

1 **Exploring Patient Information Needs in Type 2 Diabetes: A Cross Sectional Study of**  
2 **Questions**

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## 30 **Abstract**

31 This study set out to analyze questions about type 2 diabetes mellitus (T2DM) from patients and  
32 the public. The aim was to better understand people's information needs by starting with what  
33 they do not know, discovered through their own questions, rather than starting with what we  
34 know about T2DM and subsequently finding ways to communicate that information to people  
35 affected by or at risk of the disease. One hundred and sixty-four questions were collected from  
36 120 patients attending outpatient diabetes clinics and 300 questions from 100 members of the  
37 public through the Amazon Mechanical Turk crowdsourcing platform. Twenty-three general and  
38 diabetes-specific topics and five phases of disease progression were identified; these were used  
39 to manually categorize the questions. Analyses were performed to determine which topics, if  
40 any, were significant predictors of a question's being asked by a patient or the public, and  
41 similarly for questions from a woman or a man. Further analysis identified the individual topics  
42 that were assigned significantly more often to the crowdsourced or clinic questions. These were  
43 CAUSES (CI: [-0.07, -0.03],  $p < .001$ ), RISK FACTORS ([-0.08, -0.03],  $p < .001$ ), PREVENTION ([-  
44 0.06, -0.02],  $p < .001$ ), DIAGNOSIS ([-0.05, -0.02],  $p < .001$ ), and DISTRIBUTION OF A DISEASE IN  
45 A POPULATION ([-0.05, -0.01],  $p = .0016$ ) for the crowdsourced questions and TREATMENT ([0.03,  
46 0.01],  $p = .0019$ ), DISEASE COMPLICATIONS ([0.02, 0.07],  $p < .001$ ), and PSYCHOSOCIAL ([0.05,  
47 0.1],  $p < .001$ ) for the clinic questions. No highly significant gender-specific topics emerged in  
48 our study, but questions about WEIGHT were more likely to come from women and  
49 PSYCHOSOCIAL questions from men. There were significantly more crowdsourced questions  
50 about the time PRIOR TO ANY DIAGNOSIS ([-0.11, -0.04],  $p = .0013$ ) and significantly more clinic  
51 questions about HEALTH MAINTENANCE AND PREVENTION after diagnosis ([0.07, 0.17],  $p < .001$ ).  
52 A descriptive analysis pointed to the value provided by the specificity of questions, their

53 potential to disclose emotions behind questions, and the as-yet unrecognized information needs  
54 they can reveal. Large-scale collection of questions from patients across the spectrum of T2DM  
55 progression and from the public – a significant percentage of whom are likely to be as yet  
56 undiagnosed – is expected to yield further valuable insights.

57

## 58 **Introduction**

59 Diabetes is a major health problem worldwide. The prevalence of global, age-standardized diabetes  
60 is 9% in men and 7.9% in women, with the number having risen around the globe from 108 million  
61 in 1980 to 422 million in 2014 [1]. Type 2 diabetes mellitus (T2DM) is a main driver of the  
62 increase, accounting for approximately 90% of all diabetes cases [2-4]. Diabetes is a complex  
63 condition and people with diabetes have a diverse range of information needs [5-8]. Large-scale  
64 investigations such as the DAWN studies on the attitudes, wishes and needs of patients and  
65 caregivers [9, 10] have told us much, but research to date has paid little attention to exploring the  
66 information needs of patients as expressed in the questions they have about diabetes. Questions  
67 convey information needs in the patient's own voice and permit the individual and subjective  
68 experience of illness to be captured [11]. To our knowledge, no-one to date has investigated on a  
69 large scale what T2DM patients want to know at different stages of diagnosis and treatment by  
70 asking them directly what their questions are, nor have questions from the public been solicited  
71 and examined.

72 Our study concerns a new way of thinking about patient information needs in diabetes,  
73 starting not with what we know about T2DM and finding ways to communicate that information  
74 to patients but starting with what patients do not know, discovered through their own questions.  
75 Soliciting, and then responding, to patient questions on a large scale has the potential to create a

76 new information resource for T2DM, both in terms of content and organization. A questions-  
77 based approach to patient knowledge is distinct from active information seeking through which  
78 the patient searches extant information resources [5], and it is distinct from passive information  
79 receipt in which the patient is exposed either accidentally or deliberately to extant information  
80 resources [12]. A questions-based approach has the potential to create a dynamic, continually  
81 updated resource that will capture patient information needs as they evolve over time.

82           It is estimated that more than half of American adults have either T2DM or prediabetes  
83 (as measured by blood sugar levels or determined by diagnosis) and of those more than one-third  
84 are unaware they have the disease [13]. Consequently, it is crucial that we understand the  
85 information needs and voice of those who do not have diabetes, or do not know they have  
86 diabetes, but still have questions whether out of curiosity or concern for themselves or a loved  
87 one. In this paper, we report on the first stage of our work soliciting questions directly from both  
88 patients and the general public and analyzing the questions to see what they reveal.

89           Questions play a vital role in health care. Patient questions foster good communication  
90 with health professionals, resulting in better care and the right care at the right time [14-17].  
91 However, poor bi-directional flow of information between the diabetes health professional and the  
92 patient has been documented. Discrepancies have also been noted between information provided  
93 by health care providers and what patients with diabetes need [18]. Patients often cannot get as  
94 much detail as they need during office visits [19]. Time constraints, whether actual or perceived,  
95 prevent some patients from asking questions during the consultation [5, 20]. Patients also find it  
96 difficult to retain much of what they have been told by a health professional, and what they do  
97 remember is incorrect almost half the time [21-23].

