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DIABETIC Medicine

RESEARCH: EDUCATIONAL AND PSYCHOLOGICAL ASPECTS

Developing and exploring the validity of a patient reported experience measure for adult inpatient diabetes care

Olga Kozlowska[1] | Amy Tallett[2] | Samuel Bond[1] | Sarah E. Mansbridge[1] | Helen Aveyard[1] | Crispin Jenkinson[3] | Alexander Dudbridge[4] | Nicky McRobert[5] | Alistair Lumb[5,6] | Rustam Rea[5,6] | Garry D. Tan[5,6] | Helen Walthall[6,7]

[1]Oxford Institute of Applied Health Research, Oxford Brookes University, Oxford, UK

[2]Picker Institute Europe, Oxford, UK

[3]Nuffield Department of Population Health, University of Oxford, Oxford, UK

[4]Chelsea and Westminster Hospital NHS Foundation Trust, London, UK

[5]Oxford Centre for Diabetes, Endocrinology and Metabolism, Oxford University Hospitals NHS Foundation Trust, Oxford, UK

[6]NIHR Oxford Biomedical Research Centre, Oxford, UK

[7]Oxford University Hospitals NHS Foundation Trust, Oxford, UK

Correspondence
Olga Kozlowska, Oxford Brookes University, Oxford Institute of Applied Health Research, Oxford, OX3 0BP, UK.
Email: okozlowska@brookes.ac.uk

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Abstract

Aim: To develop and explore the validity of a Patient Reported Experience Measure (PREM) for adult inpatient diabetes care.

Method: 27 in-depth interviews were conducted to inform the development of the 42-item PREM which was cognitively tested with 10 people. A refined 38-item PREM was piloted with 228 respondents completing a paper ($n = 198$) or online ($n = 30$) version. The performance of the PREM was evaluated by exploring (i) uptake/number of responses and (ii) survey validity by investigating whether the PREM data were of adequate quality and delivered useful information.

Results: The PREM had low drop-out or missing data rates suggesting it was appropriately constructed. Analysis of item frequencies and variances, and problem score calculations concluded that questions provided sufficient score differentiation.

Conclusions: This new PREM allows for experiences of inpatient diabetes care to be measured, understood and reported on to help identify priority areas for improving care quality.

KEYWORDS

adult inpatient diabetes care, care quality, diabetes, Patient Reported Experience Measure

1 | INTRODUCTION

Around 18% of people admitted as inpatients in England and Wales have diabetes.[1] Of those admitted with diabetes, only 8% have a reason for admission directly related to diabetes; most (92%) are admitted because of a health problem other than diabetes itself.[2] Data confirm that people with diabetes experience hospital-acquired harm,[3] such as severe hypoglycaemia requiring rescue treatment and diabetes ketoacidosis.[2] Almost one-third of inpatients with diabetes experience a medication error during their hospital stay.[2]

To improve inpatient diabetes care, Diabetes UK recommends that every hospital has a multidisciplinary

The corresponding author should be contacted for the use of the IDC PREM.

diabetes inpatient team, and a diabetes-educated inpatient workforce.[4] National audit data are used to assess performance and to drive improvements in care. This was initially collected as part of the National Diabetes Inpatient Audit (NaDIA), which was an annual snapshot audit and included a questionnaire for people with diabetes asking about their experience of care. Inpatient data are now collected more continuously as part of the National Diabetes Inpatient Safety Audit (NDISA).

It is clear that robust evaluation of the quality of inpatient diabetes care should include feedback from people with diabetes on the inpatient care they have received. Patient Reported Experience Measures (PREMs) are designed to understand care experiences from the perspective of the patient including interactions with healthcare staff and the degree to which their needs are being met.[5,6] This approach is aligned with person-centred care crucial for the delivery of high-quality care[7–10] and increasingly linked with patient safety.[11,12]

PREM instruments measure patients' personal care experiences and focus on those aspects of care that matter to them.[13] The ability of the existing NaDIA patient experience questionnaires to capture patient experience is limited; the existing survey used in the audit contains only 13 questions and does not allow for a thorough exploration of key aspects of person-centred care such as involvement in decisions, information and support, communication, confidence and trust in staff and care continuity.

'Patient experience' is sometimes equated to 'patient satisfaction,' however, these concepts are not interchangeable. An example of a measure of patient satisfaction in inpatient diabetes care is the Diabetes Treatment Satisfaction Questionnaire for Inpatients (DTSQ-IP).[14] While patient satisfaction is concerned with patients' evaluation of the care provided relative to their expectations, patient experience—as measured by PREMs—focuses on specific interactions that patients have during their care.[15] Measures of satisfaction are strongly influenced by patients' expectations while the measures of experience are concerned with value-free reports of care.[16] Whilst satisfaction measures use evaluation-type questions (e.g. 'How satisfied were you…') experience measures use report-type questions (e.g. 'Were you involved in decisions about your diabetes during your hospital stay?'). These measurement models require appropriate evaluation techniques with the former advocating psychometric methods and the latter proposing alternative methods.[17] In the context of measuring healthcare quality, the measures of satisfaction were found fairly insensitive in detecting shortcomings in care provision[16] while PREMs offer better insight into the aspects of healthcare that patients truly value, and produce data that are more actionable for quality improvement initiatives.[18,19]

What's new?

