



**Innovation Partnership on Healthy and Active Ageing**  
**EPF Response to the Commission Public Consultation**  
*Integrated version – 3 February 2011*

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## **Introduction and methodology**

EPF welcomes the opportunity to contribute to the public consultation on the Innovation Partnership on Active and Healthy Ageing, and thanks the European Commission for selecting health and ageing as the theme of the first European Innovation Partnership.

EPF acknowledges the valuable work done by public health, consumers' and older people's organisations in the field of prevention and promotion of healthy lifestyles. Our perspective is distinct yet highly complementary: that of patients – persons diagnosed with chronic diseases or conditions.

As the general population ages, so the number of patients with chronic diseases is growing: not only do many chronic diseases become more prevalent with age, but patients with chronic diseases developed at a younger age are living longer, thanks to modern medical treatments.<sup>1</sup> As persons with chronic diseases age and older people acquire chronic diseases and co-morbidities, they develop specific needs that are distinct from the general population. Coordinated patient-centred strategies therefore need to be in place to address the needs of older patients.

EPF is pleased to provide feedback on the general principles of the European Innovation Partnership on Active and Healthy Ageing, as well as the proposed work packages. This document integrates EPF's response to the Commission's questionnaire submitted in electronic format, and our complementary response addressing some important issues not covered by that questionnaire. Our comments are based on a consultation with our member organisations, and incorporate explicit feedback and examples from the following organisations:

- International Diabetes Federation, (IDF) Region Europe
- Alzheimer Europe
- Mental Health Europe
- European Genetic Alliances Network (EGAN)
- Federation of Patients and Consumer Organisations in the Netherlands (VSOP)

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<sup>1</sup> This is now the case even in diseases like Haemophilia and HIV/AIDS: In Haemophilia, 40+ is currently the biggest age group and the proportion of older patients continues to grow. In HIV/AIDS, the proportion of 50+ has grown rapidly, and the 40-50 age bracket is now the largest category. Source: Presentation "Ageing with Chronic Diseases", given by Dr Cees Smit (EGAN/VSOP), Basel, 25.01.2011. For details please contact EPF.

- European Parkinson's Disease Association (EPDA)
- Hungarian Osteoporosis Patients Association (HOPA)

Due to the relatively short consultation period, many of EPF's member organisations have not been able to contribute more detailed views to this initial consultation, but will wish to contribute at a later stage.

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## General principles of the EPF response

EPF sees many potential synergies between the EIP-AHA and the European Year for Active Ageing in 2012, which share key objectives and in our view have complementary, mutually reinforcing roles. We consider that whilst the European Year 2012 should focus on raising political awareness and obtaining the political support and commitment of all the actors, the EIP-AHA should focus on providing the means and resources to translate these political commitments into reality in a coherent and sustainable way.

The following principles should in our view inform the EIP-AHA overall, and all the work undertaken within it.

***A cross-sectoral approach.*** A cross-sectoral, multi-stakeholder approach is needed that should cover not only health, but also health-related social policy, employment, education, housing, infrastructure, nutrition, etc., based on the principle of "Health In All Policies".

***Stakeholder participation.*** EPF welcomes the Commission's commitment to stakeholder participation. Particularly the meaningful involvement of end-users, including older patients with chronic diseases, from the very onset of the process is fundamental to the successful development and implementation of innovative solutions.

***Equity of access.*** In the context of the current economic environment, we would like to emphasise that "active and healthy ageing" rests on the cornerstone of equitable access to good quality healthcare – preventive services, acute medical treatment, chronic disease management and the necessary support services. The EIP-AHA should adopt as its overarching priority to secure the necessary financial environment for the provision of good quality health and long-term care and related social services, for all older persons across the European Union, based on the common European values of universality, access to good quality care, equity and solidarity<sup>2</sup>.

