

Patient engagement in type 2 diabetes mellitus research: what patients want

Kristina F Simacek¹
Tanya Nelson²
Mignon Miller-Baldi³
Susan C Bolge²

¹PatientsLikeMe, Cambridge, MA, USA;

²Janssen Scientific Affairs, LLC, Raritan, NJ, USA; ³Janssen Medical Information Center, Titusville, NJ, USA

Background: As patients are the ultimate stakeholder in their health, their perspectives should be included along with researchers, providers, and funders of research design, execution, and interpretation. Despite the high prevalence of type 2 diabetes mellitus (T2DM), patients are rarely directly included in these decisions.

Purpose: We sought to determine areas of research most important to patients with T2DM, identify ways through which patients with T2DM want to engage in research, and evaluate online patient research networks as a source for obtaining patient perspectives on research engagement.

Patients and methods: This study used an online patient community forum (PatientsLikeMe) to host two asynchronous moderated discussions, each with three to four prompted discussion posts. A qualitative summary of themes was derived from the posts.

Results: Eighty-eight participants with T2DM took part. Participants were mostly white (86%), averaged 58.6 years of age, half were female (50%), and over half (62%) resided in the US. Research priorities included managing T2DM with comorbidities, controlling blood sugar levels, finding a cure, and understanding causes of T2DM. Participants wanted to see direct applications of research to their lives. Clinical research was perceived to have overly restrictive eligibility criteria and to measure outcome sets that do not adequately address patient health concerns. Participants indicated broad interest in partnering in research and a willingness to apply their skills and educational background to specific stages in the research process.

Conclusion: Patients with T2DM would like researchers to address outcomes that have meaning in patients' daily lives. Initiatives to involve patients in research should leverage and enable patients to contribute as participants, advisors, or co-investigators, going beyond research topic prioritization to full participation throughout the research process based on their abilities and interest. This study provides support for the use of online patient research network discussions to generate rich qualitative data to engage patients in research.

Keywords: qualitative research, patient engagement, patient involvement, research priorities, diabetes mellitus, social networking, social media

Plain language summary

Including patients in the research process has the potential to improve research quality and relevance. The goal of this study was to understand what people with type 2 diabetes mellitus (T2DM) think should be studied and how T2DM research should be done. Another goal was to see whether posting in an online patient research network is an effective way to get this kind of information. We ran a series of discussions on an online T2DM forum on PatientsLikeMe, a website where patients can connect with others and share health information. Participants were asked what their research priorities are and how they would like to be included in the research process. Based on 88 participants who posted in the discussion, we learned that people with T2DM want to see researchers focus on health outcomes in ways that allow patients to

Correspondence: Kristina F Simacek
PatientsLikeMe, 160 2nd Street,
Cambridge, MA 02142, USA
Tel +1 617 500 1623
Fax +1 866 850 6240
Email ksimacek@patientslikeme.com

directly apply findings to help manage their T2DM, especially when they have additional serious health conditions like depression or fibromyalgia. Many participants mentioned specific ways they would like to engage in research, such as sharing results or helping to find participants. This study shows that there is a great deal of opportunity for including patients as partners in research throughout the research process. Using an online patient forum is a valuable way to engage patients in research.

Introduction

Patient input is increasingly being recognized as an important way to improve medical research priorities and procedures.¹ The overall quality, relevance, and impact of medical research stand to increase when the perspectives of those who are most impacted by its outcomes are included.^{2,3} Engaging the patient as an active partner in guiding research allows for the prioritization of issues and outcomes that are important to patients, and ultimately, increases the value of the research.⁴⁻⁷ Few studies have examined patients' motivations for engaging in research; however, one study found that patients engage with researchers because they hope to help others with the same medical conditions, learn about their own health, and make research more meaningful to patients.⁷

Due to the benefits of engaging with patients, patient involvement is increasingly being extended to all stages of research. Patients are no longer merely subjects but are imparting value as important contributors in the planning, execution, and/or translation of research.⁸⁻¹⁰ Specific activities in which potential engagement is possible include selection of comparators and outcomes, selection of study design, making an analysis plan, collecting data, participating in coding qualitative data and data analysis, reviewing and interpreting results, and translating and disseminating findings to other patients.^{11,12} Patients are engaged most commonly at the beginning of research and less often in the execution and translation of research. However, best practices for when to engage patients in research to yield the most value are as of yet undetermined.⁹

There are numerous methods available for engaging patients in research. In a systematic review of research that engaged patients in research design, common methods included focus groups, interviews, surveys, and serving on a study board, with no standout best practice among them.⁹ An alternative that has been underutilized in patient engagement in research is an online patient research network. Consulting with online patient research networks can be a fast, reliable, and meaningful means to source information generated by groups of patients who may be more diverse than clinic-based samples.¹³ Conducting a discussion online facilitates access to populations that are difficult to reach and

who are geographically diffuse, while offering results similar to those obtained from in-person focus groups.^{14,15} Further, online discussions have been used in recent years as a means of rapid qualitative data collection.¹⁶⁻¹⁸ While patients have been recruited from the Internet to participate in research engagement projects, it remains to be seen whether engaging patients within their own research network community can yield similar quality data in a shorter amount of time compared with traditional methods.¹⁹