- Patient Reported Experience Measures (PREMs) are important for auditing, evaluating and improving care quality
- There is no robust PREM informed by people with diabetes patients that assess experiences of diabetes care during hospital inpatient admissions
- This study presents a new PREM for inpatient adult diabetes care, informed and tested by people with diabetes
- The new PREM is relevant to all adults with diabetes in hospital, whatever the reason for admission
- This PREM may be a useful assessment tool in research, clinical audit and evaluating the quality of diabetes care provided to people with diabetes admitted to hospital

The aim of this study was to develop and explore the validity of a new PREM for adult inpatient diabetes care.

2 | METHODS

The Inpatient Diabetes Care (IDC) PREM was developed collaboratively by the research team including members of Oxford Brookes University, Picker Institute Europe, Oxford University Hospitals NHS Foundation Trust and the University of Oxford using an established survey-development methodology adapted to the needs of this project (Table 1).

2.1 | Process of PREM development and exploring the validity

Item generation for a PREM involves 'defining, re-defining, re-visiting, refining, and modifying a measure throughout the course of its development' (p. 140).[20] Exploring the validity of a PREM involves evaluating whether the data it collects are of adequate quality, deliver useful information and produce appropriate outcomes[21]—or that it is fit for purpose. In this context, we sought to establish if our IDC PREM encourages participation and enables respondents to adequately express their opinions on a range of aspects of inpatient diabetes care.

TABLE 1 Development and exploring the validity of the IDC PREM.

Development of the IDC PREM	
Process	**Outcome**
Qualitative scoping: 27 interviews • Thematic analysis of verbatim transcripts • Identification of main themes	A list of themes supported with quotes
Question development • Question development informed by the themes developed from qualitative interviews • Discussion with the project team	IDC PREM version 1
Cognitive testing • 10 cognitive interviews	IDC PREM version 2
Pilot: prospective survey study to explore the validity of the PREM	1. Analysis of failure to complete the questionnaire 2. Analysis of missing responses and item response distribution (on a question-by-question basis) 3. Analysis of scores discrimination: • analysis of item frequencies • analysis of item variances • the creation of problem score calculations 4. Analysis of content validity IDC PREM version 3
Refinement following pilot	IDC PREM final version

2.1.1 | Qualitative scoping

Twenty-seven in-depth semi-structured interviews were conducted to define the measure, identify main themes and form the basis of question development. The interviews were conducted between August 2019 and February 2020 within 2 weeks of discharge from inpatient care in an NHS hospital in England. The interview guide was informed by the Picker principles of person-centred care[9] recognising health and care users as individuals, encouraging them to play an active role in their care and having their needs and preferences understood and respected. The interviews were recorded using a digital voice recorder and were transcribed verbatim. Deductive and inductive thematic analyses were undertaken to identify patterns in experiences of inpatient diabetes care.[22] The person-centred care principles were applied as the main themes with 60 sub-themes developed from participants' experiences related to that theme.

Participants were recruited from inpatients in four acute NHS Trusts in the South of England. To be included, people had to be diagnosed with diabetes before the hospital episode, had a hospital inpatient episode for any reason (at least one night), and be at least 18 years old. Excluded were those unable to speak or read English, people with gestational diabetes, cystic fibrosis, MODY (Maturity Onset Diabetes of the Young), people with cognitive impairment or those receiving end-of-life care.

Potential participants meeting the inclusion criteria were identified by the diabetes clinical team and given a research pack by the research nurse at their discharge. The research pack included a letter of invitation, a participant information sheet, a reply slip and a prepaid envelope. On the return of the reply slip to the research team, one of the research team contacted them to arrange the interview. Informed consent was obtained at the time of the interview.

2.1.2 | Question development

Findings from the qualitative stage were used to inform the development of the PREM and the questions to include. Questions and response options were informed by the sub-themes that were identified from the qualitative stage. Seven headings were introduced to structure the PREM according to areas of inpatient experience (admission, managing diabetes, medication and equipment, treatment and care, communication, hospital food and leaving the hospital). The PREM also included a front page with brief instructions for completion along with a short section asking about demographics. The authors of this paper (who include academics, clinicians and experts in patient experience survey design) collectively reviewed the PREM for clarity, format and clinical accuracy before testing people with diabetes.