***Inclusiveness.*** Poverty in old age is an issue that should be addressed by the EIP-AHA, as it is linked to ill health in a multi-faceted way. Poorer people are more at risk of ill health than wealthier citizens; likewise, patients with chronic illness (particularly those with multiple diseases/conditions) and those reliant on low pensions or benefits are more at risk of poverty as a result of ill health. As one of our member organisations put it, "active ageing costs money". The EIP-AHA needs to ensure that all older people, including those on low pensions, those with low literacy, those belonging to disadvantaged or minority groups, and those living in remote areas, benefit from active and healthy ageing. We further stress the

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<sup>2</sup> Council Conclusion on Common values and principles in European Union Health Systems (<http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=OJ:C:2006:146:0001:0003:EN:PDF>)

importance of reaching out to all ethnic and cultural patient groups, and overcoming negative societal attitudes towards some chronic diseases such as neurological degenerative diseases, psychiatric illness, and HIV/AIDS.

**Alleviation of health inequalities.** Whilst acknowledging the potential of innovative tools and services for better quality and sustainability of healthcare, we should be cautious that technological innovations themselves do not become a source of new inequalities, or exacerbate the existing inequalities in access to healthcare within or between EU Member States.

**Innovation centred on users' needs.** The term "innovation" should be understood to include "low-tech", or "simple" innovations; for example in the design of health and social care systems and how care is delivered. Innovation does not need to be expensive, and it should be valued for its potential to improve quality of services, quality of care, and the quality of life: people-focused rather than technology-focused innovation.

**Respect for diversity.** Heterogeneity among older people must be taken into account. There is no "one size fits all" solution to "older people" or "older patients". All solutions must be based on respecting the needs and aspirations of the individuals, their families and carers. All healthy ageing policies should be built on the principles of equity, respect and dignity for older persons no matter what their background or individual situation.

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## **EPF's comments on the proposed work packages of the Innovation Partnership**

The three work packages are, in our view, inter-related and partly overlapping and it may not be feasible, or even desirable, to separate them completely. In order to focus the work, however, the roles of all the stakeholders, including leadership and coordination issues as well as the possible synergies between areas of work, should be carefully mapped out and clarified. Otherwise there is a risk of important issues being addressed "everywhere and nowhere".

Due to the overlapping nature of the issues, our comments below are concentrated under one work package: many of them are however equally applicable to the other work packages.

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### **Work package 1**

This work package focuses on the individual person and proposes specific diseases as possible focal areas: Alzheimer's, cardio-vascular disease, cancer and diabetes. It also addresses personalised approaches to care, clinical trials, self-management, and older people's monitoring of their own health.

EPF suggests that *dementia* and *Parkinson's disease* should be added as they are major conditions affecting older persons.

### ***The importance of a holistic approach to health***

EPF stresses the importance of a holistic approach to older people's health, encompassing both physical and mental health and social integration. Health, after all, is not only a state of physical but also mental well-being, not merely the absence of disease.<sup>3</sup>

Older people are often affected by "simple" mental health problems such as anxiety (about the future, about their financial situation, about family...), as well as psycho-somatic problems and depression. Moreover, mental health issues are often interlinked with physical health problems – such as undetermined pain, heart or circulatory problems.

Specifically, patients with chronic diseases experience particular psycho-social issues, sometimes termed "***the fear factor***". Patients with chronic diseases are very knowledgeable about their own condition(s) and medical care, and fears are often centred on no longer being able to exercise control over their own situation. Major concerns include for example:

- fear of losing physical control;
- inability to live independently;
- financial concerns;
- fear that something may happen to a healthy partner;
- concerns about social stigma; and
- discrimination in health and social care.<sup>4</sup>

Where the current generations of people with chronic diseases have experienced high levels of medical care, their expectations of future care, as they are growing older, are similarly high. However, their perception of the actual state of health/social care for older people (as they know it from their parents or grandparents) is rather low, and this is a major reason for the "fear factor".

On the positive side, older patients, who have been dealing for much longer with multiple conditions and complex therapeutic regimes, often develop extensive coping skills. They also have broad experience of interaction with a large group of medical practitioners and other health professionals, and they are well-versed in self-care. These patients can play a valuable educational and peer support role.

