Title: Copenhagen Diabetes Consensus (CODIAC) 2021: User Involvement in Diabetes Care, Prevention and Research

Short Running Title: CODIAC report on user involvement

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Abstract

Aims

User involvement is pivotal for health development, but there are significant gaps in our understanding of the concept. The Copenhagen Diabetes Consensus on User Involvement in Diabetes Care, Prevention and Research (CODIAC) was established to address these gaps, share knowledge, and develop best practices.

Methods

A literature review of user involvement was undertaken in diabetes care, prevention, and research. Moreover, a Group Concept Mapping (GCM) survey synthesized the knowledge and opinions of researchers, healthcare professionals, and people with diabetes and their carers to identify gaps between what is important for user involvement and what is being done in practice. Finally, a consensus conference discussed the main gaps in knowledge and practice while developing plans to address the shortcomings.

Results

The literature review demonstrated that user involvement is an effective strategy for diabetes care, prevention, and research, given the right support and conditions, but gaps and key challenges about the value and impact of user-involvement approaches were found. The GCM process identified 11 major gaps, where important issues were not being sufficiently practised. The conference considered these gaps and opportunities to develop new collaborative initiatives under eight overall themes.

Conclusions

User involvement is effective and adds value to diabetes care, prevention, and research, when used under the right circumstances. CODIAC developed new learning about the way in which academic and research knowledge can be transferred to more practice-oriented knowledge and concrete collaborative initiatives. This approach may be a potential new framework for initiatives in which coherence of process can lead to coherent outputs.

Keywords: User involvement, diabetes, care, prevention, research, literature review, Group Concept Mapping

Bulleted Novelty statement

What is already known?

- User involvement is pivotal for health development, but there are significant gaps in our understanding of the concept.

What this study has found?

- User involvement is an effective strategy for diabetes care, prevention, and research, but gaps about the value and impact of user-involvement approaches exist.
- Important issues for user involvement are not being sufficiently practised.

What are the implications of the study?

- Action plans to address the limitations in our current knowledge base on user involvement are being developed
- CODIAC developed a new approach to transfer knowledge into clinical practice and concrete collaborative initiatives.
- This may be a potential new framework for initiatives in which coherence of process can lead to coherent outputs.

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Introduction

User involvement in health development provides people with an opportunity to influence issues pertaining to their own lives and well-being. Although many different concepts and names exist (co-determination, shared decision-making, patient and public involvement, co-design, participatory research etc.), they are all concerned with giving users a say. Within diabetes, this has ramifications for care, prevention, and research.

In diabetes care, user involvement is often characterised by patient-centred dialogue and interaction between healthcare professionals and people with diabetes (and their relatives) to define self-management and treatment strategies that minimise the psychosocial burden of living with diabetes while promoting psychological wellbeing. In diabetes prevention, user involvement is more commonly referred to as citizen engagement, co-creation or co-production and is characterised by processes of supporting people in fulfilling their potential individually or collectively, to maintain or adopt healthy lifestyles despite all-pervading distractions and barriers. Finally, in diabetes research, user involvement is often called participatory research, action research or citizens' science and aims to generate research agendas that are relevant and meaningful to people with diabetes by inviting them to collaborate in defining and answering research questions through active participation in all phases of the research development and implementation processes.

The CODIAC initiative

Although user involvement is being increasingly enshrined in the field of health, there are significant gaps in our knowledge of the concept. Does involvement make the processes and products more effective and more culturally embedded? If so, how strong is the evidence? The Copenhagen Diabetes Consensus on User Involvement in Diabetes Care, Prevention and Research (CODIAC) was established as an international collaboration in 2019 with the aim of answering these questions and creating an environment to share knowledge and develop best practices (www.codiac2021.dk).

The overall aim of CODIAC was to summarise, communicate, and further develop existing international research-based knowledge about the value and impact of user involvement in diabetes care, prevention, and research. CODIAC, which was facilitated by Steno Diabetes Center Copenhagen (SDCC), included three phases (Figure 1):

1. a preparation phase to review the literature, compile existing evidence and map the gaps,
2. a Group Concept Mapping survey to obtain experiences and perspectives from users and professionals, and thus expand the knowledge base and qualify its gaps,
3. an innovative international 2-day conference to review the gaps, add to the knowledge base, consolidate learning, and propose future actions.

This paper summarizes the process of collaboration in these three phases, while developing recommendations for future processes of planning and implementing actions, and thus expanding the knowledge base on user involvement in diabetes care, prevention, and research.

Preparation phase

A collaborative review of the scientific literature

In preparation for the conference, three working groups, comprising international researchers from the areas of diabetes care, prevention, and research, undertook a collaborative review of the scientific literature. We define ‘collaborative review’ as a review that was designed and conducted by researchers from various scientific disciplines in consultation with user representatives and clinicians. The review findings were discussed with the CODIAC conference participants (researchers, users, and health care professionals) to inform the final outcomes presented in this paper.

CODIAC’s focus on user involvement thus inspired us to apply an interdisciplinary review approach. The review aimed to summarise the evidence about the value and impact of user involvement in diabetes care, prevention, and research to single out the methods and concepts that have demonstrated potential for future work and development. A further overarching goal was to identify significant knowledge gaps and how these could be addressed in future research projects. The full collaborative review will be presented in a separate publication. Here we briefly outline the review method before presenting the findings from each working group.

Methods

The collaborative review was conducted following systematic mapping and scoping review methods (1,2). The Danish Diabetes Knowledge Center performed a systematic mapping to identify literature, using eligibility criteria designed to include literature on involvement (e.g., community-based interventions, patient-centred interventions, patient and public involvement, and user-driven interventions and research) of users (i.e., people diagnosed with diabetes or pre-diabetes, people at risk of developing health conditions and citizens or community residents) within the context of diabetes care, prevention and research. The following databases were searched: MEDLINE, Embase, CINAHL, PsycINFO and ERIC. The search was limited to reviews to ensure that the review could be completed and analysed prior to the CODIAC conference.

