Patient Empowerment – Living with Chronic Disease

A series of short discussion topics on different aspects of self management and patient empowerment for the 1st European conference on patient empowerment
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Foreword

By Durhane Wong-Rieger,
Chair International Alliance of Patients Organizations

The International Alliance of Patients Organizations (IAPO) welcomes the opportunity to participate in this discussion on the value of patient empowerment in addressing the challenge of non-communicable diseases. The rising incidence of non-communicable diseases (NCDs) worldwide can be regarded, on the one hand, as the result of improved standards of living and increased longevity, and, on the other hand, as an impetus for declining quality of life and reduced growth and development.

The United Nations has acknowledged that this “global burden and threat of non-communicable diseases constitutes one of the major challenges for development in the twenty-first century, which undermines social and economic development throughout the world” and the World Health Organization has called upon all countries, including those in low- and middle-income countries, for comprehensive, sustainable interventions to address the “NCD epidemic.”

This paper provides examples of programmes directed to patient self-management that can be adapted in other settings to move toward a truly patient-centred healthcare system. With the European Network for Patient Empowerment and stakeholders from all sectors we look forward to making this a reality,

About this paper

This paper is a series of short discussion topics on different aspects of self management and patient empowerment. It is designed to provide some background information and context for the conference.

The paper was put together by members of The European Network on Patient Empowerment
Why is patient empowerment important?

Originally health services were organized to respond to and treat acute illnesses but today are increasingly challenged to accommodate the care and treatment of chronic disease.

Chronic diseases are now the biggest cause of death and disability worldwide – including cardiovascular diseases (CVD), cancer, diabetes, obesity, and chronic respiratory diseases – account for an estimated 86% of deaths and 77% of the disease burden in the European Region, as measured by disability-adjusted life years (WHO 2009). This development has brought about a fundamental shift in health systems and healthcare, and as a consequence, in the roles and responsibilities of patients. In line with this health transition the focus on patient responsibilities and their role in managing their health has grown substantially and is an increasing focus of health policy. With this, has come a shift towards care and treatment moving out of the hospitals and into the community and the home, leaving patients and family with a greater responsibility for their own health.

What is person-centered care?
Person-centered care is the provision of care that places the patient at the centre ensuring that the healthcare system is designed to meet the needs and preferences of patients as defined by patients themselves.

Only the patient is in a position to make a decision on what patient centered healthcare means to them, as an individual in the treatments of their condition and the living of their life. However, treatment options, therapies, models of care can be said to be patient-centered if they are based on the principles and values that define patient-centeredness. These principles and values are brought together in the only global definition of patient-centered healthcare defined by patients themselves; the International Association Patient Organizations (IAPO) Declaration on Patient-Centered Healthcare. (www.patientsorganizations.org)

The Declaration outlines five principles:

- Respect.
- Choice and empowerment.
- Patient involvement in health policy.
- Access and support.
- Information.

These principles promote greater patient empowerment, responsibility and optimal usage by prioritizing patients' needs and experience of healthcare in determining how care is delivered.
Supporting empowerment needs to happen at all levels

Empowerment of citizens and patients is a task which involves and encourages interaction of communities, health care professionals, policy makers and all other civil society actors with respect to health and well being of individuals.

Empowering patients means providing them with the opportunities and the environment to develop the skills, confidence and knowledge to move from being a passive recipient of care to an active partner in their health care.

Strengthening health literacy, protecting and promoting patient’s rights, and ensuring participation of patients and citizen in decision-making processes and providing self management support are all ways to achieve this. Empowerment needs to take place simultaneously both at the population and the individual level. It is a multi-dimensional social process through which individuals and groups gain better understanding and control over their lives. The benefits of this approach are numerous for patients, for healthcare professionals and health systems.

However, for this to occur it needs the joint action of stakeholders from the public sector, civil society organizations, professional groups and academia to support advocacy, resource generation, exchange of experiences, encourage participation, and to build capacity in communities.

The Innovative Care for Chronic Conditions Framework (ICCCF)\(^1\) (see figure on page 6) summarizes the basic elements for improving care in health systems at the community, organization, practice and patient levels and is thus a way to illustrate the comprehensiveness of working on enhancing patient empowerment.