98           Clinical information needs have been extensively studied by collecting questions from

99 physicians and analyzing them [24-44]. For patients and the general population, the situation is  
100 very different. Only recently have their health questions been studied in any depth [45-51], with  
101 few studies, to our knowledge, focusing on diabetes or investigating differences between questions  
102 from patients and those not in a patient setting. Our recent study has shown that available online  
103 sources of information do not provide answers to patient questions about diabetes and that there is  
104 an urgent need to better understand these information needs [52]. In this study, therefore, we set  
105 out to collect and investigate questions about diabetes from two sources, namely, patients attending  
106 a diabetes clinic and the public through crowdsourcing. We hypothesized that an analysis of the  
107 questions in terms of the topics they cover and the phases of disease progression they concern  
108 would provide important insights, potentially also revealing differences in information needs  
109 between patients and those outside the patient setting, who may or may not have diabetes or may  
110 be unaware they have the disease.

111

## 112 **Methods**

### 113 **Ethics statement**

114 This study makes secondary use of anonymized data. A prior service evaluation had been  
115 approved within the South Eastern Health and Social Care Trust, Northern Ireland, to assess  
116 patient information needs by approaching patients attending the diabetes clinic and asking them  
117 to provide questions. They were free to refuse if they wished to. No participant consent was  
118 needed for the service evaluation and none was sought. Questions were recorded on a sheet  
119 provided to each patient if interested, with no identifiers such as clinic time, clinician or personal  
120 information collected. No ethics committee approval was needed for our secondary analysis of

121 the collected questions. This practice conforms to the guidelines of the Health Research  
122 Authority of the UK National Health Service and current UK legislative and good practice  
123 arrangements. The authors had no direct contact with the participants and there were no minors  
124 among the participants.

## 125 **Question collection**

126 As part of a prior service evaluation, all patients attending the weekly diabetes outpatient clinic at  
127 the Ulster Hospital in Northern Ireland during February to April, 2014 had been invited to submit  
128 questions by responding to the following: *What are the one or two most pressing questions about*  
129 *your diabetes that you would like answered?* Patients were provided with a blank page to record  
130 their questions and questions from the same individual were marked as such.

131 We obtained additional questions using the crowdsourcing platform of Amazon  
132 Mechanical Turk (AMT). Crowdsourcing has become an important part of many clinical studies  
133 [53], with new platforms emerging to meet the particular requirements of research [54]. One  
134 hundred AMT participants were asked to each enter three questions s/he had about diabetes.  
135 Each participant was asked to specify age, sex/gender and if s/he had a diagnosis of type 2 or  
136 type 1 diabetes, or a diagnosis of diabetes but did not know the type, and if s/he had a friend or  
137 family member with a diagnosis of type 2, type 1 or unknown type. Crowdsourced question  
138 collection took place on July 8<sup>th</sup> -11<sup>th</sup>, 2015.

139 The clinic and crowdsourced question corpora are given in S1 File and S2 File. All  
140 questions are presented as written by the participants, with spelling and punctuation intact.

## 141 **Categorization by topic and phase**

142 Question content was determined through fine-grained manual categorization of the topics and the  
143 phases of diabetes progression the question referred to. Such detailed assessment of need is part of

144 the move towards better disease management through understanding the likely information needs  
145 of different subgroups of people at different phases of the disease, at the onset of diabetes, for  
146 example, or later when a new complication has developed.

147 An initial set of 13 topics, based on known concerns of patients with diabetes [5-10, 55-  
148 57] and our prior work on consumer questions [16], was compiled and used to conduct a  
149 preliminary categorization of the crowdsourced questions. This undertaking led to an expanded  
150 set of 23 topics for use in this study. We additionally compiled a five-part patient-oriented  
151 classification of the phases of T2DM drawing on prior work and our clinical experience [58-  
152 67].

153 Two researchers independently categorized each question by topic and phase. A question  
154 could fall under more than one topic and more than one phase, but the phases had to be  
155 consecutive, as in the range 3-5, for instance. There were therefore more question-topic  
156 assignments and more question-phase assignments than there were questions.

157 Coding was performed by CEC (all crowdsourced questions), PK (half the crowdsourced  
158 questions), VMC (half the crowdsourced questions), and PC and RH (all clinic questions each).  
159 PK and RH are clinicians, VMC and PC healthcare researchers, and CEC a non-clinical  
160 bioinformatics researcher. For each question and topic, a score of 1 indicated that the question  
161 fell under that topic and a score of 0 that it did not. If both coders scored 1 or 0 for a question and  
162 topic, it was counted as agreement. Agreement for phase was determined by an overlap between  
163 one coder and the other. Intercoder reliability was computed using Cohen's kappa with the  
164 following guidelines from [68]: slight agreement (0-0.2); fair (0.21 – 0.4); moderate (0.41 - 0.6);  
165 substantial (0.61 – 0.8); almost perfect (0.81 – 1). Disagreement between coders was resolved  
166 through consensus review by the coders and members of the project team.

## 167 **Statistical analysis**

168 The following analyses were performed for topics and stratified by sex for the crowdsourced  
169 questions. The significance threshold was set at .05 except where indicated.

