

# EPF Position Statement on the rights and needs of older patients

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## Introduction: Ageing and patients with chronic diseases

### Methodology

A first version of this paper was developed in 2012. It stemmed from our experience within the European Innovation Partnership on Active and Healthy Ageing, from the feedbacks of our members through various consultations, and the Conference on rights and needs of older patients held in 2011.<sup>1</sup> In 2013, the full EPF Membership was consulted and comments were integrated in this version. This paper will be further updated in the future according to new developments.

### Background

As the general population is ageing, many chronic diseases become more prevalent. 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 and are confronted with unique difficulties in addition to facing obstacles common to patients of all age. These difficulties can be socio-cultural (discrimination, lack of respect, isolation), structural (lack of involvement of older people in clinical trials resulting in inadequately evidenced treatment), linked to patient safety (polypharmacy), or in other areas.

Eurostat has estimated that by 2050, people aged 65 + will represent 30% of the population in the EU.<sup>2</sup> Chronic conditions currently affect 80% of people over 65 and often involve multiple morbidities. More than half of all older people have at least three chronic conditions, and a significant proportion has five or more.<sup>3</sup>

Within this context the EU has launched several initiatives to enable EU Member States to face the societal challenges of active and health ageing, whilst encouraging research and innovation. In December 2010 the decision to launch a pilot European Innovation Partnership on Active and Healthy Ageing was adopted, and the year 2012 was designated as the European theme year for active ageing and solidarity between generations. The Innovation Partnership aims to address bottlenecks and weaknesses in the way of innovation through multi-stakeholder cooperation. Its overarching goal is, by 2020, to increase the average Healthy Life Years (HLY) in the European Union by two years.

The European Patients' Forum has been very closely involved in the Partnership from the onset, resulting in a strong contribution to the Commission's public consultation on the Innovation Partnership on Healthy and Active Ageing. EPF continued to take an active role in the development of the Partnership through participation in the High-level Steering Group that drafted the Strategic Implementation plan. Following the adoption of the Strategic Plan

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<sup>1</sup> For our previous publications on this theme please consult our website: <http://www.eu-patient.eu/whatwedo/Policy/Ageing/>

<sup>2</sup> [http://www.ema.europa.eu/ema/index.jsp?curl=pages/special\\_topics/general/general\\_content\\_000249.jsp&mid=WC0b01ac058004cbb9](http://www.ema.europa.eu/ema/index.jsp?curl=pages/special_topics/general/general_content_000249.jsp&mid=WC0b01ac058004cbb9)

<sup>3</sup> F Luppi, F Franco, B Beghe, LM Fabbri (2008) "Treatment of chronic obstructive pulmonary disease and its comorbidities", ProcAm Thorac Vol. 5. Cited in the Operational Plan of the European Innovation Partnership on Healthy and Active Ageing (2011), p. 26.

of the Partnership, EPF and several of our member organisations are involved in the implementation of the Innovation Partnership in key thematic action areas, such as adherence and health literacy, integrated care, and nutrition, as well as in governance and monitoring of the Partnership.

### What are the rights of older patients?

Older patients' rights are derived from two sources: fundamental human rights among which is the right to health; and patients' rights, which have been defined as a result of the development of a patients' rights movements and have led to considering patients as active partners in healthcare. These rights are developed in the following instruments:

- The WHO defined the right to health as an inclusive right, which gives entitlements among which figure the availability and access to good quality services, goods and facilities, without discrimination<sup>4</sup>. It also adopted a policy framework on active ageing.<sup>5</sup>
- The UN Human Rights Council adopted the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, and focused particularly on its realization for older people through a thematic study.<sup>6</sup>
- The Political Declaration and Madrid International Plan of Action on Ageing of the Second World Assembly on Ageing (2002) puts an important emphasis on access to healthcare services.<sup>7</sup>
- The Charter of Fundamental Rights of the EU states that "Everyone has the right of access to preventive health care and the right to benefit from medical treatment under the conditions established by national laws and practices (article 35) and prohibits discrimination on the grounds of age and disability (article 21)."<sup>8</sup>
- The European Charter of Patients' Rights defines 14 essential rights for patients, and also highlights their right to participate in decision making.<sup>9</sup>
- The European Charter of the rights and responsibilities of older people in need of long-term care and assistance also details essential rights for patients.<sup>10</sup>
- The European Parliament adopted the resolution of 8 March 2011 on reducing health inequalities in the EU, with a specific call for action at EU level on inequalities related to age (recommendation 24).<sup>11</sup> It also called on the European Commission and Member States to address the impact of the crisis on access to care for vulnerable groups in its resolution 2013/2044/INI.<sup>12</sup>

<sup>4</sup> [http://www.who.int/hhr/activities/Right\\_to\\_Health\\_factsheet31.pdf](http://www.who.int/hhr/activities/Right_to_Health_factsheet31.pdf)

<sup>5</sup> [http://whqlibdoc.who.int/hq/2002/WHO\\_NMH\\_NPH\\_02.8.pdf](http://whqlibdoc.who.int/hq/2002/WHO_NMH_NPH_02.8.pdf)

<sup>6</sup> [http://www2.ohchr.org/english/bodies/hrcouncil/docs/18session/A-HRC-18-37\\_en.pdf](http://www2.ohchr.org/english/bodies/hrcouncil/docs/18session/A-HRC-18-37_en.pdf)

<sup>7</sup> <http://undesadspd.org/Portals/0/ageing/documents/Fulltext-E.pdf>

<sup>8</sup> <http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=OJ:C:2010:083:0389:0403:en:PDF>

<sup>9</sup> [http://ec.europa.eu/health/ph\\_overview/co\\_operation/mobility/docs/health\\_services\\_co108\\_en.pdf](http://ec.europa.eu/health/ph_overview/co_operation/mobility/docs/health_services_co108_en.pdf)

<sup>10</sup> [http://www.age-platform.eu/images/stories/22204\\_AGE\\_charte\\_europeenne\\_EN\\_v4.pdf](http://www.age-platform.eu/images/stories/22204_AGE_charte_europeenne_EN_v4.pdf)

<sup>11</sup> <http://www.europarl.europa.eu/sides/getDoc.do?type=TA&language=EN&reference=P7-TA-2011-81>

<sup>12</sup> <http://www.europarl.europa.eu/sides/getDoc.do?type=REPORT&reference=A7-2013-0221&language=EN>

- The European Parliament resolution of 6 February 2013 on the European Innovation Partnership on Active and Healthy Ageing also places a strong emphasis on the rights of older people in healthcare and on encouraging a holistic approach to health.<sup>13</sup>

All of these instruments establish a detailed corpus of rights for older patients that are recognised either at European level or universally. Most of these rights are encompassed and discussed in the paper below. The aim of this position paper is to focus on gaps in implementation of the rights of older patients, and to bring a patients' perspective on solutions to fully implement these rights in practice.

### **The EU needs to take action to implement and uphold these rights**

EPF believes that, complementing the European Innovation Partnership on Active and Healthy Ageing, further work is needed to uphold these common rights for older patients in the EU, as the EU population is ageing but at the same time important flaws have been identified by patients organisations in the care for older people.

This paper provides recommendations for the EU institutions, Member States and stakeholders (including healthcare professionals, researchers, scientists and industry) to further cooperate and work towards achieving the changes that are needed to meet the needs of older patients and uphold their rights across Europe. It centres around the following priorities that were identified by EPF and our members:

1. Integrated, holistic approach to health and social care
2. Promoting the rights of older patients and tackling discrimination and stigma
3. High-quality information and health literacy addressing the specific needs of older patients
4. Ensuring patients have access to the services they need throughout the care continuum
5. Shared decision-making and empowerment for older people and their carers
6. Development of innovative therapies and technologies to meet older patients' needs
7. Making meaningful involvement of older patients in health policy a reality

These changes are necessary to solve the challenges healthcare systems are confronted with as a result of demographic ageing and the rise in chronic diseases and multi-morbidity, and to ensure their financial sustainability in the long term while upholding older patients' rights to equitable access to safe, high-quality healthcare.

