



**EPF/FPP Conference under the Polish EU
Presidency**

**The Rights and Needs of Older
Patients**

Warsaw, 12-13 July 2011

Report

Introduction

The current challenges confronting health and welfare systems are well known. Demography, sustainability, the shift towards personalised medicines... Where does all this leave older patients and their carers? What are the opportunities and threats that confront society in addressing these challenges, whilst maintaining the respect, dignity and quality of life of older patients with chronic diseases? How do older patients fit into the current political discourse on 'Active, Healthy Ageing'? These are the questions that the EPF/FPP conference sought to address.



Over 100 participants, including high-level policy makers, representatives of health professionals, patients' organisations, and older patients themselves, gathered at the conference organised by the European Patients' Forum (EPF) and the Polish Patients' Forum (FPP) in Warsaw on 12-13 July to explore key challenges and opportunities around ageing and older patients.

Ageing is a theme of particular importance from EPF's perspective, which is that of patients with chronic diseases: the general population is ageing, many chronic diseases become more prevalent with age, and patients with chronic diseases developed at a younger age are living longer, thanks to modern medical treatments. As persons with chronic diseases age and older people acquire chronic diseases and co-morbidities, they develop specific needs.

EPF's activities on ageing started in 2010 when the EPF board decided to develop a strategy for the needs of older patients, with the aim of enhancing intergenerational solidarity in the patients' movement. EPF initiated work in this arena with a member consultation during December 2010 and January 2011, resulting in a strong patients' contribution to the Commission's consultation on the pilot European Innovation Partnership on Active and Healthy Ageing¹. The European Patients' Forum has been very closely involved in the Partnership: EPF President Anders Olauson was represented on the High-Level Steering Group, which during 2011 drafted the Strategic Implementation Plan for the partnership². The EPF Secretariat participated in "Sherpa" meetings and preparatory workshops, in which several members were also involved.

¹ <http://www.eu-patient.eu/About-EPF/Responses/EPF-responds-to-the-Commission-consultation-on-European-Innovation-Partnership--Healthy-and-Active-Ageing/>

² http://ec.europa.eu/research/innovation-union/index_en.cfm?section=active-healthy-ageing&pg=implementation-plan

In this context, the aim of the EPF/FPP conference on the rights and needs of older patients, held in July 2011 in Warsaw, was to exchange experiences and insights with stakeholders at EU and national levels on how to ensure high-quality, patient-centred, equitable care for older patients, and how to face this challenge while addressing their needs, respecting and improving their rights, quality of life and dignity.

During the conference “*real partnership*” – in the words of Deputy Director of DG SANCO, Mr Martin Seychell – between all stakeholders including doctors, carers and older patients themselves was called for, as a cornerstone for change.

Throughout the event the participants explored together the current initiatives and policy at EU level and debated how they can help address the needs of older patients: the Innovation Partnership on Active and Healthy Ageing, the EU Presidency priorities, the 2012 European Year for Active Ageing and Solidarity between Generations, and the Framework Programmes, all offer a wealth of opportunities to design a strong, multi-faceted and joint response.

Following the plenary sessions, participants reflected together in five thematic workshops that addressed fundamental issues for older patients, in order to bring forward their recommendations and ideas for actions. They held lively debates and agreed on recommendations for national and European level decision makers, for EPF and other stakeholders.

This report gives an edited version of the presentations and contributions as well as a comprehensive account of discussions which took place in the workshops and their final recommendations.

Day 1- Plenary Session

Setting the scene: Why this conference is different? What are we trying to achieve?

Mr Anders Olauson, President of EPF, opened the conference and welcomed participants and speakers. He noted that this was the first event which focused on the rights and needs of older patients at European level; a key aim of the conference was to enable patients' organisations to contribute meaningfully to EU policies on healthy and active ageing, and to the pilot European Innovation Partnership's goal to achieve two extra healthy life years for European citizens by 2020.

He highlighted that EPF had been involved at all levels of the partnership: "We are keen to ensure that the outcome of this conference will contribute meaningfully to the Strategic Implementation Plan". The recommendations will furthermore shape an EPF position paper on older patients that will feed into other policy debates such as e-health, personalised medicine, patient-centred chronic disease management, and patient safety.



Mr Tomasz Szlagowski, Director of the Polish Patients' Forum and

Treasurer of the EPF Board, also welcomed the participants, and highlighted the strong collaboration of the Polish Patients' Forum and EPF. He stressed the importance of the conference for patients in Poland. Asserting that the outcomes of the conference needed to reach the patient communities in Poland and other EU Member States, he highlighted that the conference should not be "only words and no action". He then drew an analogy between current challenges facing our healthcare systems and the challenge of rebuilding a great capital city, such a Warsaw after the war, and concluded the aim was to eventually build great healthcare systems together.

Opening Session: Framing this Conference within EU Policy on Active and Healthy Ageing

Speaking in the opening plenary, **Mr Andrzej Witold Włodarczyk**, the Polish Undersecretary of state for Health, expressed his pleasure that the meeting was taking place in Warsaw at a time where the city became the capital of Europe for a few months. He noted that the topic of the conference fitted within the Polish Presidency of the EU, as the ministry of Health had identified older age problems as one of the leading subjects and stressed that the problems of older people were well understood by the Polish government. In the near future, the population in Poland, and Europe, would have a much greater proportion of older people. Therefore, the Polish government decided to take proactive action to meet the challenges facing our healthcare systems.

Mr Włodarczyk then presented actions to meet this challenge in Poland. This included the creation of an Institute of Geriatrics to train specialists, promote a holistic approach to older patients, and develop solutions to be implemented in the Polish healthcare system. Its objective would also be to raise the profile of geriatrics as a speciality and make it more attractive. This institute would also be in contact with other similar institutions across Europe. Further, the Polish government had plans to create a team to modernise the financing of social and healthcare of older people.