170 Because consecutive questions are more likely to stem from the same questioner in each  
171 corpus, the samples cannot be assumed to be independent. We therefore determined which, if  
172 any, individuals had highly correlated questions in terms of their topic assignments using the  
173 Pearson correlation coefficient. Then, following the guideline that multicollinearity may be a  
174 problem in a data set if any pairwise  $|r| > 0.7$  [69], we removed the questions from any individual  
175 who had strongly correlated questions ( $|r| > 0.7$  for any pair of his/her questions). For each  
176 corpus, we also examined all pairwise correlations between topics, in terms of the questions  
177 assigned to them, removing those topics, if any, that were strongly correlated.

178 To determine which topics, if any, were significant predictors of a question's coming  
179 from a patient in the clinic or from the public through crowdsourcing, we used Lasso regression  
180 with the Least Angle Regression (LARS) algorithm [70,71], Lasso-LARS is a model selection  
181 algorithm that uses repeated internal cross-validation to select variables and estimate coefficients  
182 in the presence of collinearity. We applied Lasso-LARS both before and after removal of highly  
183 correlated questions and topics. Computations were performed using the *LassoLarsCV* function  
184 from the *scikit-learn* python package with 10-fold cross validation and default parameters [72].  
185 Lasso-LARS regression was also performed on the crowdsourced questions to determine which,  
186 if any, topics were significant predictors of a question's coming from a woman or a man.

187 We also examined each topic individually to determine if it was assigned significantly  
188 more often to the clinic or the crowdsourced questions, correcting for multiple comparisons  
189 using the Benjamini–Hochberg false discovery rate (FDR) [73-75]. For the crowdsourced



190 questions only, we similarly asked for each topic if it was assigned significantly more often to  
191 the questions asked by men or those asked by women. The 2-tailed z-test provided 95%  
192 confidence intervals (CI) for these estimates. This analysis told us something about the topics, in  
193 contrast to the Lasso-LARS analysis that told us something about the questions and the people  
194 asking them. The z-tests were performed after confirmation that the distribution of questions  
195 over topics was approximately normal. That is, we confirmed that the number of questions per  
196 topic was approximately normally distributed for both the crowdsourced and clinic questions  
197 under the Shapiro-Wilk test, both before and after removal of the correlated questions, and  
198 similarly for the female and male questions [76]. For the phases of disease progression, a similar  
199 analysis was done to determine which phases, if any, were assigned significantly more often to  
200 the clinic or the crowdsourced questions.

201 To gain additional understanding of the differences between the clinic and crowdsourced  
202 questions, the top three (85th percentile) and top five (75% percentile) topics in terms of the  
203 number of questions to which they were assigned were identified for each corpus. Those that  
204 were top in one corpus and not the other were recognized as characteristic of that corpus. A  
205 similar analysis was done for the phases of disease progression.

206

## 207 **Descriptive analysis**

208 In addition to topic analysis and the analysis by phase of disease progression, the combined  
209 corpus of questions was reviewed from a holistic and descriptive perspective to ascertain any  
210 inferences implicit in the questions that might reveal underlying concerns or issues for the person  
211 generating the question. It was apparent that the questioners, not all of whom had diabetes, were  
212 seeking more than just factual information. A limited qualitative analysis of the combined corpus

213 was therefore undertaken to address this need for a broader interpretation of the questions beyond  
214 their literal content. This analysis was not exhaustive but illustrative, identifying themes that  
215 might inform a detailed analysis of a larger collection of questions.

216

## 217 **Results**

### 218 **The topics**

219 A preliminary categorization of the crowdsourced questions using a core set of categories  
220 derived from earlier work [5-10, 16,55-57] produced a Cohen’s kappa score of 0.61 overall,  
221 which represents moderate to substantial agreement [68]. A subsequent round-table discussion by  
222 members of the project team (CEC, PK, VMC, MFM, ES, JGW and PC) led to the formulation of  
223 the 23 categories described in Table 1. Several diabetes-specific categories, namely LIFESTYLE /  
224 BEHAVIOR CHANGE (hereafter abbreviated simply to LIFESTYLE), EXERCISE, DIET, WEIGHT, and  
225 CURE OR REVERSAL, were added to the core categories. For this last topic, we note that a more  
226 clinically oriented topic descriptor would be CONTROL OR REMISSION. However, our experience to  
227 date with patient and general-public questions is that the lay perception centers on the idea of  
228 completely getting rid of a disease and for this reason we use the descriptor CURE OR REVERSAL.  
229 The topic of COMPLICATIONS derived from earlier work was split into DISEASE COMPLICATIONS  
230 and TREATMENT COMPLICATIONS to properly represent the types of questions found for T2DM.