As its ultimate goal, the ICCCF envisions informed, activated communities and patients – thus an empowered patient – interacting with a prepared, proactive, motivated practice team, resulting in high-quality, satisfying encounters and improved outcomes.
Innovative Care for Chronic Conditions Framework

Positive Policy Environment
- Strengthen partnerships
- Support legislative frameworks
- Integrate policies
- Provide leadership and advocacy
- Promote consistent financing
- Develop and allocate human resources

Community
- Raise awareness and reduce stigma
- Encourage better outcomes through leadership and support
- Mobilize and coordinate resources
- Provide complementary services

Health Care Organization
- Promote continuity and coordination
- Encourage quality through leadership and incentives
- Organize and equip health care teams
- Use information systems
- Support self-management and prevention

Better Outcomes for Chronic Conditions
How do health systems need to be re-shaped in order to empower patients?

Health systems have often been organized with the needs of the clinician and the system taking priority in the delivery of care to patients. In such a model the professional is at the center of the system – he or she has exclusive access to knowledge and the patient is expected to comply with the instructions given by health professionals.

In many countries this is now changing: health care is considered a process of co-production in which professionals and patients jointly work on solving health problems with the inclusion of the wider support networks such as his/her family and support group.

In order to implement such a model the following changes are suggested:

- Both professionals and patients are required to change a mindset which is based on hierarchical expectations towards one based on dialogue and co-production.
- Health systems and their functioning need to become more “readable” so that patients can navigate them according to their needs.
- Health professionals need to be effective communicators and listeners.
- Information needs to be much more easily available and understandable.
- Patients need to prepare for the interaction with the health care systems, ask questions, express needs and expectations and implement jointly agreed treatment programmes.

Health services and health professionals support patient empowerment by supporting self-management, working with the patient in an equal partnership, on an equal platform. This means that the focus is very much on the patient. What is important to note is that this empowers the lives of not only the patient but also of those who support people with long-term health conditions.
Characteristics of an empowered patient

An empowered person is able to actively participate in the management of their health.

An empowered activated patient:

- Understands their health condition and its effect on their body.
- Feels able to participate in decision-making with their healthcare professionals
- Feels able to make informed choices about treatment.
- Understands the need to make necessary changes to their lifestyle for managing their condition.
- Able to challenge and ask questions of the healthcare professionals providing their care.
- Takes responsibility for their health and actively seeks care only when necessary
- Actively seeks out, evaluates and makes use of information.

Empowered patients will better understand how to navigate the many players in the healthcare system including family, physicians, health insurers, healthcare regulators, pharmacists and when unsure about where to go or what to do next, will feel confident to ask for the information they need.

As an empowered patient, it is likely that they feel confident in following the jointly agreed decisions they have made with their healthcare providers which leads to an improved patient experience.

Not every patient is capable, or wants to make decisions about their health and not all patients have the skills to interpret the choices and instructions formulated by the health care provider.

Healthcare providers need to take the psychological wellbeing and the person’s ability to take responsibility for their health into consideration when involving the patient in making choices in the treatment and management of their long term health condition.
Empowering families of people with chronic disease

It is not only important to empower patients, but to support families and other informal carers. Informal carers may carry a large share of care provision. Supporting their role, training, and protecting their well-being has positive outcomes for the health of carers and the people they care for.

Key actions are:

- Provide official recognition, financial support and social security benefits to informal carers.
- Involvement of informal carers in decision-making processes regarding health policy and services.
- Provide professional home visits and regular communication between professionals and informal carers, including assessment of health and safety conditions and technical aids.
- Use the informal carers’ experience of the cared-for individual in the training of professional carers.
- Provide mental health protection measures for informal carers such as possibilities for flexible and part-time work, peer support, self-help, training and tools to evaluate carers’ own mental health needs.

Families can also be empowered by being invited by healthcare providers to participate in meetings between the patient and the healthcare provider. Also, families can be empowered by setting up family networks in local communities where family members have the opportunity to share knowledge, experiences and worries with other family members in terms of psychosocial support and training.
What is Chronic Disease self-management?