Mr Martin Seychell, Deputy Director-General for Health and Consumers (DG SANCO), presented the context behind the European Innovation Partnership on Active and Healthy Ageing, and its ambitious target to increase the average healthy lifespan by two years by 2020. He warned that although our life expectancy is growing, this is not matched by an equivalent increase in healthy life years,

which means that people will live longer but with their last years in ill health. The Partnership is a vital element of Europe's response to the demographic change: he affirmed that we needed to take action now to avoid the risk of being overwhelmed by budget constraints and unsustainable healthcare systems.

The Partnership pursues a triple win for Europe: enabling EU citizens to lead healthy, active and independent lives while ageing; improving the sustainability and efficiency of social and health care systems; and boosting and improving the competitiveness of the markets for innovative products and services, responding to the ageing challenge at both EU and global level, thus creating new opportunities for businesses. It does not create a new financial instrument but aims at maximising the potential of existing tools³. The partnership had agreed on three priority areas: early diagnosis and prevention; care and cure; and independent living. He claimed the Innovation Partnership could trigger "a paradigm shift" towards better care and quality of life, partly through the introduction of innovative products, devices and services.

Mr Seychell stressed that "patients and older citizens need to play a very important and central role, and to be involved in the process"; he noted the important role EPF played as an ambassador within the Steering Group to echo the views of patients, and advocate for their rights and needs. "An ageing Europe needs, more than ever, patients who will be sufficiently aware and informed to be able to take decisions on their own and inform other decisions" he declared.

³ More information about the partnership is available at: <http://ec.europa.eu/active-healthy-ageing>

Dr Antonia Parvanova, Member of the European Parliament (ALDE, Bulgaria) highlighted that the European Commission's Innovative Partnership was a very ambitious initiative, as it would also take into account the economic crisis, and because of the great challenges ahead. Discussing the goal of two more healthy life years, she asked whether adding two years of "life without disability" is enough; adding that indicators should be developed to measure not only physical but also mental health, well-being and social inclusion. This echoed a key recommendation which many participants stressed throughout the conference: health needs to be addressed in a holistic way.



Ms Parvanova further said that examining the rights and needs of older people we need to look at health policy in a wider way, but EU Member States are reluctant to co-operate in this area. Pointing out health inequalities, illustrated by huge differences in morbidity rates for tuberculosis and cancer between countries, she said: "We have to challenge this ... issue at EU level." A number of changes were needed in healthcare: appropriate drugs for patients; investment in innovation and infrastructure; and healthcare management which need to be readjusted both geographically and in terms of organisation. She also stressed that by 2020 there would be a shortage in Europe of one million healthcare professionals: as a result new ways have to be found of attracting young people into caring for older people, including better training and pensions. Mrs Parvanova also stressed the importance of health literacy, as the burden of chronic diseases is increasing and as patients tend to be affected by multiple diseases. People need to have "self-management" skills for their health, for example to be able to take the decision to see a doctor early enough when they have symptoms.

Ms Marie-Claire Pickaert, from the European Federation of Pharmaceutical Industry Associations (EFPIA), started her intervention presenting a picture of an old woman with the statement "I'm old and I like it" to illustrate that a change of the perception of ageing is necessary in our society. She observed that healthy ageing is a lifelong challenge. She stressed the support of EFPIA for the Innovation Partnership, calling it a "dynamic process to develop fresh ideas" and summed up the triple win as "healthy older people, healthy public finances and healthy business". But she warned that learning how to introduce innovation in healthcare systems is a challenge. An integrated approach is needed to prevention, early diagnosis, care and cure, to improve standards and adherence and better use of resources



Industry could contribute expertise in the self-managing of conditions, and the linked issues of adherence and polypharmacy; in exploring the role of specific therapeutic or preventative interventions like vaccinations; and in providing access to data which could allow for a

better understanding of treatments in older patients. Healthcare outcomes research and Health Technology Assessment are also areas where the industry could give input. To conclude her intervention, she came back to the issue of adherence, explaining that barriers to adherence to therapy are more common in older patients and warrant particular attention in clinical management. For older patients memory difficulties may be exacerbated by other medications or early dementia. In addition, they often receive treatment for several other chronic health conditions simultaneously.

Commenting on what he heard throughout the session, Anders Olauson, who chaired the meeting, highlighted that the picture drawn by the speakers of how the citizens will be tomorrow, illustrated that a very different healthcare would be necessary in future to respond to their needs.

A case study on older patients with chronic respiratory disease



Prof Bolesław Samoliński, Chairman of the Subcommittee of the Ministry of Health for Priorities of the Polish Presidency at the Medical University of Warsaw, said the leading public health priority of the Polish presidency was “to close the gap in the health status of the EU’s member states”. Concerted action was needed for decreasing premature mortality through public health measures aimed at reducing harm caused by smoking, hazardous alcohol drinking, inappropriate diet and lack of physical activity. A ministerial conference

would be held on 7-8 November 2011 in Poznan with the aim to adopt draft Council Conclusions⁴.

Prof Samoliński further highlighted that brain diseases were a particular type of problem, due to their impact on older patients, their family and society: diagnosis and treatments are costly, and not always efficient; and the diseases often lead to disabilities. He said guidelines should be included in the European Union documents on, for example, improving care through an interdisciplinary, professional and multi-sectoral approach, integrating health and social assistance.

Other health priorities of the Polish Presidency were the prevention and control of respiratory diseases in children, and the prevention and treatment of communication disorders in children, including with the use of eHealth and innovative solutions. Taking the second priority as a case study, Professor Samoliński explained that rhinitis, allergic rhinitis and asthma are the most common chronic non-communicable diseases in children – and they are a risk factor in developing COPD in older age. Prevention, health education, and pro-health attitudes in society therefore have a key role to play in preventing the occurrence of respiratory diseases in children and at a later age. He concluded that “healthy ageing starts with children’s health”.