2.1.3 | Cognitive testing

Cognitive interviews[23] were used to assess question comprehension, interpretation and response processes to ensure that people understand the questions as intended and can respond accurately. Cognitive interviews were conducted remotely with 10 participants who had previously taken part in in-depth interviews to inform the PREM content. Participants were asked to think aloud when answering questions and were probed as to why they gave the answer and what they understood by the terms used; the interviewer was guided by the cognitive interview protocol developed for this study.[24] Participants were asked about their experience of completing the PREM and to comment on its length, format and clarity of instructions including for routing questions. Each interview lasted between 45 and 180 min with the majority lasting about 75 min.

2.1.4 | Pilot

The PREM was piloted for content with the target population; inpatients with diabetes were recruited by research nurses to complete a paper or an online version of the PREM; the choice of the questionnaire format was with the participant. Participants were recruited by research nurses (RNs) across 10 NHS trusts across England; the inclusion and exclusion criteria were the same as for the qualitative scoping stage. Recruitment to the pilot stage began immediately after the Trusts restarted supporting non-COVID-19 studies; the recruitment lasted between March and June 2021. The RNs were introduced to the project during virtual meetings and virtual initiation site visits. The recruitment capacity and recruitment success rates varied due to changing circumstances and priorities at the individual sites. The recruitment success rates were also dependent on the strategies used by RN teams to enable participation; for example, some RN teams provided postal boxes in discharge areas to encourage posting, some nurses phoned participants who agreed to a follow-up call, some nurses recruited by going to the wards while others disseminated information about the study via clinical diabetes teams acting on the information provided by direct clinical teams.

The pilot was conducted to assess the mode of administration and to explore survey validity investigating whether the PREM data were of adequate quality and delivered useful information. Item frequencies were examined for the proportion of missing or non-evaluative responses, to detect early drop-out from the questionnaire, and to identify potential floor or ceiling effects. Item variances were examined to ensure questions provided sufficient score differentiation. Additionally, problem scores were calculated for survey questions to show the percentage of participants whose response indicates that a particular aspect of their care could have been improved. This summary measure can assist with prioritising areas for improvement. Problem scores are calculated by combining the per cent of respondents answering with suboptimal response categories and removing the non-applicable response options. In the example below, the problem score will be '23% of respondents felt that healthcare staff did not definitely know about their diabetes when they first went into hospital'.

Question text	Answer options	No. of responses	% responses	Problem score
When you first went into the hospital, did the healthcare staff know about *your* diabetes?	Yes, definitely	139	62%	n/a
	Yes, to some extent	27	12%	23%
	No	25	11%	
	Do not know/ cannot remember			

2.1.5 | Ethical approval

The project received ethical approval from the Oxford Brookes University Research Ethics Committee (ref. 2019–2013) and the Proportionate Review Sub-committee of the London—Surrey Borders Research Ethics (10 April 2019; ref. 19/LO/0644) and approval from the Health Research Authority and Health and Care Research Wales (HCRW) (4.06.2019). All participants were provided with a participant information sheet and consented to participate.

3 | RESULTS

3.1 | Qualitative scoping, item generation and cognitive testing

Twenty-seven in-depth interviews were conducted lasting 30–90 min; all interviews but one (on the phone) were face-to-face. This was followed by the development of the PREM with 42 questions (version 1) (31 experience questions plus 3 open-ended, plus 8 demographic questions), that were cognitively tested, to produce a refined 38-item questionnaire (version 2) (31 experience questions plus 1 open-ended and 6 demographic questions). The recruitment strategy aimed to reflect the demographics and clinical characteristics of the population of inpatients with diabetes and achieved it to some extent; the characteristics of participants are shown in Table 2.

TABLE 2 Qualitative scoping participant characteristics (sample in the qualitative scoping phase vs population based on NADIA 2017 - hospital level data).

Category	Sample characteristics	Population of inpatients with diabetes
Type of diabetes	Type 1: $n=7$ (25%) Type 2 insulin: $n=20$ (29.5%) Type 2 non-insulin: $n=10$ (37%) Type 2 diet only: $n=2$ (7.5%)	Type 1: 6.6% Type 2 on insulin: 28.6% Type 2 non-insulin: 43.5% Type 2 diet only: 19.3%
Type of admission	Elective: $n=11$ (41%) Non-elective: $n=16$ (59%)	Elective: 13.1% Non-elective: 86.9%
Sex	Male: $n=15$ (55.5%) Female: $n=12$ (44.5%)	n/a
Age (years)	18–29: $n=1$ (4%) 30–39: $n=1$ (4%) 40–49: $n=1$ (4%) 50–59: $n=6$ (22%) 60–69: $n=6$ (22%) 70–79: $n=12$ (44%) An average age of 60.5	n/a

Ten cognitive interviews were conducted. The PREM was amended after the first five cognitive interviews based on feedback, and then again after the last five interviews. For example, the wording in question 'When you first went into hospital, did the healthcare staff have knowledge *about* diabetes?' was changed to 'When you first went into hospital, did the healthcare staff have knowledge *of your* diabetes?' to clarify that the question was not about the general diabetes knowledge among clinicians, but about their awareness of the respondent's diabetes. Another change related to introducing text preceding the questions to reassure participants that they were invited to complete the questionnaire even if their admission was not diabetes related; the following text was added: "We want to hear about your experience of diabetes care when you were an inpatient, whether or not the admission was related to diabetes."

