

Power to the people

The effects of many common chronic diseases can be significantly reduced by empowering people to take more personal responsibility for their condition. **Brian Johnson** reports

Can the burden of chronic disease be significantly reduced by empowering people to take more personal responsibility for their condition? That was the overarching question posed at a conference hosted by ALDE deputy Jorgo Chatzimarkakis in the European parliament earlier this month. The event, held under the banner of Chatzimarkakis' European Life Science Circle (ELSC) centred on the issues of self management, empowerment of both physicians and patients, motivation for lifestyle change and the importance of factors other than medicines on patients' lives.

According to Chatzimarkakis, empowering chronic patients to take responsibility for the day to day management of their disease may significantly enhance their medical outcome. "Patients who are empowered to act self-responsibly may also contribute to lowering the costs of health care by avoiding costly and potentially life-threatening complications." So is it possible for patients, with the proper medical guidance, to influence the course of common chronic diseases such as cardiovascular and kidney disease, diabetes and asthma, and can health systems use patient empowerment to improve the medical and economic outcome of their disease management? The event, appropriately entitled "Patient Empowerment – a new paradigm in disease management?" Set out to answer these questions.

Outlining the key issues and setting the scene for the conference, professor for medical psychology at Leiden university medical centre, Dr Adrien A Kaptein argued that "quality of life should be one of the major medical outcomes," in any treatment programme, and alluding to the 'new paradigm'

"Patient empowerment is the best way to bring down costs for health systems"

Jorgo Chatzimarkakis MEP

of physicians of one type or another, Kaptein asked, "who here is afraid of the empowered patient?"

In a session on the effects of patient empowerment on managing diabetes, Professor David Klonoff, clinical professor of medicine at the University of California San Francisco, outlined a presentation on "Suggestions for enhanced transparency and efficacy – the benefit of health measures using the example of diabetes management". Klonoff focused on the

European
Life Science Circle

Patient Empowerment -
a New Paradigm in
Disease Management?

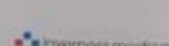
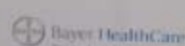
Tuesday 2 March 2010
9:00 - 15:30
Room PHS 4B001

European Parliament Brussels

This event is mainly sponsored by



This event is kindly supported by





Patient empowerment and self-management: an EU call for action

Speakers at the ELSC event called for patient empowerment and self-management of chronic diseases to be established as a priority in the new European commission's work programme, and for the issue to be positioned at the centre of all relevant EU policy initiatives.

In a statement read out by the European federation of allergy and airways diseases patients associations (EFA) board member Lina Buzermaniene, the ELSC said that, "chronic diseases are life-long conditions with a profound impact on a patient's health, well-being and life expectancy and that the burden of chronic, non communicable diseases on societies and health care systems is without question one of the biggest challenges in the twenty-first century."

The text also suggested that a "more equitable share of the benefits from effective behavioural interventions would bring significant added value for people with chronic conditions and health care systems of EU member states."

The statement also highlighted that "there are many discussions worldwide on how to determine the most effective way to deliver patient education. Behavioural changes must be implemented. To get there we must help people with chronic diseases to manage their condition better and provide education, incentives and tools for self-management and care."

"By empowering people with a chronic disease to take responsibility for their condition, the burden of chronic NCD can be significantly reduced. National governments can help to protect the health of their citizens while at the same time controlling health spending, by integrating prevention and self-management into national health plans and chronic disease frameworks. These programmes should support and promote positive self-care behaviour as a key to delay the onset of, or even prevent, complications that cost health systems millions in treatments."

The statement ended with a three point EU call to action to:

- Establish patient empowerment and self-management of chronic diseases as a priority of the new Commission in its work programme and in all new EU health policy initiatives.
- Ensure EU-wide care models for chronic diseases that include behavioural and educational programmes to enable patients to take responsibility and manage their condition.
- Ensure that core models and recommendations for health technology assessments currently developed at EU level follow predictable, common criteria and methodologies, which take into account the actual patient-self-management activity in the investigated treatment procedure.

benefits of self monitoring of blood glucose for patients with diabetes. "There are positive effects shown in several studies," he said explaining that self monitoring enables patients to be more aware of their conditions and more alert to managing their disease. "Patients know what their problems are," he said, adding, "So does self-management actually lead to patient empowerment? The answer is yes. The evidence seems to be pretty overwhelming that self-monitoring of blood glucose has a direct and positive effect, both to patients and on an economic level." However Klonoff said that additional data was still required and that a "common methodology" was needed to assess any new data.