⁴ http://www.consilium.europa.eu/uedocs/cms_Data/docs/pressdata/en/lsa/126522.pdf



Ms Christine Rolland, Vice-President of the European Federation of Allergy and Airways Diseases Patients' Associations (EFA) said new thinking was needed in finding solutions for the millions of patients with COPD, allergy and asthma. Describing the scale of the problem, she said that currently in Europe, 4 to 10 per cent of adults (or 44 million) have COPD, costing €102 billion and increasing; 21 per cent of COPD patients are severely disabled; and "COPD is predicted to be

the third leading cause of death in 2030" according to WHO. In addition, 80 million people have allergy, and one person every hour dies from severe asthma in the Western world.

She drew a picture of the multiple difficulties faced by patients in their everyday life: Patients may be afraid of dying to their next asthma attack, or may be itching all the time because of atopic eczema. They also need to be prepared for what may come around the corner, whether it is second-hand smoke or a peak of air pollution. The impact on life can be heavy, particularly when the disease leads to early retirement, with negative financial consequences, social exclusion, and psycho-social issues, as well as challenging situations for carers.

She said that older people, including those with chronic diseases, should be seen as a resource – not a burden. The focus should be on what could be done – not what could not; and that greater use should be made of the "army of volunteers". Commenting on Professor Samoliński's presentation, she welcomed the focus on respiratory diseases in children of the Polish Presidency, but highlighted that from a patients' perspective what is needed to truly bring about change is an integrated approach addressing all aspects: inequalities, healthy ageing and innovation, sustainability, health in all policies, and chronic diseases. This could be done, Mrs Rolland said, through an EU strategy/action plan that facilitates comprehensive patient-centred national programmes, and a chronic disease agenda with work streams for different diseases.

2012: European Year for Active Ageing and Solidarity between Generations – exploring its potential impact in promoting the rights of young and older patients

Ms Halina Potocka, Vice President of AGE Platform Europe, a social NGO which represents 30 million older people, said there should be greater focus on older people being a resource, “not a burden”. AGE manages six expert groups in 27 different countries, tackling issues from discrimination to pensions and health, aiming to voice and defend the interests of older people. The association also participated to several health related projects, including the EUSTACEA project on elder abuse, which led to the publication of a European charter and guide on the rights and responsibilities of older people in need of long-term care and assistance. Ms Potocka called for a holistic approach to the definition of healthy ageing. She quoted the definition from the Healthy Ageing Project, which ended in 2007: “Healthy [and active] ageing is a process of optimising opportunities for physical, social and mental health to enable older people to take active part in society without discrimination and to enjoy an independent and good quality of life”.

2012 is the European Year for Active Ageing and Solidarity between generations, and Ms Potocka emphasised this as an opportunity to promote positive images of older people. AGE had played a leading role in the campaign for the theme year, with the objective to promote active ageing in employment, in the community, promote healthy and independent living, and enhance cooperation between generations. She noted that synergies exist between AGE and patient organisations, and that for the year 2012, everyone has a role to play.

Ms Potocka also presented the perspective of AGE on the Innovation Partnership: innovation should not be only focused on pharmaceutical and healthcare industry, but we should mobilise and build synergies between all relevant EU programmes to empower stakeholders at all levels – also looking at complementarities with the European Year 2012’s objectives⁵.



Dr Piotr Błędowski, a gerontologist representing Eurocarers, pointed out the increasing 80+ cohort combined with the low birth rates. He presented statistics predicting an important rise of single households of people aged over 65 in Poland. At the same time, a 2009 self-assessment of health condition survey conducted in Poland in 2009 showed that as people age, they tend to assess their health condition as poor; only 2 per cent in the 16-29 age group do so, but in the 75+ age group it is 58 per cent. At the same time 63 per cent of 60-74-olds declared they have long term health problems.

Thought should be given to who will take care of “the silent army of informal carers”. Profound changes to social services are needed to help families and individuals, and it is of the utmost importance that public administration gives support to informal carers through training and support to remain in employment, he said.

⁵ <http://europa.eu/ey2012/>

How to encourage a coordinated research agenda that centres of the needs and rights of older patients: New opportunities within the EU Framework Programme on Research and Development (FP7)

Research on ageing is a relatively young field, said **Ms Beatrice Lucaroni**, Project Officer at the European Commission's Directorate General for Research and Innovation, who gave an overview of new opportunities within the Seventh EU Framework Programme (FP7), which has received €6.1bn for collaborative health research. She explained collaborative includes research between countries, different types of organisations, and across policy fields. She observed that Framework Programme funding creates multidisciplinary platforms to address basic scientific issues, diseases, as well as public health and quality of life. She noted that in FP7, already €127m were invested in human development and ageing, and call 6 had up to €220m flagged topics to support the Active and Healthy Ageing Partnership, making ageing the first priority in this call.

Ms Lucaroni went on to give examples of collaborative projects, such as PHASE⁶ or CHANCE⁷, and highlighted projects on patient involvement in research and clinical trials, mentioning that patient involvement was encouraged within the call for proposals recently opened. The EPF-led Value+ project, which provides an overview and analysis of current practice and trends on patient involvement in EU health projects, was used a reference point under certain calls; the PatientPartner project⁸ on patient involvement in clinical trials, and PREDICT⁹, which looked at the participation of older people in clinical trials and led to the publication on a charter, were also referred to.

She also explained how DG research identifies research priorities for the future: a number of bodies are involved in the process, such as the Health Advisory Group for the 7th Framework Programme, in which EPF President Anders Olauson participates, Programme Committee, and National Contact Points; The priorities are also based on conclusions from existing projects, on EU policy in the fields, and on the opinion of other institutions such as the Economic and Social Committee.

Ms Avril Daly, from the Irish association Fighting Blindness, and an EPF Board member, presented a case study on patients as partner in research, drawing on the work of her association, whose mission is to find treatments and cures for sight loss and provide support to patients. She took the success story of the associations' research on wet Age-Related Macular Degeneration as an example: the disease is the leading cause of blindness in the Western world and has social, economic and psychological impacts on patients.