231

232 Table 1. Topic Categories for T2DM Questions.

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**CAUSES**

Questions about the causes of diabetes or one of its complications. Includes

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	causal factors that might increase risk and causes of symptoms.
<b>RISK FACTORS</b>	Questions about factors that raise the risk of developing diabetes or any of its complications (not necessarily causal factors, for example, gender).
<b>PREVENTION</b>	Questions about the prevention of diabetes or the prevention of complications arising from diabetes.
<b>DIAGNOSIS</b>	Questions about diagnostic tests for diabetes or any of its complications. Includes questions about signs or symptoms that might lead to a diagnosis. Includes methods for determining the difference between pre-diabetes, type 1 and type 2.
<b>MANIFESTATIONS</b>	Questions about signs or symptoms of diabetes or any of its complications.
<b>TREATMENT</b>	Questions about treatments for diabetes. Includes medication and self-management behaviors that could be part of a treatment plan.
<b>ANATOMY</b>	Questions that make reference to any particular part of the body, such as questions about a location affected by diabetes.
<b>CURE / REVERSAL</b>	Questions about a cure for diabetes or about the reversal of symptoms to the point where one could be considered condition free or in remission.
<b>DIET / NUTRITION</b>	Questions about the role of diet or nutrition in the prevention, development or management of diabetes and its complications.
<b>EXERCISE</b>	Questions about the role of exercise in the prevention, development or management of diabetes and its complications.
<b>WEIGHT</b>	Questions about the role of weight in the prevention, development or management of diabetes and its complications.
<b>LIFESTYLE</b>	Questions about things a person can or must do to prevent or manage diabetes or its complications (including diet, exercise, or weight).
<b>DISEASE COMPLICATIONS</b>	Questions about the problems diabetes causes. This includes the risks faced by patients with diabetes and the nature and experience of the complications.
<b>TREATMENT COMPLICATIONS</b>	Questions about problems arising from specific treatments for diabetes or one of its complications.
<b>PERSON OR ORGANIZATIONS</b>	Questions about a person or organization involved with a disease. This can include medical specialists, hospitals, research teams, insurance payments, or support groups for a particular disease.
<b>PROGNOSIS</b>	Questions asking about life expectancy, quality of life, or the probability of success of a given treatment.
<b>DISTRIBUTION OF A DISEASE IN A POPULATION</b>	Questions about the occurrence of diabetes in a population and questions about the distribution of complications in the population of people with diabetes.
<b>INHERITANCE PATTERNS</b>	Questions about inheritance patterns in diabetes.

<b>TRANSMISSION PATTERNS</b>	Questions about transmission patterns for diabetes (when conceived of as an infectious disease).
<b>RESEARCH</b>	Questions about research on diabetes. Includes questions about clinical trials.
<b>PSYCHOSOCIAL</b>	Questions about the social-emotional ramifications of diabetes.
<b>OWN HEALTH RECORD RELATED</b>	Questions that relate specifically to the questioner's own health or that reference information in the person's health record. Includes questions about "my" medication, etc.
<b>OTHER</b>	Questions that do not belong to any of the above. Includes non-medical questions about a disease, such as policy decisions, for example.

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235

## 236 **The questions**

237 One hundred and sixty-four questions were collected from 120 patients during 12 outpatient  
238 clinics. Most of the questions were about diabetes (N=155) with the remainder related to clinic  
239 operation (N=9). Of the questions on diabetes, 152 from 101 patients were about T2DM and  
240 these questions were retained for our analysis. Although only 1 to 2 questions were asked for, 2  
241 patients gave 3 questions each. Most of the patients attending the clinic had T2DM (95%).  
242 These questions are given in S1 File.

243 For the crowdsourced questions, 100 AMT participants each contributed three questions  
244 about diabetes (N=300). Most of the questions were about T2DM (N=284) with a smaller  
245 number related to type 1 diabetes (N=15) and 1 question duplicated by one of the questioners. Of  
246 the 100 questioners (F 34, M 66), 9 had diabetes (6 type 2, 2 type 1, one unknown type) and 91 a  
247 friend or family member with diabetes (30 type 2, 17 type 1, 44 unknown type). The 284  
248 questions about T2DM were retained for analysis. These questions are given in S2 File . For the  
249 clinic questions overall, agreement between the coders was substantial (Cohen's kappa=0.77, SD  
250 = 0.18). For the crowdsourced questions overall, agreement between the coders was almost  
251 perfect (Cohen's kappa = 0.86 SD = 0.1). Disagreements were resolved by consensus between

252 the coders.

253 We found that for the crowdsourced questions, 16 of the 100 individuals had strongly  
254 correlated questions ( $|r| > 0.7$  for any pair of their 2 or 3 questions) and, for the clinic questions,  
255 3 of the 101 patients. After removing the questions from the identified individuals there were 236  
256 crowdsourced questions from 84 individuals and 147 clinic questions from 98 patients  
257 remaining. We did not find the topics in the crowdsourced questions to be correlated at the 0.7  
258 criterion value, but for the clinic questions, TRANSMISSION PATTERNS was correlated with  
259 INHERITANCE PATTERNS at the 0.7 level. We therefore dropped the category TRANSMISSION  
260 PATTERNS, which had only 2 questions in the crowdsourced corpus and 5 in the clinic corpus, all  
261 of which also fell under other topic categories and consequently did not need to be removed.

## 262 **Topics and the clinic and crowdsourced questions**

263 The clinic questions had an average of 2.8 topics per question (min 1, max 7) and the  
264 crowdsourced questions had an average of 2.1 topics per question (min 1, max 5). The results of  
265 the Lasso-LARS regression on all questions showed slightly higher odds ratios in favor of  
266 questions that were OWN HEALTH RECORD RELATED and about TREATMENT coming from the  
267 clinic patients (1.143 and 1.114 respectively). The odds ratios for all other questions were less  
268 than 1.062. The optimum alpha value found was 0.0009 with a mean squared error of 0.151 for  
269 both the training and test data. Lasso-LARS regression on only the non-correlated questions  
270 revealed similar slightly higher odds ratios in favor of the clinic questions for the same two  
271 topics (1.173 and 1.156 for OWN HEALTH RECORD RELATED and TREATMENT, respectively), with  
272 all other odds ratios less than 1.1. The optimum alpha value was 0.0006 with a mean squared  
273 error for the training data of 0.132 and 0.187 for the test data.