The working groups used their expertise to select publications for in-depth analyses based on the relevance attached to the reviews. Papers that explicitly described the relationship between the nature of involvement and the outcomes and provided insight into facilitators and barriers were considered *highly relevant* as “these could contribute to theory building and/or testing” (3). All working groups could include supplemental papers not identified by the literature search to supplement the literature search.

The reviews identified through the literature search were also categorized by the Danish Diabetes Knowledge Center and presented in an interactive Evidence Gap Map (https://www.unicef-irc.org/evidence-gap-maps) to ensure transparency and allow others to formulate an overview of the evidence and identify reviews relevant to their work and interests. The gap map is available at www.codiac2021.dk/gapmap.

The preliminary analyses of each working group were presented at the CODIAC conference in October 2021 and discussed by the conference participants.

Findings

The literature search was conducted in November 2019 and yielded 8,648 potentially relevant records, of which 79 reviews were included for analysis (Appendix 1). 43 were considered relevant to diabetes care, 31 to diabetes prevention and 10 to diabetes research (www.codiac2021.dk/reviews). 11 reviews were considered relevant to more than one category. The care working group added 1 additional paper and the prevention working group added 3 additional papers to their analyses that were not identified through the formal literature search.

The diabetes care review covered user involvement in care and support of individuals with diabetes within various settings, including hospitals, general practices, municipalities, civil society, and patient associations and included emotional and behavioural aspects of care. The prevention review examined both primary and secondary prevention and focused on prevention of diabetes in at-risk and healthy groups in settings including municipalities, general practices, residential areas, and civil society. Finally, the research review assessed the literature on user involvement relating to research into diabetes complications, care, and prevention and included varied research disciplines, such as biomedicine, epidemiology, health promotion, and education.

Diabetes Care

44 reviews about user involvement in diabetes care were included (S1-S44), of which 24 were considered as “highly relevant” (S1-S23, S44).. All but one (S26) of the reviews addressed individual user involvement in their own care and encompassed evaluation of a range of interventions with the purpose of improving diabetes self-management and/or HbA1c among people with diabetes, primarily type 2 diabetes. The interventions evaluated different methodologies to increase ‘the involvement of the person with diabetes in own care’ by offering individual consultations, education sessions or coaching/counselling or group-based training or education in diabetes self-management conducted by healthcare professionals. Some interventions involved the family of the person with diabetes (S24, S25, S34, S42), caregiver (S17) or peer support (S27, S32, S40). The user involving methodologies

included person-centred, personalized, individualized, and collaborative care concepts and models which sought to increase participation, empowerment, and engagement of users in diabetes self-management.

Regarding the level of user involvement, most strategies focused on users as consultants or collaborators with shared decision-making or using decision aids as the most frequently mentioned approach (S7, S8, S11, S15, S16, S19, S23). Shared-decision making was effective in reaching treatment goals and could be implemented at low cost. Other methods investigated collaborative goal-setting (S3) and motivational interviewing (S39). A framework for organising and delivering diabetes education and support together with users has been developed (S9), and collaborative education has been successful in improving outcomes such as knowledge, psychological well-being and short-term behaviour changes (S2, S6, S20, S22, S36, S44), however, some studies were inconclusive (S1) and associations between the different approaches and quality of life were not found (S6, S15, S19). Studies with user involvement aiming to improve cardio-metabolic risk markers, particularly glycaemia are frequently reported in literature (S1, S2, S4, S6, S11, S15, S20, S22) and have shown some success (S2, S4, S6, S20, S22).

Whilst many studies identify the impact of interventions with elements of user involvement, none of the included reviews focused on the specific contribution of user-involvement in the interventions, thus the association between the degree of user-involvement and the outcomes were not measured specifically. Furthermore, insufficient descriptions of intervention components in primary papers were also an obstacle in identifying specific and effective mechanisms and settings for successful patient and public involvement in diabetes care. Moreover, the literature included does not identify any single approach that consistently improves specific outcomes. No user-led intervention could be identified among the reviews identified although user-led initiatives, such as insulin delivery closed-loop (DIY) groups, play an important role in the field.

Only one of the articles dealt with organisational or collective user involvement studying quality of clinical guidelines. The study concluded that end-users were rarely present in the development of guidelines, and thus the impact could not be assessed (S26). A recently published review of reviews on the impact of patient and public involvement in health research and healthcare, but not specifically addressing diabetes care, included studies related to organizational or collective user-involvement (S43). Impact was reported in the areas of clinic level service development and improvement in terms of input into decisions, priorities, and policies, e.g., defining problems and clinical priorities, changed recommendations and relocation of services (S43). Impact was also reported in relation to information development and dissemination, to improvements of access to healthcare (for example, improved public transport, car parking and fast track emergency) and in designing new health care buildings and environments (for example, waiting rooms) (S43). There is a gap in knowledge and practice regarding collective user-involvement in diabetes care in all aspects such as development and evaluation of services, interventions, clinical guidelines, and education.

Focussing on key factors that enable or hinder user involvement in diabetes care, three main categories could be identified. The first category contained barriers related to healthcare professionals, such as insufficient training and development of professional competences and staff resources allocated to interventions (S1, S12, S13, S15). The second was the barrier caused by the belief among people with diabetes that clinicians or healthcare professionals should make health decisions based on their expertise (professional-as-agent-model) and the passivity this creates among the users (S19). Additionally, the use of new technologies was a barrier, particularly for older users, because of a lack of digital skills (S14, S21).

