

## Why Patients Should Be More Empowered: A European Perspective on Lessons Learned in the Management of Diabetes

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### Abstract

Patient empowerment has emerged as a new paradigm that can help improve medical outcomes while lowering costs of treatment. The concept seems particularly promising in the management of chronic diseases. Diabetes may provide a blueprint for implementing patient empowerment because empowering patients has been instrumental in achieving the successes we have witnessed in the management of diabetes in recent decades. Looking at the example of diabetes, this article investigates the role and contribution of patient empowerment to therapy success and derives actions that need to be taken in order to fully leverage the potential of this concept for patients, health care professionals, and health systems.

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### Introduction

Patient empowerment has emerged as one of the most interesting keywords used by health politicians, academics, and practitioners in Europe in recent years.<sup>1,2</sup> Many hope that empowering patients to take co-responsibility for the management of their condition will enhance medical outcomes at lower cost, thus providing a possible key to solving the ever more pressing issue of exploding health care costs. But to prove that it is more than a keyword, patient empowerment needs to be put into practice to demonstrate that it really generates value.

As a politician with an interest in a healthy Europe, I am convinced that we should invest in the concept of patient empowerment in order to master the challenges facing modern health systems and individuals across Europe.

This article discusses why we need to empower patients, how the concept can be put into practice, and what we as policy makers need to do in order to leverage the potential of patient empowerment for health systems and individuals.

### Why Do We Need to Empower Patients?

Be it coincidence or not, patient empowerment is occurring at a time when patients in Europe have more information at hand than ever before. We can access medical information via the internet and easily communicate with health care providers, patients, support groups, and other experts. This wealth of information can be very powerful, but it can also be confusing, in particular if the

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**Abbreviations:** (ELSC) European Life Science Circle, (EU) European Union, (HTA) health technology assessment, (MEP) Member of the European Parliament, (SMBG) self-monitoring of blood glucose

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individual patient cannot do much with the information. Being knowledgeable is useful only as a necessary prerequisite to being able to act self-responsibly. In this respect, empowering patients means enabling them to make good use of their available knowledge by providing tools, techniques, and support.

Adding to this political view is the fact that health care professionals across many disciplines are experiencing the benefit of empowered patients who take a more active role in the management of their disease. This is particularly true for chronic diseases, the treatment or management of which have been moved gradually from the doctor's office or hospital to the patient's day-to-day life. While this gain in independence is a blessing for affected patients and can dramatically increase their quality of life, it also means that patients need to take a more active role in the management of their condition, from lifestyle changes to the use of medical devices and implementation of therapy adjustments following discussion with their doctor or nurse.

## How Can Patients Be Empowered? The Example of Diabetes

The changing role of patients towards increased self-responsibility in the management of their own condition is particularly evident in the case of diabetes, in particular type 2 diabetes. The evolution of diabetes from a serious and potentially fatal disease to a manageable chronic condition would not have been possible without patients gaining the knowledge and capability to count carbohydrates, administer insulin, adjust their lifestyle, and maintain their motivation and discipline every single day of their life.

A breakthrough in this century-long process was achieved with the introduction of self-monitoring of blood glucose (SMBG) in the 1970s, freeing patients from the need for regular hospitalizations or consultations. The benefit of SMBG has been repeatedly confirmed.<sup>3–6</sup> We know it works, and we know what is required for it to be effective. Evidence shows that SMBG can be more effective in helping patients stay motivated and implement the necessary lifestyle changes if it is used as part of a structured diabetes management program.<sup>7–9</sup> To further maximize the benefit of SMBG, a common understanding of when, how, and how often to test should be established, depending on factors such as the type of diabetes and treatment approach.<sup>10</sup> Recent research indicates that pattern analysis is a systematic approach that improves diabetes outcome.<sup>11</sup> Visualizing SMBG

results empowers patients to better control their blood glucose levels and empowers physicians to better understand and respond to individual patient patterns.<sup>12</sup>

Empowering people with diabetes to self-monitor their blood glucose has proven effective not only for the individual patient, but also for the health system as a whole, as studies have shown that SMBG provides fair value for money, long term costs can be reduced if people with type 2 diabetes use SMBG as part of a diabetes management program.<sup>13–15</sup> The equation is simple but compelling: The costs of treating diabetes increase with the incidence of secondary complications, which trigger the need for hospitalization, emergency care, and treatment by a specialist. The risk of secondary complications can be reduced effectively by managing diabetes on a daily basis and putting an empowered patient into the center of a well-structured management plan, as recommended in international guidelines.<sup>16–20</sup>

In order to counter the risk posed by the spread of diabetes in Europe and protect both the individual and our national health systems, politicians at the European Union (EU) and country levels are beginning to take action. A focal point is the EU Diabetes Working Group, in which members of the International Diabetes Foundation and the European Parliament are joining forces to promote the exchange of best practices and to establish common standards in the management of diabetes across Europe.<sup>21</sup> The EU Commission will hopefully join in and start supporting our call for concerted action.