274 In terms of the individual topics, topics that were assigned significantly more often to the

275 crowdsourced than the clinic questions were CAUSES (CI: [-0.07, -0.03],  $p < .001$ ), RISK  
 276 FACTORS ([-0.08, -0.03],  $p < .001$ ), PREVENTION ([-0.06, -0.02],  $p < .001$ ), DIAGNOSIS ([-0.05, -  
 277 0.02],  $p < .001$ ), and DISTRIBUTION OF A DISEASE IN A POPULATION ([-0.05, -0.01],  $p = .0016$ ). In  
 278 contrast, the topics TREATMENT ([0.03, 0.01],  $p = .0019$ ), DISEASE COMPLICATIONS ([0.02, 0.07],  
 279  $p < .001$ ), and PSYCHOSOCIAL ([0.05, 0.1],  $p < .001$ ) were assigned significantly more often to the  
 280 clinic questions. See Table 2.

281  
 282 **Table 2. Topics Assigned to the Crowdsourced and Clinic Questions.**  
 283

	<b>Crowdsourced (N=236)</b>	<b>Clinic (N=147)</b>	<b>CI*</b>	<b>FDR- adjusted p- values, 2- tailed z-test</b>
<b>Causes</b>	49 / 675**	14 / 598**	(-0.07, -0.03)	< .001
<b>Risk Factors</b>	64 / 675	23 / 598	(-0.08, -0.03)	< .001
<b>Prevention</b>	33 / 675	7 / 598	(-0.06, -0.02)	< .001
<b>Diagnosis</b>	31 / 675	6 / 598	(-0.05, -0.02)	< .001
<b>Manifestations</b>	45 / 675	43 / 598	(-0.02, 0.03)	.747
<b>Treatment</b>	61 / 675	91 / 598	(0.03, 0.01)	.0019
<b>Anatomy</b>	20 / 675	29 / 598	(-0.0, 0.04)	.1383
<b>Cure / Reversal</b>	47 / 675	28 / 598	(-0.05, 0.0)	.1383
<b>Diet / Nutrition</b>	8 / 675	5 / 598	(-0.01, 0.01)	.6942
<b>Exercise</b>	12 / 675	9 / 598	(-0.02, 0.01)	.747
<b>Weight</b>	65 / 675	56 / 598	(-0.03, 0.03)	.8721
<b>Lifestyle</b>	33 / 675	43 / 598	(-0.0, 0.05)	.1383
<b>Disease Complications</b>	16 / 675	40 / 598	(0.02, 0.07)	< .001

<b>Treatment Complications</b>	7 / 675	16 / 598	(0.0, 0.03)	.0696
<b>Person or Organization</b>	41 / 675	41 / 598	(-0.02, 0.03)	.6973
<b>Prognosis</b>	18 / 675	7 / 598	(-0.03, -0.0)	.1207
<b>Distribution of a Disease in a Population</b>	26 / 675	5 / 598	(-0.05, -0.01)	.0016
<b>Inheritance Patterns</b>	15 / 675	20 / 598	(-0.01, 0.03)	.3251
<b>Research</b>	20 / 675	20 / 598	(-0.02, 0.02)	.747
<b>Psychosocial</b>	4 / 675	47 / 598	(0.05, 0.1)	< .001
<b>Own Health Record Related</b>	27 / 675	30 / 598	(-0.01, 0.03)	.5244

284 \*Confidence intervals at the .05 level

285 \*\*The denominator in each column is the number of topic assignments in total for the corpus.

286

287 The three most frequent clinic topics (Table 2) were TREATMENT (91 questions), WEIGHT  
288 (56) and PSYCHOSOCIAL (47). The three most frequent crowdsourced topics also included  
289 WEIGHT (65) and TREATMENT (61), but included RISK (64) rather than PSYCHOSOCIAL. The topic  
290 PSYCHOSOCIAL therefore characterizes the clinic questions and the topic RISK FACTORS the  
291 crowdsourced questions. The next two clinic topics were MANIFESTATIONS (43) and LIFESTYLE  
292 (43), which were not in the top crowdsourced topics, and therefore further characterize the clinic  
293 questions. The next two crowdsourced topics were CAUSES (49) and CURE / REVERSAL (47),  
294 which were not in the top clinic questions, and therefore further characterize the crowdsourced  
295 questions.

296 For the crowdsourced questions, Lasso-LARS regression showed a slightly higher odds  
297 ratio (1.122) for a question about WEIGHT coming from a woman rather than a man. The

298 optimum alpha value found was 0.0024 and the mean squared error for the training data was  
299 0.193 and 0.235 for the test data.

300 In terms of the individual topics, the only topic that was more strongly associated with  
301 one gender over another was PSYCHOSOCIAL (CI: [0.02, 0.05],  $p = .1497$ ), which was more  
302 strongly represented in the male questions, but only at the 0.2 level. For both men and women,  
303 the topics LIFESTYLE (women 24 questions; men 41 questions), RISK FACTORS (24; 41), and DIET  
304 (19; 28) were most frequently assigned. There was one topic appearing uniquely in the top five  
305 for men and one for women that might in addition be thought of as characterizing the two  
306 groups. These were MANIFESTATIONS (women 18 question) and PROGNOSIS (men 24 questions).

## 307 **The phases of disease progression**

308 The five phases of T2DM progression we identified from the literature and our experience  
309 were: PRIOR TO ANY DIAGNOSIS; PRE-DIABETIC (DIAGNOSED); ONSET OF T2DM; HEALTH  
310 MAINTENANCE AND PREVENTION; COMPLICATIONS – MINOR (ONSET) OR MAJOR  
311 (DOMINANCE). These are listed in Table 3 along with a description of each phase.