Diabetes Prevention

34 reviews on diabetes prevention were included in the analysis (S40, S45-S77), 12 of which were considered “highly relevant” (S40, S45-S55). The literature described various kinds of user involvement including (S45-S47):

- Consultation between members of the public and healthcare professionals through targeted inputs in meetings and workshops with limited influence on decision-making
- More systematic collaboration where members of the public contributed to the decision-making process during intervention development and implementation

- User-driven interventions

A wide range of positive effects of user involvement were described with reference to individual behaviour, its determinants and direct outcomes (e.g. knowledge, participation, body mass index) (S45), but also at the social level (e.g. fostered sense of community) (S50, S52) or the environmental level (e.g. increased availability of healthy food outlets) (S48). By contrast, a small number of negative effects were reported including young people feeling ignored or overwhelmed (S49, S50).

Based on a broad view of preventive fields of actions, the papers were sub-divided into person-centred interventions (e.g. motivational interviewing) (S40, S53), single-setting interventions (e.g., schools and virtual settings) (S49, S50, S52) and multi-setting interventions (e.g. communities) (S45, S47, S48, S51, S54). While for person-centred interventions, peer-support strategies seemed more effective among “hardly reached” groups (S40), results from single-setting interventions were more mixed.

Active user-involvement strategies in digital game-based interventions were associated with lower effectiveness on behavioural outcomes (S49), while for school-based interventions a wide range of positive effects on a personal, organizational and stakeholder level were reported (S50, S52). For multi-setting interventions, in turn, the importance of power imbalance and the organisation’s ability to ensure participation processes that are inclusive, accessible, and supportive of citizens seemed crucial (S48).

Regarding key factors affecting user involvement, several aspects on micro-, meso- and macro-level could be identified. Amongst others, these included professional competencies and supportive leadership, the establishment of a safe and trusting environment that creates an open and valuable atmosphere, but also ensuring early involvement and support in developing skills of members of the public (S47). Moreover, motivation and creating quick and tangible wins were reported as enabling factors for both citizens and organisations.

Diabetes Research

10 review papers on diabetes-related research were analysed (S45, S46, S51, S59, S78-S83), eight of which were rated as “highly relevant” (S45, S46, S51, S78-82). In contrast to diabetes care, some papers described how users had been involved in all stages of the diabetes research (idea, field work, analysis, dissemination) while others addressed community interventions with reference to diabetes and other non-communicable diseases with a focus on minorities. Specific attention was paid to the involvement of users to help increasing participant enrolment in clinical studies (S46). Various arguments to highlight the importance of user involvement were introduced, including a moral obligation and an ethical perspective as individuals should have the right to be involved in research that potentially affects them (S82).

From a methodological perspective, public and patient involvement could result in higher quality research with potentially higher impact (S46). The reviews emphasized promising benefits of user involvement in community and culturally centred intervention approaches, particularly for minority groups (S45, S51, S80). One review concluded that community-based participatory research projects improved community outcomes, but failed to show clear associations with health improvements (S79).

It is important to emphasize that although data demonstrating a benefit of user involvement on clinical research outcomes are not strong, many funding agencies have started requesting clear demonstration of user involvement in the research projects such as in the UK where the National Health Research institute has issued a handbook on Patient and Public involvement in Health and Societal Care Research (www.rds-yh.nihr.ac.uk/wp-content/uploads/2015/01/RDS_PPI-Handbook_2014-v8-FINAL-11.pdf).

Determinants for successful user involvement included a shared understanding of the purpose and process of public and patient involvement among users and researchers. This requires a relationship that is characterized by openness and mutual respect. Moreover, a key person willing to coordinate the whole involvement process as well as users with a strong connection to the study population were identified as success factors. In addition to providing sufficient resources, the study design should meet the requirements of the setting where user involvement takes place (for example, community based participatory research).

Key conclusions across the three areas

Overall, all three areas demonstrated that user involvement is an effective strategy for diabetes care, prevention, and research, given the right support and conditions. This is particularly promising considering that the concepts, methodological approaches, and scope of the reviews differed considerably. However, the literature review also identified a series of gaps and key challenges about the value and impact of user-involvement approaches. A key limitation concerned the insufficient description of the level, nature, and process of user involvement. Most studies were not designed with the purpose of investigating the impact of user involvement, making it difficult to attach an outcome to a specific form and strategy of user involvement or to elaborate on the extent to which components of user involvement (and underlying implementation mechanisms) contributed to the specific outcomes. While in clinical research, randomized controlled trials are often seen as the gold standard to generate high quality evidence, this form of study design is more problematic in non-clinical contexts. For example, it may not be possible to design studies with proper community-based placebo groups and waiting control groups may be unethical due to the long-term duration of interventions. To overcome these problems, researchers and users should consider priorities and study designs together, including the development of shared endpoints. Other limitations include the relatively short duration of most diabetes care studies and the lack of cost-benefit analyses.

A further challenge is the use of different terms, concepts, and forms to describe user involvement (for example, participation, public and patient involvement, co-creation), which restrains comparison across studies and fields of action. One possible way of addressing the multiple methodologies is the use of the GRIPP2 checklist which is an international guide for reporting on patient and public participation in health and social care research (4,5). This tool has the potential to aid the development of user involvement strategies based on the best evidence and to report user involvement in a consistent and transparent manner.

For diabetes prevention, several follow-up questions arose from the factors that hinder or promote user involvement. For instance, a safe environment and professional competencies were identified as important preconditions for genuine and effective user involvement strategies (S47, S48). However, it remains unclear what constitutes a “safe context” and how it can be created for different settings (for example, clinics, schools, communities) or what specific competencies are needed and how a supportive leadership can be developed. Regarding the need for competencies, the development of a curriculum framework represents a gap and so does the need for researchers to be trained in public and patient involvement.

Finally, while numerous studies are analysing patient and public involvement in individual care, there is lack of a knowledge of the feasibility and impact of user involvement at a collective level in diabetes care. More evidence of user-led initiatives such as peer-to-peer support groups or DIY groups is also needed.

