

European Health Forum Gastein “Management of chronic disease: the potential of patient empowerment”

Grand Park Hotel, 1 October 2015
Workshop Report

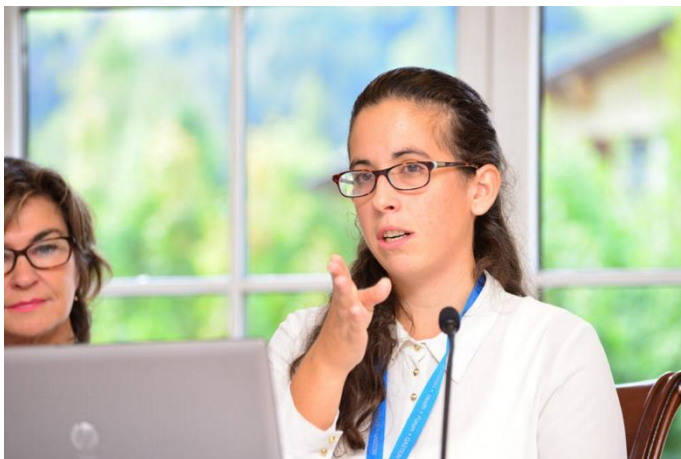


Tamsin Rose (Non-resident fellow, Friends of Europe) welcomed participants and reminded those present of the objectives of the meeting, i.e.

- Highlight how patients can contribute to high-quality, sustainable healthcare systems;
- Focus on 'empowerment in practice in three key areas, i.e. information to patients, the patient-health professional relationship and self-management of chronic conditions;
- Raise policy-makers' and stakeholders' awareness of the importance of patient empowerment;
- Ne informed of/get involved with EPF's 'Patients prescribe E5 for sustainable health system' campaign,

The main question to be addressed related to what it means to be an empowered patient. Tamsin apologised on behalf of **Theo Raynor (University of Leeds)** and **Anders Olason (EPF)** who could not attend the meeting due to health problems.

1 The Concept of Empowerment



The first speaker was **Marta Ballester (Avedis Donabedian Research Institute – UAB)** who provided information on the theoretical and research framework as well as on the concept of patient empowerment, as addressed by the EMPATHiE project. This EU/financed project, which was carried out by an international consortium, aimed to help understand the concept of patient empowerment as a prerequisite to exercise patient rights. EMPATHiE defines empowered patients as 'having control

over the management of their condition in daily life. They take action to improve the quality of their life and have the necessary knowledge, skills, attitudes and self-awareness to adjust their behaviour and to work in partnership with others where necessary, to achieve optimal well-being'.

The project was focused on a conception of empowerment at an individual level, where it relates to actions patients take to manage and control their condition(s) but it can also be conceived as collective empowerment, where it relates to patients participating on health policies. Empowerment does not only feature in the area of healthcare; it is a much wider societal concept, and in many areas it is already much more developed (e.g. rights of minorities, reproductive rights). In a sense, healthcare has to catch up with the rest of society.

EMPATHiE aimed to develop a common framework of how to understand patient empowerment, and the following three dimensions were proposed:

- Health literacy improvement and education
- Shared decision making on condition management
- Self-management of health care

The project carried out a systematic review of recent and current studies in these three areas for selected chronic conditions (diabetes, cardiovascular, respiratory, mental health and complex patients) and it was analysed for multiple outcomes including clinical outcomes, quality of life, use of health services, patient and professional perception related measures,

It was found that some self-management programmes (generic and specific) in all the conditions and patient education schemes (especially for diabetes) have positive results; strategies that might work relate to recent innovative practices introducing technology mediated elements and multi-dimensional approaches to patient empowerment. However, the evidence of self-management support programmes combining face-to-face and virtual or technology mediated delivery is inconclusive.

EMPATHiE found a huge increase in the interest in patient empowerment; however, there are some specific areas of empowerment where the number of studies is still limited. For instance, only one study was found in relation to complex patients. There is abundant research in the areas of health literacy and self-management, but shared decision-making has not been the focus of many research projects for chronic diseases.

EMPATHiE also carried out focus groups and surveys across Europe. The focus groups identified multiple barriers and facilitators to empowerment that were clustered in 19 topics. When different stakeholders were asked to prioritise them in a survey it was found that almost all coincided in the same top 5 priorities (time to communicate with patients, holistic view of patients, well-coordinated care, patients feel responsible for their health and professionals work together), although different stakeholders had different order of priorities within those top 5.