312  
313 **Table 3. Phases of Disease Progression for T2DM.**

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PHASE 1	<b>PRIOR TO ANY DIAGNOSIS</b>	Given that 27.8% (8.1 million) of those estimated to have diabetes in the USA are undiagnosed, it is important to understand the questions people may have prior to a diagnosis. Given the increasing prevalence of T2DM, many people have family members or friends with a diagnosis. Questions may therefore not be about their own susceptibility but about giving support to others with the condition.
PHASE 2	<b>PRE-DIABETIC (DIAGNOSED)</b>	On being diagnosed as pre-diabetic, a person's questions may reveal a response of confusion, denial or fear. In coming to terms with the fact that s/he may be facing a serious chronic illness, the person may have questions about the choices s/he has to make.

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PHASE 3	<b>ONSET OF T2DM</b>	With the onset of T2DM, questions may reveal a response of anger or denial or a wait-and-see attitude. In accepting that s/he has to live with a serious chronic illness, the person may have questions about new knowledge that must be acquired and a new and possibly demanding self-care regimen that must be adjusted to. If the onset of diabetes is abrupt, the adjustment may be particularly difficult and questions may reflect this struggle.
PHASE 4	<b>HEALTH MAINTENANCE AND PREVENTION</b>	After initial diagnosis, questions may reveal a person energized to manage his/her diabetes. A lack of questions may indicate a person trying to ignore his/her diabetes. As treatment focuses on the prevention of diabetes complications, questions may focus on the new self-care behaviors that must be maintained.
PHASE 5	<b>COMPLICATIONS – MINOR (ONSET) OR MAJOR (DOMINANCE)</b>	With the onset of complications, a person may be energized by the complications to manage his/her diabetes. Or s/he may respond with fatalism or increased distress. Questions may reflect attempts to understand and accept a new condition trajectory. Questions may focus on maximizing quality of life, especially as complications come to dominate the person’s life. Questions may seek emotional support, not just knowledge, as the person’s self-image as a functioning, healthy adult undergoes possible change. The person must learn to live with challenges that may affect his/her activity levels, functional abilities, and emotional and social well-being. As the person’s condition progresses, new questions will arise.

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For both the clinic and consumer questions, intercoder reliability for categorization by phase was moderate ( $k = 0.64$  clinic;  $k = 0.67$  crowdsourced). Given the exploratory nature of this categorization by phase, by consensus the coders agreed to assign a phase category to a question if either one of the coders did so. In this way, the judgements of all coders (clinical and non-clinical) could be taken into account.

320

321

## **Phases and the clinic and crowdsourced questions**

322

There were significantly more crowdsourced questions that concerned Phase 1, the time PRIOR

323

TO ANY DIAGNOSIS (CI: [-0.11, -0.04],  $p = .0013$ ), and significantly more clinic questions about

324 Phase 4, HEALTH MAINTENANCE AND PREVENTION (CI: [0.07, 0.17],  $p < .001$ ). See Table 4.

325

326 **Table 4. Phases Assigned to the Crowdsourced and Clinic Questions.**

327

	<b>Crowdsourced (N=236)</b>	<b>Clinic (N=147)</b>	<b>CI*</b>	<b>FDR- adjusted p- values, 2- tailed z-test</b>
<b>Phase 1: Prior to any Diagnosis</b>	118 / 756**	32 / 386**	(-0.11, -0.04)	.0013
<b>Phase 2: Pre-diabetic (diagnosed)</b>	127 / 756	49 / 386	(-0.08, 0.0)	.0692
<b>Phase 3: Onset of T2DM</b>	220 / 756	91 / 386	(-0.11, -0.0)	.0647
<b>Phase 4: Health Maintenance and Prevention</b>	148 / 756	122 / 386	(0.07, 0.17)	< .001
<b>Phase 5: Complications – Minor (onset) or Major (dominance)</b>	143 / 675	92 / 386	(-0.0, 0.1)	.0647

328 \*Confidence intervals at the .05 level

329 \*\*The denominator in each column is the number of phase assignments in total for the corpus.

330

331 The most frequently applied phase in the clinic questions was Phase 4 (HEALTH  
332 MAINTENANCE AND PREVENTION, 122 questions). This was followed by Phases 5 and 3, then  
333 Phases 2 and 1. The most frequently applied phase in the crowdsourced questions was Phase 3  
334 (ONSET OF T2DM, 220 questions) followed by Phases 4 and 5, then Phases 2 and 1. Phase  
335 assignment numbers for clinic and crowdsourced questions are shown in Fig 1.

336

337 Fig 1. Clinic and Crowdsourced Questions by Phase.

338

## 339 **Descriptive analysis**

340 Our descriptive analysis identified four themes to pursue in future studies: (1) the specificity  
341 found in questions; (2) questions revealing the emotion behind an information need; (3)  
342 questions disclosing information needs not yet recognized in standard patient information  
343 resources; and (4) the potential for questions to identify specific constituent groups with their  
344 own information needs.

### 345 **(1) The specificity of questions**

346 Questions encourage specificity. The topic “diabetes and prognosis,” for instance, does not  
347 capture the specificity of the following four prognosis-related questions taken from our corpora:

- 348 • Is diabetes a death sentence?
- 349 • Will all Type 2 eventually go on to insulin?
- 350 • Is there any potential for a cure within the next few years, according to current research?

