

## Highlights from the literature from the Care Panel Group

### Introduction

We reviewed the research literature (reviews) analysing public and patient involvement (PPI) in diabetes care. We identified in the literature a base of 42 relevant papers, among which 14 were considered *highly relevant*. With few exceptions all reviews regarded PPI in (own) individual care and encompass evaluations of a range of interventions with the purpose of improving diabetes self-management and HbA1c among people with diabetes, primarily type 2 diabetes (T2D). The interventions evaluate several different methodologies to increase the involvement of the person with diabetes in own care. One review involved users (a patient advisory group) in the design of the review paper (Coulter et al 2015). The patient advisory group advised on various aspects of the review (protocol, outcome measures and emerging findings). None of the identified literature addressed PPI in the planning, design and development of concepts and models for education and diabetes care practice. One paper dealt with collective PPI (Bancos et al 2012) by investigation user involvement in the development of clinical practice guidelines

### Main conclusions on the impact of PPI

In diabetes care PPI is mainly identified at consultant or collaborative level, and almost exclusively in relation to involving users in their self-care. A frequently reported approach is shared-decision-making (SDM) with the use of decision aids. Regarding impact, the literature suggests SDM to be largely successful in achieving the treatment goals, moreover SDM also has the potential to be implemented at relatively low costs without increasing the overall time spent during the consultation. Another frequently used impact measure is the improvement of patients' resources to improve ability to take active part in their own care, e.g., by aiming to increase the empowerment skills of the individual. Collective PPI was rarely investigated in the reviews. A review studying clinical guidelines concluded that end-users were rarely present in the development of guidelines, and thus the impact cannot be assessed. Likewise, user-led interventions were not present in the identified review literature although user-led initiatives, such as peer-to-peer support groups and user-driven insulin delivery closed-loop (DIY) groups are well-known.

Education has been successful in improving outcomes such as knowledge, psychological well-being and short-term behavior changes. Studies aiming to improve cardio-metabolic risk markers, particularly glycemic control are also frequently reported in literature and have also shown some success. However, long-term improvements in diet and exercise have been difficult to show. Identification of long-term outcomes often suffer from insufficient follow-up in primary studies.

### Key factors, enabling or hindering user involvement

Overall, main barriers to successful PPI interventions reported across the literature is insufficient training of health care professionals, time constraints and lack of health care professional resources allocated to the interventions. Among people with diabetes an identified barrier was a preference for passivity because some users believe that they should rely fully on the expertise of the clinician for the best choices.

Among the many interventions that include new technology, a frequently mentioned barrier is lack of technical skills among some users, where the elderly as a group are mentioned repeatedly across the study reports.

Barriers regarding study designs mainly consist of short follow-up in the primary studies and relatively short duration of the interventions. Insufficient descriptions of intervention components in primary papers are also an obstacle in identifying specific and effective mechanisms and settings across studies, which are necessary

for successful PPI in diabetes care. Thus, we have been unable to describe in detail what characterizes successful PPI from less successful one.

### **Key questions, gaps and challenges**

There is a growing body of literature on PPI in own care. A main limitation across the existing reporting is, that the impact of studies with a user involving component have been not tested in a sufficiently extensive manner to generate reviews that can identify solid evidence for this impact. Thus, we know that some interventions with user involving components have been successful, but not to what extent the user involving component has contributed to the specific outcomes.

Compared to the literature on PPI in own care, there is a huge lack of evidence for the impact of collective PPI and user led initiatives or interventions. More knowledge is needed to understand the feasibility and impact of collaboration with users at collective level in diabetes care. Moreover, more systematically gathered evidence of user led initiatives is also needed.

In conclusion there is a plentiful amount of studies analyzing PPI in individual care. However, studies of higher quality, including sufficiently detailed reporting of the applied PPI and analyses of the mechanisms involved regarding positive outcomes, are needed to advance the field. Moreover, studies on collective PPI are lacking and this field needs further exploration to identify potentially positive effects of PPI in diabetes care.

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