One disease with widespread impact in the US is type 2 diabetes mellitus (T2DM), which has reached epidemic proportions, and affects an estimated 30.2 million people in the US with an additional 1.7 million incident cases each year.^{20,21} Given the prevalence of T2DM in the US population, it is important to invest in research that may help address the needs of patients with T2DM and subsequently help reduce the risk of morbidity and mortality. Further, as patient and clinician research priorities differ, with providers showing a greater preference for commercial drug research, it is critical to include perspectives from patients when prioritizing T2DM research, as is being done by Diabetes UK and the James Lind Alliance in the UK.^{22,23} Such priorities have not been as well studied in the US.

Despite the perceived benefit of patient engagement in research, by both patients and physicians, little is known about how and why patients with T2DM may want to contribute to medical research about their condition.⁷ Furthermore, there is a lack of qualitative research in diabetes that does not use a clinic-based sample.²⁴ While such samples are convenient, they may lack diversity in access to services, sociodemographic features, care needs, and priorities. For example, prior research has found that both need for care and care quality differed dramatically between a diabetes clinic with patients who were primarily of a high socioeconomic status and another that primarily served patients of low socioeconomic status.²⁵ Thus, alternative methods are required to go beyond individual clinics to represent a more diverse cross-section of patients when a random, representative sample is not available. Online patient research networks may be able to fill this gap by facilitating connections with patients, rapidly and without geographic bounds, in a space where they are already engaged and activated with others who share their health condition.^{26,27}

The goals of this study were to leverage the collective preferences of an online patient research network of people with T2DM to, 1) determine what areas of research are most important to patients with T2DM, 2) identify ways through which patients want to engage in research, and 3) explore

the value of online patient research network forum discussions as a methodology for obtaining perspectives on patient research priorities and willingness to engage. To achieve these goals, we conducted a series of question and answer discussions on a forum within an online patient research network, PatientsLikeMe (PLM), to source perspectives of patients with T2DM on patient-centered research, including topics, motivations, and logistics of bringing the patient voice into the research process.

Materials and methods

Participants

PLM is an online patient-powered research network, designed to offer patients a way to enter and track their own health status, to connect and share health information with peers, and to participate in research studies, regardless of geographic location.^{13,28–31} The PLM community consists of over 600,000 members with over 2,800 health conditions, including T2DM, who contribute self-reported health and demographic data, making it an ideal source to gather their perspectives on the goals and motivations of patients participating in all phases of medical research.

Procedures

This study used a moderated online T2DM forum to host asynchronous discussions with members of PLM. Two discussion events were held in 2015, each consisting of three to four prompted posts to start discussions among members of the T2DM community. Each post was reviewed prior to fielding by a patient advisor, an active patient member of PLM with T2DM who had previously expressed interest to PLM in advising research projects. Discussions were open for 2–3 weeks each, and any member of PLM who visited the T2DM forum was eligible to post a message in the discussion.

Online forum recruitment was augmented through direct messages sent to all patients with T2DM through the PLM private message system. For each of the two events, three types of messages were sent. The first was an introduction to the upcoming event with a general description of the topics to be covered. The second was a preview message sent through the PLM website with shortened versions of the starter posts. Finally, to further encourage participation, reminder messages were sent along with several quotes from actual posts from participants.

Starter posts were established and monitored daily for activity by a forum moderator (a PLM employee), who had access to all posts in the forum and was tasked with overseeing the discussions to ensure that policies, such as advertising

restrictions, were followed and that discussions remained focused on the topic. Moderators in online health communities have an established rapport with forum participants, and it is not unusual for a moderator to post new topics for discussion in order to facilitate discussion activity among members.³² The T2DM forum moderator was provided with a list of follow-up prompts to use based on possible responses posted by participants. Forum posts were also observed by a researcher as the discussion unfolded so that the researcher could identify unanticipated comments upon which the moderator could ask for clarification or follow-up.

Materials

The first series consisted of three starter posts around the theme of prioritizing research topics and applicability of research to patients with T2DM. Participants were asked what research they felt was most important for people with T2DM, how they felt that current research applies to them, and why they look for information about T2DM (for full text of the starter posts, see Supplementary materials). The first series was open from May 4, 2015 through June 14, 2015.

The second series contained four starter posts on the subject of the logistics of including patients with T2DM in research, including activities, data sources, prior participation experiences, and helping others with T2DM. The first post asked patients to reflect on a list of ways in which patients could be involved in continuing effectiveness research¹¹ and identify those parts in which they were most interested. Participants were also asked what, when, and how researchers should go about obtaining real-world data from patients, and finally were asked about their own experiences with research participation. The second series was open for 7 days, from December 14, 2015 through December 21, 2015.

The forum posts also included a statement informing patients that the results will be used for research purposes and also be shared with the sponsor (Janssen Scientific Affairs, LLC; see Supplementary materials). This study was approved by the New England Independent Review Board on April 23, 2015 (study number 15-147). A waiver of documentation of informed consent was obtained from the New England Independent Review Board as this study involved minimal risk, the document would be the only record linking personally identifiable information with participants, and the principal risk of the research is breach of confidentiality.