351 The first concerns a worst outcome, the second the inevitability of a treatment, and the third a  
352 best outcome. Numerous questions contemplated a decline in health, for example:

- 353 • Will it get worse [?]
- 354 • Will my condition only worsen [?]

355 Many asked about the likelihood and hoped-for outcome of specific treatments, for example:

- 356 • Can I ever reduce insulin & meds and feel good [?]
- 357 • Can diabetes be cured or rendered almost gone overtime through medicine and nutrition  
358 [?]
- 359 • Could a pancreas transplant cure diabetes in a person?
- 360 • What dictates the type of treatment needed/required for diabetes, and is directly injecting  
361 insulin ever avoidable?

362 Prognosis questions that were about a possible cure for diabetes were prominent. See S1 Table.  
363 All questions contained the word “cure,” or similar, such as “reverse,” “heal,” “[fully] go away,”  
364 “[completely] get over.” Many questions looked to scientific research for a cure and  
365 acknowledged it as a matter for the future. A smaller number specifically referred to diet or  
366 lifestyle changes, something an individual can do to affect the course of diabetes. Those asking  
367 such questions may be more receptive to taking action on their own behalf.

### 368 **(2) Questions revealing the emotion behind an information need**

369 Consider the following two questions, both ostensibly seeking to understand why the questioner  
370 has diabetes.

- 371 • How on earth I ever got diabetes in the first place. Never over weight blood pressure  
372 always fine never eat sweet food [?]
- 373 • Why me?

374 The first question shows some understanding of risk factors for the condition without, it seems,  
375 fully understanding genetic risks. Puzzlement and frustration are expressed. The second question  
376 is less a plea for information and more an expression of frustration and defeat. Its meaning, and  
377 what counts as an adequate answer, will differ depending on when it is asked – at diagnosis, at a  
378 periodic review of the patient’s care, when a new complicating factor has arisen that will affect  
379 self-management, or when there is a transition in care, such as with age-related changes or a  
380 change in the care team [77].

### 381 **(3) Questions disclosing as yet unrecognized information needs**

382 It is crucial that information on diabetes covers not only what health professionals consider  
383 important for people to know but also what the different constituent groups want to know,  
384 whether considered important to health professionals or not. Directly solicited, open-ended

385 invitations to ask questions are a way to reveal information needs that may not be anticipated by  
386 health educators. Take the following questions that in effect ask for a severity index for diabetes.

- 387 • Are there variations in severity to diabetes and what determines severity?
- 388 • To what extent does it exist on a spectrum, such that people may be classified according  
389 to the degree to which they are diabetic, even if they are not diagnosable as diabetic  
390 according to present criteria?
- 391 • Are there variations in severity to diabetes and what determines severity?

392 This topic is covered in the literature [78] but not prominently or not at all in the trusted and  
393 vetted sources of patient-oriented diabetes information resources. It may be important to some  
394 patients' needs to fully understand their condition. A related set of questions reveals a similar and  
395 important wish, whether feasible or not, to be able to monitor one's health before it gets to a  
396 point of no return [79], as explicitly stated in this question:

- 397 • If you suspect you have Type 2 diabetes, at which point will it become impossible for you  
398 to reverse it by only changing your diet and exercise habits (and without requiring  
399 medication or the need to see a doctor?)

#### 400 **(4) Questions from specific constituent groups**

401 Diabetes information is important not only for people with diabetes but also friends and family of  
402 people diagnosed with diabetes and for caregivers, those family members, neighbors, friends or  
403 paid persons who regularly look after someone with diabetes. Our corpora included several such  
404 questions.

- 405 • What are some ways to help a family member accept a diagnosis of diabetes?
- 406 • How hard is it to treat when the person who needs help isn't very receptive to their  
407 condition?

408 • What are some things you can do to help a family member better manage an appropriate  
409 diet for type 2 diabetes?

410 • What is the best way I can help my friends and family members with controlling their  
411 diabetes?

412 For other chronic conditions such as mental-health disorders, for instance, the role of family and  
413 friends is broadly acknowledged and discussed in education and information resources. Question  
414 collection on a massive scale may suggest a more prominent place for this topic in diabetes  
415 education.

416

## 417 **Discussion**

### 418 **Principal results**

419 The topics associated with the clinic questions (OWN HEALTH RECORD RELATED, DISEASE  
420 COMPLICATIONS, TREATMENT, and PSYCHOSOCIAL) confirm what might be expected, namely that  
421 patients whose condition is actively being managed are most concerned about complications of  
422 the condition specific to their medical history, with a primary concern being about psychosocial  
423 matters related to their disease. T2DM is a complex condition that has different disease  
424 progressions for different people and for the same person over time and as life circumstances  
425 change [69]. Significant effort has to go into making sense of the experience. A recent study  
426 comparing people seeking online health information for their own problem against those seeking  
427 information for someone else's showed that the first group in contrast to the second focused  
428 primarily on symptoms and matters related to their own disease history [80].

429 The crowdsourced questions' focus on CAUSES, RISK FACTORS. PREVENTION, DIAGNOSIS,

430 and DISTRIBUTION OF A DISEASE IN A POPULATION most likely reflects the fact that the  
431 crowdsourced questioners were in the main (91%) not themselves diagnosed but knew someone  
432 who was and so likely sought to understand what leads to diabetes and who among their family  
433 members may be at risk. Those seeking online information for someone else's health problem  
434 have been shown to focus primarily on causes of a disease and disease terminology [80].