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<sup>13</sup> <http://www.europarl.europa.eu/sides/getDoc.do?pubRef=-//EP//TEXT+TA+P7-TA-2013-0046+0+DOC+XML+V0//EN>

## 1. Integrated, holistic approach to health and social care

Integrated care solutions are paramount to meet the needs of older patients. Patients indicated as one of their essential demands the wish to remain independent<sup>14</sup>/autonomous<sup>15</sup> for as long as possible, which can only be achieved with adequate support from primary and secondary care.

Fragmented organisation, financing and delivery of care form major barriers to good quality care. In our current health systems older patients encounter many obstacles and often report they feel they need to ‘fight the system’ to get the care they need. Professionals sometimes tend to look after their individual specialities rather than the patient as a whole, and overall quality of life issues can be overlooked. Healthcare and social services are often not well coordinated.

Care for chronic disease is very different from care for acute conditions: it is long term, and involves an important amount of self-management by the patients with the assistance of families and carers. Organisational and budgeting “silos” between medical and social care and between different medical specialities have to be broken. Integration should be vertical (between different levels within the whole healthcare system) and horizontal (between health and social care).

### Holistic care

Another key aspect is that care needs to be holistic, centred on the person, not the disease. Key issues when living and ageing with chronic diseases include the loss of independence or/and autonomy, 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, which often go unrecognised and untreated. Malnutrition and undernutrition are important issues among older patients; therefore appropriate screening of nutritional status and follow-up care need to be provided to prevent functional decline.<sup>16</sup> Other barriers when dealing with the healthcare system include loss of cognitive function for some older patients.

### Informal carers

Informal carers play an important role in patients’ well-being and their quality of life by enabling them to remain autonomous and benefit from home care longer. Their role in supporting care must be recognised by decision-makers and healthcare providers. They

<sup>14</sup> Independence can be defined as the ability to make decisions and live your life free from the control or influence of other people.

<sup>15</sup> Autonomy comprises the following aspects the capacity of creation of ideas and goals for life, 2) the capacity of moral insight, “self-legislation” and privacy, 3) the capacity of rational decision and action without coercion, 4) the capacity of political involvement and personal responsibility, 5) the capacity of informed consent. Source: Alzheimer Europe: <http://www.alzheimer-europe.org/Ethics/Ethical-issues-in-practice/The-ethical-issues-linked-to-the-use-of-assistive-technology-in-dementia-care/AT-ethical-issues-and-legislation?#fragment-3>

<sup>16</sup> Hickson M. “Malnutrition and ageing”. *Postgraduate Medical Journal* 2006;82:2–8. doi: 10.1136/pgmj.2005.037564 <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2563720/>

need to receive adequate support for their role, including opportunities to receive appropriate training and respite.

Issues that older patients face are also encountered by informal carers, who are often older persons themselves: they have to accept the disease of the loved one they care for; they may feel exhausted, fear the loss of independence and experience social isolation and financial insecurity. As a result, they may develop health problems themselves. Employment is a key issue for informal carers still of working age: caring may lead to difficulties balancing paid work with care responsibilities. Carers may also give up on work due to their caring activities, or may lose their job.