Self management is generally defined as the day to day activities that an individual carries out to manage their long term health condition. Self management recognizes that the individuals own behaviors, beliefs and emotional state can significantly affect their health outcomes and quality of life, and that the individual is responsible for making changes to these behaviors with the support of the health care professionals.

These activities may include:

- Changing diet and levels of exercise.
- Learning to deal with anxiety and depression.
- Making changes to employment.
- Actively monitoring their symptoms and reporting unusual changes to their health care team.

On another level, self management may be seen as the transformation of the doctor /patient relationship away from a traditional paternalistic arrangement to one of partnership, where the patients experience and expertise is fully utilized.

Self management support refers to the services put in place to support the person to make positive changes to their lives and to maintain those changes. This may include courses for people when newly diagnosed e.g. diabetes, angina or generic courses that provide support for the management of common symptoms and behaviours such as pain, fatigue, stress and diet. Individual coaching, telephone support and online programmes are also commonly used.

Skills for health care professionals

To ensure that self management and self management support is effective then it is essential that both people with long term health conditions and the care teams are supported in developing the core skills that enable changes in health behaviors and beliefs’.

The skills for health care professionals have been identified as (but not limited to) (Wagner et al. 2001):

- Establishing an empathic clinician-patient relationship
- Joint agenda setting for each consultation
- Collaborative goal setting
- Exploring ambivalence about change
- Using problem-solving skills
- Using systematic tools to support goals’ follow up.
Implementing support for self management

From the perspective of health care professionals (HCP), who want to set up educational programs, there are many possible approaches.

Self management programmes may be delivered by a variety of people including health care professionals, clinical psychologists and trained lay people who may be volunteers. To some extent who delivers the programme is dependent on the outcomes required.

Health care professionals are effective where information and support around treatments and medications are important, peer programmes are very effective for lifestyle change. Programmes may take the form of small groups, one to one support, web based group and individual programmes.

Key points to consider:

- Programmes need to be fully integrated into the local care system and community services.
- Programmes need to be adapted to meet regional and cultural differences.
- Good support from senior clinicians is essential.
- Local charities and the voluntary sector can be very good at delivering self management support provided it is closely linked to the care pathway.
- Programmes that use goal setting, problem solving, and motivation and are interactive and encourage participation are more effective that those that just providing information.²
- Referral to self management programmes should be based on identification of support needs through a collaborative process with their clinician.
- The quality of the people delivering the programme can have a significant impact on outcomes.
- Patients themselves are a good resource. With the right training and support they can deliver non clinical health education to the same standard as health professionals.
- Detailed planning matters – consider carefully the venue, time of day, transport and access, length and timing of sessions.
- Put in place systems for monitoring outcomes and quality.
- Actively engage with participants before courses start; make sure people attending courses are well informed of what to expect and are encouraged to attend- just sending a letter is not enough.
- Systems for evaluation/ assessment should be developed parallel to the programme.
The evidence for self-management programmes

The evidence for self-management is still developing and there is a lack of systematic reviews to draw upon. The definition of self-management is very broad so studies often involve very different interventions and populations which make comparative reviews problematic.

The Danish Centre for Health Technology Assessment found that overall, most studies in the field indicate that group-based patient works. However, the level of evidence and results vary between different types of interventions and target groups and therefore there are inconclusive findings.

The varied quality of research in this area means that further evaluations of group-based patient education and self-management interventions are needed to build a solid evidence base.³

Although Self-management support and research into what works is still in its infancy, there is rapidly growing agreement across health departments and in Governments that self-management does work and those strategies which enable behaviour change are fundamental to improving health outcomes.

Self-management interventions are very varied. There is emerging evidence that those interventions that specifically aim to increase patients' levels of self-efficacy or activation are more likely to produce positive outcomes in terms of behaviour change and health outcomes.⁴

An example of an evidence-based self-management program is The Chronic Disease Self-management Program (CDSMP) developed by the Stanford Patient Education Research Centre.⁴ A review conclude there is moderate to strong evidence that the program improves the patients' self-rated health, health distress, pain, fatigue, disability, cognitive symptom management, physical activity and self-efficacy⁶ and one review concluded the program might have a potential to have an impact on public health if implemented in a large scale.⁷

Researchers have also started to consider the wider benefits of self-management support meaning its social impact on people's everyday lives.