Analysis

Demographic information was obtained from self-reported data provided by patients on the PLM member profiles.

Participant demographic variables included sex, age, country, race, ethnicity, and comorbidities. Descriptive statistics were computed on demographic and comorbidity variables.

At the close of each discussion series, each thread was analyzed using conventional content analysis to provide an overview of the themes discussed.³³ Analysis was performed by two coders (KS and a research assistant) trained in qualitative content analysis. First, all posts in each thread were read through to identify initial broad themes. Next, a preliminary code list was developed and then applied to all posts; codes were modified or combined as themes became progressively clearer.³⁴ Similar themes were aggregated into summary themes when applicable. In this paper, we provide the summary themes or the highest-level themes from each of the discussions and their frequency of mention. Direct quotes from participants were selected to illustrate the themes. Data analysis was conducted using ATLAS.ti, version 1.6.0 (484).³⁵

Results

A total of 88 individuals, all with T2DM, participated in the discussions (Table 1). Participants were mostly female (50%), on average 59 years old, white (86%), and over half (62%) resided in the US. Compared with the general T2DM population on PLM, participants were similar in age, while a higher proportion of participants were female, white, and non-Hispanic. Participants were less likely to have reported T2DM as their primary condition (61%; their chief reason for using PLM) than members who report T2DM (80%). Most participants (92%) posted in just one of the discussion series, with 8% posting in both events.

Overall, discussion participants reported a median of four comorbid conditions on their PLM profiles, with the most common being hypertension, major depressive disorder, and diabetic neuropathy. While these rates are higher among participants than PLM members with T2DM in general, this is likely due to a higher level of engagement and data sharing on the website among participants rather than in any actual difference in prevalence among the groups.

Series I – research topics and applicability

When asked which topics are most important for T2DM research, the topic most frequently mentioned was comorbidities (18/33) as they affect and are affected by T2DM (Table 2, post 1a). As one patient described, serious physical or mental health comorbidities, such as posttraumatic stress disorder (PTSD), can make managing T2DM less of a priority compared with other health concerns:

Table 1 Participant demographics (N=88)

	Discussion participants* (N=88)	All PLM members with T2DM** (N=19,550)
Sex, n (%)	(n=87)	(n=18,278)
Female	44 (50)	11,185 (61)
Age	(n=87)	(n=18,155)
Years, mean (SD)	58.6 (11.2)	53.7 (11.4)
Country, n (%)	(n=81)	(n=13,454)
United States	50 (62)	7,499 (56)
United Kingdom	15 (19)	2,346 (17)
Australia	4 (5)	444 (3)
Canada	4 (5)	1,256 (9)
Others	8 (9)	1,909 (14)
Race, n (%)	(n=78)	(n=9,610)
White	67 (86)	7,851 (82)
Mixed race	5 (6)	335 (3)
Asian	4 (5)	798 (8)
Black	1 (1)	462 (5)
Native American	1 (1)	126 (1)
Native Hawaiian or other Pacific Islander	N/A	38 (<1)
Ethnicity, n (%)	(n=74)	(n=9,136)
Not Hispanic	71 (96)	7,640 (84)
Hispanic	3 (4)	1,496 (16)
T2DM is the primary condition, n (%)	54 (61)	15,587 (80)
Commonly reported comorbidities, n (%)		(n=15,587)
Hypertension	28 (31)	1,719 (9)
Major depressive disorder	18 (20)	998 (5)
Diabetic neuropathy	13 (14)	574 (3)
High cholesterol	11 (12)	664 (3)
Osteoarthritis	11 (12)	662 (3)
Fibromyalgia	11 (12)	1,722 (9)
Hypothyroidism	9 (10)	644 (3)
Number of self-reported comorbidities, median (IQR)	4 (1–8.25)	1 (0)
Event participation, n (%)		N/A
One event	81 (92)	
Two events	7 (8)	

Notes: *Demographics for participants with missing data were not included in the table. All demographic figures are based on optional, self-reported information provided by participants on their PLM member profiles. **All PLM population figures are current as of August 1, 2016. Only conditions with ≥10% prevalence among forum event participants are included. Comorbidity count only includes those with T2DM as a primary condition.

Abbreviations: SD, standard deviation; IQR, interquartile range; T2DM, type 2 diabetes mellitus; PLM, PatientsLikeMe; N/A, not applicable.

Mental illness for me pretty much just acts like a multiplier. When I'm more symptomatic, managing diabetes becomes a really minor thing compared with managing PTSD and Depression.