**To encourage the implementation of integrated care, EPF makes the following recommendations:**

- Examples of *integrated care* systems that “work” from the users/patients’ and carers’ viewpoint should be identified. Critical success factors and common elements of such systems that are transferable across EU member and also across disease-areas should be identified and their implementation supported at EU level. Two such solutions have already been flagged as models that fit patient needs:
  - To ensure better coordination of care, models whereby older patients are entitled to a “*care manager*” or coordinator<sup>17</sup> should be investigated and implemented,
  - Member States should ensure older patients have access to *healthcare solutions that meet their needs and preference*. Patients who wish to remain at home should have access to home care solutions and support. Care homes should be an integral part of the community rather than large scale institutions.
- Barriers to the successful implementation of integrated care systems should also be identified and addressed, e.g. funding structures of medical and social care.
- Stakeholders, including patients’ organisations, should be involved in developing *quality principles* to define what a quality service is. This should be based on existing work in this area, for example the WeDo project<sup>18</sup> which selected and defined principles (respectful of human rights and dignity; person-centred...) and published guidelines to encourage their implementation. These quality principles should also address integration of care.
- The situation of *informal carers* needs to be assessed across the EU. Recognition should be given to the work of informal carers. Member States should provide them with adequate support, including financially. We support the European Parliaments( call for a *carers’ leave directive*. The European Commission and Member States

<sup>17</sup> A care manager/coordinator is a person whose task is to act as an advocate for the older patient and their family, 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.

<sup>18</sup> <http://age-platform.eu/en/wellbeing>

should also ensure cooperation in scaling up good practices to ensure informal carers receive adequate training and support to provide care, and that enable carers to combine caring and employment.

- A formal dialogue should be established at European level to promote a *cross-sectoral approach for cultural and psycho-social issues* in order to exchange information and work towards actions that cover not only health, but also health-related social policy, employment, education, housing, infrastructure, and nutrition of older persons to implement the principle of “Health in All Policies”.

## 2. Promoting the rights of older patients and tackling discrimination and stigma

In addition to medical and psycho-social issues, patients can face social stigma and discrimination. There is already stigma attached to growing old, which is even stronger for older women; and people living with certain diseases, for example hepatitis, HIV/AIDS, Parkinson’s, Alzheimer’s, mental illness or chronic pain. For older people, discrimination in healthcare provision may include the rationing or limitation of services based on age. In addition, the European Parliament has recognised older people are potentially vulnerable to health inequalities and discrimination.<sup>19</sup> Yet non-discrimination is one of the key principles in all the instruments on patients’ rights mentioned in the introduction.

EPF would like to stress the importance of moving away from a negative perception of older people. *An older person is a person with rights and capabilities.* Older patients have a wealth of expertise that is a potential untapped resource in our societies; they are a source of knowledge and sometimes know more than even healthcare professionals about managing their disease. They can pass on knowledge and experience of navigating the healthcare system, and share coping strategies. As informed patients, they may be willing to support others and develop networks, help themselves by helping others.

Older patients need to be treated with dignity and respect, and their needs should be met taking into account the heterogeneity of this group and the diversity of this population: EPF advocates for equitable rights for all, regardless of gender, sexual orientation, ethnic or socio-economic background. Patients’ essential rights such as dignity, personal integrity in health or illness, the right to palliative<sup>20</sup> care, to support and to redress need to be implemented to effectively implement the principle of non-discrimination.

<sup>19</sup> <http://www.europarl.europa.eu/sides/getDoc.do?type=TA&language=EN&reference=P7-TA-2011-81>

<sup>20</sup> <http://www.who.int/cancer/palliative/definition/en/>

**To promote the rights of older patients and tackle discrimination and stigma we recommend that:**

- The European Commission and Member States should take action to examine carefully the situation as to *employment* of older patients and possibilities to encourage their participation in society through work and volunteer activities according to the wishes and abilities of the older patient.
- Older people's *right to autonomy* should be promoted at national level. With regard to health and wellbeing, this should include the right to choose one's place of residence and care, and the provision of adequate and varied healthcare options which are adapted to older people with specific medical conditions (i.e. older people should not be considered a homogeneous group).
- Patient and carer organisations, as well as decision makers, need to work together on addressing the specific issues of *older people who have lost their autonomy*, providing them with the social and legal protection they need. We support the implementation of the rights defined in the European Charter of rights and responsibilities of older people in need of long-term care and assistance,<sup>21</sup> developed by Age Platform Europe.
- The EU and Member States should ensure that the principle of "*reasonable accommodation*"<sup>22</sup> is applied in relation to the provision of healthcare and social services for older people in order to reduce interpersonal and structural discrimination and to promote social inclusion.