Group Concept Mapping

A Group Concept Mapping (GCM) survey, facilitated by the Danish Diabetes Knowledge Center, was conducted to synthesize the knowledge and opinions of international researchers, healthcare professionals, and users (i.e. people with diabetes and their carers). The survey aimed to identify gaps between what is important for user involvement and what is being done in practice. The results then informed discussions about user involvement priorities and recommendations at the CODIAC conference.

GCM is a participatory method to collect, organise and represent ideas from a group through qualitative concept analyses and multivariate statistical analyses (6,7). In brief, the process comprises a brainstorming exercise to generate ideas formulated as short statements about a given topic, which are then structured into thematic groups with each statement being rated on scales (for example, from 0 to 5) by respondents. The statistical analyses then elicit differences and similarities about how respondents view the topic. Like a Delphi process, GCM can create consensus (for example, about research gaps) that can be summarised with statistics in tables and text (8,9). Unlike a standard Delphi process, a GCM exercise also creates a visual concept map reflecting themes in the statement sample that may support deliberation and engagement between stakeholders.

Methods

From June to October 2020, 73 people with diabetes, healthcare professionals and researchers participated in an online brainstorming to identify the important issues for user involvement. 338 suggestions emerged from this exercise, which were synthesised into 81 statements by researchers, information specialists and people with diabetes.

These statements were incorporated into an online survey that asked respondents to rate the importance of each statement (referred to as *importance*) and whether the statement reflected something that was currently happening (referred to as *commonality*). Ratings were on an 11-point scale from 0 ("I don't see a point in that" for importance and "It never happens" for commonality) to 10 ("It is extremely important" and "It always happens"). Thus, participants were asked to rate the 81 statements twice (Appendix 2A). Respondents were also asked to sort the statements into thematic groups which were meaningful to them (Appendix 2B).

The survey was designed, and responses were analysed using GroupWisdom, a software designed to conduct GCM studies (www.groupwisdom.com).

The survey was conducted from September to October 2021. Participants were identified through the networks of those engaged in CODIAC's Scientific Organizing Committee and working groups. They were invited to participate by email which included a web link to the survey. People were encouraged to forward the invitation to anyone interested in user involvement. In total, 237 people participated in at least one part of the GCM with 112 people participating in the rating, which is the prime focus of our analysis.

The cluster map function of GroupWisdom was used to form the thematic clusters of statements based on the data from the sorting exercise. The GoZone function of GroupWisdom was used to identify those statements that could reflect gaps regarding user involvement. For this paper, we only report statements that we consider major gaps for user involvement. We define major gaps as statements with an above-average importance value and a below-average commonality value, with the importance value twice as high as its commonality.

At the CODIAC conference, participants were presented with preliminary results from the GCM survey. This analysis identified statements which were gaps as a whole and gaps stratified by stakeholder group (people with diabetes and their carers, healthcare professionals, and researchers as shown at https://codiac2021.dk/group-concept-mapping).

A complete list of the 81 statements, their average ratings on importance and commonality, and a visual map of the thematic clusters are available in the supplementary information (Appendix 2A/B).

Group Concept Mapping results

Overall, 237 people participated in at least one part of the GCM. 65 identified mainly as people with diabetes, their relatives, and carers; 49 as healthcare professionals; and 48 as researchers; while the rest identified as other or did not answer this question.

The following results are based on responses from 112 people who rated the importance and, among these participants, 79 people who rated the commonality of selected statements. Among those who rated importance, 32 identified as people with diabetes or carers, 26 as healthcare professionals, 36 as researchers, and 18 people who did not identify as any group. Of the participants who rated commonality, 22 identified as people with diabetes or carers, 14 as healthcare professionals, 30 as researchers and 13 who did not identify as any group.

Table 1 lists 11 statements that are considered major gaps. The greatest gap is to involve people with diabetes and other members of the public in health projects from the project beginning until its end (major gap factor = 2.5). This gap is followed by statements that highlight the need to train healthcare professionals and their managers in how to involve users (major gap factor = 2.3); to involve users in developing health information that counters prejudices, stigma and misunderstandings about diabetes and other chronic diseases (major gap factor = 2.2); to dedicate time and financial resources for involvement activities (major gap factor = 2.2); and that results and technologies from projects with user involvement are made available to everyone (major gap factor = 2.2).

There are differences between the three groups of respondents. For example, the importance of involving users from the beginning to the end of health projects was rated higher by researchers (importance = 8.7) than by people with diabetes and their carers (importance = 7.3) and healthcare professionals (importance = 7.2). People with diabetes and their carers also rated the importance of time and funding lower than both healthcare professionals and researchers (importance = 7.0 vs. 8.2 vs. 8.2). Overall, the differences between the respondent groups are minor in the presented data. More information on the findings of the GCM survey is presented in the supplementary information (Appendix 2A/B)

The Consensus Conference October 2021

The consensus conference was a hybrid event with 70 onsite participants in Copenhagen and 30 participants online. The participants included 20 users, 25 healthcare professionals and 45 researchers as well as 10 policy and decision makers. The conference comprised three sections and half a day was allocated to each of these sections:

- SHARING the evidence from the literature reviews and the Group Concept Mapping survey.
- DISCUSSING and qualifying the main gaps in the current literature and practice
- CREATING new evidence aiming to fill the gaps and shortcomings identified.

Based on presentations and discussions of the findings from the literature review and the Group Concept Mapping survey, the conference participants qualified the gaps and identified suggestions for new collaborative initiatives under eight overall themes (Table 2). The listed gaps do not necessarily represent the most important gaps identified by the Group Concept Mapping survey. They rather represent needs and gaps highlighted by conference participants while working in groups to define ideas for future initiatives that would contribute much needed evidence to the field of user involvement. After the conference, the further development of the ideas into concrete projects commenced. These are now at various stages of development (see www.codiac2021.dk/conference-output).