Early findings from social return on investment (SROI) studies indicate that having access to self-care programs can support individuals to become re-engaged with the local community as productive citizens with meaningful activities. This can take many forms including improved relationships with family and friends, engagement in volunteering, further education, or positive employment-related outcomes.⁸
Seeing people with long term condition as a resource

People living with a long term health condition have a unique set of experiences which enables them to support others through volunteering or indeed paid employment, and provide a different perspective to that of health professionals.

Studies have shown that lay people are effective in providing self management support. People with long term health conditions who are actively managing their own condition and have made positive life changes can act as effective role models and support to others to make positive life changes.

Since we spend more than 99 % of our life without health care professionals present, the potentials in the knowledge-sharing and peer support are nearly unlimited. Every person has experience and tools for handling numerous challenges. If this potential is structured so that people can learn from each other, the need to use health services will be reduced, leaving more time to discuss issues where the presence of health care professionals are indisputable.

People living with a long term health conditions are often regarded as a cost to health services and a drain on resources. In fact people living with chronic disease can be a rich resource and an asset.

Engaging with patients and seeing them as a resource is known as co-production. It is an acknowledgement that people’s needs are better met when they are involved in an equal and reciprocal relationship with professionals – working together to get things done. There are six core principals:

- Recognising people as assets.
- Building on people’s capabilities.
- Promoting mutuality and reciprocity.
- Developing peer support networks.
- Breaking down barriers between professionals and users.
- Facilitating rather than delivering.
CASE STUDIES

A series of short case studies of programmes that support patients to take control.

Case study 1
Substance and Alcohol Misuse – SAM

Expert Patient Programme CIC in partnership with Wirral Drug and Alcohol Action Team (DAAT) piloted a programme for people in recovery from substance and alcohol misuse. The courses delivered have been very successful with self-reported changes to lifestyle and an increased awareness of healthy behavior. There is also an improved knowledge of how to access external agencies. This creates a sense of gaining control over the recovery process and enhances self-esteem and confidence. A Social Return on Investment (SROI) study demonstrated favorable outcomes for the course.

http://www.expertpatients.co.uk/

‘I used drugs for 30 years, my life was in a mess and I couldn’t take it anymore. I contracted Hepatitis C because of my drug use and while in recovery, someone recommended the Expert Patients Programme Substance and Alcohol Misuse (SAM) course to me. It came at a crucial time as I really needed the support as it was still early days in my recovery. The things I learnt and the group I was part of helped my confidence to grow and I started to achieve things I hadn’t thought I was able to do before.’

Dougie, Wirral
Case Study 2  
Active Learning Facilitators (ALF)  
– Lambeth, London

The ALF Project a small scale, local pilot project which has succeeded in engaging people with long term health conditions to become actively involved with improving the lives of other patients and service users. The core activity is a skilled conversation between a trained learning facilitator and patients and service users attending local GP surgeries. We have learned from listening to many patients on how valuable these conversations have been in helping them think about becoming actively involved in learning. key aims were to:

- Mobilize the potential of local people with long term health conditions including expert patients/service users to become expert facilitators of informal adult learning.
- Design and implement a model of self-managed learning that drew its strength from self-management and self-care in the health sector.
- Engage with people from amongst those sections in our community who experience on a daily basis, the human cost of social exclusion, health inequalities, loneliness and isolation.
- Offer help and support to patients and service users by encouraging them to become actively involved in learning of their choice and by doing so increase confidence and interest in learning and personal development.
- Recruit new cohorts of active learning facilitators from amongst patients and service users whom we were to meet in GP surgeries and other health related locations.
- Explore the potential of GP surgeries to become the organizational context for developing new learning activities in support of active patient and public involvement.