### ***Access to good quality diagnosis and treatment***

It is essential in chronic diseases, particularly in degenerative conditions like dementias, that prevention and treatment strategies encompass equitable access to early diagnosis, treatment and support services. Early intervention enables patients to live independently for longer and place less stress on health services. The EIP-AHA should encourage partnership between neuroscientists, health workers and patient organisations to devise ways to improve access to needed care for all people with chronic neurological degenerative and psychiatric illnesses, such as Parkinson's disease, and foster practice guidelines to assist healthcare workers in the management of medication side-effects especially among the elderly. EU-wide standards and guidelines for quality care, such as the Code of Good Practice

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<sup>3</sup> Preamble to the Constitution of the World Health Organization, signed on 22 July 1946 by the representatives of 61 States and entered into force on 7 April 1948.

<sup>4</sup> "50 Plus" study by the Terrence Higgins Trust, [www.tht.org.uk/50plus](http://www.tht.org.uk/50plus); Report "Support. Stay. Save" by the Alzheimer's Society (UK), January 2011, [http://alzheimers.org.uk/site/scripts/documents\\_info.php?documentID=1453](http://alzheimers.org.uk/site/scripts/documents_info.php?documentID=1453)

and European Consensus Papers developed for Multiple Sclerosis could be taken as examples for other disease areas. National plans for specific diseases exist in many countries, but in order to ensure they are implemented the necessary funding must be secured and ring-fenced.

### ***The challenge of co-morbidities***

EPF strongly supports the proposal for work around co-morbidities and associated problems. These are a major issue from the perspective of older patients with chronic diseases, many of whom are affected by more than one chronic condition. Long-term problems associated with co-morbidities include:

- *Functional limitations* – physical deterioration and fatigue;
- *Psychological symptoms* – fear, depression, feeling of losing control, less ability for self-care;
- *Social problems* – decrease of social contacts, lack of understanding;
- *Societal problems* – less able to participate in labour and leisure activities, increased financial impact of illness and risk of poverty.

In this context, issues related to *poly-pharmacy*, *medication safety*, and questions of *adherence/concordance* present major challenges to older patients with chronic diseases. Adverse drug reactions are more common among older people, while most adverse reactions may be avoidable with appropriate medication safety systems in place.<sup>5</sup> Work on adherence to therapies should be based on the concept of concordance<sup>6</sup>, and encompass health literacy, user-friendly information, and patient-health professional communication.

### ***Inclusion of older people in clinical trials***

EPF stresses the importance of patients' meaningful involvement in the development of geriatric therapies and personalised medicine approaches for older patients. This is crucial to improve knowledge of medicines' effects in older persons, accurate dosage and formulations for the elderly; leading to better health outcomes, better adherence and overall medication safety.<sup>7</sup>

The participation of older people in clinical trials does present particular challenges, including specific information and communication needs; ensuring meaningful informed consent; specific strategies regarding vulnerable patient groups such as people affected by mental illness or dementia; and meaningful involvement of patient organisations in all aspects of the research process. The EIP-AHA should support older patients' participation in clinical research in a meaningful, ethical way. Several EU projects have explored patient involvement in clinical research and can contribute valuable knowledge:

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<sup>5</sup> WHO report 'Priority Medicines for Europe and the World', Kaplan and Laing, 2004, pages 90-91. Available online at <http://archives.who.int/prioritymeds/report/final18october.pdf>

<sup>6</sup> This is not synonymous with adherence, but a relatively recent term that refers to the nature of the interaction between doctor and patient, which is one of equals. The aim of concordance is the establishment of a "therapeutic alliance between the clinician and patient". Concordance is a key concept of patient-centred care. *Br J Clin Pharmacol*. 2007 November; 64(5): 710–711.

<sup>7</sup> Ibid.

- The PatientPartner project has identified some of the barriers for partnerships in clinical trials, as well as good practices.<sup>8</sup>
- Lessons from the RESPECT project (participation of children and their families in clinical trials) regarding ethical and empowerment issues could be applied to research in older persons.<sup>9</sup>
- The VALUE+ project has created targeted resources for patient organisations and project coordinators, as well as a set of policy recommendations to promote meaningful patient involvement in projects, which could be applied to the clinical trials environment.<sup>10</sup>

### **Health literacy and information to patients**

EPF calls for an EU-wide strategy on health literacy and information to patients, including “e-health literacy”. This should include a targeted strategy focused on the specific information needs older people and older people’s (e-)health literacy. A strategy on health literacy is key to build the necessary skills and knowledge to enable older people and patients to use innovative solutions with confidence.