## Taking Patient Empowerment from Concept to Practice

The lessons learned with patient empowerment and self-management in diabetes can be of use for many chronic conditions, as they all require patients to actively manage their condition on a daily basis. So what are these lessons? How do we take patient empowerment from concept to practice? What do we need to do and consider? Taking the experience gained in the management of diabetes to a broader level, I would like to derive three basic principles.

### *Principle 1: Empowerment Means Enablement*

First, empowerment means enablement. Patients need to “know,” “be able,” and “want.” This means that empowerment should include education and practical training, tools and techniques for self-management, and motivational factors for patients to really act as we expect them to. Health politics should support this by

strengthening the preventative part of disease management, knowing that this upfront investment will be more than compensated by savings in later disease stages.

### ***Principle 2: Empowered Patients Need Strong Partnerships with Doctors and Caregivers***

Empowering patients must never mean disempowering health care professionals. Patients can only be empowered by their doctor or caregiver, and they need the medical feedback and endorsement for their way towards self-responsibility. The doctor-patient relationship will certainly change as the patient gains responsibility, and it may likely become more important to have this strong relationship. Health politics should ensure that doctors and other health care professionals have the freedom they need to effectively personalize therapy to the individual patient.

### ***Principle 3: Patient Empowerment Is a Paradigm, Not a Technique***

Patient empowerment is a new paradigm, with the potential to change the way we think about the role of the patient and the doctor-patient relationship. The health care system—meaning all parties involved in the health care decision-making process—needs to develop a mutual understanding of the concept and its benefits. If not, we may soon be evaluating individual empowerment tools and techniques only to realize that they cannot be evaluated as individual measures, but only as part of a more holistic disease management concept. Health politics should keep this in mind when using the emerging discipline of health technology assessment for decision making.

## **Politicians Need to Endorse Patient Empowerment**

Often, medical practice is already one step ahead of politicians. Health care professionals actively empower their patients in their daily practice, and they are beginning to join forces in order to better understand the potential of patient empowerment and to learn from each other's experience. Policy makers should join the effort and actively support this paradigm shift. At a recent European Life Science Circle (ELSC)<sup>22</sup> titled Patient Empowerment—A New Paradigm in Disease Management?, representatives from academia, medical practitioners, and patients covering different chronic disease areas met to exchange experience and insights. Agreeing that the potential of patient empowerment is significant, the ELSC speakers signed a call to the EU:<sup>23</sup>

- Establish patient empowerment and self-management of chronic diseases as a priority of the new commission's work program and position these topics at the center of all relevant EU health policy initiatives.
- Introduce EU-wide care models for chronic diseases that include behavioral and educational programs that enable patients to take responsibility and manage their condition.
- Ensure that core models and recommendations for health technology assessments (HTAs) 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.

As a politician who is convinced that we Europeans can benefit greatly from learning from each other, I cannot leave the latter aspect without comment. We have seen HTA reports and related discussions at the EU country level, including work in the area of diabetes, which left more open questions than they answered. These discussions typically evolve around the chosen methodology or eligibility criteria for studies to be included in an HTA. For the latter, suggestions have been made concerning the optimal study design for evaluating diabetes management.<sup>24</sup> Applying such common standards would greatly help HTA in Europe win the endorsement and support needed for it to become an accepted and trusted body in the European health decision-making process. But as long as decisions about standards and methodologies are left to the discretion of national HTA bodies, debate will continue about whether they are the right body to rule over the distribution of scarce resources in European health. For this reason the EU must actively participate in the consultation and, moreover, set the standards in order to allow for a clear discussion and to achieve reasonable conclusions.

## **Integrating the Patient's View**

Whatever initiative will be taken to bring patient empowerment from concept to practice, integrating the patient's experience will be essential. Any concept that medical practice and health care politics may come up with will need to win acceptance from patients. Ultimately, patient empowerment will work only if patients are able to integrate their increased responsibilities into their everyday lives. In this regard,

patient empowerment may provide an opportunity to enhance multidisciplinary dialogue, foster networked thinking and planning, and take a more holistic view of patients and their diseases. This may not make our work easier, but likely more effective—and certainly more beneficial to patients living in Europe.

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