⁶ <http://www.lumc.nl/con/9099/>

⁷ <http://www.chancesfp7.eu>

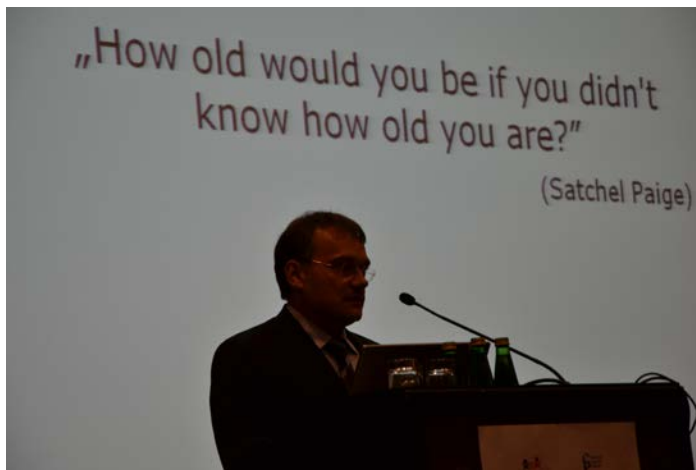
⁸ <http://www.patientpartner-europe.eu/en/home>

⁹ <http://www.predicteu.org>

While treatments have been developed, research is still necessary to improve them and particularly to facilitate treatment delivery, to improve efficacy, find preventive measures and a cure. Patient-led research @WIT established the link between obesity and the incorrect distribution of macular pigment, which increases the chance of developing AMD. Patient-led research @TCD is looking into the development of molecules capable of opening and closing the blood-retinal barrier (to allow drugs taken orally and dissolved in the blood). She concluded that patient-driven research, in partnership with key stakeholders, is giving results and must become a priority.

She also presented the key findings of the EPF-led project Value+ on the obstacles preventing patient involvement in research – prejudices, lack of resources, language and terminology barriers – as well as its benefits, which include the integration of researchers' theory expertise with patients' real-world knowledge and experiences, leading to higher trust and enhanced visibility for research results¹⁰.

Innovative Treatments for Older Patients



Dr Michal Kaźmierski, of the High Level Working Group for Innovation in Healthcare at the Medical University of Warsaw, drew attention to the fact that most clinical trials exclude people aged over 65, so little is known about how innovative treatments work in older patients. He called for change to include older patients in research to ensure the benefits and side effects of treatments are known. In addition, several other elements are necessary to enable older patients to benefit

from innovative treatments, such as the clinician's mindset, the patient's adherence, reimbursement policy, and even the packaging (as a study showed 40 per cent of patients aged 70 to 95 were not able to open child-proof bottles).

The High Level Group's main goal is to increase access to modern treatments and technologies through proposing systemic solutions supporting healthcare reforms. "Now is the time for action. It will be harder if we don't act," said Dr Kaźmierski. He highlighted that the recommendations of the working group were prepared by a number of specialists including doctors, economists, sociologists and patients. In 2010 they recommended to organize an expert-led professional debate on the legitimacy and opportunities to increase healthcare financing, as the group found lack of funds negatively affects the necessary modernization of infrastructure, upgrading of equipment, professional education, and wider usage of modern treatment options.

¹⁰ <http://www.eu-patient.eu/projects/valueplus>

A national perspective – integrating the needs and rights of older patients into national policies on ageing

Dr Eva Nilsson-Bågenholm, the newly appointed National Coordinator for Elderly Care at the Swedish Ministry of Health and Social Affairs, presented the context in Sweden. Like in the rest of Europe the population is ageing and developing multiple chronic diseases, but at the same time there is more publicly financed ‘elder’ care than anywhere else in Europe. She said there was dissatisfaction among older people, and a lack of knowledge on co-morbidities. Polypharmacy was also a major challenge.



She reported that Sweden was beginning to introduce a “compensation by results” system to improve health and social services for older patients. Currently patients can choose the hospital they want, but the government wants to extend that choice to social care, too. It has allocated 3.75 billion SEK for a three-year programme of widespread system reform. It is a huge task, and the country is developing quality indicators, making a start with the treatment and care of the most vulnerable group, the frail older people. The government is developing benchmarking between counties; the publication of results, aimed at improving the system, also provides patients with information.

Although different laws govern health and social care, Dr Nilsson-Bågenholm said that in her opinion, by 2014, Sweden would have taken quite a few steps towards coordinating health and social care throughout the country.

Day 2 – Workshops

On the second day, participants had the opportunity to explore in depth specific issues of crucial importance for older patients, in five parallel workshops. Below is a summary of the discussions that took place in the workshops, and their main recommendations addressed to policy-makers, other actors in healthcare, and patient organisations.

Workshop 1: Shared decision-making and empowerment for older patients

Moderator: Professor Dieter Lüttje (European Union of Medical Specialists, UEMS)

Report by Mr Gareth Davies (European Cleft Organisation, ECO)

Patients' empowerment and involvement is a key principle of patient-centred chronic disease management. This workshop explored how a concordance and shared decision-making approach with health professionals can support older patients' empowerment and involvement in their own care, contributing to better quality of life. Adherence to therapies and managing multiple medications were used as a case study.



Defining “old”

The participants started by exploring definitions of old age. For the WHO it is 65 and participants considered that over 80 is another sub-category. Old does not mean ill, but older people are more likely to experience multi-morbidity, and there will often be issues around polypharmacy which may present difficulties.

Barriers and enablers for shared-decision making

The group then brainstormed on key words that could capture the sense of ‘what *enables and/or what are the barriers to older patients being an accepted PARTNER in their care?*’

The following were identified as potentially either barriers or enablers: Time, Resources (money), Education, Coordination, Communication, Patience, Empowerment, Complexity (of treatment), Mistrust, Taboo health conditions (in the eyes of the patient), Psychological difficulties, Language (medical *versus* user friendly), Sensory problems.