In the words of one ALF:

*I now have the confidence to go to engage with patients, service users and NHS staff in GP surgeries in Lambeth. I can understand and empathize with people with long term health conditions who are caught up in dealing with their health condition. I help facilitate their learning and focus on self-management and decision-making skills. They trust me as I have a long term health condition myself but I am a facilitator and active expert patient. I identify with the issues they’re going through and am a resource for them for further learning and engagement in the local health system.*

Institute for Leadership and Service Improvement Faculty of Health and Social Care, London South Bank University
Case study 3
Involving patients in creating a disease specific self management programme

The National Rheumatoid Arthritis Society (NRAS) and Expert Patient Programme CIC jointly developed the Rheumatoid Arthritis Self-Management Programme (RASMP) which is a disease-specific self-management programme for adults who are currently being treated for autoimmune inflammatory disease (rheumatoid arthritis (RA)). The programme has been developed with input and feedback from people living with RA and rheumatology health professionals at each stage. The pilot evaluations for RASMP have shown very encouraging outcomes and a clear increase in the acquisition of health-related skills and techniques with which to manage symptoms. www.expertpatients.co.uk/
Case study 4
Patients as mentors

EPP CIC working in partnership with the South Central Strategic Health Authority (SHA) and three universities in the south of England has developed a mentorship programme. Volunteers who live with long-term health conditions have been trained as mentors to students undertaking the Health & Social Care Foundation degree course. The primary aim of the project is to offer students an opportunity to gain a greater insight into the day-to-day lives and associated challenges of those who are living with long-term conditions. Mentoring facilitates students learning through reflection and helps them develop a clearer understanding to positively influence future health and social care practice. This programme empowers by placing healthcare service users at the centre of the education of healthcare students.

www.expertpatients.co.uk/
Case study 5
A government led initiative
– The Expert Patient Programme (England)

The Expert Patients Programme was a government initiative started in 2002 in England and later Wales with the aim of providing and evaluating large scale self management support using the ‘Chronic Disease Self-Management Programme’ (CDSMP) developed by the centre for patient education at Stanford university and derivatives of, throughout England, in line with the objectives of the Government’s White Paper “Our Health, Our Care, Our Say”. One of the main purposes of EPP is to improve the health and well-being of individuals in their own community and to reduce health inequalities. Its’ health programmes are designed, developed and delivered with and by people living with long-term health conditions. The results of a randomised controlled trial showed the programme to be fully cost effective.

The CDSMP has been delivered in a number of community languages and the programme has also been converted into a number of condition specific programmes for example: Substance and Alcohol Misuse, mental health, Persistent Pain as well as adoptions for the visually impaired and people with learning disabilities.

In 2006 the Department of health created a community interest company – the Expert Patient programme CIC to continue the programme.

http://www.expertpatients.co.uk/
Case Study 6
An integrated approach to self management – Co Creating Health

The Co Creating health project worked across four disease types (diabetes, depression, Pain, COPD) and eight acute and primary care sites this to combines self management courses for patients with skills training for clinicians supported with appropriate service re-configuration.

The early evidence from phase one shows that after attending the Self Management Programme people indicated:

- Significant changes in positive engagement in life (statistically significant.)
- Adopting a more constructive attitude and approach to their condition.
- Having more positive emotional well being.
- Increased usage of self management skills and techniques.

After completing the training, clinicians are more likely to:

- Apply self management support practices in their consultations.
- Have an increased motivation to improve their practice and greater belief that improvement is possible.
- Increased job satisfaction and a greater sense that they are now ‘helping people’ in a way that reflects why they came into healthcare.

These programmes demonstrate the added benefit of integrating self management support across the care pathway.
Case study 7
Switzerland: Evivo – implementing the Stanford model with a partnering approach

Careum, a private independent Swiss Foundation, has been working with British and Danish organizations on implementing the Stanford model in Switzerland and German-speaking countries. Careum’s main reason of working with the Stanford model is the main principle of peers as course leaders and, thus, emphasizing a new role of “patients” in health and social care. Most importantly, patients and their families and partner organizations are always involved in the process and provide valuable feedback, which facilitates the implementation.