### 3. Ensuring patients have access to the services they need throughout the care continuum

#### Access to healthcare services and therapies

Particularly in the current economic environment, we would like to emphasise that "active and healthy ageing" rests on the cornerstone of equitable access to good quality and safe healthcare – preventive services, timely access to diagnostic testing and screening, acute medical treatment, chronic disease management and the necessary support services. For patients, access means availability and affordability. The needs of older patients should be given particular focus to tackle health inequalities effectively.

<sup>21</sup> [http://www.age-platform.eu/images/stories/22204\\_AGE\\_charte\\_europeenne\\_EN\\_v4.pdf](http://www.age-platform.eu/images/stories/22204_AGE_charte_europeenne_EN_v4.pdf)

<sup>22</sup> "Reasonable accommodation means necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms" United Nations Convention on the Rights of Persons with Disabilities, article 2  
<http://www.un.org/disabilities/convention/conventionfull.shtml>



## Prevention

Investing in prevention and health promotion throughout life is essential to ensuring healthy and active ageing. While not all diseases are preventable it is possible to delay the onset of some chronic conditions with appropriate support.

## Diagnosis

Many chronic diseases are degenerative in nature, making early detection essential. This entails timely access to diagnostic testing and screening. Early diagnosis followed by timely treatment is crucial to ensure good health outcomes and quality of life for patients, and to avoid deterioration and complications that require complex medical interventions that burden both the patient and the healthcare system. Prevention and treatment strategies should encompass equitable access to early diagnosis, treatment and support services.

Patients, when well treated and supported, are able to function in society and for example continue working for longer, thus reducing the burden on their families while also benefiting the economy and society as a whole. Certain chronic diseases are often underdiagnosed, or diagnosed at a late stage of a disease. This is for example the case for diabetes and COPD.<sup>23</sup>

### **In order to promote equitable access, EPF recommends:**

- Member States should support actions to *promote health at community level*, with the participation of health and older people NGOs' and patient organisations as they can facilitate community outreach.
- The European Innovation Partnership on Healthy and Active Ageing should encourage partnerships between neuroscientists, health professionals 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.
- *National plans* for specific diseases, which include screening and diagnosis, exist in many countries, but in order to ensure they are implemented we call on Member States to secure and ring-fence the necessary financial and human resources. Where appropriate, Member States should ensure that these plans integrate in a comprehensive manner the needs and rights of older patients.
- Adequate measures should also be taken to ensure that pricing and reimbursement decisions are taken with the involvement of users and with transparent and fair criteria.
- That EU decision makers show commitment to *tackle barriers to access to care* through supporting the setting of a multistakeholder platform as we call for in our manifesto for EU elections 2014.<sup>24</sup>

<sup>23</sup> Joceline Pomerleau, Cécile Knai and Ellen Nolte "The burden of Chronic Diseases in Europe" in *Caring for people with chronic conditions*" ed Ellen Nolte and Martin McKee (Open university Press, 2008)

<sup>24</sup> [http://www.eu-patient.eu/Documents/Campaign-2014-EU-Elections/epf\\_manifesto\\_EN.pdf](http://www.eu-patient.eu/Documents/Campaign-2014-EU-Elections/epf_manifesto_EN.pdf)

## 4. High-quality information and health literacy addressing the specific needs of older patients

Patients can only make informed choices when they have full and accurate information, presented in a format that is understandable and easily accessible. Knowing about the condition and treatment helps the patient deal with what is happening. Beyond this, health literacy skills are necessary: According to the WHO health literacy “entails people’s knowledge, motivation and competences to access, understand, appraise and apply health information in order to make judgements and take decisions in everyday life concerning health care, disease prevention and health promotion to maintain or improve quality of life during the life course”.<sup>25</sup>

Older people need information on how to stay active and how to manage their disease, to empower them to make informed choices and play their role in the patient-health professional partnership, to the extent of their willingness and capacity to do so.