There followed a wide discussion about the aim of partnership approaches. The group felt that if older patients were treated as partners in their care management, and with respect for their views and wishes, they would remain functional and independent. There is a clear economic argument for this.

Helping to realise older people’s full potential

Society's view of older people was identified as a major obstacle. Even in countries with opportunities to specialise in elderly care, there is a lack of people interested in taking up these positions. For example, in Sweden the majority of people interested in a career in medicine were attracted to more 'exciting' areas such as children's health or trauma. Furthermore, coordination of care is seen as vital for older patients: often health

professionals look after their individual specialities rather than the patient as a whole, and overall quality of life issues can be overlooked.

Society needs to learn to value older people and engage with them. Like young people, old people needed to be helped to realise their full potential. Older people could play not only a part in managing their own treatments but also supporting others. A positive example came from Belgium with evidence from the Alzheimer Cafés (La Ligue Alzheimer)¹¹. Not all of a person's faculties are affected by disease, and other mental functions can be stimulated to generate a sense of value and worth. Other examples of existing initiatives included the Expert Patient training programme developed in the UK, a concept that could be expanded and targeted at older people, with the aim of self-help and the training of older people to look after others. Who better can understand their needs than their own peer group? Perhaps old people are the solution, rather than the problem!

Other good examples included a small project in the Netherlands, funded by insurers and pharmacies, that showed how polypharmacy can be managed expertly; and the models for “patient universities” developed in Spain. The group stressed that the conference was the start of a process, not an end. Policy statements based on conference discussions would steer a strategic path towards solutions.

Recommendations

1. A single person should have the coordinating role in managing overall care

An older person needs a “care manager” or coordinator to bring all the elements of care together and ensure everyone talks to each other. The coordinator could be a general practitioner, but could come from a variety of backgrounds – which need not be medical – and could possibly be provided and funded by patient groups or other NGOs.

2. Existing good practice models from the national level should be collected, evaluated and learned from

A re-mapping of the entire infrastructure of healthcare in Europe would take too long; we need solutions now. There must be examples of good practice already happening in some parts of Europe; we need to find these, evaluate them and build on them. Best practice, no matter how small, need to be shared.

3. EPF should continue to campaign for health literacy

The European Patients’ Forum can play a key role in advocating for promoting health literacy at an EU level.

4. Specific education on the needs of older people for formal and informal carers and older people

There needs to be expert education on matters relating to older people and ageing, for patients, professional care givers and informal carers. There has been insufficient investment in research into ageing, and consequently expertise is lacking. Drugs are tested on the young, so their effects on older persons are not well known, especially with polypharmacy.

¹¹ http://www.alzheimer.be/index.php?option=com_eventlist&view=categoriesdetailed&Itemid=4

5. NGOs should promote the changing of public perceptions: an old person is a person, with rights

Patient groups can play a key role in changing societal perceptions of older people. The example from the previous day's plenary; *"I'm old, and I like it!"* is where we all need to be aiming.

Workshop 2: Linking health and social care in self-management

Moderator: Dr. Ian Banks (European Men's Health Forum, EMHF)

Report by Ms. Hanna Milczarek (Child's Heart Foundation, Poland)

Fragmentation between health and social care provision is a major barrier to good quality, integrated chronic disease management. The patient and, where appropriate, the carer, has a central role in co-managing care in partnership with a well-coordinated team of health and social care professionals. This workshop explored the challenges and good practices in linking health and social care, including patients' collective involvement in developing more patient-centred health and social policy.

Social care has recently become a "hot topic" as it is a growing business, especially in the context of the aging population of Europe. Older people are also becoming a stronger voting electorate, therefore they are more and more empowered and should use this power to their benefit. The discussion of the group focused around a few key words: older patients; rights and needs; health care; social care; and self-management. Participants



decided we should not seek to redefine older patients, and affirmed that we should fight for older patients' rights and needs. They defined self-management as "control of one's own destiny and body".

Key rights and needs of older patients

Through the discussion, participants identified two key rights and needs of older patients: to keep their autonomy; and to be listened by carers and health/social care professionals. We need to find solutions to achieve this. However, there are many other needs and rights which need to be identified, and this is very individual depending on the patient. One example of good practice came from Denmark, where persons over 70 who are discharged from hospital can be visited by a nurse to establish what their follow-up needs are.

Barriers to linking health and social care

The workshop identified a lack of cooperation between social carers and health carers as a major issue. This is combined with a lack of satisfactory information accessible to patients. Two compounding factors are low (health) literacy of patients, and inadequate knowledge and training of health professionals.

The European Innovation Partnership: the right platform to exchange and combine experience

the issues indicated by older patients and their representatives should be brought from the local level to the national level, and the European Innovation Partnership should function as the main platform for exchanging experiences and continuing discussion, with the involvement of all stakeholders, including social carers and industry.

Recommendations

1. The rights and needs of older patients should be defined by surveys and focus groups, conducted by NGOs and presented to professionals

NGOs are a premiere source of collective information on their members, including older patients; therefore they are well placed to identify their needs. EPF should initiate a large scale discussion on the topic of the needs and demands of older patients. This discussion should involve patients, social careers, general practitioners, other professionals, and organisations dealing with older patients. NGO representatives should be involved in the decision-making process by the decision-making bodies at national and EU levels. NGOs and decision-makers should also ensure that the recommendations are implemented.

2. The Innovation Partnership should work on identifying and overcoming the barriers between patients and professionals, with the help of the NGOs and using the good practices in every country

Some barriers were already highlighted by participants, but there may be more that need to be targeted. Good practice examples exist, which need to be mapped out and shared across countries.

3. Every EU Member State should have a National Plan dealing a comprehensive manner with the needs, rights and problems of older patients

One model indicated for the national plan was EUROPLAN¹², an EU co-funded project that supports national strategies for rare diseases in all EU Member States.