3.2 | Exploring the validity of PREM

The demographic and clinical characteristics of the pilot sample were similar to those of the population described in NaDIA 2017—hospital-level data (Table 3).

There were 243 returned PREMs out of 627 invited (39% overall response rate). The response rate was higher for those invited to complete a paper survey (198 responses out of 455 invited; 44% response rate) compared to those who were invited to respond to an online version (30 responses out of 172 invited; 17% response rate). Out of 243 returned PREMs, 228 were included in the final analysis (the response frequencies and variances and problem scores analysis). Only non-consented PREMs (12) and PREMs answered partially (4) were excluded from the final analysis; there was no rule set up to include or exclude PREMs depending on the number of questions answered. The missing responses were excluded from the statistical analysis.

3.3 | Free-text question uptake and analysis of exhaustiveness of PREM content

Open-ended Q32 ('If there is anything else you would like to tell us about your experiences of diabetes care in the hospital (good or bad), please do so here') was answered by 99 participants (43%). Participants tended to provide further details of their experiences identified in the closed PREM questions than identifying new aspects of their experience in the open-ended responses, indicating that the PREM adequately covered aspects of inpatient diabetes care relevant to them. There were three participants who mentioned testing for ketones not explicitly mentioned in the PREM; while three comments were not enough to warrant the team to add another question on ketones, this may be reviewed in the revised version of IDC PREM.

3.4 | Drop out of the survey (analysis of failure to complete the PREM)

There was no tendency to discontinue completing the PREM before responding to all items; 142 (62%) of PREMs were completed to the very last closed question. There was no specific place in the survey where the remainder of people dropped out. Three participants started completing the PREM from Q13; there was no explanation

TABLE 3 Pilot participant characteristics (sample in the exploring validation phase).

Category	Sample characteristics	Population of inpatients with diabetes
Type of diabetes	Type 1: $n=33$ (15%) Type 2: $n=182$ (85%) Not sure: $n=2$ (1%) Missing data: $n=10$ (4%)	Type 1: 10% Type 2 on insulin: 30% Type 2 non-insulin: 40% Type 2 diet only: 20%
Type of admission	Elective: $n=37$ (17%) Non-elective: $n=179$ (83%) Missing data: $n=12$ (5%)	Elective: 20% Non-elective: 80%
Type of procedure	Surgical: $n=80$ (38%) Non-surgical: $n=133$ (62%) Missing data: $n=15$ (7%)	n/a
Sex	Male: $n=123$ (58%) Female: $n=90$ (42%) Missing data: $n=15$ (7%)	n/a
Age (years)	25–34: $n=4$ (2%) 35–44: $n=10$ (5%) 45–54: $n=22$ (10%) 55–64: $n=58$ (26%) 65–74: $n=73$ (33%) 74–84: $n=42$ (19%) 85 and over: $n=11$ (5%) Missing data: $n=7$ (3%)	n/a
Ethnicity	White $n=182$ (83%) Mixed/Multiple Ethnic Groups $n=1$ (1%) Asian/Asian British $n=23$ (10%) Black/African/Caribbean/Black British $n=9$ (4%) Other Ethnic Groups $n=4$ (2%) Missing data: $n=9$ (4%)	n/a

provided, however, the booklet format of the PREM might have been the reason for it if pages got stuck together (Q13 opens page no 4); these were excluded from analyses of missing responses and problem-scored items.

3.5 | Item non-response (analysis of missing responses)

The response frequencies (Table 4) were examined for the proportion of missing responses to each question. Item nonresponse for Q33–Q38 (demographic information) was above 5% for two questions (Q35 (7%)'Did you have an operation or procedure during this stay in hospital?) and Q37 (7%) 'What is your sex'). Q37 did not have 'prefer not to say' or a non-binary response option to stay aligned with the ONS recommendations and census form at the time of developing this PREM; these may need reviewing in future PREM versions.

Item nonresponse for Q1–Q31 was low throughout the PREM and was below 5% for all except Q19d (6%), questions Q28/29/30 routed from Q26 (6%, 6% and 7% respectively), and Q31 (25%). The low response rate to Q31 ('Before you left hospital, were you given information about how to manage your diabetes when you got back home?') was possibly due to some participants completing the PREM before their discharge.