Stakeholders and decision makers within the healthcare system should strive to develop patient-friendly information which enables patients to navigate the health systems and make informed choices. Information should come in a variety of formats taking into account patients’ diversity and varying competences e.g. levels of health literacy and use of computers.

Patients’ preferences should 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. 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.

Whichever media is used, information needs to be accurate and high-quality, easily accessed and understandable by the patient. To ensure this, all information providers should adhere to the core quality principles developed at the High Level Pharmaceutical Forum.<sup>26</sup>

### **To ensure older patients have access to the information they need, EPF recommends:**

- To establish an EU-level strategy on information to patients and health literacy. EU Institutions should work together with all stakeholders, including patient organisations, to formulate a coherent and ambitious, patient-centred strategy on information to patients. In order to develop health literacy programmes backed up with evidence that respond to the diverse needs of patients, this strategy should encompass cost-benefit analysis of best practices.

<sup>25</sup> Ilona Kickbusch, Jürgen M. Pelikan, Franklin Apfel & Agis D. Tsouros “*Health Literacy: The solid facts*” World health Organisation, 2013, p4

<sup>26</sup> These principles include: objective and unbiased, patient-oriented, evidence based, up-to-date, reliable, understandable, accessible, transparent, relevant, and consistent with statutory information. For more details please see: [http://ec.europa.eu/enterprise/sectors/healthcare/files/docs/itp\\_quality\\_en.pdf](http://ec.europa.eu/enterprise/sectors/healthcare/files/docs/itp_quality_en.pdf)

- To implement the EPF recommendations on health literacy and of the consensus paper “Making health literacy a priority in EU policy”.<sup>27</sup>

## 5. Fostering shared decision-making and empowerment of older patients and their carers

Shared decision-making<sup>28</sup> is a key solution to improve the quality and sustainability of healthcare. It can improve adherence to therapies, self-management, and therefore health outcomes and quality of life. Yet there are a number of barriers that can hamper building a therapeutic partnership between patients and healthcare professionals: time, resources (money), education, coordination, communication, patience, empowerment, complexity (of treatment), mistrust, taboo health conditions, psychological difficulties, mental incapacity, language (medical versus user-friendly) and sensory problems.

Older patients should be enabled and empowered to become equal partners in their care to the extent that they are able and willing to do so. To enable shared decision making, communication between patients and their health professionals is an important aspect of management of chronic disease.

Health professionals need to be educated and trained to involve patients and their carers in treatment decisions and management of chronic conditions, as equal and empowered partners, without shifting responsibilities inappropriately to the patient. There is a specific issue regarding the perception of older patients in healthcare. Training of healthcare professionals still tends to focus more on acute care than preserving or improving functions of older people with functional limitations. There are also stereotypes about older people with certain health conditions having no quality of life, or in the case of dementia about dementia consisting solely of advanced dementia. Addressing how older people are perceived by healthcare staff as well as health researchers is a necessary step towards ensuring high quality care.

### To foster shared decision-making, EPF recommends:

- Developing *expert education* on matters relating to older people and ageing for health professionals, and ensuring sufficient numbers of specialists in geriatrics. Training should focus on preserving and improving quality of life and functions of older patients. Some countries in Europe still do not recognise *geriatrics* as a specialty; and in undergraduate teaching, some EU countries do not include geriatric