4. Solutions should be introduced, and financed, in every Member State to allow older patients to have a person of their choice as a carer

Older patients need, and should have the right, to select the person they would like to have as a carer. This could be a family member or a neighbour, a person the patient knows well, and such a person (after giving their consent) should be trained to a professional carer and be financed by the state.

¹² <http://www.europlanproject.eu/Home.aspx>

Workshop 3: Cultural & psychological aspects of ageing with chronic diseases



Moderator: Dr Maria Navarro (Spanish Patients' Forum)

Report by Ms Heather Clarke (European Parkinson's Disease Association, EPDA)

This workshop took as its starting point a holistic approach to health and the inter-linkages between physical and mental health. It explored the specific psycho-social issues faced by patients with chronic

diseases as they get older, but also the valuable contribution that older patients can make in support of younger patients, e.g. through long experience, knowledge and coping skills. The workshop aimed to identify good practices for sharing and ideas with potential for further development in the context of the European Innovation Partnership.

The many challenges of living and ageing with chronic diseases

Key issues when living and ageing with chronic diseases include the loss of independence, and social isolation, together with other concerns that can be aggravating factors: financial insecurity, guilt, and fear of death. Moreover, older patients with chronic diseases often have comorbidities. In addition to these psycho-social issues, patients highlighted social stigma and discrimination. There is already stigma attached to growing old, which is even stronger for older women; and living with certain diseases, for example hepatitis, HIV/AIDS, Parkinson's, Alzheimer's, or chronic pain tends to increase this stigma.

Discrimination in healthcare provision for older people may include the rationing or limitation of services based on age. Other barriers when dealing with the healthcare system include loss of cognitive function for many older people. This is especially associated with certain illnesses (e.g. Parkinson's and Alzheimer's disease). Sight loss and hearing loss are also important issues, as well as the loss of motivation. Even loss of taste could lead to problems in caring for oneself.

A lot of thought was given to the situation of informal carers. They also have to accept the disease. As well as feeling exhausted, they can also fear the loss of independence, increasing social isolation and financial insecurity, and can feel guilt and resentment.

Older patients as a resource

Looking to the "advantages", the patient is the expert in their disease. They are a resource of knowledge, and sometimes know more than even healthcare professionals about managing the disease. The patient can pass on knowledge and experiences of navigating the

healthcare system and therapies, and share coping strategies. Informed patients who are willing to support others and develop networks help themselves by helping others. They feel useful and regain confidence by working in and for the disease.

Recommendations:

5. Rights of older patients should be put on the political agenda

The rights of older patients should be taken into account and put on the political agenda, with political acknowledgement and the necessary support – including resources. This should be done with the involvement of patients and carers.

6. Promote employment rights of patients and carers

The situation as to employment of both groups needs to be examined carefully, as loss of employment can lead to insecurity and social isolation. Informal carers may wish to keep working, and solutions should be found to make this possible. Recognition should also be given to the work of informal carers, and they should be provided with adequate support including pay and holidays.

7. Define and uphold the rights of those who have lost independence

Patient and carer organisations, as well as decision makers, should work on addressing the specific issues of those older people who have lost their independence and therefore need special protection, providing them with the social and legal protection they need.

8. Invest in prevention and health education throughout life

Stakeholders and decision-makers should seek to prevent what is preventable, adopting a life-course approach that starts with children. Children, too, can educate their parents and grandparents for healthier life styles.

9. Create European standards of integrated care with the involvement of patient organisations

Participants felt that integrated care, also across the health and social care teams and including informal carers, is an essential part of the solution to provide patients with care that corresponds to their needs and takes into account the whole picture of health, including cultural and psycho-social aspects. One basic but essential point the participants particularly stressed is that all healthcare professionals should take into account that older patients and their family may need to be given extra time for consultations.

Workshop 4: Low-tech and high-tech innovation for older patients

Moderator: Dr Konstanti Radziwill (Standing Committee of European Doctors, CPME)

Rapporteur: Ms Jacqueline Bowman-Busato (European Platform of Patient Organisations, Science and Industry, EPPOSI)

The objective of this session was to explore how high and low-tech innovative solutions can support older patients' self-management and control daily life. Participants also identified barriers and success factors for the take-up of innovation by older patients.



Definition of “high-tech” and “low-tech”

To begin with the participants discussed definitions of high-tech and low-tech, concluding that “high-tech” corresponds to engineering in the conventional sense, while “low-tech” encompasses systems and “soft skills”, and usually appears user-friendly to older patients. The “high-tech” category changes with time, since what is considered high-tech now will be low-tech in 10 years. High-tech was seen as an enabler for organisational and systemic organisation. Participants then defined the main barriers to the take-up of innovation by older patients, and made recommendations on the success factors for innovation.

Recommendations

1. Promote cross-sectoral attitudinal change

The take-up of innovations depends on two essential factors: communication and education. Changes in these two domains will bring forward necessary attitudinal change on part of all actors. In terms of *communication*, there is a need to improve interaction between healthcare professionals. Changing the current health professional-patient relationship is also critical. One way to achieve this would be to clearly define each party's rights and responsibilities. Patients and carers should also be included in the entire innovation pathway in order to develop appropriate products and services.

As for *education*, the main problematic is accessible information: all stakeholder groups need access to information and knowledge which is trustworthy, and this should circulate between the different groups. All stakeholder groups are also producers of such information, therefore they all need to ensure that what they produce is trustworthy, high-quality information.

2. Adopt a partnership approach

Health outcomes are influenced by more than one group or one sector of society. Therefore to successfully improve health outcomes of patients, a partnership approach is critically needed. For a real partnership to take place, opinions have to be equally considered in the decision-making process. Partnerships need to bridge the gap between care boundaries – addressing both health and social care.