Participants sometimes wrongly answered questions that did not apply to them by missing routing instructions at Q7, Q10, Q13 and Q26. This was only a problem for the paper survey as the online survey had the routing logic set up (so participants automatically skipped questions that were not applicable to them). There were between 4 and 54 unnecessary responses on the paper survey (Q8–54, Q9–36, Q11–22, Q9–36, Q11–22, Q12–18, Q14–27, Q27–5 and Q28–4). For data analysis (calculating item frequencies and problem scores), the team filtered out and removed data from participants answering questions not relevant to them.

3.6 | Item response distribution (analysis of frequencies and problem-scored items)

Frequencies were used to present a full breakdown of responses to each question (number and percentage) (Table 4). All questions but Q7, Q10 and Q26 had

TABLE 4 The response frequencies and problem-scored items.

Q	Responses									Problem score
	Count	**Missing**	**Response items (frequencies and percentages)**							
Admission to hospital										
Q1	When you first went into hospital, did the healthcare staff know about *your* diabetes?									
	Total	Missing	Yes, definitely	Yes, to some extent	No	Do not know/cannot remember				
Count	**226**	2	139	27	25	35				52 of 191
Per cent		1%	62%	12%	11%	15%				27%[a]
Q2	Did you get the chance to tell the healthcare staff what you do to keep your glucose in your target range?									
		Missing	Yes, definitely	Yes, to some extent	No, but I would have liked to	This was not needed	Diabetes was not on my mind	Do not know/ cannot remember		
	224	4	60	33	37	45	**26**	23		70 of 130
		2%	27%	15%	17%	20%	**12%**	10%		54%
Managing your diabetes during your hospital stay										
Q3	Did *you* continue checking your blood glucose levels when you were in the hospital?									
		Missing	This was not needed	Yes, always	Yes, sometimes	No, but I wanted to	No, but I was unable to (for example I was too unwell or needed help)	No, but I do not normally do this at home	Diabetes was not on my mind	
	226	2	47	51	14	22	44	39	**9**	36 of 87
		1%	21%	23%	6%	10%	19%	17%	**4%**	41%
Q4	Did you continue managing your diabetes with diet when you were in the hospital?									
		Missing	Yes, always	Yes, sometimes	No, but I wanted to	No, but I was unable to (for example I was too unwell)	No, but I do not normally do this at home	Diabetes was not on my mind		
	225	3	67	45	26	37	27	**23**		71 of 138
		2%	30%	20%	12%	16%	12%	**10%**		51%
Q5	Did you continue managing your diabetes by being active and moving enough when you were in the hospital?									
		Missing	Yes, always	Yes, sometimes	No, but I wanted to	No, but I was unable to (for example I was too unwell or needed help)	No, but I do not normally do this at home	Diabetes was not on my mind		
	224	4	24	39	13	120	12	**16**		52 of 76
		2%	11%	17%	6%	54%	5%	**7%**		68%

(Continued)

TABLE 4 Continued

Q	Responses							Problem score
	Count	**Missing**	**Response items (frequencies and percentages)**					
Q6	Did you receive foot care when you were in hospital?							
		Missing	Yes, definitely	Yes, to some extent	No, but I wanted or needed this	This was not needed	Do not know/cannot remember	
	224	4	36	34	53	88	13	87 of 123
		2%	16%	15%	24%	39%	6%	71%
Medication and equipment								
Q7	Was there a change to your diabetes medication during your hospital stay?							
		Missing	Yes, I was put on new medication GO TO Q8	Yes, the dose of my usual medication was changed GO TO Q9	Yes, one or more of my medications were stopped GO TO Q9	No, there were no changes to my medication GO TO Q10	Do not know/cannot remember GO TO Q10	
	222	6	36	32	19	120	15	n/a
		3%	16%	14%	9%	54%	7%	n/a
Routed Q8	Were you given enough information by healthcare staff about how to use your new diabetes medication?							
		Missing	Yes, definitely	Yes, to some extent	No	This was not needed (for example I have had this medication before)	Do not know/cannot remember	
	36	0	9	11	12	2	0	23 of 32
		0%	25%	31%	33%	6%	0%	72%
Routed Q9	Did the healthcare staff discuss with you why there was a change to your diabetes medication?							
		Missing	Yes, definitely	Yes, to some extent	No	This was not needed	Do not know/cannot remember	
	85	2	37	25	22	1	0	47 of 84
			44%	29%	26%	1%	0%	56%
Q10	Were you given any diabetes equipment for you to use which was new to you when you were in the hospital?							
		Missing	Yes	No				
	221	7	16	205				n/a
		3%	7%	93%				n/a
Routed Q11	Were you told or shown by healthcare staff how to use this new diabetes equipment?							
		Missing	Yes, definitely	Yes, to some extent	No			
	16	0	11	2	3			5 of 16
		0%	69%	13%	19%			31%