<sup>27</sup> [http://www.eu-patient.org/eu-patient/publications/EPF\\_HealthLiteracyConference\\_2008\\_Report.pdf](http://www.eu-patient.org/eu-patient/publications/EPF_HealthLiteracyConference_2008_Report.pdf) [http://www.eu-patient.eu/Documents/Policy/HealthLiteracy/Health-literacy-concept-paper\\_FINAL.pdf](http://www.eu-patient.eu/Documents/Policy/HealthLiteracy/Health-literacy-concept-paper_FINAL.pdf)

<sup>28</sup> “a process in which clinicians and patients work together to clarify treatment, management or self-management support goals, sharing information about options and preferred outcomes with the aim of reaching mutual agreement on the best course of action.” Its’ essential elements are “the provision of reliable, balanced, evidence-based information outlining treatment, care or support options, outcomes and uncertainties; decision support counselling with a clinician or health coach to clarify options and preferences; [and] a system for recording, communicating and implementing the patient’s preferences.” Angela Coulter, Alf Collins, “Making shared decision-making a reality”, p.2. The King’s Fund, 2011.

training as a mandatory course.<sup>29</sup> Yet it has been shown that even relatively brief training can improve the way healthcare professionals deal with older patients.<sup>30</sup>

- The European Commission and Member States should put in place a coordinated approach, with the participation of appropriate stakeholders, to identify and implement good practices related to ensuring shared decision making in healthcare:
  - this should address guardianship, mental capacity, informed consent and patients' rights, promotion of shared decision making and patients' right to access information, and protecting patients from abuses and discrimination.
  - particular attention should be given to the training of healthcare professionals. This includes training on communication skills, concordance/shared-decision making, and attitudes towards patients, as well as on specific needs of older people. One example of good practice is the competency framework for adherence developed by the project Ascertaining Barriers to Compliance.<sup>31</sup>
- Member States should secure adequate resources to ensure patients are given an appropriate amount of time to discuss with their healthcare professionals during consultations, especially those involving general practitioners. Many older people have particular needs in this area due to their multiple and often complex health conditions and possible communication difficulties.
- Member States should take measures to improve shared-decision making and patient empowerment in *end-of-life-care*. Guidelines have been produced by Alzheimer Europe (*'End-of-life care for people with dementia'* and *'The use of advance directives by people with dementia'*), covering quality of life, advance planning, specific care issues (e.g. pain management), and consideration of personhood, dignity, autonomy and capacity.<sup>32</sup> These guidelines should be implemented and their adaptation to other chronic conditions explored.

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<sup>29</sup>Michel, J.-P., Huber, P., Cruz-Jentoft, A. J. et al (2008), "Europe-Wide Survey of Teaching in Geriatric Medicine". *Journal of the American Geriatrics Society* 56: 1536–1542.

<http://onlinelibrary.wiley.com/doi/10.1111/j.1532-5415.2008.01788.x/full>

<sup>30</sup>Diachun L, Van Bussel L, Hansen KT, Charise A, Rieder MJ. "But I see old people everywhere": dispelling the myth that eldercare is learned in nongeriatric clerkships" *Acad Med*. 2010 Jul;85(7):1221-8. doi:

10.1097/ACM.0b013e3181e0054f

<sup>31</sup><http://abcproject.eu/img/ABC%20Final.pdf>, pp 350-357

<sup>32</sup><http://www.alzheimer-europe.org/Ethics/Ethical-issues-in-practice/End-of-Life-care-for-people-with-dementia/Executive-summary-and-recommendations>

## 6. Development of innovative therapies and technologies to meet older patients' needs

Innovative solutions are an essential component in the future vision of healthcare, but they are currently not sufficiently centred on the people who use them. Older patients are very diverse, and have different level of skills and resources when it comes to accessing and using technology such as eHealth solutions. Innovation should be understood as including also “low-tech” solutions, such as changes in the way care is delivered, and structural, system and social innovation.<sup>33</sup>

Older patients lack access to evidence-based treatments, because of the exclusion of older people from clinical trials. In addition, older patients often have co-morbidities, and there is a lack of research related to polypharmacy. This results in poor knowledge regarding how medicines work in older patients, and how different therapies interact.