The concept of health literacy encompasses not only access to high quality information, but the capacity to make informed decisions about one’s health in an everyday context, and the capacity to navigate the health system.<sup>11</sup> EPF believes health literacy is both a key right, and a critical strategy towards patient empowerment and patient-centred healthcare.

The EIP-AHA should aim at identifying and promoting the implementation of successful health literacy and patient information approaches at national, regional or local levels.

In particular, the **valuable experience and knowledge of patient organisations** should be used more effectively. In many countries, they have undertaken educational initiatives that could be recognised as good practices at EU level and shared, across borders and possibly across disease-areas. Some examples include:

- *The Spanish Patients’ University*, run by the University of Barcelona in cooperation with the Spanish Patients’ Forum and the Joseph Laporte Library, which includes courses and information toolkits for patients about specific chronic diseases and disease self-management;<sup>12</sup>
- *The Parkinson’s Decision Aid (PDA)*<sup>13</sup> is an online educational toolkit that seeks to put people with Parkinson’s in the best possible position to make the right choices so they themselves can actively work with their healthcare professional to improve the quality of life and make informed choices together. PDA provides a wealth of up-to-date, expert-reviewed information about Parkinson’s, in an easy-to-understand style.
- *The “East East” project* where representatives of government, independent experts and patient organisations work together to implement the principles of patient safety

<sup>8</sup> [www.patientpartner-europe.eu](http://www.patientpartner-europe.eu)

<sup>9</sup> <http://www.patientneeds.eu/>

<sup>10</sup> <http://www.eu-patient.eu/Initatives-Policy/Projects/EPF-led-EU-Projects/ValuePlus/>

<sup>11</sup> See report from EPF’s Spring Conference on Health Literacy (2008) available online at [http://www.eu-patient.eu/Documents/Publications/ConferenceSeminarReports/EPF\\_HealthLiteracyConference\\_2008\\_Report.pdf](http://www.eu-patient.eu/Documents/Publications/ConferenceSeminarReports/EPF_HealthLiteracyConference_2008_Report.pdf)

<sup>12</sup> [www.universidadpacientes.org](http://www.universidadpacientes.org), also using social media – Facebook

<sup>13</sup> [www.parkinsonsdecisionaid.eu.com](http://www.parkinsonsdecisionaid.eu.com)

and patient-centered care in the countries of eastern Europe and selected Asian countries;<sup>14</sup>

- *Hungarian initiatives on Osteoporosis*, including online and social media resources such as an online “patient university”<sup>15</sup> and the “Don’t Fall Don’t Break” campaign on Facebook;<sup>16</sup>
- *User-friendly patient tools* produced by the Danish Patient Safety Society<sup>17</sup> in Danish and English, with the aim of empowering patients to contribute to their own safety in the healthcare environment.

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## Work package 2

EPF welcomes the focus of this work package on addressing “more integrated approaches to delivery of care in order to meet the needs of the elderly in all situations”. This is a key aspect of good quality, patient-centred health care. The EIP-AHA provides a vital opportunity for coordination of work in this area, which is constantly identified by patients with chronic diseases as *a major obstacle in the way of good quality care and quality of life*, but not sufficiently addressed to date.

Barriers relating to the organisation and delivery of health and social care include financial structures, productivity targets, and attitudinal barriers. The result of organisational and financial fragmentation is that patients need to spend significant time and energy in “fighting the system” just to get the services they need. Older people in particular do not always have the energy, or indeed the health literacy, to accomplish that. Some examples of barriers include the following:

- An example from a patient with Diabetes concerning lack of integration within the hospital: “the doctors may want to introduce a simple innovation that makes care better and cheaper, but the hospital laboratories may be against since because the system is organised in such a way that the lab will lose “productivity” and therefore related income.”
- A national plan for Alzheimer’s in France provides for the training of informal carers. However, if no arrangements are offered for the interim care of the patient, the carers – although they need and want training – simply cannot access it. Effective implementation of the plan therefore requires coordination across the various services.
- According to a new survey<sup>18</sup> by the Alzheimer’s Society (UK), independent living is a key wish of patients, but around half of the respondents – patients, informal and home carers – reported not receiving adequate support to realise this goal. The report demonstrates a lack of “joined-up” working across the health and social support services and provides recommendations for policy-makers and service providers.

