di·a·be·tes lit·er·a·cy

SEVENTH FRAMEWORK PROGRAMME

Public Summary

Diabetes Literacy
Interim Report
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Project no: 306186
Project Acronym: Diabetes Literacy
Project Full Name: Enhancing the (cost-) effectiveness of diabetes self-management education: A comparative assessment of different educational approaches and conditions for successful implementation

Description of project context and objectives

Diabetes mellitus is the fourth largest cause of death in the European Union. Approximately 32 million people in the EU live with Type Diabetes (T2D), many of whom are unaware of their condition. Diabetes care takes up a significant amount of the health costs. T2D is strongly associated with being overweight and obese, the prevalence of which is rapidly increasing. In conjunction with the demographic evolution towards an ageing population and changing food environments, the prevalence of T2D is set to increase. In view of these developments the capacities of the health systems in the EU Member States with regard to treatment and care must be strengthened. One of the critical success factors to address diabetes is the investment in the self-management capacity of patients. However several questions must be addressed before large scale implementation. Firstly, while DSME for people with diabetes has been shown to have positive outcomes, the cost-effectiveness of these interventions is not sufficiently substantiated. Secondly, while the effectiveness of DSME education could be enhanced by methods using information technology, the relative effectiveness of these approaches has not been well researched. Thirdly, the success of a diabetes education program depends on the quality of its implementation, which in the case of diabetes self-management has hardly been researched at all. Fourthly, the effectiveness of DSME also depends on various patient characteristics. Apart from age, sex and ethnicity, the level of health literacy plays a key role. However, while low literacy is likely to impede self-management, its moderating role in improving self-management behaviours in persons with diabetes has not yet been systematically investigated. Finally, the (cost-) effectiveness of DSME also depends on the organization of the health services.

The goal of the Diabetes Literacy project is to provide evidence to increase the effectiveness of diabetes self-management education in the EU. The outcomes will inform policy decisions on improving the care for the growing number of people with diabetes. The specific objectives of the project are to (1) perform a comparative analysis of national diabetes strategies across the EU MS and non-EU nations; (2) compile a compendium of DSME programs in the EU MS; (3) document the existing costing practices for T2D at the national level; (4) develop an appropriate patient level costing methodology for T2D and estimate the comparative cost of T2D education per patient; (5) compare the relative effectiveness and cost-effectiveness of existing individual, group, IT based DSME and self- help programs; (6) assess the moderating impact of low health literacy on the effectiveness of DSME programs, differentiating between individual, group, IT based and self-help programs; (7) assess the role of multidisciplinary competent professionals, patient follow-up systems, and evaluation of services as conditions for DSME effectiveness; (8) assess the role of

implementation fidelity for the effectiveness of DSME programs; (9) determine whether interactive and audio-visual features of internet delivery-based DSME education materials can improve engagement and health literacy; and (10) make recommendations for the development of best practice models for DSME as part of a comprehensive diabetes strategy at EU level.

The Consortium responsible for the Diabetes Literacy project consists of partners from six EU Member States (Austria, Belgium, Germany, Ireland, the Netherlands and the UK), as well as Israel, the US and Taiwan. The project, which runs from November 2012 through November 2015, is organized in nine work packages (WPs). Two work packages deal with the management of the project: WP1 for overall management and WP2 for evaluation. Six work packages deal with the content: WP3 focuses on the analysis of national diabetes strategies and programs, WP4 evaluates the costs of diabetes education, WP5 compares the (cost-)effectiveness of different forms of diabetes self-management education, WP6 considers the organizational conditions for program effectiveness and the impact of health literacy, WP7 explores the role of implementation fidelity of diabetes self-management programs, and WP8 pilots literacy-appropriate self-management materials. WP9 focuses on the dissemination of the results and on policy recommendations. While each work package is led by one of the partners, all partners contribute to the activities of all work packages. As approximately 40 to 50% of the research activities in the work packages will be performed by all partners, collaboration is a prerequisite for the successful implementation of the project.

Description of work performed and main results

In the first 18 Months of the Diabetes Literacy project, a strong organizational and scientific basis was laid to reach the goals and objectives of the project.

In terms of the organization of the work, the work undertaken in WP1 ensured an agreement on the procedures for project management and communication within the Consortium, and guidelines were developed to guarantee a smooth and effective implementation of these procedures. A Steering Committee was set up to oversee the work, as well as a Scientific Advisory Board with independent experts from selected fields. The Consortium met four times in two-day Consortium meetings. Via an amendment of the Grant Agreement, Taipei Medical University (TMU) from Taiwan joined the Consortium as a ninth partner. In addition, two collaborating partners joined the Consortium: the University of Pretoria (UP) from South Africa, and Aarhus University (AU) from

Denmark. In terms of the scientific basis, systematic literature reviews were carried out for WP4, WP5, WP6 and WP7; tools and instruments were developed for the different work packages; and common research protocols were developed. Ethical approval was requested for the work in WP3 through WP8 in preparation of the data collection. In WP2, an evaluation plan was developed to monitor the quality of the project implementation and its outputs and outcomes, and an internal interim evaluation report was drafted providing a self-evaluation and suggestions for taking action.