3. Financial investment in outcomes

A key issue is that high-tech solutions of today involve a bigger initial investment cost to healthcare budgets. To overcome this, financial mechanisms to fund innovation should be rationalised across the innovation pathway – from research to implementation. Participants

also called for a more societal approach to health technology assessment, with patients and carers' involvement in the process.

Workshop 5: (e)Health literacy and information for older patients

Moderator: Mr Paul de Raeve (European Federation of Nurses Association, EFN)

Report by Ms Peggy McGuire (European Institute for Women's Health, EIWH)

This session's objective was to explore health literacy and information to patients from the perspective of the specific information needs of older patients, including e-Health literacy and older patients' use of ICT applications.

Health literacy: an overarching term with several distinct areas: health information, awareness, patient empowerment

Health literacy is a broad term which covers many aspects from patient information needs, to the need for health self-management resources. Older people need information on how to stay active and healthy and how to manage their disease, to empower them to make informed choices. Empowerment is essential for patient health and wellbeing. Communication between patient and their health professional is an important aspect of self-management of chronic disease; the patient needs to have an understanding of their disease and know the right questions to ask from the health professional. Knowing about the condition helps the patient deal with what is happening. Patients can make informed choices when they have the correct information. But their preferences need to be assessed as to the amount of information they want to receive, how it should be presented, and how they want to take part in the decision-making about their health.

Participants gave examples of creating awareness of specific diseases and how they empower patients with information on their own disease area. "Some patients do not know how treatments work," a participant said, but patient groups can explain treatment options and their implications. Moreover, health literacy is strongly linked with the health inequities that exist across Europe, with many older patients not being able to access proper treatment and other care for chronic diseases. Given that access to treatments is different across the EU, the financial aspects of access need to be addressed, but health literacy can be a powerful tool towards more equity.

This group also identified the shortage of geriatricians and care workers as a problem, which is partly due to the stigma attached to working with older patients. Participants highlighted that young people are not interested in taking up a career in geriatrics, and this need to be addressed at education and policy levels.

Older patients are not a homogenous group as regards (e)Health literacy

(e)Health literacy of older patients varies according to certain factors, including the local situation (e-health is not developing evenly across the EU), financial stability, educational status, and family and social support of the patient. Disease literacy can be much better among patients. If a person has a chronic disease from an early age, they will be more likely to develop knowledge on the disease.

Many older people are now using the Internet for different aspects of their lives, but many of them cannot or do not access the Internet: this can be due to low income, lower education,

or failing to understand the opportunity. This can be exacerbated by complicated medical conditions and/or disability. Participants said there needs to be a better understanding of older people's situations, and what are the common issues regarding the use of information technology.

Recommendations

2. Agree on a definition of health literacy

The group felt EPF's definition and recommendations (EPF Spring Conference, 2008¹³) are still valid, but should be reviewed in light of older patients' needs.

3. Identify the existing good practice models and adapt them to suit local contexts

In order to learn and share best practices, we need to know what they are (the "evidence barrier"). The best health literacy practices should be collected in a database which can be added to. This should be accessible to all sectors, including policy makers and stakeholders. A cost benefit analysis is also necessary to determine what initiatives work. There is such diversity in patients' situations across Europe that developing health literacy programmes needs to be backed up with evidence.

4. Health Literacy needs a lifespan and cross-sectoral approach

Health information at an early age and at different stages of life could potentially prevent the development of chronic disease in later life. Health literacy is not just important for older patients; it needs to begin in childhood, targeting children for example at school. Older patients should be seen as a resource: their experience, knowledge and expertise could be used by making visits to schools telling their stories and imparting information on how to stay healthy and avoid chronic diseases in later life.

5. Training for healthcare professionals, but also for politicians, on the importance of health literacy

Capacity-building is urgently needed to inform health professionals, but also politicians of the issues around health literacy, of its importance for ageing patients, and of the needs of older people and patients. There is a disconnection between policymakers and patients, as policymakers do not understand or do not know patients' needs in relation to health literacy. Yet investment in health literacy could contribute to the sustainability of health systems. Hospitals will need to meet the needs of older patients in the future; Europe will have an ageing health workforce and ageing patients. Guidelines need to be developed for health professionals treating and caring for older patients with multiple conditions, including on specific issues such as polypharmacy.

6. Information should come in a variety of formats taking into account patients' diversity and varying e-Health competence

Depending on the situation of the older patient, different information opportunities and strategies will have to be developed, such as Internet, newspapers and magazines, TV, or leaflets. Many older patients still regard the doctor as the main source of information.

¹³ http://www.eu-patient.eu/Documents/Publications/ConferenceSeminarReports/EPF_HealthLiteracyConference_2008_Report.pdf

Whichever media is used, the information must be accurate and high-quality, easily accessed and understandable by the patient.

7. Adopt a patient-centred approach and support patient organisations

Europe is facing enormous challenges with the ageing population and the increase of chronic diseases. It is more important than ever that health system adopts a patient centred approach. Healthcare needs the involvement of the patient to ensure adherence to treatments and effective self-management. There should be shared decision-making between the patient and health professional. Many patients are experts in their own right as they have learned the skills and have the knowledge and experience of coping with a chronic disease.

E-health strategies and programmes need to be focused on the user, and older people need to be involved in the design and implementation of policies and programmes to ensure they meet their needs (as well as families' and carers'). Key questions to ask include older patients' views on the health services, and their information needs.

Patients are increasingly involved in dialogue and political discussions, and their representative organisations have a key role to play for health literacy: they are experts in their own area; they collect information, do their own research and can act as a resource not just for patients but for health professionals and policymakers. Most organisations however lack resources and manpower: it can even be difficult to have a good website, a crucial tool to inform patients and the public. Patient organisations therefore need adequate support to build organisational capacity and support patients.