A core emphasis has been on networking and collaborating with national as well as international partners in order to translate, adapt, and successfully implement the Stanford approach in Switzerland as well as Austria and Germany – here it is known as the course program «Evivo – Gesund und aktiv mit Krankheit leben». Later in 2012, a French version of Evivo will be available.

Early findings from the very first Evivo courses in Switzerland and Austria suggest that the Stanford model is working in these countries and the experience of both participants as well as providers mirrors those described in other countries. Early feedback underlines the impact of the program on motivation, self-efficacy, lifestyle change, decision-making and action planning.

Of particular value for Evivo’s implementation is the partnering approach based on Careum’s principle of an on-going dialogue with various stakeholders in the healthcare system. Implementing Evivo not only includes partnering with organizations that deliver courses but also more strategic partnerships with institutions.

Besides working towards a French version of Evivo and running its evaluation until 2013 Careum will develop additional programs for people with chronic conditions based on the principle of patient engagement and partnering. Especially working with ethnic minorities and vulnerable groups will be pursued and the development of an online approach for self-management support for chronic illness is a top priority.
Case study 8
Denmark: Implementation of Chronic Disease Self-Management Programme (CDSMP) – the Danish version

In 2003, the Danish National Board of Health (NBH) was approached by the Danish Arthritis association (Gigtforeningen). They wanted to test the programme CDSMP from Stanford University. At the same time a need had been identified for exploring the implications and possibilities of patient education, as one of the strategies in the national recommendations. The National Board of Health decided to test CDSMP, with the focus of suitability for implementation, recommendations for cultural changes and the response from Danish patients.

A pilot study was conducted in 2004-5 and the conclusion was, that the programme was suitable for a national dissemination in Denmark From 2006-2009 the Danish Committee for Health Education in cooperation with the National Board of Health introduced the Danish version of CDSMP (Lær at leve med kronisk sygdom) to 78 out of 98 municipalities.

The central tasks of KFS was:

- Education, supervision and certification of peer educators.
- Support of operation in the municipalities.
- National publicity.
- National research studies of outcomes using randomized control trial and longitudinal studies.
- Implementation of programmes to specific groups.

National quality assurance and support of local quality assurance, e.g.: Providing and operating web based evaluation tools that makes it simple to work with QA on a local basis within the municipalities as well as a on a national basis.

KFS has also adapted the Chronic Pain Self-management Program for people with chronic pain conditions and New Beginnings, a program for people with mental health problems. The pain program is implemented in 45 of 98 municipalities and the outcomes are evaluated by Aarhus University Hospital, Denmark. New Beginnings is being tested during 2012.

KFS has participated in creating a patient education programme targeting Heart disease, Lung disease and Diabetes type 2. the first preliminary results have been positive. KFS teaches health care professionals about patient empowerment strategies and chronic disease as well as supporting national and international partners in implementation.
Case Study 9
The WHO-European Commission Partnership Project on Empowerment in Mental Health

The World Health Organization Regional Office for Europe and the European Commission started a partnership project on “Empowerment in Mental Health” in 2008 with the objective to build environments in which people with mental health problems are enabled to develop and express their full potential as equal citizens, are free from discrimination, and they receive services according to their needs and choice.

Partners from mental health service user and family associations and other experts from policy, human rights, civil society, health services and academia planned and developed a broad range of project deliverables such as the conferences on Mental Health and Well-being at the Workplace – Protection and Inclusion in Challenging Times in Berlin, Germany, in 2009 and on “Empowerment in Mental Health – Working towards Leadership” in Leuven, Belgium, in 2010, a WHO statement on empowerment in mental health including recommendations for action, as well as empowerment indicators applicable at national level and about 100 examples of good empowerment practice from 30 countries across the European Region.

The WHO-EC partnership project, its outcomes and deliverables, will also inform the new WHO Mental Health Strategy for Europe to be presented in 2013. This strategy will signal the direction for mental health activities in the European Region, covering a broad scope including population mental wellbeing across the life stages, protection of rights of service users, effective forms of interventions, access to good health care and social inclusion.
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