Other research topics suggested by participants included improved options for control of blood sugar levels and

Table 2 Forum discussion series 1 – major themes for research topics

Theme	n	Description
Post 1a. What's important? Research topics to help people living with T2DM (N=33)		
Comorbidities interacting with T2DM	18	Management of comorbidities, along with T2DM, interactions among comorbidities' symptoms
Control of T2DM	16	Better understanding of how to improve control of T2DM, including adherence
Cure for T2DM	9	A cure for or reversal of T2DM
Causes for T2DM	4	Root causes for T2DM
Post 1b. How does research apply to you – or not? (N=10)		
Direct applications	6	Patients have directly applied research to their self-management
Gaps in research	5	Patients identify gaps in research, where research does not apply to their unique needs
Post 1c. Why do you look for information about T2DM? (N=19)		
Self-advocacy	11	To gain information to help them ask better questions of their provider
Inadequate information elsewhere	9	Information given by providers is inadequate
Seeking improvement	8	To improve results of self-management

Note: Themes are not mutually exclusive; participants were not limited in the number of themes they could discuss.

Abbreviation: T2DM, type 2 diabetes mellitus.

understanding of the root causes of T2DM. Several participants expressed disappointment with the lack of scientific discovery and curative treatments in this space.

The disease is manageable, so why waste any more money on incremental improvements in management. Any time spent on anything else except a cure is pretty much killing every one of us.

When asked about how research applies to them, six out of the 10 participants who responded had found ways to directly apply research to their self-management (Table 2, post 1b). Yet, half (n=5) felt that research did not provide value for them, either as research participants or as consumers of research reports. For example, one patient observed a lack of research relevant to people with irregular schedules:

My job is a bus driver and I work different times every day. One day I can start at 5 am another I can finish at 1 am. So I can't eat at regular times and no research I've seen gives any advise [t]o my situation.

In order to supplement the information they received from providers about managing their T2DM, participants sought out information on better tools and treatments aimed to improve their ability to be self-advocates in their care (Table 2, post 1c). Some successfully found and applied information from research studies, citing examples about managing their T2DM through diet and exercise. Others indicated they were forced to seek out information on their own due to frustration with inadequate, and sometimes conflicting, information from providers. As one participant described, more information was not necessarily useful.

I looked for information to help me control my diabetes better but in the end found that there were too many

contradictions and if you take all the supplements recommended it would cost you a fortune and most of them are not proven. Diet and exercise are the best way of controlling blood sugar.

Series 2 – logistics of patient engagement in research

When presented with a list of ways that patients can be involved in research, many limited their responses to suggesting specific research topics (Table 3, post 2a). Specific research ideas included incorporating assessment of lifestyle and social factors, using longitudinal methods, and developing and assessing educational programs to support people with T2DM and their caregivers. When discussing their potential engagement in research, participants were not interested in every step of the research process, with two participants framing their participation as a way to apply existing skills, such as education or work experience, to research design.

In a discussion with 18 participants about where and how to get real-world data, nearly half (eight out of 18) were interested in sharing their health data openly with researchers, while two participants gave the caveat that their data should be de-identified (Table 3, post 2b). The group suggested specific ideas to improve the relevance of research to real-world patients, including gathering data about comorbidities, lifestyle, and social contexts of patients living with T2DM. In addition, specific study ideas included evaluating diabetes education, better understanding lifestyle management, longitudinal studies of T2DM, and understanding T2DM in the 18–30 age range.

Twenty-two participants contributed to the discussion about experiences participating in research (Table 3, post 2c). Many expressed an interest in being included in research;

Table 3 Forum discussion series 2 – major themes for research activities

Theme	n	Description
Post 2a. Which research activities would you most want to be involved with? Why? (N=17)		
Topic ideas	9	A specific research topic is suggested
Want to get involved	6	General, nonspecific interest in research participation
Specific activity	3	Specific activity is endorsed relating to research participation, such as sharing results with others
Transfer skills	2	Participant wants to use their skills/background to help researchers
Barriers	2	Concerns about barriers to patients participating in research, such as recruitment or being able to interpret the results
Post 2b. Where, when, and how should researchers go about getting real-world information? (N=18)		
Share data openly	8	Willingness to share own health data openly with researchers, de-identified
Understand me/lifestyle	4	Include information about life events, lifestyle, social aspects
Need consistent information	4	Information from providers and leaders in T2DM seems inconsistent; participants want to see more alignment
Study ideas	5	Ideas for new research studies; eg, comorbidities, lifestyle, longitudinal studies, patients under age 30.
Post 2c. What research have you participated in? (N=22)		
Want to participate	9	Expressed general interest in research participation
Participated	6	Has experience as a research participant, whether a clinical trial is specified or not
Barrier	5	Experienced or perceives barriers to research participation, such as comorbidities or safety concerns
Do not know how	4	Lacks information about how to get involved in a research study
Declined	2	Participant has chosen to decline research participation

Note: Themes are not mutually exclusive; participants were not limited in the number of themes they could discuss.

Abbreviation: T2DM, type 2 diabetes mellitus.

however, some were unsure of how to go about it. Further, participants' definition of research was broad, and included types of research beyond clinical trials. While six patients said they had participated in research in the past, only one participant specified that the research was a clinical trial, while two indicated they had participated in survey research only. Another group of topics discussed in this thread included barriers to participating in research, such as restrictive inclusion criteria, concerns about effects on comorbidities, and an inability to find information. One participant described a number of concerns about trial participation, including transportation, comorbidities, and worry that their T2DM could get worse:

I have been asked to participate in research. I don't have transportation so that is the main reason I declined. In addition, I have so many other health issues I don't think I would get very far in the screening process. It took me a very long time to get a decent and somewhat healthy A1c number and I would hate to have that change because before I was close to normal I felt terrible. I want to move forward, not backward.