In conclusion, Marta stated that empowerment should be viewed as a continuous multi-dimensional process and it should be considered that progress might not be linear (experiences of disempowerment, changes in the condition...). Effective good practices need to be shared, disseminated and transferred to other areas. Health systems need to be changed to cater for the trend towards increasing empowerment.

2 Patient information and Health Literacy

Moving to the next part of the session, addressing practical examples of the three empowerment dimensions as identified by EMPATHiE, Tamsin Rose presented **Theo Raynor's** statement relating to information to patients and health literacy. Theo underlined that 'Education' is arguably the most important of the 5 E's of the EPF campaign. However, in order to be empowering, information has to be relevant, accessible and understandable. Information alone is not a panacea; the goal should be to improve information to patients in general, rather than focus on the least health literate.

Health literacy is a two-way street and there is a need for an equal focus on 'deficiencies' related to professionals and health services. The principle of 'universal precautions' needs to be adopted for all patients and all information materials, as health literacy problems are common and hard to recognise. Health professionals should assume all patients may have difficulty with health information and should communicate in ways that anyone can understand.

In order to do this, health systems need to be structurally changed, building in information that is understandable to everyone. Although user involvement is not yet accepted as common practice, patients do start to become visible and present when decisions are being taken. As an example, Theo

presented a Patient Information Leaflet, which was developed and significantly improved due to the input of patients.

Lastly, Theo emphasized that it is important to remember that information is central to empowerment as it enables patients to make choices. However, informed patients may not necessarily be obedient patients. Informed patients have the capacity to make decisions on their health and health outcomes. They will not be miraculously compliant. This will require change in attitude on the side of health care professionals, as an informed patient may decide to do what they see as right for him/her and not follow professional advice. This is a good outcome if we truly believe in the ‘empowered patient’

3 Patient and Health Professionals’ relationships

The next speaker, **Professor Inger Ekman (University of Gothenburg)** focused on shared decision-making in health care. In the person-centred approach, patients are viewed as persons with capacities and self-respect, interacting with others. The person/centred care – partnership that Inger is involved in has the following stages:



1. Initiating the partnership – patient narrative
2. Working the partnership – mutual understanding and creation of a health plan
3. Safeguarding the partnership - documenting the agreed goals and a health plan

Making a plan with the patient consists of defining the goals (the patient’s goal), looking at the resources and strengths of the patient (will-power, decisiveness), health-professional and patient formulate and document the personal health plan together but it is the patient’s document.

This person-centred care programme takes place in the hospital and primary care and the effects are very positive: it reduces the patient’s uncertainty, improves self-efficacy, reduces symptom burden and improves quality of life. The number of hospital days has also been reduced with 30 % - 50% and the cost of care has decreased with 40%. There are many examples from controlled studies demonstrating the astonishing effects of actually listening to patients but the challenge remain to implement and evaluate person-centred care over time.

Patients are happy with these partnerships, but the question is if health professionals are ready for this approach.

4 Self-management of Healthcare



The final panellist was **Nicolaj Holm Faber (Danish Committee for Health Education)** who informed the audience of a Danish programme addressing self-management of chronic illness. Using drawings, he underlined that, when we have a chronic condition, we spend 2% of our lifetime in the presence of healthcare professionals; the other 98% we need to deal with our condition ourselves. This 98% influences the 2%, so perhaps the focus of managing a condition should

be on the 98% rather than the other way around.

Empowerment and self management are fragile concepts. The current health system actually disempowers patients, as we tell patients what they need to do – there is no room for choice. If we are serious about patient empowerment, health systems will need to be changed.

The Danish self-management programme works with the CDSMP (Chronic disease self-management program), which was developed at Stanford University. The programme initially focused on the individual patients, but when implementing the programme it was found that (organisations of) health professionals also needed to be part of – and supportive of - the programme. At first, it was not so easy to get the health professionals on board, as there was some distrust of a patient-lead system. However, the positive experiences that could be shared was convincing and helped to build mutual trust. The next level to engage was the municipal level, and the initial resistance there was overcome because all relevant stakeholders were involved. Municipality support is crucial for the success of the programme, and so is support at the political level; it is crucial to bring research showing the positive effect of self-management into the political decision-making process.

The programme links to all Es but especially to the second E in the EPF's 'Patients prescribe 5E's' campaign, i.e. Expertise. In conclusion, Nicolaj reemphasized that the focus needs to be on the 98% of the time when patients manage their conditions themselves, since the outcomes of treatment is. Apart being more satisfactory for patients, it also helps cut costs and better use of scarce resources.