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<sup>14</sup> [www.federacjapp.pl/index.php?option=com\\_content&view=article&id=29&Itemid=30](http://www.federacjapp.pl/index.php?option=com_content&view=article&id=29&Itemid=30)

<sup>15</sup> [www.obme.hu/category/hirek/torodjunk-egeszsegunkkel-betegek-egyete-a-facebook-on-angolmagyar.html](http://www.obme.hu/category/hirek/torodjunk-egeszsegunkkel-betegek-egyete-a-facebook-on-angolmagyar.html)

<sup>16</sup> [www.facebook.com/pages/Ne-ess-Ne-torj/115112535184732?v=info&ref=ts](https://www.facebook.com/pages/Ne-ess-Ne-torj/115112535184732?v=info&ref=ts)

<sup>17</sup> <http://patientsikkerhed.dk/en/about-the-danish-society-for-patient-safety/activities/>

<sup>18</sup> Report “Support. Stay. Save” by the Alzheimer’s Society, January 2011. Available online at [http://alzheimers.org.uk/site/scripts/documents\\_info.php?documentID=1453](http://alzheimers.org.uk/site/scripts/documents_info.php?documentID=1453)



### **Coordination of care**

Solutions should be found to enable persons with chronic disease(s) to manage their own situation for as long as possible, with sufficient support from specialised medical professionals (concerning specific disease) and a home physician or GP concerning more general health, as appropriate. Ideally there should be “one trusted health professional” responsible for the coordination of care.

Specialised nurses often can play a key role in ensuring access to medications, advocating for patients' rights, and coordinating care. One example is the Parkinson's Disease Nurse Specialist programme in the UK: the PDNS is a specialist practitioner whose essential skills are “clinical leadership, research awareness, development of nursing knowledge, acting as consultant, educator, change agent, and evaluator of care”. Experiences of PDNS have been very positive, and access to a PDNS is cited as the no.1 priority for UK patients with Parkinson's and their carers.<sup>19</sup> Similar initiatives exist in Multiple Sclerosis<sup>20</sup> and other chronic disease areas in some countries. The EIP-AHA could map these for sharing and mutual learning.

The **role of informal and home carers** is paramount to enable older people and patients remain independent for longer. Strategies and policies should be developed not only for the recruitment and retention of healthcare professionals, but also for home carers as well as greater support to informal caregivers. Educational guidelines and standards are needed for formal and informal carers, particularly in challenging areas like psychiatric illness, Alzheimer's and other dementias, and Parkinson's disease.

### **Priorities for the EIP-AHA**

The EIP-AHA should aim to **identify examples of integrated care systems that “work” from the users/patients' and carers' viewpoint** in delivering good quality services. Critical success factors, or common elements of such systems that are transferable across EU Member States and also across disease areas, should be identified and their implementation supported. The results of EU-funded pilot projects should be coordinated and presented as part of the Partnership.

The EIP-AHA should encourage the **meaningful involvement of older patients in the provision of their health and social care and services**, both at individual level and collectively at the policy level, through meaningful involvement of older people's and patients' organisations. Patient involvement is among the shared operating principles of European health systems, as recognised in the Council Conclusions of 2006; nevertheless in practice there is wide divergence across the EU in the level of involvement. THE outcomes of the VALUE+ project (referred to above) include resources and practical tools which have potential for application in the context of the EIP-AHA.