Discussion

This study contributes to the literature on patient preferences for engagement with T2DM research by illustrating some of the topics and types of engagement that patients with T2DM value. In addition, this study uses a unique method to learn about patient preferences for research engagement

by hosting a discussion on an online T2DM patient research network. Overall, the consistency with previous studies indicates that an online discussion series is a valuable method for obtaining patient input on research priorities and understanding the ways in which patients may wish to engage with research.

Patient priorities in research included managing T2DM along with comorbidities, better control of blood sugar levels, finding a cure, and understanding causes of T2DM among different patients. Participants wanted to be able to directly apply research to their lives, especially around diet and exercise. These findings generally reflect previous research into diabetes patients' priorities in research using other methodologies.^{13,22,36–38} For example, one study using three in-person focus groups with 39 ethnically diverse diabetes patients in a primary care clinic identified nine patient research priorities: improving information, lack of public awareness, improving information about food, one-to-one support, health services, prevention and screening, difficulties of comorbidity, value of exercise, and self-management.³⁶ Similar to previous research, participants in our study tended to prioritize research into nondrug treatments, such as lifestyle changes, over pharmaceutical solutions, with some participants outright questioning the motivations of the pharmaceutical industry to produce beneficial treatments.²²

When it comes to contributing to research, participants indicated that they are both interested in being research subjects and in being partners in research, hoping to apply their skills from their work and educational background to

such opportunities. Similar to previous research, participants indicated greater interest in the planning and translation of research than in the execution of research, as these felt more in line with their skills.^{19,39} While one option is to train patients in research engagement, a balance must be struck between the extremes of complete integration through all stages of research as a patient-researcher at one end of the spectrum, which is time consuming and expensive, and tokenism at the other end.^{9,12,19}

This study provides further support for the use of online patient research network discussions to elicit patient perspectives and to generate rich qualitative data. Using an existing patient forum and professional moderator to execute conversations, we were able to carry out the study with established rapport with participants.^{32,40} No participant questioned the motives of the moderator or the use of their data, as this was made clear in the initial starter post. We were able to obtain a relatively large sample size for these discussions compared with previous research in online focus groups.^{16–18} Participants came from around the world in a non-clinic setting to represent diverse perspectives. Further, no transcribing was necessary as all discussion occurred through online messages, decreasing the data cleaning and analysis time. Finally, discussions were able to be completed rapidly, within weeks, and at participants' convenience.

Limitations

There are several limitations to this study. First, these data, including diagnosis, are self-reported and have not been independently verified. Second, this sample was from an online community of patients with T2DM and their attitudes may not be representative of the general population of people with T2DM. In particular, the demographic features of participants do not reflect general population estimates with regard to distribution by race and underrepresent individuals living in developing countries, where rates of T2DM are higher.^{41,42} Furthermore, given the international distribution, self-management and exposure to research opportunities may vary based on the participant's location.²⁵ This sample was diverse in ways that would be difficult to recreate in person, such as the global distribution of participants who were able to interact with each other in a conversational format. However, the conversation was limited to those who could read and write in English. Finally, as a limitation of the methodology, not all follow-up questions were answered, as might have been expected in a face-to-face discussion. As is the expectation in an online forum, participants may come and go from the discussion, and this limited the capacity to

continually engage with the same participant over multiple exchanges. Further, participants may not feel obligated to post a response if someone else has already made their point. However, this flexibility in participation also enabled newcomers to review the previous conversation and to add new perspectives, something that would be impossible in a face-to-face focus group or in an online chat done at a set time.

Conclusion

Research priorities for patients with T2DM span issues that have meaning in patients' daily lives, such as managing other health conditions along with T2DM, understanding the causes of T2DM, developing better methods for managing blood sugar levels, and finding a cure. Discussions held within patient research network groups are a valuable method for eliciting patient perspectives. Involving input from patients with T2DM may provide researchers insights that best incorporate the varied perspectives and capabilities of patients and ultimately improve the quality and relevance of research.

Implications

As new technologies facilitate opportunities for data collection and synthesis, understanding the complexity of managing T2DM along with comorbidities and lifestyle context will continue to be an emerging area of research. Engagement with online patient research networks is an emerging methodology for eliciting rich and potentially sensitive qualitative information from patients.^{16,27,30} By leveraging direct-to-patient outreach in an environment where they are already engaged in discussions about their health, we can reach a wider audience at a lower cost with more participant flexibility and in less time than with traditional face-to-face or synchronous methodologies.