5 The EPF Patient Empowerment Campaign

The next speaker, **Camille Bullot (EPF)** thanked Sanofi for its cooperation in organising this workshop and informed the audience of the EPF's campaign 'Patients subscribe 5 E's for sustainable health systems'. The objectives of the campaign are to develop a common understanding of empowerment and health literacy. In addition, a structure needs to be developed to enable EU decision makers to put in place a strategy on patient empowerment. The campaign has 5 main dimensions:

- Education: patients can make informed decisions about their health if they are able to access all the relevant information, in an easily understandable format.
- Expertise: patients self-manage their condition every day so they have a unique expertise on healthcare which needs to be supported.
- Equality: patients need support to become equal partners with health professionals in the management of their condition.
- Experience: individual patients work with patient organisations to represent them, and channel their experience and collective voice.
- Engagement: patients need to be involved in designing more effective healthcare for all, and in research to deliver new and better treatments and services

Camille urged participants to actively support the campaign and to take action to spread the word. She provided many examples of action that could be taken by those [present, such as

- Signing the online pledge
- Taking a picture with the pledge ad paste it on social media
- Posting testimonials from patients and professionals promoting empowerment
- Sharing experiences the EPF blog
- Organising an event on empowerment

EPF has developed camping materials that can be put to use and shared. Camille concluded with formally launching the EPF campaign video, stating that patients are no longer the passive recipients of care: they are active and are ready to play a role.



6 The role of the industry

The final speaker, **Eric Racine (Sanofi)** addressed the role of the industry in relation to patient empowerment.

As Eric is in charge of the company’s global patient advocacy activities he is working with the patient community all around the world. He has found that a focus on patient empowerment is a reality around the world, and this focus is fuelled by many trends, such as increased access to information (e.g. via the Internet and other digital means). Patients are becoming more empowered and shared decision-making is on the increase. This is a positive development and industry embraces the concept of empowerment.

Patients spend a lot of time managing their condition and health. Therefore, the relationship with healthcare professionals should be made more efficient. Critical innovation can only work if patients are empowered.

Adherence is a case in point. Some 50% of patients stop taking their medication and true partnership with health professionals could help avoid this. Traditionally, the pharma industry's main focus has been on biology and prescribers - however, there is a need to also focus on the patients as the patient is the ultimate stakeholder and this is what we see happening throughout the industry. Therefore, Sanofi is committed to supporting campaigns like the EPF's 'Patients prescribe 5E's' and is also involved with patient education programmes. One of the most important aspects in co-operating with patients relates to listening and Sanofi has systematised this approach: from the early research stages of to the process of commercialisation, patients are involved. This has considerably changed Sanofi's offerings and insights. In general, if the concept of patient empowerment is to be systematised, the current political silo culture has to change. Moreover, the level of mutual trust needs to improve. In conclusion, Eric congratulated EPF with its campaign and with its work in general, as EPF, bringing together patients and engaging with other stakeholders, is a leader in the world.

Discussion

In the discussion the following issues were raised:

- Patients and their organisations need financial support in order to work professionally; they have the knowledge but not the resources
- Questions were asked about the (negative) attitudes of health professionals towards patient empowerment as the meeting was giving the impression that they are the problem. However, when asked, most doctors, nurses and other health professionals would agree with the need and importance of patient empowerment. There are many explanations why everybody would support patient empowerment supports in theory but not in practice. Patients and doctors may have differing goals, with doctors trying to cure and patients seeking for the highest possible quality of life.
- Patients demand better communication and teaching future health professionals how to better communicate this should be an integral part of medical curricula. 'Bed side manner' and communication are not a priority in the education of health professionals. Current health systems still support the old way of dealing with patients. Patients need empowering tools but health professionals need the tools to deal with empowered patients. There is often a lack of time to really listen to the patient. Education as well as current structures both play a role. Even when a health professional has the right attitude he/he may not know how to deal with it in practice.
- EPF works closely with the organisations of doctors, nurses, health managers, as this will help increase awareness and amplify its voice. These partnerships are a strategic requirement.
- There is a lack of evidence relating to how IT solutions can help empowerment. There are some studies that indicate the positive effect of interactive and self-monitoring platforms as well as patients' forums for exchange and discussion.

- There is a role for schools of and for patients and peer to peer learning processes. EPF facilitates this as this is one of the key reasons for its existence; members meet and have exchanges on policy; training is also being organised on a variety of topics.
- The concept of user involvement needs a movement as it involves cultural change – a cultural revolution. It involves citizens and the way health conditions are being viewed and managed.

Tamsin Rose, closing the meeting, underlined some of the highlights, i.e. the need for a cultural revolution, the focus on both education of health care providers as well as required system change and the need to jointly decide on health outcome. Questions remain as to how to measure the performance of health care system and professionals.