Discussion

The most important overarching conclusion of the CODIAC process is that user involvement is essential, effective, and adds value to diabetes care, prevention, and research, when used under the right circumstances. Involvement can play a major role in ensuring that the experiences of users and their needs are considered in the processes of providing care, preventing diabetes, and conducting research and providing education. Incorporating involvement may lead to more appropriate care, better tailored prevention initiatives and more relevant research.

Each component of the CODIAC process contributed to the findings by exploring the potential and feasibility of integrating involvement in different ways and from different perspectives. Much of the obvious potential related to user-involvement is yet to be realized, as indicated by the gaps between “what is important” and “what is common” identified during the Group Concept Mapping survey.

The findings of the literature review, Group Concept Mapping and conference were coherent, and each built on each other to create the understanding of the importance of user involvement. While the literature review highlighted what is currently known, the Group Concept Mapping identified those areas where there were gaps in practice. The conference then provided an opportunity to discuss these insights to create action plans to improve user involvement in future. Consequently, each component was dependent on its predecessor.

The literature reviews and Group Concept Mapping used existing methodologies and so the novel aspects of CODIAC were to combine these with a new format of conference to develop a pathway to improved user involvement. We are unaware of any previous group that has adopted this approach to bringing researchers, clinicians, and people with diabetes to create a concrete action plan from academic and research-based knowledge. The conference actively involved people with diabetes and their carers in its planning and conduct to create an environment that allowed people with diabetes and their carers, healthcare professionals, researchers and policymakers an equal say.

The discussions were not always easy; even defining user involvement across the topics of diabetes care, diabetes prevention and diabetes research was problematic. However, this ensured a deeper understanding of which elements of involvement were relevant.

A concrete outcome of the CODIAC process was the establishment of new working groups with specific initiatives and research ideas based on each of the CODIAC components. Among these there were new projects as well as enhanced existing projects based on invigorated collaborations. Having identified the gaps in current practice, the working groups are tasked with identifying solutions that are feasible; while these may not be possible in every setting, consideration of how to implement the solutions will be an important component of the tasks of the working groups.

The inclusion of so many different equally important delegates created a sense of genuine participation where all perspectives were encouraged during the conference. This created a sense of equity with meaningful contributions from all without significant power inequalities. This fits well with “authenticity theory” (10), which explains how “authentic” relationships create a sense of genuine caring, with people or professionals possessing important skills or knowledge. Because most participants had a genuine role to play, there was no strict division or hierarchy among conference facilitators and participants. As the processes leading up to the conference and the conference itself relied on mutual involvement, the acceptance of the thematic contents was shared and accepted beforehand, ensuring that the themes presented were accepted as authentic by all attendees. This is important knowledge for anyone planning future user involvement processes.

In conclusion, CODIAC has developed new learning about the way in which academic and research-based knowledge can be transferred to more practice-oriented knowledge and concrete collaborative initiatives. Of the important points pertaining to process, product and outputs that are highlighted in Table 3, the most important outcome may be the process itself and we view this as a potential new framework for future initiatives where a framework in which coherence of process can lead to coherent outputs.

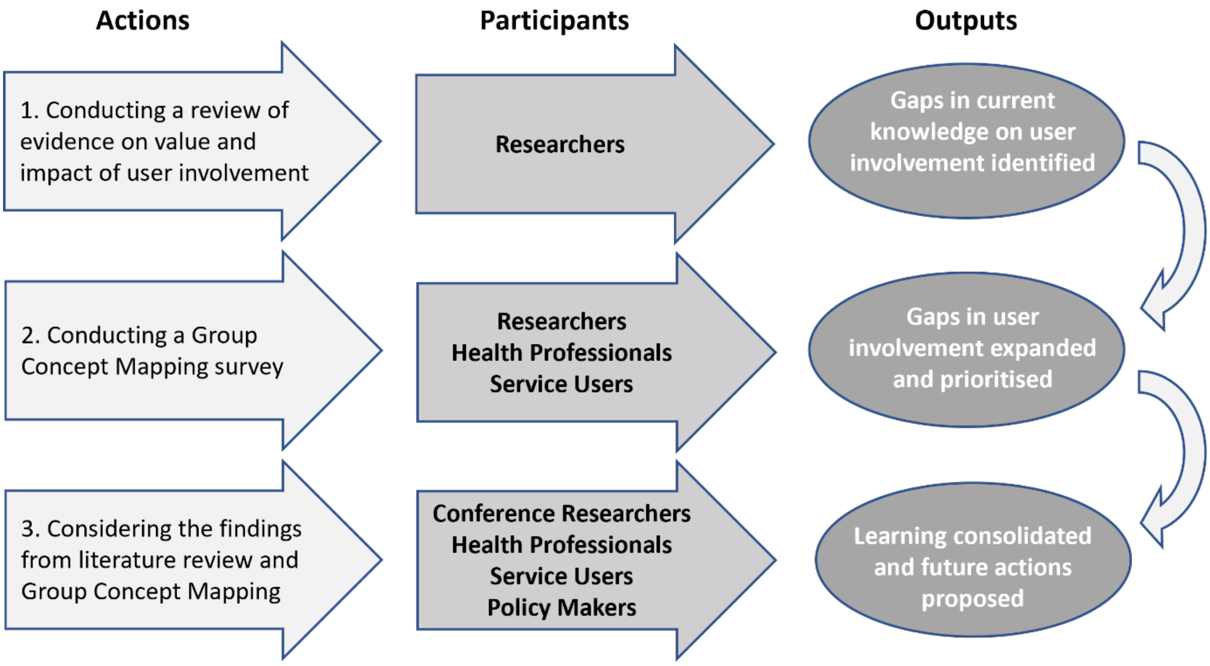

Figure 1. The three phases of the CODIAC process: 1) Summarising the scientific evidence on user involvement in diabetes care, prevention, and research, 2) conducting a Group Concept Mapping survey together with users, healthcare professionals, and researchers, and 3) implementing a conference to discuss and consolidate the findings, while planning for action and further evidence building.