Taken together, the findings suggest several areas of research that would be valuable to understand patient experience with T2DM to inform research priorities. First, a better understanding of the barriers presented by comorbidities (eg, mental and physical health conditions) as they may affect adherence to medication and lifestyle change is warranted. Second, engaging patients as research collaborators requires support and responsiveness to patient partners' abilities and preferences, as well as roles and expectations.⁴³ Initiatives to involve patients in research design must enable patients to contribute in a meaningful way while avoiding tokenism.¹² While asking patients for research ideas can generate some important topics for prioritization, creating a relationship with patients and including them as partners in research

requires an understanding of the motivations and challenges driving participation. Finally, the results of this study suggest that programs should be developed to educate patients about what kinds of contributions they can make to the research process and to help them leverage their contributions in a way that is meaningful by their own standards, whether as participants, advisors, or as co-investigators.

Data sharing statement

The data generated and analyzed during this study can be made available in de-identified format to third parties, upon request.

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Disclosure

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References

- Sacristán JA, Aguarón A, Avendaño-Solá C, et al. Patient involvement in clinical research: why, when, and how. *Patient Prefer Adherence*. 2016;10:631–640.
- Fleurence R, Selby JV, Odom-Walker K, et al. How the Patient-Centered Outcomes Research Institute is engaging patients and others in shaping its research agenda. *Health Aff*. 2013;32(2):393–400.
- Chafe R, Born KB, Slutsky AS, Laupacis A. The rise of people power. *Nature*. 2011;472(7344):410–411.
- Chalmers I, Bracken MB, Djulbegovic B, et al. How to increase value and reduce waste when research priorities are set. *Lancet*. 2014;383(9912):156–165.
- Entwistle V, Calnan M, Dieppe P. Consumer involvement in setting the health services research agenda: persistent questions of value. *J Health Serv Res Policy*. 2008;13(Suppl 3):76–81.
- Snow R, Crocker JC, Crowe S. Missed opportunities for impact in patient and carer involvement: a mixed methods case study of research priority setting. *Res Involv Engagem*. 2015;1(1):1–13.
- Forsythe LP, Frank L, Walker KO, et al. Patient and clinician views on comparative effectiveness research and engagement in research. *J Comp Eff Res*. 2015;4(1):11–25.
- Vayena E, Brownsword R, Edwards SJ, et al. Research led by participants: a new social contract for a new kind of research. *J Med Ethics*. 2016;42(4):216–219.
- Domecq JP, Prutsky G, Elraiyah T, et al. Patient engagement in research: a systematic review. *BMC Health Serv Res*. 2014;14(1):89.
- Shippee ND, Domecq Garces JP, Prutsky Lopez GJ, et al. Patient and service user engagement in research: a systematic review and synthesized framework. *Health Expect*. 2015;18(5):1151–1166.
- Mullins CD, Abdulhalim AM, Lavalley DC. Continuous patient engagement in comparative effectiveness research. *JAMA*. 2012;307(15):1587–1588.
- Forsythe LP, Ellis LE, Edmundson L, et al. Patient and stakeholder engagement in the PCORI pilot projects: description and lessons learned. *J Gen Intern Med*. 2016;31(1):13–21.
- Schroeder EB, Desai J, Schmittiel JA, et al. An innovative approach to informing research: gathering perspectives on diabetes care challenges from an online patient community. *Interact J Med Res*. 2015;4(2):e13.
- Turney L, Pocknee C. Virtual focus groups: new frontiers in research. *Int J Qual Methods*. 2005;4(2):32–43.
- Campbell MK, Meier A, Carr C, et al. Health behavior changes after colon cancer: a comparison of findings from face-to-face and on-line focus groups. *Fam Community Health*. 2001;24(3):88–103.
- Stewart K, Williams M. Researching online populations: the use of online focus groups for social research. *Qual Res*. 2005;5(4):395–416.
- Thomas C, Wootten A, Robinson P. The experiences of gay and bisexual men diagnosed with prostate cancer: results from an online focus group. *Eur J Cancer Care (Engl)*. 2013;22(4):522–529.
- Oringderff J. “My way”: piloting an online focus group. *Int J Qual Methods*. 2004;3(3):1–10.
- Forsythe LP, Szydowski V, Murad MH, et al. A systematic review of approaches for engaging patients for research on rare diseases. *J Gen Intern Med*. 2014;29(Suppl 3):S800.
- Centers for Disease Control and Prevention. National diabetes statistics report: estimates of diabetes and its burden in the United States, 2014. Atlanta, GA: US Department of Health and Human Services; 2014.
- International Diabetes Federation. *IDF Diabetes Atlas*. 8th ed. Brussels, Belgium; International Diabetes Federation, 2017.
- Crowe S, Fenton M, Hall M, Cowan K, Chalmers I. Patients’, clinicians’ and the research communities’ priorities for treatment research: there is an important mismatch. *Res Involv Engagem*. 2015;1(1):2.
- Diabetes UK. Type 2 diabetes priority setting partnership. Diabetes UK website; 2017. Available from: <https://web.archive.org/web/20170927142650/https://www.diabetes.org.uk/research/our-approach-to-research/have-your-say/type-2-diabetes-priority-setting-partnership>. Accessed January 1, 2017.
- Hennink MM, Kaiser BN, Sekar S, Griswold EP, Ali MK. How are qualitative methods used in diabetes research? A 30-year systematic review. *Glob Public Health*. 2017;12(2):200–219.
- Lutfey K, Freese J. Toward some fundamentals of fundamental causality: socioeconomic status and health in the routine clinic visit for diabetes. *Am J Sociol*. 2005;110(5):1326–1372.