In WP3, the Diabetes Literacy Survey was used to collect information on the policies and existing programs for diabetes self-management education in the EU. In WP4, a literature review was performed on activity based costing, and cost practices across the health systems of the participating countries were documented. As a result, a patient level costing method for T2D was proposed, and a protocol was drafted to study the costing component of interventions in the pre-post evaluation study of the effectiveness of DSME programs. In WP5, a review was made of the literature on methods and outcome measures for diabetes self-managed education, providing a basis for developing a Diabetes Self-Management Outcome Framework (DSMOF). Using this framework, a protocol and survey was developed for the pre-post evaluation study. Instruments for the evaluation study were also selected. The work of WP6 provided background information and guidance for the selection of health literacy measurement tools, to be used for assessing the impact of low health literacy on program outcomes. The project will use the recently validated 6-item version of the European Health Literacy Survey Questionnaire (HLS-EU-Q6). A literature review on the organizational factors impacting on the effectiveness of diabetes self-management education was also carried out. In WP7, a literature review on implementation fidelity models as applied to diabetes self-management education led to a review paper that was submitted and accepted for publication. Building on this review, an assessment tool was developed to evaluate the implementation fidelity of diabetes self-management programs. In WP8, a website for diabetes self-management for low literacy persons was designed, providing audio-visual and interactive features tailored by gender and attitudes to physical activity in several languages. Feedback of an expert panel was used to ensure the usability of the website, and a qualitative study of user views of the website was completed using 'Think Aloud' interviews. WP9 concentrated on the development of a dissemination strategy and publication policy. The website www.diabetesliteracy.eu was created and went online in April 2013. In addition, intermediate results for the different work packages were disseminated through presentations at various international conferences and national meetings. The Consortium also co-operated in organizing a pre-conference at the 2nd European Health Literacy conference.

Expected final results and potential impacts

The project will produce scientific evidence to support the Member States to improve the organization of health service delivery, more specifically with regard to diabetes self-management. The self-management capacity of patients is one of the critical success factors to tackle the diabetes epidemic, as diabetes requires extensive self-care. The Diabetes Literacy project will provide a systematic review of costing models for diabetes care across the EU, and assess per patient cost information on clinical outcomes of self-management education programs. By comparing the national diabetes strategies of the 28 EU Member States and making a compendium of self-management training programs for diabetes, it will address the comparability of health care practices across Europe, while critically considering the role of the patient, provider and organizational characteristics therein. By comparing the effectiveness and cost-effectiveness of different methods for diabetes self-management education it will provide a benchmark for best practices on care processes for diabetes care in Europe, while also taking cost containment issues into consideration. It will provide concrete individual level data on the use of interventions in economic and clinical terms, increased levels of integrated care, and greater awareness of the cost implications of clinical activities. By systematically assessing the implementation fidelity of current diabetes self-management education programs and the conditions for effectiveness in the way the health services are organized, it will contribute to optimizing the organization of care processes, including the professional roles and competencies. By considering the moderating role of health literacy on the effectiveness of diabetes self-management education and by developing literacy-appropriate diabetes education materials, the project will contribute to the development of patient-centered care systems and programs. This will be further strengthened by also considering the potential of patient self-help groups for diabetes education.

The project will be one of the first to compare different individual and group-based methods of diabetes education in terms of their (cost) effectiveness, and to study the relative cost-effectiveness of novel IT based education methods. It will link to the growing scientific debate on healthy literacy by investigating the moderating role of low health literacy on the effectiveness of diabetes self-management education, and will develop web-based materials for patients with low health literacy. It will also study the impact of the quality of the health system such as the availability of health care professionals with multidisciplinary competences, easy access to care for people with diabetes, an efficient information system allowing patient follow-up, and evaluating of

the services to strengthen competences and excellence of the services, on the effectiveness of diabetes self-management education.

The results of Diabetes Literacy will be disseminated widely to the scientific community, health policy makers at regional, member state and EU levels, and other interested stakeholders including health professionals and patient groups. To that effect, the project has a specific work package on implementation of a targeted dissemination strategy. The latter will be based on a systematic stakeholder analysis and includes articles in peer-reviewed journals, presentations, policy dialogues and a final Diabetes Literacy conference in November 2015. The aim of the Diabetes Literacy project is not only to produce scientific evidence, but also to support the Member States of the EU to improve the organization of health service delivery. Therefore, it will translate the findings of the project into recommendations for policies via policy dialogues, and publish policy briefs that target specific health policy makers but also support a broader advocacy by targeting a wide but knowledgeable audience. While the immediate target groups of the project are the scientific community and health policy makers, the ultimate goal of the project is to improve the practices regarding the care processes for diabetes patients in Europe. Therefore, health professionals, as well as professional organizations in the field of diabetes management and care are targeted for dissemination. Channels will be (1) the Diabetes Literacy website, (2) the Annotated Compendium with an overview of programs for diabetes self-management education in Europe, and (3) the Diabetes Literacy conference in November 2015.

Public website address: www.diabetesliteracy.eu

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