8. Feed recommendations from the conference into activities at EU and national level

The health literacy debate needs to move forward, models of good practice should be identified, adapted and implemented at national level throughout the EU. This shouldn't be restricted by financial barriers. Opportunities for involvement of stakeholders, including patient organisations, need to be identified and mapped out, e.g. for EU-funded projects under the Research Framework Programme, or the Health Strategy. Possibilities to use Structural/Cohesion Funds to implement health literacy programmes at national level should be developed. The recommendations from these workshops need to be fed into current activities at EU level, e.g. the cancer partnership and the Joint Initiative on Alzheimer's, and work on health literacy at EU level. Health literacy should be a priority for the Innovation Partnership.



Closing Plenary Session

Moving forward on policy and practice: Reflections from the patients', professionals' and European Commission's perspectives

Prof Antonio Cherubini, from the European Union Geriatric Medicine Society (EUGMS), began by presenting the perspective of healthcare professionals. He highlighted that a key unmet need for older patients is *evidence-based treatment*, because of their exclusion from clinical trials. The PREDICT project showed that more than half of clinical trials for heart failure have poorly justified criteria which exclude older patients. Patients who do participate are “cherry picked” as they correspond to certain enrolment criteria. As a result healthcare professionals do not have the necessary evidence base for clinical practice. He stressed that this discrimination based on age is both unacceptable and costly for healthcare systems. Related issues are inappropriate prescriptions for older patients, and the increase in adverse drug reactions seen in patients over 60.

A second unmet need is the *education and training of healthcare professionals*. Training still tends to focus on acute care in the hospital, but not on preserving or improving functions of older people with functional limitations. Some countries in Europe still do not recognise geriatrics as a specialty; and in undergraduate teaching, some EU countries do not include geriatric training, yet it has been shown that even relatively brief training can improve the way healthcare professionals deal with older patients.

The last unmet need identified by Prof Cherubini is in *integrated long-term care systems*, with integration of health and social services and appropriate methodology. With a comprehensive geriatric assessment, patients have significantly better outcomes, tend to be able to stay at home, and are less institutionalised. He concluded that evaluation of treatment, appropriate training and care systems, and the involvement of patients and carers would allow addressing the most important healthcare needs of older patients.

Mr Philip Chircop, EFP Board member from Malta, summed up from the patients' perspective and recapped the challenges and opportunities for older patients' rights, and the main conclusions that had emerged from the discussions throughout the conference:

- *Shared decision-making* as a key solution to improve the quality and sustainability of healthcare. All patients, including older patients, should be enabled and empowered to become equal partners in their care. Shared decision-making can improve adherence to therapies, self-management, and therefore health outcomes and quality of life. To achieve this, meaningful patient involvement on individual and collective levels needs to become a reality. Many speakers highlighted that existing good practices and guidelines, such as the Value+ resources, need to be better applied.
- *Integrated care solutions* are a key wish of patients. Fragmented organisation and delivery of care forms a major barrier to good quality care. “Silos” between medical and social care and between different medical specialities have to be broken.

- *A holistic approach to health*, encompassing both physical and mental health, as well as social integration, is particularly relevant for older patients.
- *Innovative solutions centred on users' needs*. Innovative solutions are an essential component in the future vision of healthcare, but participants felt that they are currently not enough centred on the people who use them. To meet users' needs, they have to be involved in the design, development and implementation. Innovation should be understood as including "low-tech" solutions, such as changes in the way care is delivered, and structure, system and social innovation. In pharmaceutical innovation, a key challenge is to improve the evidence-base for older people's treatment.
- *Health inequalities* need to be effectively tackled. Many participants raised concerns about the wide health inequalities in Europe and called for strong responses at national and EU level. In his speech, Philip Chircop said: "We cannot stress enough that for patients with chronic diseases, 'active and healthy ageing' rests on the cornerstone of equitable access to good quality, patient-centred healthcare."
- *Patient empowerment through health literacy and quality information*. Another message that was echoed throughout the conference was the need for a strong strategy to improve patient information and (e)-health literacy, taking into account the particular needs of older patients.

Philip Chircop stressed that patient empowerment is essential to bring a real change in all of these areas, and should be a joint priority; yet it is not a reality so far. Many patients and their families may find it hard to participate in healthcare decisions or to challenge or question health professionals. Others may have only a limited understanding about health, and its different aspects, and may not know where to seek the appropriate information, which is clear, trustworthy, and easy to understand. They need a supportive environment to sound their concerns and their questions, and to speak up about important issues which concern them.

This cannot be achieved without healthcare professionals' recognition that it is ethically fundamental to share important decisions with patients. They should also be committed to invest in assisting patients and their families and pay particular attention to provide accurate, personalised information, encouraging patients to ask questions and express their preferences. Policy-makers should adopt policies that encourage shared decision making and consider its measurement as an incentive for improvement.

In his final remarks he pointed out the growing need for a comprehensive approach to chronic diseases, both at EU and national levels, embracing prevention, patient-centred medical and social care, and patient empowerment. He stressed the role of patient organisations in this: "Member organisations within the European Patients' Forum have a wealth of experience and expertise – and we are more than happy to share it," he concluded.

Mr Wojciech Dziworski, senior economist and policy analyst in the European Commission DG SANCO unit on innovation and ageing, gave the final address. He stressed that indeed patients and citizens need to remain at the centre of the debate; this requires attitudinal change and the involvement of all.

In response to the various speeches he heard throughout the conference, he explained that the idea is to create a scheme that invites rather than prescribes initiatives and actions. The Innovation Partnership would not try to re-invent the wheel, or necessarily create new devices to solve issues such as health inequalities; it encourages simple solutions, and above all actions that are feasible and replicable. This includes also low-tech innovation, as well as best practices and the development of generic solutions that can be adapted at local level.

While there was strong commitment, he said, it was important to discuss what the Steering Group members could implement themselves and which stakeholders can work together. He finished by describing the next steps for the Partnership, stressing that, once adopted, the Strategic Implementation Plan would be submitted to the Council and the European Parliament, and the formal debate on the Innovation Partnership would be extended to the wider community.

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