Meaningful involvement of patients includes **patients' involvement in Health Technology Assessment**, a key requirement to ensure that evidence-based innovations are developed

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<sup>19</sup> Information about PDNS is available on the website of the European Parkinson's Disease Association, [www.epda.eu.com/projects/learning-in-partnership-lip/past-years/2008/benefit-of-pdns-to-parkinsons-patients-and-carers](http://www.epda.eu.com/projects/learning-in-partnership-lip/past-years/2008/benefit-of-pdns-to-parkinsons-patients-and-carers)

<sup>20</sup> See [http://www.mssociety.org.uk/for\\_professionals/developing\\_services/ms\\_nurses/index.html](http://www.mssociety.org.uk/for_professionals/developing_services/ms_nurses/index.html); [www.emsp.org/ms-need/](http://www.emsp.org/ms-need/)



with the patients' needs at the centre. EPF welcomes the European HTA network established by the draft Directive on the application of patients-rights in cross-border healthcare, which is based on the principle of broad involvement of stakeholders including patient organisations and provides a base for future European cooperation on HTA.

Finally, for improvements to happen, providers must have **adequate financial and human resources** available to them. Given that most services are provided at local or regional level, regional and local actors must be engaged and committed to action. The use of EU Structural Funds for this purpose should be promoted more effectively. Industries should also be engaged as innovation partners in identifying sustainable funding models that guarantee equitable access to good quality healthcare regardless of the patient's ability to pay.

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### Work package 3

EPF has identified the uptake and implementation of already existing innovative solutions as a major challenge equally important as the development of new innovative solutions. We therefore welcome the focus of this work package on addressing the barriers that prevent this. The work package particularly mentions "solutions ... to help [older people to] be active and autonomous at home, at work, in the community and on the go (e.g. daily life support platforms, chronic disease management solutions, fall prevention systems)".

From the perspective of older patients with chronic diseases, fully integrated chronic disease-management systems are key to **enable patients to fit the management of their disease or condition into their daily life**. eHealth and telemedicine have many potential applications in this context. One Dutch diabetes patient reports with great satisfaction of the eHealth system being piloted in his hospital: he has online access to his x-rays, test results and advice from the responsible health professional, as well as regular e-mail contact with his doctor and nurse. Instead of having to go to the hospital, he can send a sample of blood to the hospital. Unfortunately such systems are still the exception, even in the most 'advanced' EU Member States. The same comments apply here as under Work package 2 on integrated care.

The EIP-AHA should also focus on strategies to **enable patients with chronic conditions to remain in employment** for as long as possible. This is important for a good quality of life and avoiding the additional factor of lost income to the financial impact of chronic illness. The EIP-AHA should promote the implementation of flexible employment arrangements, supporting the necessary workplace adjustments, and importantly addressing discrimination against persons with chronic illness by employers. Guidelines or education for employers could be produced, and the use of Structural Funds in this area should be promoted.

#### **Barriers identified by patients with chronic diseases**

Most of the barriers listed in the questionnaire have relevance, and that many of them are interlinked; for example end-users' resistance, lack of training and lack of involvement of end-users; the lack of evidence for specific innovations and the scattered nature of the evidence; the lack of funding/partial funding, lack of interoperability and unwillingness of authorities to buy innovative solutions. Key barriers identified from a patients' perspective include:

- *Low awareness of existing innovative solutions*, including eHealth applications – not only among patients and patient organisations, but among health professionals and health providers. One important task for the EIP-AHA could be to compile this information and make it available at EU level to all stakeholders.
- *Low acceptance and trust among end-users*. See discussion under WP1 on the importance of building health literacy and confidence among patients and older people.
- *The “silo” approach within and between health and social care systems* (as discussed under WP2) is another key barrier that prevents the implementation of integrated care solutions and the take-up of innovative solutions.
- *Existing reimbursement systems* – lack of reimbursement for innovative solutions (e.g. remote monitoring solutions for chronic disease self-management), their inclusion within national health insurance schemes.
- *Training needs and attitudinal barriers* among health professionals and health managers. Appropriate training is needed including the necessary skills to communicate with patients and modify attitudes to adapt to a new health professional-patient relationship, brought about by patients’ increasingly active involvement in care, including self-management through ICT applications. New skills should be built into the professional curricula for health professionals. The EIP-AHA can facilitate the understanding of future educational needs for health professionals from the perspective of all stakeholders.
- *Social “taboo” of dementia and mental illness*. The EIP-AHA should prioritise awareness-raising to break such taboos and adopt a multi-stakeholder approach in combating discrimination in the provision of health and social services.

