

Policy Brief

Diabetes Self-Management Education and Costs in the European Union

Diabetes Literacy Consortium
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Diabetes Literacy Policy Brief

Diabetes Self-Management Education and Costs in the European Union

This is the first of two policy briefs of the European Diabetes Literacy project. It provides an overview of the current practice and cost of diabetes self-management education (DSME) in Europe. Like the second policy brief, which focuses on the effectiveness of diabetes self-management education, this first policy brief combines the results of the Diabetes Literacy project with the outcomes of policy dialogues that were held during the 18th European Health Forum Gastein 2015 and the 23rd World Diabetes Congress 2015.

The results of the Diabetes Literacy project show that there is a window of opportunity to empower patients to take up diabetes self-management. Education for self-management is a crucial success factor, and a wide variety of DSME programmes is available in Europe. However, the quality and effectiveness of existing DSME programmes can be improved. This can be done by: tailoring education to the target groups; looking at conditions and components that make the programmes more effective; using opportunities for IT-based education; improving the training of programme providers, and using patient-level costing to demonstrate cost effectiveness.

Diabetes Self-Management

The number of people with type 2 diabetes in European Union (EU) Member States and worldwide is increasing at an alarming rate, costing EU Member States between 5–15% of their total health expenditure. Worldwide, 1 in 11 adults have diabetes, and this will rise to 1 in 10 in 2040. Health systems need to consider cost-effective

measures to fight the growing burden of diabetes and to improve the health and quality of life of people with or at risk for diabetes.

Self-management depends on a patient's capacity to obtain, process and understand basic health information. As such, the basis for improving capacity in diabetes self-management is education. The level of health literacy of a patient is a critical factor in successfully addressing diabetes and improving the outcome of treatment.

The initial focus of DSME was on enhancing knowledge and compliance to treatment. Recently, we have come to recognize that diabetes education should address knowledge, behaviour and psychosocial aspects, and provide ongoing support.

Diabetes Literacy

Diabetes Literacy (www.diabetesliteracy.eu) is a pan-European project aimed at strengthening patient self-management by exploring what programmes for diabetes self-management exist, what is their effectiveness and cost-effectiveness, and what is the potential

for improvement. The Diabetes Literacy project (2012-2015) received funding from the EU's 7th Framework Programme for research, techno-

logical development and demonstration. The project was implemented by a Consortium of research organizations from six EU Members States (Austria, Belgium, Germany, Ireland, Netherlands, UK), three non-EU countries (Israel, Taiwan and US) and two collaborating partners (Denmark and South Africa).

Management Education and Diabetes Costs

The Diabetes Literacy project assessed the current state of national diabetes self-management education, based on the input of multiple stakeholders. It also developed best-practice costing models for diabetes care, and

assessed existing costing practices for diabetes self-management education as well as costs related to complications. This policy brief summarizes the results of the assessments of diabetes education and costs, and presents the main messages.

National Diabetes Strategies and Diabetes Self-Management Education Programmes

The Diabetes Literacy project assessed the current state of national policies and diabetes self-management programmes in the European Union. It was based on a survey amongst multiple stakeholders from all European countries. An inventory of existing DSME programmes was published in a Compendium, describing the programmes for each EU Member State against the background of the country's health care and policy environment, the prevalence of type 2 diabetes per country, and the barriers and gaps for program implementation.

Information Basis

The analysis of existing diabetes strategies and programmes was based on information collected through the online Diabetes Literacy Survey, as well as on a review of policy documents and research. Additional information on diabetes education programmes was collected via a wiki tool and an expert survey focusing on the health policy and economic aspects of diabetes education. In the EU sample, 33% of the respondents were patients, family members and relatives, 47% were care providers, and 20% were policy-makers and researchers.

Existing diabetes self-management should be made more interesting and accessible to patients, tailored to specific needs to increase attendance and adherence

Main Findings

Approximately 75% of the respondents in EU Member States reported that there are structured DSME programmes for adults in their country. However, the reported availability varies widely between countries, ranging from 92% in Ireland to 50% in Spain. Only 42% of the respondents reported that their country

offered specific DSME programmes for older people. About 30% stated that the diabetes education programmes in their country are accessible for people with limited literacy. This percentage ranges from 21% (Portugal) to 50% (Denmark). About half of the respondents thought that patients with type 2 diabetes know enough to manage their illness. However, most respondents believed that patients do not know enough about the legal aspects of the disease, about coping strategies and about depression.

