# Highlights from the literature on user involvement in diabetes prevention

## Introduction

We reviewed the impact of user involvement on the prevention of diabetes. The review included scientific literature relating to primary and secondary prevention. This implies that emphasis was on measures to maintain healthy living and minimise the risk of contracting type 2 diabetes among citizens. The review disclosed 35 relevant review papers of which 11 were considered *highly relevant*. The most relevant papers were those that most explicitly described the relationship between the nature, outcomes and determinants (i.e. facilitators and barriers) of user involvement. Some of these papers explicitly addressed type 2 diabetes while others addressed preventable health conditions more generally or community development more widely. This wide scope of the papers is consistent with the universal concord that *the prerequisites and prospects for health cannot be ensured by the health sector alone ...health promotion demands coordinated action by all concerned* (WHO, Ottawa Charter, 1986). Thematically, the reviewed papers were divided into three categories based on their reference to **1) person-centred interventions** such as peer support and motivational interviewing, **2) single-setting interventions** such as virtual-world setting (e.g. games for health) or real-world settings (school-based health promotion), or **3) multi-setting interventions** such as community engagement and collective action.

## Main conclusions on the impact of user involvement

It is evident from the reviewed literature that citizen involvement may have positive effects on interventions to prevent type 2 diabetes. Various kinds of involvement were described pertaining to one or more phases of intervention development, e.g. context analysis, needs assessment, ideation, design, planning, implementation and evaluation. Citizens were involved in **consultations** with professionals where they represented the target group and provided targeted inputs through meetings, interviews, workshops or panels but where they had limited influence on subsequent decision-making. Citizens were also involved as **collaborators** where they contributed to intervention development and implementation and took part in consensus-based decision-making together with professionals. Finally, citizens were **driving** intervention processes collectively and invited professionals to contribute only when assistance was required. A wide spectrum of effects of citizen involvement were described. Some of these were short-term and output-related (e.g. knowledge acquisition) while others were long-term and outcome-related (e.g. reducing crime rates); some were structural (e.g. establishing income-generating activities) while others were behavioural (e.g. high rates of participation); some were health-specific (e.g. improved access to care or lowered BMI) while others were social (e.g. fostered a sense of identity and community) or environmental (e.g. increased availability of healthy food outlets); some were positive (e.g. improved collaboration) while others were negative (e.g. intensified conflicts of interests). Although user involvement generally demonstrates an impact in diabetes prevention, it is often difficult to refer this impact to a concrete or specific form of user involvement (e.g. consultant, collaborator, driver), which makes it difficult to learn from. This is partly due to the design of the studies (often not designed with the purpose of investigating the effect/impact of various forms of user involvement) and partly due to that we miss a (shared) language of user involvement with "grasps" real life situations.

Within the area of **person-centred interventions** especially peer-support strategies seem to be more effective among 'hardly reached' compared to other groups indicating that user involvement might contribute to reducing inequality in health. Within the area of **single-setting interventions** the results were mixed with active forms of user involvement (participatory design) showing lower game for health effectiveness for behaviour, while participation in school-based health promotion was associated with a wide range of personal, organizational or social effects. Finally, within the area of **multi-setting interventions** the literature emphasises the importance of power imbalances and organisations' (lack of) willingness to address such imbalances. The literature suggests that meaningful participation of citizens can only be achieved if organisational processes are adapted to ensure that they are inclusive, accessible, and supportive of citizens.

**Key factors, enabling or hindering user involvement**

Numerous micro-, meso- and macro-level factors influencing the outcomes of citizen involvement were described. The most pronounced categories were: Network structure; organizational capacity; support of government; support of non-profit sector; management and leadership; democratic structure; strategies of initiatives; pre-existing conditions and motivation. More concrete factors included: Ensuring staff provide supportive and facilitative leadership (including professional competences) to citizens based on transparency; creating a safe and trusting environment enabling citizens to provide inputs that are considered valuable and are taken serious; ensuring citizens' early involvement; sharing decision-making and governance control with citizens; acknowledging and addressing citizens' experiences of power imbalances between citizens and professionals; investing in citizens who feel they lack the skills and confidence to engage; creating quick and tangible wins; talking into account both citizens' and organisations' motivations.

**Key questions, gaps and challenges**

While many questions, gaps and challenges of practice and knowledge remain unanswered, one overarching question must be addressed in order to realize the full potential of citizen involvement for prevention: *How do we reach consensus among citizens, practitioners, politicians and researchers on standards and priorities of implementation and evaluation of preventive interventions that cut across sectors, professions and scientific traditions for achieving and documenting sustainable outcomes in the complex context of everyday life?* More specifically, the following questions are important to address:

- Structuring a safe context seems to be an important precondition for genuine and effective user involvement strategies in diabetes prevention. But what exactly makes up a "safe context" in places like schools, clinics and the community setting and how do we build it?
- Professional competences seem to be crucial for involving citizens in genuine and effective ways. But what exactly do these competences include and how do we develop them?
- Some user-involvement strategies seem to be beneficial for the "hardly reached" citizens. But how do we generally make sure that all groups of citizens benefit from user involvement strategies and that no one is "left behind" or marginalised?

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