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### **How can the European Innovation Partnership could support active and healthy ageing through innovation in EPF’s view?**

The EIP-AHA should be seen as framework for implementing good practices identified through pilot projects and policy initiatives. We would suggest the following areas in particular:

- *Collation and sharing of information* on innovative products, processes and services that are available for implementation, and existing national, regional and local initiatives that can be shared as good practices. Address all relevant levels (national, regional, local), and examples from specific disease areas that can *be transferred* to other disease areas;
- Consider also the sharing of negative experiences as *examples of what does not work* from the perspective of older persons/patients and their families and carers, or what could have been done differently;
- Examine *realistic and sustainable funding models* to promote take-up of innovative solutions at appropriate level of health/social care provision, and to ensure equitable access for all patients to innovation;
- Provide structured and process and outcome *evaluation* to demonstrate the added value of innovation – economic and quality-of-life. Quality of life is a key

consideration for persons living with chronic disease, and evaluation indicators should reflect this dimension as defined by older persons themselves. Appropriate and relevant indicators should be used for each disease-area; it is important to bear in mind that indicators may vary across Europe depending on the current level of treatment and individual healthcare systems.

- Full involvement of end-users (older persons/patients) throughout the innovation process ensures that their needs and preferences are met. The EIP-AHA can offer a *platform for cooperation of all relevant stakeholders*, including patient organisations, older persons' organisations, youth organisations, and health professionals' organisations, and encourage them to involve older patients within their work and work together towards common goals.

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### **How can the European Patients' Forum contribute to the work of the Innovation Partnership?**

EPF agrees with the Commission that "users, and more broadly demand-side needs, should be involved and possibly represented in the Partnership's governance at steering level. Users should not be seen uniquely as a consultative or validation partner."<sup>21</sup> We strongly support this premise and would propose that the most effective role for EPF would be on the *Steering Board* of the Innovation Partnership along with other appropriate stakeholder organisations. EPF differs from other consumer groups for older people, who deal with a broad range of issues around participation in society, while most of them have relatively little experience of the complexities of chronic diseases and the ageing process.

We could contribute our expertise and experience in particular in the following areas:

- an overall "evaluator" role, in assessing the planned activities, projects and initiatives to ensure that the perspective of older persons living with chronic diseases is adequately considered and represented within all relevant activities;
- supporting the effective roll-out and replication of activities to the wider older patient networks across the EU through our network of 47 member organisations and numerous allied patient organisations;
- supporting the effective dissemination of the EIP-AHA objectives and opportunities to the older patient communities across the EU down to the grassroots level;
- supporting the building of confidence and trust in innovative solutions and helping explain their benefits to older patients.

Finally, EPF believes it is very important to include an organisation representing older patients in each of the three task forces, in order to ensure a strong user involvement in all projects. EPF can identify suitable patient representatives for these task forces from among its membership and allied patient groups from across the EU in many different disease areas, including Parkinson's, Alzheimer's and dementias, and Diabetes.

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<sup>21</sup> Report of the Stakeholder Consultation Conference, 26 November 2010, [http://ec.europa.eu/information\\_society/activities/einclusion/deployment/ahaip/consultation/index\\_en.htm](http://ec.europa.eu/information_society/activities/einclusion/deployment/ahaip/consultation/index_en.htm)

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## **EPF Flagship Conference under the Polish EU Presidency, 12-13 July 2011**

EPF will hold a conference co-organised with the Federation of Polish Patients, under the patronage of the Polish EU Presidency, in Warsaw on 12-13 July 2011. This conference is centred on the theme “The rights and needs of older patients” and may include sessions on the following topics:

- intergenerational solidarity as a strategy to foster active and healthy ageing for young and older patients
- how to encourage a coordinated research agenda that centres on the needs of older patients, their families and carers
- older patients’ adherence to therapies
- linking health and social care
- psychological aspects of ageing with chronic disease
- (e-)Health literacy and information/training needs of older patients

We believe the conference aims are very complementary to the aims of the EIP-AHA, and the conference could provide a very useful forum for reflection and networking around the EIP-AHA strategy. Its outcomes and recommendations could provide input into some of the details of the operational action plans. EPF will be happy to provide more detailed information on the conference in the near future.