TABLE 4 Continued

Q	Responses								Problem score
	Count	Missing	Response items (frequencies and percentages)						
Routed Q12	Were you confident in using this new diabetes equipment when you got home?								
		Missing	Yes, definitely	Yes, to some extent	No				
	16	0	12	3	1				4 of 16
		0%	75%	19%	6%				25%
TREATMENT AND CARE									
Q13	If your blood glucose levels were too high or too low in the hospital, was this dealt with quickly enough by healthcare staff?								
		Missing	Yes, always GO TO Q14	Yes, sometimes GO TO Q14	No GO TO Q15	My blood glucose levels were not too high or too low GO TO Q15	This was not needed as I was taking care of my diabetes GO TO Q15	Do not know/ cannot remember GO TO Q15	
	224	4	87	30	25	63	5	14	55,142
		2%	39%	13%	11%	28%	2%	6%	39%
Routed Q14	Was the reason for your blood glucose levels being too high or too low discussed with you?								
		Missing	Yes, definitely	Yes, to some extent	No, but I would have liked this	This was not needed	Do not know/cannot remember		
	140	1	47	33	43	13	5		76 of 123
		1%	34%	24%	31%	9%	4%		62%
Q15	Did you have confidence in the decisions made about your diabetes during your hospital stay?								
		Missing	This was not needed as I was taking care of my diabetes	Yes, always	Yes, sometimes	No	Do not know/cannot remember		
	223	5	18	129	36	33	7		69 of 198
		2%	8%	58%	16%	15%	3%		35%
Q16	Were you involved in decisions about your diabetes during your hospital stay?								
		Missing	Yes, always	Yes, sometimes	No, but I would have liked this	No, but I was unable to (for example I was too unwell)	This was not needed	Do not know/ cannot remember	
	225	3	53	34	60	17	55	6	94 of 147
		1	24%	15%	27%	8%	24%	3%	64%

(Continued)

TABLE 4 Continued

Q	Responses							Problem score
	Count	**Missing**	**Response items (frequencies and percentages)**					
Q17	Did you have enough information and support from healthcare staff to make decisions about your diabetes care in hospital?							
		Missing	Yes, definitely	Yes, to some extent	No, but I would have liked this	This was not needed	Do not know/cannot remember	
	224	4	66	43	54	55	6	97 of 163
		2%	29%	19%	24%	25%	3%	59.5%
Q18a	Were you confident that the healthcare staff looking after you in the hospital were: - a) Checking your blood glucose levels at the right times?							
		Missing	Yes, definitely	Yes, to some extent	No	Not needed/Not possible	Do not know/cannot remember	
	227	1	156	49	18	0	4	67 of 223
		0%	69%	22%	8%	0%	2%	30%
Q18b	Were you confident that the healthcare staff looking after you in the hospital were: - b) Giving you your diabetes medication (including tablets or insulin) at the right times?							
		Missing	Yes, definitely	Yes, to some extent	No	Not needed/Not possible	Do not know/cannot remember	
	222	6	127	43	30	19	3	73 of 200
		3%	57%	19%	14%	9%	1%	36.5%
Q18c	Were you confident that the healthcare staff looking after you in the hospital were: - c) Changing how your diabetes was managed if your blood glucose levels became too high or too low?							
		Missing	Yes, definitely	Yes, to some extent	No	Not needed/Not possible	Do not know/cannot remember	
	218	10	85	29	29	65	10	58 of 143
		4%	39%	13%	13%	30%	5%	40.5%
Q19a	Did you have confidence and trust in the following healthcare staff managing your diabetes during your hospital stay? - a) Ward nursing staff?							
	226	Missing	Yes, definitely	Yes, to some extent	No	Did not see these staff	Do not know/cannot remember	
		2	167	43	14	1	1	57 of 224
		1%	74	19%	6%	0%	0%	25%
Q19b	Did you have confidence and trust in the following healthcare staff managing your diabetes during your hospital stay? - b) Diabetes nurse specialists?							
		Missing	Yes, definitely	Yes, to some extent	No	Did not see these staff	Do not know/cannot remember	
	217	11	68	16	27	**95**	11	43 of 111
		5%	31%	7%	12%	**44%**	5%	39%