26. Fleurence RL, Curtis LH, Califf RM, Platt R, Selby JV, Brown JS. Launching PCORnet, a national patient-centered clinical research network. *J Am Med Inform Assoc*. 2014;21(4):578–582.
27. Brady E, Segar J, Sanders C. Accessing support and empowerment online: the experiences of individuals with diabetes. *Health Expect*. 2017;20(5):1088–1095.
28. Wicks P, Massagli M, Kulkarni A, Dastani H. Use of an online community to develop patient-reported outcome instruments: the Multiple Sclerosis Treatment Adherence Questionnaire (MS-TAQ). *J Med Internet Res*. 2011;13(1):e12.
29. Workman TA. *Engaging Patients in Information Sharing and Data Collection: The Role of Patient-Powered Registries and Research Networks*. Rockville, MD: Agency for Healthcare Research and Quality; 2013.
30. Daugherty SE, Wahba S, Fleurence R, et al. Patient-powered research networks: building capacity for conducting patient-centered clinical outcomes research. *J Am Med Inform Assoc*. 2014;21(4):583–586.
31. Fleurence RL, Beal AC, Sheridan SE, Johnson LB, Selby JV. Patient-powered research networks aim to improve patient care and health research. *Health Aff*. 2014;33(7):1212–1219.
32. Huh J, McDonald DW, Hartzler A, Pratt W. Patient moderator interaction in online health communities. In: *AMIA Annual Symposium Proceedings of the American Medical Informatics Association, Washington, DC*; November 16–20, 2013:627–636.
33. Hsieh HF, Shannon SE. Three approaches to qualitative content analysis. *Qual Health Res*. 2005;15(9):1277–1288.
34. Weiss RS. *Learning from Strangers: The Art and Method of Qualitative Interview Studies*. New York: Simon and Schuster; 1994.
35. Muhr T, Friese S. *User's Manual for ATLAS.ti 5.0*. Berlin: ATLAS ti Scientific Software Development GmbH; 2004.
36. Brown K, Dyas J, Chahal P, Khalil Y, Riaz P, Cummings-Jones J. Discovering the research priorities of people with diabetes in a multicultural community: a focus group study. *Br J Gen Pract*. 2006;56(524):206–213.
37. Arnolds S, Heckermann S, Heise T, Sawicki PT. Spectrum of diabetes research does not reflect patients' scientific preferences: a longitudinal evaluation of diabetes research areas 2010–2013 vs. a cross-sectional survey in patients with diabetes. *Exp Clin Endocrinol Diabetes*. 2015; 123(5):299–302.
38. Gadsby R, Snow R, Daly AC, et al. Setting research priorities for type 1 diabetes. *Diabet Med*. 2012;29(10):1321–1326.
39. Finney Rutten LJ, Morris MA, Schrader LM, et al. Approaching patient engagement in research: what do patients with cardiovascular disease think? *Patient Prefer Adherence*. 2015;9:1061–1064.
40. DiCicco-Bloom B, Crabtree BF. The qualitative research interview. *Med Educ*. 2006;40(4):314–321.
41. Harris MI, Eastman RC, Cowie CC, Flegal KM, Eberhardt MS. Racial and ethnic differences in glycemic control of adults with type 2 diabetes. *Diabetes Care*. 1999;22(3):403–408.
42. Chen L, Magliano DJ, Zimmet PZ. The worldwide epidemiology of type 2 diabetes mellitus – present and future perspectives. *Nat Rev Endocrinol*. 2012;8(4):228–236.
43. Johnson DS, Bush MT, Brandzel S, Wernli KJ. The patient voice in research – evolution of a role. *Res Involv Engagem*. 2016; 2(1):1–6.

Supplementary materials

Forum Starter Posts and Response Prompts

Event 1: Patients' Research Priorities

Starter Post 1.1:

Subject:

What's important? Research topics to help people living with T2D.

Body:

We're working with our partners at Janssen Scientific Affairs, L.L.C. to find out what people who have type 2 diabetes think that researchers should be looking into. When you share your thoughts on this thread, you'll be adding your voice to new diabetes research.

Much of current type 2 diabetes research focuses on treatments and lifestyle changes, as well as quality of diabetes care. Are these your priorities? What research do you think needs to happen in Type 2 Diabetes? This could be broad (like genetic markers) or narrow (like effect of sleep on blood sugars or finding better ways to monitor blood sugar levels). How do you imagine this research could help you?

Moderator follow-up question bank:

- Why is research on X important?
- What's the one specific question you need an answer to that you don't have?
- Can you give me an example of that?
- How would more research on X help patients?
- What problems are you having right now, related to your type 2 diabetes, that need a solution?

Starter Post 1.2:

Subject:

Why do you look for information about type 2 diabetes?

Body:

We're working with our partners at Janssen Scientific Affairs, L.L.C. to find out why people who have type 2 diabetes would go looking for information about their condition and treatment. When you share your thoughts on this thread, you'll be adding your voice to new diabetes research.

