Highlights from the Group Concept Mapping of what is important for user involvement

Introduction

To stimulate discussions on the gaps in user involvement knowledge and practice, we conducted a collaborative mapping process in 2020-21. In short, it consisted of:

- **An online brainstorm** about what is important for user involvement. Here, 73 contributors consisting of users (i.e. people with diabetes, their relatives and carers), health professionals, researchers and others contributed with 338 suggestions about what is important for user involvement in diabetes prevention, care and research.
- **A synthesis process** where researchers, users and information specialists collaborated about synthesising the 338 suggestions into 81 statements.
- **A questionnaire asking informants to rate** the 81 statements according to how important they think each statement is (0 = I don't see a point in that; 10 = It is extremely important) and how common it seems to be (0 = It never happens; 10 = It always happens). The statements were rated in importance by 112 people, in how common they are by 77, and sorted by 57.
- **A sorting activity** where informants were asked to categorise the 81 statements into themes.

This survey is based on the Group Concept Mapping (GCM) method. GCM is a participatory and mixed methods approach that captures and organises a group's ideas, opinions, beliefs, and values on any topic through rigorous analytics. You can read more at codiac2021.dk/gcm

Potential gaps in user involvement knowledge and practice

Our hope is to inspire the discussions of gaps in knowledge and practice concerning user involvement. The results below highlight statements that reflect what is both most important and most uncommon.
The main results are provided in the three tables below. Each table represents the responses from one responder group: users, healthcare professionals and researchers, respectively.

- The rating questions are stated in the table header. Each statement in the table is a continuation of the question in the table header.
- Green statements reflect gaps shared by all three responder groups.
- Yellow statements reflect gaps shared by two responder groups. Look at the page title and the right column to see who shares a given yellow-marked gap.
- White statements are unique gaps according to the responses from each group.
- The left column titled with a # indicates the statement number. This will be useful to have when Lauge Neimann Rasmussen elaborates on the results in session 2.
- The mean importance value within each group is also presented in each table.

You might consider

- What characterises the unique and shared gaps of the groups?
- Are the gaps relevant to your thematic group (cf. the group work in session 2)? If so, how?
- Should any of the gaps be priorities for future user involvement activities? If so, which and how?

Please note

Although some statements are listed as gaps only for some responder groups, it does not mean that they are unimportant to the other groups. For example, it might reflect that other groups consider them relatively common. Technically, the listed statements are those statements that are rated as above-average important and below-average common within each responder group.

For questions and comments, you are welcome to contact Lauge Neimann Rasmussen at lauge.neimann.rasmussen@regionh.dk

Users' identified gaps?

#	When involving people with diabetes or other members of the public in diabetes prevention, care or research, how important/common is it…	Mean importance	Shared by
44	… to have leaders, managers and politicians that support the involvement of people with diabetes and other members of the public?	8,0	All
80	… that results and technologies from projects involving people with diabetes and other members of the public are made available to everyone, not only those involved?	8,8	All
2	… that research literature about patient and public involvement is available without anyone having to pay for it?	7,8	Health professionals
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?	8,6	Health professionals
48	… that people with diabetes or other members of the public help make health information easily understandable?	7,8	Health professionals
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?	8,3	Health professionals
14	… that the European Association for the Study of Diabetes (EASD) involves people with diabetes and members of the public in its work?	8,3	Researchers
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	Researchers
50	… that people with diabetes and other members of the public are involved in health projects from the beginning, when objectives and questions are formed, until the end of the project?	7,5	Researchers
52	… that expectations, roles, responsibilities, frameworks and definitions are discussed and agreed with relevant stakeholders, including people with diabetes and other members of the public?	7,6	Researchers
7	… that people with diabetes or other members of the public participate in health conferences?	7,7	
23	… to measure treatment satisfaction and quality of life when assessing the value of involvement?	8,1	
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?	7,5	
68	… to detect prediabetes and support the prevention of diabetes?	8,0	
72	… that inclusion and diversity are encouraged and ensured?	7,9	
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?	8,0	

Health professionals' identified gaps?

#	When involving people with diabetes or other members of the public in diabetes prevention, care or research, how important/common is it…	Mean importance	Shared by
44	… to have leaders, managers and politicians that support the involvement of people with diabetes and other members of the public?	8,4	All
80	… that results and technologies from projects involving people with diabetes and other members of the public are made available to everyone, not only those involved?	8,6	All
2	… that research literature about patient and public involvement is available without anyone having to pay for it?	8,0	Users
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?	8,0	Users
48	… that people with diabetes or other members of the public help make health information easily understandable?	8,5	Users
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?	9,1	Users
34	… to document how people with diabetes and other members of the public are involved?	8,0	Researchers
49	… that people with diabetes and other members of the public are treated as having a fundamental and democratic right to be involved?	8,8	Researchers
54	… that time and funds are dedicated to discuss how to improve involvement and act on it together?	8,1	Researchers
57	… that health professionals and their managers are trained in how to involve people with diabetes and other members of the public?	8,8	Researchers
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?	8,0	
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?	7,8	
38	… that involving people with diabetes and other members of the public is treated as something valuable in itself?	8,2	
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.	8,6	
47	… to know which research methodologies are suited for involving them? For example, action research.	8,0	
70	… that the health care systems, health professionals, researchers and those involved create shared success criteria?	8,3	
75	… that there is clear scientific evidence of whether and how the involvement made a difference and had an impact?	7,8	
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?	8,1	
79	… to have explicit visions, purpose and ambitions for the involvement?	8,5	

Researchers' identified gaps?

#	When involving people with diabetes or other members of the public in diabetes prevention, care or research, how important/common is it…	Mean importance	Shared by
44	… to have leaders, managers and politicians that support the involvement of people with diabetes and other members of the public?	8,4	All
80	… that results and technologies from projects involving people with diabetes and other members of the public are made available to everyone, not only those involved?	8,6	All
14	… that the European Association for the Study of Diabetes (EASD) involves people with diabetes and members of the public in its work?	7,8	Users
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?	7,8	Users
52	… that expectations, roles, responsibilities, frameworks and definitions are discussed and agreed with relevant stakeholders, including people with diabetes and other members of the public?	8,1	Users
50	… that people with diabetes and other members of the public are involved in health projects from the beginning, when objectives and questions are formed, until the end of the project?	8,3	Users
34	… to document how people with diabetes and other members of the public are involved?	7,6	Health professionals
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	Health professionals
54	… that time and funds are dedicated to discussing how to improve involvement and act on it together?	8,2	Health professionals
57	… that health professionals and their managers are trained in how to involve people with diabetes and other members of the public?	8,7	Health professionals
28	… that the approach is systematic and structured?	7,6	
32	… that people with diabetes and other chronic diseases are considered experts?	7,7	
33	… to investigate what supports (facilitators) and inhibits (barriers) the involved parties in involvement, shared decision-making and joint learning?	8,7	
39	… that both adults and children have opportunities to discuss, set goals and make decisions about their health and medical treatments?	8,7	
55	… to follow-up and tell those involved to what extend their contributions made a difference?	8,2	
64	… to spend time developing trustful partnerships between people with diabetes, members of the public, health professionals and researchers?	8,5	
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?	8,5	