TABLE 4 Continued

Q	Responses							Problem score
	Count	**Missing**	**Response items (frequencies and percentages)**					
Q19c	Did you have confidence and trust in the following healthcare staff managing your diabetes during your hospital stay? - c) Ward doctors?							
		Missing	Yes, definitely	Yes, to some extent	No	Did not see these staff	Do not know/cannot remember	
	216	12	112	45	31	17	11	76 of 188
		5%	52%	21%	14%	8%	5%	40%
Q19d	Did you have confidence and trust in the following healthcare staff managing your diabetes during your hospital stay? - d) Diabetes specialist doctors?							
		Missing	Yes, definitely	Yes, to some extent	No	Did not see these staff	Do not know/cannot remember	
	214	14	54	8	35	**105**	12	43 of 97
		6%	25%	4%	16%	**49%**	6%	44%
Q20	Were healthcare staff sensitive to your emotional needs and feelings relating to your diabetes during your hospital stay?							
		Missing	I did not need this	Yes, definitely	Yes, to some extent	No	Do not know/cannot remember	
	225	3	65	80	37	35	8	72 of 152
		1%	29%	36%	16%	16%	4%	47%
COMMUNICATION								
Q21	Was there enough communication between the healthcare staff and you about your blood glucose levels and diabetes treatment when in the hospital?							
		Missing	Yes, definitely	Yes, to some extent	No	Do not know/cannot remember		
	225	3	103	72	40	8		112 of 215
		1%	46%	32%	18%	4%		52%
Q22	When healthcare staff gave you information about your diabetes when in hospital, did you understand this?							
		Missing	Yes, definitely	Yes, to some extent	No	I was not given any information	This was not needed	Do not know/cannot remember
	224	4	87	43	15	**50**	26	3	58 of 145
		2%	39%	19%	7%	**22%**	12%	1%	40%
Q23	If you had any questions about your diabetes during your hospital stay, did you get answers that you understood?							
		Missing	Yes, always	Yes, sometimes	No	I did not have any questions	I did not get the chance to ask my questions	Do not know/cannot remember
	223	5	61	39	28	70	**21**	4	67 of 128
		2%	27%	17%	13%	31%	**9%**	2%	52%

(Continued)

TABLE 4 Continued

	Responses							Problem score
Q	**Count**	**Missing**	**Response items (frequencies and percentages)**					
Q24	Sometimes in the hospital, a member of staff will say one thing and another will say something quite different. Did this happen to you in relation to your diabetes?							
		Missing	Yes, always	Yes, sometimes	No	Do not know/cannot remember		
	222	6	19	43	147	13		62 of 209
		3%	9%	19%	66%	6%		30%
Q25	Did you ever have to repeat information about your diabetes to different healthcare staff?							
		Missing	Yes, and this bothered me	Yes, but I did not mind	No, I only had to say it once	I did not talk to any healthcare staff about my diabetes	Do not know/cannot remember	
	225	3	33	47	92	**41**	12	80 of 172
		1%	15%	21%	41%	**18%**	5%	46.5%
HOSPITAL FOOD								
Q26	Did you have any hospital food during your stay?							
		Missing	Yes GO TO Q27	No, I did not need any food GO TO Q31	No, I was not offered any food GO TO Q31	No, the options were not suitable GO TO Q31		
	223	5	211	7	3	**2**		n/a
		2%	95%	3%	1%	**1%**		n/a
Routed Q27	During your stay in the hospital, were you offered food choices that were suitable to your diabetes?							
		Missing	Yes, always	Yes, sometimes	No	Do not know/cannot remember		
	211	12	108	47	48	8		95 of 203
		5%	51%	22%	23%	4%		47%
Routed Q28	During your stay in the hospital, did you have access to meals and food at times that were suitable for managing your diabetes (outside of meal times)?							
		Missing	Yes, always	Yes, sometimes	No, but I wanted or needed this	No, but I did not want or need this	Do not know/cannot remember	
	209	14	106	36	31	32	4	67 of 173
		6%	51%	17%	15%	15%	2%	39%

TABLE 4 Continued

Q	Responses								Problem score
	Count	**Missing**	**Response items (frequencies and percentages)**						
Q29	Was the food appetising?								
		Missing	Yes, always	Yes, sometimes	No	Do not know/cannot remember			
	209	14	66	105	36	2			141 of 207
		6%	32%	50%	17%	1%			68%
Q30	Were you given enough information about the hospital meals in order to make appropriate choices about what to eat?								
		Missing	Yes, always	Yes, sometimes	No	Do not know/cannot remember			
	208	15	104	39	59	6			98 of 202
		7%	50%	19%	28%	3%			48.5%
LEAVING HOSPITAL									
Q31	Before you left the hospital, were you given information about how to manage your diabetes when you got back home?								
		Missing	Yes, but too much information	Yes, but not enough information	Yes, the right amount of information	No, but I wanted or needed this	This was not needed	Do not know/cannot remember	
	172	56	6	4	39	21	92	10	31 of 70
		25%	3%	2%	23%	12%	53%	6%	44%

[a]When calculating the problem score (%), the non-applicable responses such as 'not needed', 'don't know/can't remember' were not included. This ensures the score only applies to those to whom the question was applicable. The grey values indicate problem-scored items.

a problem score calculated; frequencies for non-optimal answers (greyed cells in Table 4) were added to provide their problem score (the last column in Table 4). For example, for Q1, the non-optimal responses included 'yes, sometimes' and 'no' resulting in a problem score of 27% of respondents who felt that healthcare staff did not definitely know about their diabetes when they first went into hospital. The response distributions of the problem-scored items were explored to understand if all answer options were used and whether any were dominant (floor/ceiling effects). No problem scores had more than 50% of respondents answering a particular response option. No question had 0 responses to any of the response options and the lowest % for a specific response option was 2% (question 31).