Table 1. Major gaps in user involvement identified through the Group Concept Mapping survey. Data represent the ratio of importance over commonality (importance rating/commonality rating).

Statement: It is important…	Major gap factor ≥2 (importance/commonality)			
	All respondents (n=112/ n=79)	People with diabetes and their carers (n=32/ n=22)	Health care professionals (n=26/ n=14)	Researchers (n=36/ n=30)
… that people with diabetes and other members of the public are involved in health projects from the project begins until it ends	2.5 (8.0/3.2)	(7.3/2.6)	(7.2/2.9)	(8.7/2.9)
… that health professionals and their managers are trained in how to involve people with diabetes and other members of the public	2.3 (8.6/3.7)	(8.2/4.4)	(8.9/2.5)	(8.8/3.5)
… that people with diabetes and other members of the public are involved in developing health information that counters prejudices, stigma and misunderstandings about diabetes and other chronic diseases	2.2 (8.3/3.7)	(8.5/2.9)	(8.0/2.9)	(8.4/4.3)
… that time and funds are dedicated to involvement	2.2 (7.8/3.5)	(7.0/3.8)	(8.2/2.5)	(8.2/3.2)
… that results and technologies from projects that involve people with diabetes and other members of the public are made available to everyone	2.2 (8.4/3.9)	(8.9/3.9)	(8.6/3.8)	(8.3/4.0)
… to pay attention, reach out and respectfully involve people who are marginalized, vulnerable, hard to reach, socially isolated, indigenous, or otherwise excluded or overlooked	2.1 (8.8/4.2)	(8.5/4.2)	(9.3/3.7)	(9.0/4.4)

… to explore if there is an agreement between what is said and what is done when someone claims to involve people with diabetes and other members of the public	2.0 (7.7/3.8)	(7.4/3.8)	(8.1/3.8)	(7.5/3.3)
… that expectations, frameworks, and definitions are discussed and agreed with relevant stakeholders, including people with diabetes and other members of the public	2.0 (7.9/3.9)	(7.5/2.8)	(8.1/4.4)	(8.5/3.9)
… that research literature about patient and public involvement is made freely available to everyone	2.0 (7.6/3.8)	(7.7/3.8)	(8.2/2.7)	(7.0/4.2)
… that the European Association for the Study of Diabetes (EASD) involves people with diabetes and members of the public in its work	2.0 (8.0/4.0)	(8.1/3.9)	(7.9/2.7)	(8.0/4.6)
… that the most important wishes, needs, and ideas of people with diabetes and other members of the public involved are the starting point for diabetes prevention, care, and research	2.0 (8.0/4.0)	(7.9/4.5)	(7.2/4.0)	(8.8/3.7)

Table 2. Main gaps and needs for user involvement (in bullets) and eight suggestions for new collaborative initiatives (in titles) identified at the CODIAC conference.

1. **The family (including children and adolescents) as a setting for mutual and positive involvement**
    - Lack of knowledge of how best to involve families of people with diabetes in user involvement across the life course for children and young adults

2. **The clinic as a setting for mutual learning and positive involvement**
    - Lack of feeling of safe space in clinical consultations
    - System incentives to engage in user involvement
    - What do users want to be involved in and are there any limitations?

3. **Clinical research: the value and impact of the involvement of users**
    - How to get started
    - Proving the impact
    - Results and technologies from projects involving people with diabetes and other members of the public are rarely made available to anyone

4. **The language and the concepts: How do we put involvement into words, so it fits with the 'real world'? Do we need a shared language?**
    - Mostly professionals or researchers define the problems and where to involve users and not the users themselves
    - The biomedical focus in language and communication

5. **The voice and the impact of the users: Can users increase their impact as a movement instead of an association?**
    - Decision makers and citizens' knowledge and views on diabetes are outdated

6. **The local community as a setting for synergy and positive involvement**
    - Integrated action against multimorbidity across sectors, disciplines, and population groups in disadvantaged urban neighbourhoods

7. **Technology and social media: Potential or barrier for positive involvement?**
    - There is a need to activate more PWD in user-involvement where social media remains an arena for recruitment

8. **Vulnerable groups as powerful users: the need for a culturally embedded approach**
    - There is a need for collecting examples of good practice on how to include vulnerable groups as users. The collection should ideally be followed by an overview and dissemination in a publication
    - There is a need for recognizing that vulnerability is not an individual but a societal responsibility. This should, for example, be adapted into the planning of health care services
    - There is a need for concrete projects to show case how to empower staff and vulnerable people

Table 3. Process, product, and potential outputs of the CODIAC initiative**.**

Process	Product	Potential outputs
Identify key people with research expertise, clinical/professional experience, and experiential knowledge	Form a core planning group of researchers, health professionals and service users	A multidisciplinary network for future initiatives
Investigate what is already known Identify knowledge gaps from the literature	Organise and summarise to enable review of the gaps	A literatur review that can be widely disseminated to inform future research and practice
Use the core planning group to create a list of potential conference participants, drawing upon existing relationships and networks across research, health care and service users	Involve people in prioritising the user involvement gaps Compile a list of potential gaps reflecting participant views of what is important	A list of gaps in user involvement to inform future activities and policy making
Involve participants in reviewing the gaps, discussing the challenges, and considering what could be done to address them	Produce a description of new projects and/or expansion of exisitng initiatives to address the gaps	New or expanded working groups

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Appendix 2A. The 81 statements in the Group Concept Mapping about what is important for user involvement.

The average importance value across all statements is 7.6, with the average commonality value being 4.4. Below are five tables. One for each thematic cluster (see the thematic cluster map below). In each table, statements considered major gaps are highlighted in a light blue colour. Note, statements were originally formulated as questions but have been slightly revised into statements in the white paper.