An analysis of current diabetes programmes in Europe confirmed the main outcomes of the survey. Although some Member States lag behind, an adequate number of DSME programmes for adults are available. Most diabetes education programmes are group based. However, only one-third of these programmes are for people with lower literacy levels. Almost half of the people with diabetes do not take part in diabetes education programmes. This holds true for patients in all age groups.

Cost of Diabetes Self-Management Education

The Diabetes Literacy project reviewed best practice costing models for diabetes care. Quantitative and qualitative analyses were performed of the cost of diabetes education per patient in relation to the health outcomes achieved, and an exploration was made of the costs of complications within the context of the total cost of diabetes self-management education.

Information Basis

To study the cost of type 2 diabetes care, the Diabetes Literacy project used a mixed methods approach, consisting of expert interviews and a survey in seven EU countries. For comparative cost analysis of the DSME programmes, a protocol was developed based on the principles of Time-Driven Activity-Based Costing (TD-ABC). This information was used in combination with health outcome data to calculate the programme cost per patient per hour of education. The care pathways of the five most common profiles of patients with type 2 diabetes were identified. Cost data were collected from a sample of diabetes clinics in three countries to explore the cost of complications in the context of the total cost of diabetes self-management education.

Economic evidence was collected to support the finding that early intervention in primary and community care will prevent the progression of diabetes and escalation of costs

Main Findings

Significant variations in costing practices for healthcare exist across EU Member States, leading to a lack of comparability of the cost of diabetes care between countries. The UK is more advanced than other countries in providing data on patient-level costing, but several other countries are also moving in this direction. The cost per patient per hour of education vary both within and between countries. High administrative hours booked for some education programmes resulted in a high cost of delivery. A relationship was found between the type of DSME programme, the cost of delivery and the health outcomes achieved, particularly for quality of life, and diabetes-specific health literacy. The costing methods applied in this study also created insight into the cost for the care processes for different type 2 diabetes complications within and across countries. TD-ABC permits a more accurate understanding of the costs for low, moderate and high risk patients.

Policy Recommendations

National Strategies and Diabetes Education Programmes

Diabetes self-management education, anchored in the EU Member States' health policy strategy, is crucial to meet the challenges of increasing numbers of diabetes patients. With the growing awareness of the need to support diabetes patients through education, there is a window of opportunity for improving diabetes self-management.

In Europe a wide variety of DSME programmes is available, but these programmes are not equally distributed among the population and across countries, and do not reach all the target groups. Existing programmes must be made more available and accessible to patients.

The Diabetes Literacy project indicates a need to tailor DSME programmes towards the culture, ages and health literacy of the programme participants.

Adapting DSME programmes to the specific needs of patients and to the cultural and organisational context while maintaining the core programme components can enhance self-management effectiveness and empowerment.

More use can be made of modern IT technology to enhance DSME programmes.

Ensuring follow-up as part of diabetes education programmes will contribute to improving the quality of the programmes.

Costs of Diabetes Self-Management Education

The Diabetes Literacy project calls upon the European Commission to mandate harmonization of costing practices for healthcare expenditure across Europe.

There are variations in the costs of DSME both within and between countries. Some education programmes have high administrative hours and consequently a high cost of delivery.

Compared to the overall costs of diabetes care and treatment of diabetes complications, the costs of DSME programmes in Europe are low, thus permitting the inclusion of patients who do not receive diabetes education.

Time-Driven Activity-Based Costing has a great potential to identify unnecessary process steps in the delivery of programmes. It can be

As people with diabetes often suffer from other chronic diseases or complications, integrating a multi-morbidity perspective adds value to diabetes education.

Intensifying and improving the training of providers of DSME programmes, including a greater focus behavioural and psychosocial expertise, is essential to ensure the quality of DSME programs.

EU Member States that lag behind in the implementation of DSME strategies should be supported.

an effective tool to make the business case for diabetes self-management education.

Clinical data should be collected before and after the delivery of diabetes education by the national programmes as a matter of course.

Most countries are not investing enough in either primary or community care. Non-specialist healthcare providers have inadequate support to educate patients properly.

The Diabetes Literacy project has found economic evidence to support the finding that early intervention in primary and community care prevents the progression of diabetes and the associated escalating costs.

It is recommended that policymakers use patient-level costing to demonstrate the cost effectiveness of investment in primary and community care.

The Diabetes Literacy project shows that currently only 50% of the people with diabetes in Europe take part in diabetes self-management education. Strong evidence was found that DSME is effective, although the quality of self-management education can still be improved. The implementation of effective and cost-effective programmes should be increased to make these programmes available and accessible to all patients in Europe.