What makes you look for information about type 2 diabetes? What would you like to figure out? It may be that your A1C levels are not where you want them to be, or maybe you have new symptoms that you suspect might be related to your

diabetes. Share why you would do your own research into type 2 diabetes – we're looking for you to weigh in.

Moderator follow-up question bank:

- What would make you want to look up information about treatment options?
- Are you looking for information or for support?
- Have the reasons for looking up information changed since you first found out you had type 2 diabetes?
- What would convince you to change the way you're managing your type 2 diabetes?
- How do you decide whether or not to change what you're doing to manage your type 2 diabetes?
- What are your next steps if you don't find the information (or support) you've looked for?

Starter Post 1.3:

Subject:

How does research apply to you – or not?

Body:

We're working with our partners at Janssen Scientific Affairs, L.L.C. to find out what people who have type 2 diabetes think about diabetes research and the real world. When you share your thoughts on this thread, you'll be adding your voice to new diabetes research.

Clinical trials look for efficacy of treatments, or how treatments work in an ideal setting. Participants are chosen (or not) based on many factors and the research team ensures everyone is following protocol and taking the medicines as prescribed. Effectiveness though is how treatments work in the real world – where people may alter their dosage, miss a day, or have other factors at play.

“We're not talking about any trials that are currently happening – but rather your general preferences and perspectives – so share your voice even if you haven't participated. It would be great to hear from those not interested!”

How applicable is diabetes research to the way you manage your diabetes? How could researchers make sure they understand the real-world effectiveness of new treatments for patients like you?

Moderator follow-up question bank:

- Do you ever have trouble managing your diabetes exactly how your doctor recommended? Were there studies or

resources that helped you decide about whether or how to make changes?

- Do you think researchers should pay more attention to certain groups of people? Why do (or don't) you think so?
- Why do you think researchers haven't been including <group or type of information>?
- How would including <group or information> help?
- Is it more important to be inclusive of a wide range of patients, or to get treatments and information out to people more quickly?

Event 2 – Research Involvement

Starter Post 2.1:

Subject:

Including you in research design.

Body:

Throughout these forum events with Janssen Scientific Affairs, L.L.C, we've been including patient research partners in different steps of the research process to help give context and improve the projects. In this event, we're taking a step back to figure where people think they can contribute the most.

Imagine you could work with a researcher in the activities below (which are different steps of the research process). Which two or three of these would you most want to be involved with? Why? Are there any activities where you wouldn't know where to start?

Develop a research plan – from prioritizing a topic to deciding on a specific question that is relevant and useful to people living with T2D
Choose what is important to measure or track to answer the research question
Give feedback on study procedures and their acceptability to T2D patients
Help identify the appropriate audience to invite to participate in the research study
Figure out the best place to get data (eg, medical records, drug trials, interviews, etc)
Find people to participate in the research study
Make sense of the results and translate them into simple language
Share research results with others

Moderator follow-up question bank:

What do you think about helping researchers make sense of the results?

Is there anything missing from this list? Are there other ways you'd like to be involved in research?

Why are you not interested in this?

Starter Post 2.2:

Subject:

Research in the real world: what do you want?

Body:

In our last forum event, we heard about some of the challenges managing T2D, especially with respect to other conditions. We're working with our partners at Janssen Scientific Affairs, L.L.C. again, to find out how to best learn about what it's like to live with diabetes including day-to-day challenges and which treatments work.

We'd like to know what you think about the practical side of learning this information. Where, when, and how should researchers go about getting this information? What's the best time and place to ask you about taking part in research? How do you feel about researchers looking at your medical or pharmacy records?

Moderator follow-up question bank:

What are your concerns? In what situations would you be comfortable with it?

Where would you look if you wanted to learn about opportunities to take part in research?

Where have you ever seen or heard about a research project related to T2D?

Starter Post 2.3:

Subject:

What research have you participated in?

Body:

We're working with our partners at Janssen Scientific Affairs, L.L.C., to find out what your experience is with research in type 2 diabetes – the good, the bad, and the ugly.

Clinical trials are research studies done to test the safety and effectiveness of certain treatments, drugs or medical devices. Have you ever been asked to participate in a clinical trial? We'd like to know more about it! Why did you decide to participate? What was it like?

Clinical trials are not the only research that goes on with T2D. Other kinds of research might be taking part in a survey about life with T2D or attending a test program for T2D management. What other research related to T2D have you participated in? What did you think of your experience? Would you recommend it? Would you do it again?

Moderator follow-up question bank:

- When you participated in the clinical trial, did you have the option to choose from more than one trial?

- How did you find out about the trial?
- What was the best thing about participating in the trial?
How about the worst thing?
- Did you ever learn what the results of the trial were?
- Would you recommend that other people participate in this trial?
- How could clinical trials be made better for patients?
- Why didn't you take part in the trial?
- Where would you like to see more information about trials?
- How did you find out about the research study?
- What did you like about participating?
- Did you learn anything by taking part?
- Did you ever learn about the results of the study?

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