Cluster theme: Focus on user(s)				
No.	**Statements: How important/common is it…**	**Mean *importance* of statement (n=112)**	**Mean *commonality* of statement (n=79)**	**Gap factor**
6	… that perspectives of people affected by diabetes are used to embrace the complexity of the disease?	8.3	4.9	1.7
10	… to explore the priorities of different interest groups? People with type 1-diabetes, type 2-diabetes, and funders may, for example, have different priorities.	7.9	5.1	1.5
20	… that involvement is used to make health projects and treatments more culturally acceptable and valued by people with diabetes and other members of the public?	7.7	4.7	1.6
21	… to be flexible and use a diversity of strategies tailored to the expectations and needs of those involved? One size does not fit all.	8.6	4.8	1.8
25	… that you pay attention to your own role, power, expertise and where it ends?	8.1	6.0	1.3
27	... to talk about 'health professional involvement' or 'researcher involvement' in people's lives? Terms like 'user involvement' or 'patient involvement' reflect the perspective of health professionals and researchers rather than the people it is all about.	5.5	2.7	2.0
31	… that people with diabetes and members of the public personally experience that their involvement is effective and valuable?	8.5	5.5	1.6
32	… that people with diabetes and other chronic diseases are considered experts?	7.5	4.4	1.7
35	… that health professionals and people with diabetes attend the same educational courses for a reasonable participation fee?	5.1	2.1	2.4
37	… that all parties act with mutual respect?	9.3	6.3	1.5

38	… that involving people with diabetes and other members of the public is treated as something valuable in itself?	8.0	4.8	1.7
39	… that both adults and children have opportunities to discuss, set goals and make decisions about their health and medical treatments?	8.8	4.7	1.9
40	… that people with diabetes and other members of the public support each other. exchange experiences and share knowledge when meeting in person and through social media?	7.8	5.8	1.3
45	… that people with diabetes can comment on health professionals in their patient health record? Like health professionals write about the person in their patient record.	4.8	1.3	3.6
51	… to pay attention, reach out and respectfully involve people who are marginalised, vulnerable, hard to reach, socially isolated, indigenous, or otherwise excluded or overlooked?	8.8	4.2	2.1
57	… that health professionals and their managers are trained in how to involve people with diabetes and other members of the public?	8.6	3.7	2.3
59	… that health professionals and researchers genuinely listen to those involved and are willing to make changes?	9.2	5.3	1.7
63	… that the people with diabetes and members of the public involved feel valued as individuals with resources, needs, demands, and rights to manage their own lives?	8.8	5.5	1.6
64	… to spend time developing trustful partnerships between people with diabetes. members of the public, health professionals and researchers?	8.2	4.4	1.9
72	… that inclusion and diversity are encouraged and ensured?	8.4	4.8	1.8

Cluster theme: Ways to involve				
No.	**Statements: How important/common is it…**	**Average rating**	**Average rating**	**Gap factor**
3	… that people with diabetes and other members of the public decide what should be researched in the future?	6.5	2.6	2.5
5	… to hire people with diabetes or their relatives as specialists with an office in diabetes clinics?	5.1	1.7	3.0
7	… that people with diabetes or other members of the public participate in health conferences?	7.1	3.9	1.8

14	… that the European Association for the Study of Diabetes (EASD) involves people with diabetes and members of the public in its work?	8.0	4.0	2.0
15	… that the entirety of local communities is involved, including people with (or at risk of) diabetes, their families, other residents, community-based organizations, and informal social networks?	6.9	3.2	2.2
16	… that people with diabetes and other members of the public are involved in developing health information that counters prejudices, stigma and misunderstandings about diabetes and other chronic diseases?	8.3	3.7	2.2
17	… that people with diabetes or other members of the public involved are elected through transparent and democratic procedures? As in elections for a school board, for example.	5.8	3.0	1.9
42	… that people with diabetes or other members of the public are involved in decision-making bodies that develop treatment guidelines for diabetes and related diseases?	7.5	3.5	2.2
43	… that people with diabetes are central in changes and new initiatives that impact their lives? For example, video consultations implemented because of COVID-19.	8.1	4.5	1.8
48	… that people with diabetes or other members of the public help make health information easily understandable?	8.3	4.5	1.9
49	… that people with diabetes and other members of the public are treated as having a fundamental and democratic right to be involved?	8.2	4.4	1.9
50	… that people with diabetes and other members of the public are involved in health projects from the project begins until it ends?	8.0	3.2	2.5
56	… that parents and caregivers are involved in projects and activities that aim to increase healthy eating and physical activity among children?	8.2	5.1	1.6
65	… to have formal service user councils in hospitals and diabetes clinics that discuss questions and ideas from people with diabetes or other health service users?	7.6	4.2	1.8
71	… that people with diabetes or other members of the public are involved in hiring health personnel, for example, by defining criteria for the ideal candidate, selecting interview candidates, and participating in the job interviews?	5.1	2.2	2.3

81	… that the most important wishes, needs, and ideas of people with diabetes and other members of the public involved are the starting point for diabetes prevention, care, and research?	8.0	4.1	2.0