435         The stronger representation of PSYCHOSOCIAL questions from men warrants further  
436 investigation. Gender-based notions of masculinity have been shown for some people to be in  
437 conflict with effective self-management of T2DM, a central component in the treatment of  
438 diabetes [81]. The stronger representation of questions on WEIGHT from women is perhaps not  
439 unexpected, but with recent research showing that men are developing T2DM at lower levels of  
440 adiposity than women, this may change [82].

441         The clinic questions, not surprisingly, predominantly concerned post-diagnosis issues  
442 whereas the onset of diabetes dominated crowdsourced questions. The number of crowdsourced  
443 questions asking, in effect, how you know if you have diabetes accounts for the high number of  
444 questions categorized under Onset of T2DM. Such a concern is consistent with the fact that over  
445 30 percent of those with diabetes in the United States are unaware they have the disease [13]. It  
446 also perhaps indicates that the public health message about the prevalence of diabetes is being  
447 heard and people are wondering about their own health status.

## 448 **Related studies**

449 There is a long and extensive record of questions being collected from health professionals and  
450 analyzed. Questions have been collected at the point of care, from email consultation with  
451 specialists, and through queries to information systems [26, 31, 33, 35-38]. Clinical questions  
452 have been categorized as to the kind of knowledge they sought and the kind of answers they

453 needed, with taxonomic and other organizing structures proposed for them [24, 27, 35, 37]. The  
454 questions of family-medicine, elder-care, and rural-health physicians have been explored [25, 29,  
455 30, 32, 34, 44]. Experiments have been done on different ways of capturing clinical questions  
456 through voice and other input media [28, 39-43]. Clinical questions associated with specific  
457 disorders have been evaluated, most notably cancer [42], and T2DM [31]. A systematic review  
458 of three decades of studies on clinical information needs [30] found that roughly 30% of the  
459 question types accounted for 80% of the questions clinicians asked, where a question's type was  
460 relative to a 64-item taxonomy [24].

461         Studies of questions from healthcare consumers are relatively recent. In [45], 276 health-  
462 related questions posted on a social media question-answer website were subjected to qualitative  
463 content analysis, focusing on meta-characteristics of the questions such as the users' motivations  
464 for asking the questions. In [46] and [47] a manual topic-based analyses of consumer questions  
465 was done using topics from the UMLS. In [49], 365 questions from a mailing list were analyzed  
466 in terms of topics and the type of question. In [50] and [51] smaller question collections (72 and  
467 12) were subjected to detailed semantic, attitudinal or linguistic analysis. An increasing number  
468 of studies concern the development of question-answering technology for consumer health  
469 questions [83-87]. Patients have different information needs about T2DM at different points as  
470 their disease progresses. However little is known about these needs and how they change over  
471 time or across varying health or life circumstances [77] — even though there has been a  
472 significant amount of research on what the different phases of T2DM are [58-67]. It is in cancer  
473 care that the needs of patients at different stages of their disease have been most thoroughly  
474 studied [88-~~90~~91]. These studies, show, for instance, that while most (91%) female breast-cancer  
475 patients wanted to know their prognosis before beginning adjuvant treatment [91], after the first



476 consultation, their needs often shifted to matters of support, with 59-63% primarily wanting  
477 reassurance and hope and patients with advanced disease often desiring less information about  
478 their illness [88]. It is important that we develop a similar understanding of the changing needs  
479 of people with T2DM.

## 480 **Further research**

481 The urgent need for resources allowing patients with T2DM to find answers to their questions  
482 has recently been documented [52]. One longer-term goal of this study is to develop a question-  
483 answer system, informed by the analysis of a very large number of questions and vetted answers  
484 and based on the automated identification of topics in questions. The twenty-three categories we  
485 devised for this study will almost certainly need further refinement, with a hierarchy of topics or  
486 an ontology possibly providing a better representation. In addition, *answer* topics as well as  
487 question topics need to be defined. For example, suppose a patient's question is "I'm 44 and  
488 recently diagnosed with Type 2 diabetes, and now I am having difficulty reading fine print. Is  
489 this related to my diabetes?" This question falls into four possible answer categories. The first  
490 relates to temporary changes in eyesight when blood glucose fluctuates. The second concerns a  
491 side effect of the drug pioglitazone. The third is about diabetic retinopathy that leads to  
492 blindness. And the fourth concerns normal age-related changes in eyesight.

493         Finer-grained characteristics that are important in the management of diabetes are also  
494 needed. For example, the capacity of a person to act in any given environment (known as  
495 agency) seems to be expressed differentially in our questions [92]. The following question about  
496 a cure for diabetes appears to locate agency within the patient: "What stuff do you have to do to  
497 cure diabetes?" This is in contrast to a question that appears to locate agency within the broader  
498 society: "How close is science to finding a cure for diabetes?" If patients over time asked

499 questions that differed in the location of agency, that would be of interest and possible clinical  
500 significance. In our follow-up studies when new questions are collected from patients, we will be  
501 labeling each question by the stage the questioner is in relative to his or her own disease  
502 progression. In this way a record of the questions asked in the aggregate by patients at each  
503 phase of the disease can be compiled along with the progression of questions for each patient  
504 individually, providing a broader and deeper perspective on the complex needs of those affected  
505 by or at risk of T2DM.

506

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759 **Supporting information**

760 **S1 Table. Questions about Cure or Reversal.**

761 **S1 File. Clinic Questions.**

762 **S2 File. Crowdsourced Questions.**

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