Sharing the same session, Professor Stephan Martin of the West German centre for diabetes and health in Düsseldorf presented the findings of the recent "ROSSO in Praxi" observational study on type 2 diabetes. Martin said that the costs of medical complications arising from diabetes increase over time, and that a lack of exercise and rising obesity levels were exacerbating the problem. To fully manage type 2 diabetes in the long term, the medical community needed to realise that a purely pharmacological approach was not the answer. Instead, patients needed to be motivated to make lifestyle changes. "The question then is how to motivate people, and the answer

"Does self-management actually lead to patient empowerment? The answer is yes"

Professor David Klonoff

to that question is through self monitoring of blood glucose. As people become more involved in managing their own disease, they become more motivated to make the necessary lifestyle changes." This, Martin said, was the main result of the ROSSO in Praxi study.

In a session on the practical and economic aspects of patient empowerment, Dr Stephanie Stock, from the Institute for Health Economics and Clinical Epidemiology in Köln, outlined some of the preliminary findings from 'Germany's disease management programme (DMP)'. "The way disease management is conducted can drive change in the way we approach health care", Stock said. The goal of the DMP legislation in Germany was to optimise chronic care and to integrate health care. She added that the intention had been to have a strong focus on secondary prevention, and that as patients became better at self managing they became more educated. "Health care delivery systems are designed for acute care, not geared for chronic care. We need to change the system, as the disease management approach has the potential to change the way we deliver healthcare." The hallmarks of the DMP were, said Stock, that it was physician based, patient centred, quality targeted, rationally implemented, and used financial incentives.



Professor Adrien Kaptein, Miroslav Mikolasik MEP and Jorgo Chatzimarkakis at the recent ELSC event on patient empowerment

On patient activation, she said individualised health care plans were used in combination with education. Speaking about chronic care in Europe, Stock said that chronic care structures should be harmonised at EU level and that the EU should focus on establishing recommendations for patient self management and empowerment of patients across new health policy initiatives. In addition, patient education needed to go “beyond increasing knowledge and skills and include behavioural change and self motivation and management support.”

Economically, patient empowerment had many cost benefits, outlined Jim Furniss, director of global market access strategy at Bridgehead international, which advises pharmaceutical and medical device companies on market access issues for healthcare products. Using evidence from three European countries and the ROSSO in Praxi study on the cost-benefit relation of patient empowerment in the management of Type 2 diabetes, Furniss said significant savings could be made through the use of self management of blood glucose across European countries. Concluding, he said that the ROSSO in Praxi study provided a sound basis for future work and that other studies had showed similar results. He added that the EU should ensure that core models and recommendations for health technology assessments follow predictable and common criteria.

In a presentation on how to “Learn to live with chronic respiratory diseases”, European federation of allergy and airways diseases patients associations (EFA) board member Lina Buzermaniene explained that the organisation had begun putting together experienced patients with inexperienced ones for peer support. She also said that a proper partnership between patients and doctors was crucial in empowering patients. “Peer support helps inexperienced patients to better communicate with doctors about their concerns and conditions, making doctors better able to treat the patient.” She

called on the European commission to establish patient empowerment as a priority.

Closing the event, Chatzimarkakis warned that the task ahead was to convince national actors and insurance companies of the importance of patient empowerment and noted that German health minister Ulla Schmidt was “under attack from all sides” for wanting to do the slightest changes, showing

“The question then is how to motivate people, and the answer to that question is through self monitoring”

Professor Stephan Martin

the difficulty of reforming the health system. “Patient empowerment is the best way to bring down costs for health systems” he said, and urged the commission to take the lead. “Let’s turn Europe into the healthiest region on earth” he said, and concluded by saying that in the end, it was up to member states to take action. ★

The European Life Science Circle

Launched in 2006 by German ALDE deputy Jorgo Chatzimarkakis, the European Life Sciences Circle (ELSC) was established to ‘facilitate the dialogue with interested stakeholders on relevant issues in the context of life science and pharmaceuticals.’

According to Chatzimarkakis, Europe has many strong assets in being the world’s “biozone”, but must ensure it keeps up with global developments. “Politics has to underline this with a modern legal framework. The ELSC offers the opportunity to shape the debates on that framework.”

The ELSC meets at least four times a year and includes participants from the European parliament, high-ranking officials of the European commission and council, interest groups, including patient associations, and industry representatives, particularly from the pharmaceutical and biotechnology sectors.