Cluster theme: Best practices and conditions

#	**Statements: How important/common is it…**	**Average rating**	**Average rating**	**Gap factor**
19	… to acknowledge that it takes more than a questionnaire to do and understand true involvement?	8.7	4.9	1.8
28	… that the approach is systematic and structured?	7.8	4.6	1.7
33	… to investigate what supports (facilitators) and inhibits (barriers) the involved parties in involvement, shared decision-making, and joint learning?	8.1	4.2	1.9
44	… to have leaders, managers and politicians that support the involvement of people with diabetes and other members of the public?	8.4	4.4	1.9
52	… that expectations, frameworks, and definitions are discussed and agreed with relevant stakeholders, including people with diabetes and other members of the public?	7.9	3.9	2.0
54	… that time and funds are dedicated to involvement?	7.8	3.5	2.2
55	… to follow-up and tell those involved to what extend their contributions made a difference?	8.0	4.5	1.8
58	… that people with diabetes and other members of the public who contribute as user-experts are compensated or paid for their time and contributions?	5.9	3.3	1.8
60	… to do it in a way that makes people want to stay engaged and return to participate again another time?	8.1	5.2	1.6
62	… to apply a whole system approach in which multiple stakeholders, including people with diabetes and organizations, are involved in creating an overall and broad picture of the issue they are collaborating around?	7.5	3.8	2.0
70	… that the health care systems, health professionals, researchers and those involved create shared success criteria?	7.6	3.9	1.9
74	… that involvement is implemented and further developed according to established guidelines and conceptual frameworks?	7.5	4.9	1.5

76	… that ethical issues and legal rights are explicitly addressed?	7.9	5.0	1.6
77	… to explore if there is an agreement between what is said and what is done when someone claims to involve people with diabetes and other members of the public?	7.7	3.8	2.0
78	… that the involved people with diabetes and other members of the public represent a variety of backgrounds across age, gender, ethnicity, cultural affiliation, social and economic status?	8.6	4.7	1.8
79	… to have explicit visions, purpose, and ambitions for the involvement?	8.1	4.9	1.7

Cluster theme: Outcomes and documentation				
No.	**Statements: How important/common is it…**	**Average rating**	**Average rating**	**Gap factor**
9	… to distinguish between the value for people directly involved in research and the value for people who are meant to benefit from the results afterwards?	7.2	4.6	1.6
22	… that the effect of involvement is tested through randomized controlled trials?	5.9	2.9	2.0
23	… to measure treatment satisfaction and quality of life when assessing the value of involvement?	7.9	4.7	1.7
24	… that it helps save money?	5.0	4.3	1.2
26	… that it gives insights into our biases and blind spots?	8.0	5.0	1.6
30	… that it has an impact?	8.3	5.6	1.5
34	… to document how people with diabetes and other members of the public are involved?	7.7	4.1	1.9
46	… to use qualitative methods (for example, interviews and focus groups) to grasp the complexity of the “real” world?	8.1	5.4	1.5
47	… to know which research methodologies are suited for involving them? For example, action research.	7.2	4.3	1.7
73	… that patient reported outcomes (PRO) are collected from people with diabetes via questionnaires about their health and quality of life to systematically improve their consultations with health professionals?	7.8	4.7	1.7
75	… that there is clear scientific evidence of whether and how the involvement made a difference and had an impact?	7.1	3.5	2.1

80	… that results and technologies from projects that involve people with diabetes and other members of the public are made available to everyone?	8.4	3.9	2.2

Cluster theme: Health care

No.	Statements: How important/common is it…	Average rating	Average rating	Gap factor
1	… that health professionals "get a dose of their own medicine" by trying the tools and devices and follow the treatment plans that people with diabetes live with every day, 24/7?	5.5	2.4	2.3
2	… that research literature about patient and public involvement is made freely available to everyone?	7.6	3.8	2.0
4	… to be conscious about the specific life situations of those involved? For example, if they are teenagers or pregnant.	8.9	6.5	1.4
8	… that health professionals say the same when explaining what it entails to involve people with diabetes and other members of the public?	6.7	4.3	1.6
11	… that psychological and social aspects are addressed?	8.6	5.2	1.6
12	… that health professionals support and guide those involved?	7.8	6.5	1.2
13	… that relevant information is transparent and accessible?	9.0	5.0	1.8
18	… that the people involved, health professionals, and researchers know each other well? It means a lot to meet the same persons again.	6.8	5.0	1.4
29	… to focus on how new technology impacts the short time people with diabetes and health professionals have at their disposal?	6.7	4.6	1.4
36	… that health professionals personally experience that involvement is effective and valuable?	8.2	5.1	1.6
41	… that health professionals step in to take the lead at the right moments?	7.3	6.3	1.2
53	… to avoid calling people with diabetes for "patients"?	5.7	3.5	1.7
61	… to avoid calling people with diabetes for "diabetics"?	6.4	4.4	1.4
66	… that health care systems can manage people with more than one diagnosis and complications?	9.0	5.2	1.7
67	… to measure blood sugar and other biological outcomes when assessing the value of involvement?	4.7	4.6	1.0

68	… to detect prediabetes and support the prevention of diabetes?	8.0	4.7	1.7
69	… that health professionals and researchers are conscious about their language, communication style and how they listen to people with diabetes or other members of the public?	9.0	5.2	1.7

Appendix 2B. Thematic cluster map on what is important for user involvement.

Below is a map that visualises the data from 55 respondents who completed the sorting exercise. Each numbered point represents one of the 81 statements from the GCM survey. The statement for each number can be found in the tables above. In brief, the map illustrates how statements relate when the GroupWisdom software is used to create five themes based on how each of the 55 respondents sorted the 81 statements. The more often respondents have placed a statement in a pile with another statement, the closer the two points of the given statements are to each other on the map. Thus, based on statistics, it may be inferred that the two statements reflect a similar theme in the aggregated view of the respondents.

For example, statement 22 (about the importance of testing the effect of involvement through randomized controlled trials) and statement 75 (about the importance of getting clear scientific evidence of whether and how the involvement made a difference and had an impact) are very close to each other and seem to reflect a common theme (i.e. the yellow area of grouped statements that we have called Outcomes and documentation). Comparatively, statement number 5 (about the importance of hiring people with diabetes or their relatives as specialists with an office in diabetes clinics) is placed on the opposite side of the cluster map meaning it has rarely, if ever, been piled together with statement 22 and 75 by survey respondents.