Some of the non-evaluative responses, although not contributing to the problem scores, may need further attention. Questions Q2, Q3, Q4 and Q5 included a response option 'Diabetes was not on my mind' indicating some participants not considering diabetes care as part of their inpatient experience. For Q19 and the response option 'did not see these staff,' Q22 and the response option 'I was not given any information,' and Q23 and the response option 'I did not get the chance to ask my questions,' may indicate a missing element of care if these were expected to occur (to see diabetes specialists, to receive information about one's diabetes or to get a chance to ask questions about one's diabetes).

4 | DISCUSSION

We report on the development of the IDC PREM and investigation of its validity in capturing peoples' experiences of diabetes care throughout their inpatient stay from admission to discharge. The measure enables people with diabetes to provide feedback on how they felt about the management and self-management of their diabetes during their hospital stay, their care including medication and equipment, managing their diabetes with meals, the healthcare staff looking after them, communication about diabetes with healthcare staff and emotional needs in relation to diabetes. The PREM also provides an opportunity for the respondents to add free-text comments about diabetes care.

The PREM was developed in collaboration with people with diabetes and was informed by qualitative interviews, tested using cognitive interviews, and piloted. The tool performed well in the pilot with a low drop-out and missing data. Analysis of item frequencies and variances, and problem score calculations concluded that questions provided sufficient score differentiation.

A substantial number of eligible patients invited to complete the pilot survey did not participate (399 invitees out of 627 invited did not participate). There were a number of factors that affected participation. The feedback from the recruiting research nurses indicated that some survey recipients did not perceive themselves as eligible because their admission was not directly diabetes related or their type 2 diabetes was diet managed. Other survey recipients communicated that they did not want to complain therefore they preferred not to participate. Providing clearer information on eligibility (in writing and when talking to potential participants) and emphasising the value of all feedback independent of the type of diabetes or the positivity/negativity of the feedback, may help when developing recruitment strategies to maximise participation. Another factor that might have impacted participation rates was the timing of giving out the recruitment packs (which was dependent on research nurse availability).

Because of the participant identification strategy, the recruitment bias cannot be excluded; the use of a predefined sampling approach that stratifies by particular demographics to identify all eligible candidates may help to limit this bias. Some populations of inpatients with diabetes from ethnic minority groups were excluded. The exclusion of those who could not communicate in English to the level enabling participation means that the PREM has not been adequately tested with those who could not communicate in English about their diabetes care when inpatients. A translation helpline and/or having the survey available in other languages could improve accessibility in the future.

There was a substantial difference in uptake of the paper and online PREM; it is important to understand whether differences were likely due to recruitment methods or differences in those opting for one form over another.[25] There were differences in the ease of recruiting to the paper and online PREM with research nurses preferring to distribute research packs with paper PREM; paper PREM had also a higher response rate. There is not enough evidence to explain the preference for paper over online PREM. There is also not enough information to determine if the way of recruiting to the online PREM was efficient (the link www.brookes.ac.uk/prem was included in the written invitation or a clickable link was forwarded in an email by RNs to those participants who agreed to be contacted that way). The prevalent social context at the time of the study, of media discussion regarding the sharing of patients' health records with private companies,[26] might have impacted the willingness of participants to engage with online content for research in the NHS.[27]

5 | CONCLUSION

This new IDC PREM allows those staying in hospital as inpatients to share their experiences of diabetes care with the intention to improve existing services; this can be used as an audit tool, a service evaluation and improvement tool and a research tool.

The new IDC PREM functioned well in the pilot; item completion rates were good and there was no evidence of survey fatigue. The scoring system (problem scores) demonstrated a good capability of showing discrimination. Problem scores provide actionable feedback on specific aspects of care. We have not advised providing an aggregated score of patient experience as this would mask the granularity of the data that is obtained from looking at data on a question-by-question basis.

The tool may aid clinicians to better understand the patient's perspective and to suggest patient-focused goals. There is a need to improve the accessibility of the tool (e.g. for those who do not speak English or for patients with cognitive impairment) in patients with diabetes in acute hospitals.

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CONFLICT OF INTEREST STATEMENT

No conflicts of interest are declared by the authors.

ORCID

Olga Kozlowska https://orcid.org/0000-0003-2782-407X
Alistair Lumb https://orcid.org/0000-0001-7041-9534
Rustam Rea https://orcid.org/0000-0001-6515-8325

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