7. Partridge N, Scadding J. The James Lind Alliance: patients and clinicians should jointly identify their priorities for clinical trials. *Lancet*. 2004;364(9449):1923-1924.
- Oliver N, Holt RIG. The James Lind Alliance research priorities for diabetes. *Diabet Med*. 2019;36(3):267-268.
- Alliance JL. Diabetes (Type 1) Top 10. 2011 Accessed May 21, 2024. https://www.jla.nihr.ac.uk/priority-setting-partnerships/ diabetes-type-1/top-10-priorities/

- 10. Gadsby R, Snow R, Daly AC, et al. Setting research priorities for type 1 diabetes. *Diabet Med*. 2012;29(10):1321-1326.
- 11. Aims and scope. Diabet Med. 2019;36(3):264.
- 12. DeSalvo DJ, Noor N, Xie C, et al. Patient demographics and clinical outcomes among type 1 diabetes patients using continuous glucose monitors: data from T1D exchange real-world observational study. *J Diabetes Sci Technol*. 2023;17(2):322-328.
- Foundation DRaW. Hybrid closed loop systems recommended for people living with type 1 diabetes. 2023 Accessed May 21, 2024. https://www.drwf.org.uk/news-and-events/news/hybri d-closed-loop-systems-recommended-for-people-living-withtype-1-diabetes-1/
- Alliance JL. JLA Guidebook Version 10. 2021 Accessed May 24, 2024. https://www.jla.nihr.ac.uk/jla-guidebook/downloads/ JLA-Guidebook-Version-10-March-2021.pdf
- 15. Klaprat NMD, Askin N, MacIntosh A, et al. Filling gaps in type 1 diabetes and exercise research: a scoping review and prioritysetting project. *BMJ Open Diabetes Res Care*. 2020;8(1):e001023.
- 16. Hendrieckx C, Russell-Green S, Skinner T, et al. Diabetes research matters: a three-round priority-setting survey consultation with adults living with diabetes and family members in Australia. *Patient*. 2024;17(4):441-455.
- 17. Mc Sharry J, Fredrix M, Hynes L, Byrne M. Prioritising target behaviours for research in diabetes: using the nominal group technique to achieve consensus from key stakeholders. *Res Involv Engagem*. 2016;2(1):14.
- Wenz A, Al Baghal T, Gaia A. Language proficiency among respondents: implications for data quality in a longitudinal faceto-face survey. *J Survey Stat Methodol*. 2020;9(1):73-93.
- Harrison R, Newman B, Chauhan A, Sarwar M. Employing cofacilitation to balance power and priorities during health service codesign. *Health Expect.* 2023;27:e13875.
- 20. Ekezie W, Cassambai S, Czyznikowska B, et al. Health and social care experience and research perception of different ethnic minority populations in the east midlands, United Kingdom (REPRESENT study). *Health Expect.* 2024;27(1):e13944.
- Heponiemi T, Jormanainen V, Leemann L, Manderbacka K, Aalto AM, Hyppönen H. Digital divide in perceived benefits of online health care and social welfare services: National Cross-Sectional Survey Study. *J Med Internet Res.* 2020;22(7):e17616.

SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

How to cite this article: Newman C, Kinsella S, Rooney P, et al. The top 10 priorities in adults living with type 1 diabetes in Ireland and the United Kingdom – A James Lind Alliance priority setting partnership. *Diabet Med.* 2024;00:e15429. doi:<u>10.1111/dme.15429</u>