### Medicines

The European Medicines' Agency has identified some key differences between older and younger people that have an impact on their treatment with medicines: They are more susceptible to certain diseases (Alzheimer, heart diseases, bone diseases and mental illness); to co-morbidities; they may be weaker and therefore more affected by risks of a treatment, they take up and eliminate medicines differently compared to younger patients. For these reasons the Agency has put in place the EMA geriatric medicines strategy.<sup>34</sup>

Older people can be stereotyped as vulnerable by researchers: it may it may be more empowering to recognise older people, including those who have dementia, as being *potentially* vulnerable and to foster best practice in their involvement in clinical research. For example, older people with dementia (particularly the oldest age-group) are traditionally excluded from clinical trials due to the additional challenges linked to their involvement, yet very often they are the ones who will take such medical drugs. Consequently, the safety of drugs for these groups has not been scientifically proven. To tackle this exclusion Alzheimer Europe published recommendations on involving people with dementia as part of the “*Ethics in dementia research*” report<sup>35</sup>.

Personalised medicine is an important emerging area for older patients, which can lead to better tailored treatments, ensuring patients will have access to “the right drug at the right dose for the right patient at the right time”. But to achieve this potential and ensure older patients benefit from this approach it is essential to address barriers to their involvement in medicines' development.

<sup>33</sup> As recognised also in the [strategic implementation plan](#) of the EIP-AHA.

<sup>34</sup> [http://www.ema.europa.eu/ema/index.jsp?curl=pages/special\\_topics/general/general\\_content\\_000249.jsp&mid=WC0b01ac058004cbb9#](http://www.ema.europa.eu/ema/index.jsp?curl=pages/special_topics/general/general_content_000249.jsp&mid=WC0b01ac058004cbb9#)

<sup>35</sup> <http://www.alzheimer-europe.org/Ethics/Ethical-issues-in-practice/Ethics-of-dementia-research/Involving-people-with-dementia#fragment-1>

## Technologies

In the context of an ageing population, the development and uptake of innovative technologies is an important factor in ensuring the sustainability of health systems. Such technologies include eHealth, medical devices, assistive technologies, and other services. Many ethical issues are linked to the use of assistive technologies in particular; therefore meaningful patient involvement in their development and decision-making about their use will ensure that issues that are important to patients, such as promotion of autonomy and respect for dignity, are considered and addressed by manufacturers and decision-makers.

Whilst acknowledging the potential of innovative tools and services to lead to 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.

### To ensure older patients have access to innovative technologies, EPF calls for:

- *Patients' meaningful involvement in research and development of innovative 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. 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<sup>36</sup>; and meaningful involvement of patient organisations in all aspects of the research process. These challenges need to be discussed and addressed at EU level through relevant legislation, including the Clinical Trials Regulation that is currently under revision, and through developing common principles and good practices.
- Legal measures to protect potentially vulnerable older people should be balanced against those to promote their autonomy and respect the principle of equity, whereby all citizens should have an equal right to contribute towards society, even if this includes taking risks.
- Ensuring older patients are meaningfully involved in the development of *assistive technologies and medical devices* through appropriate legislation and practices. This will ensure these technologies are developed ethically, with patients' needs at the centre, and can also foster better uptake of these technologies. Through its research on "*ethical issues related to the use of assistive technology in dementia care*"<sup>37</sup> Alzheimer Europe has developed an ethical framework for making decisions linked to

<sup>36</sup> One good practice example is Alzheimer Europe's research 'The ethics in dementia research' which addresses how to involve people with dementia in research (from a robust definition of what is research, how to involve people with dementia in research, informed consent, protection of the well-being of the participant in research, his / her protection, the evaluation of the risk / benefit / burden and paternalism). Such recommendations should be implemented, and could be adapted and used as a good practice for other patients' group.

<sup>37</sup> <http://www.alzheimer-europe.org/EN%C2%B8/Ethics/Ethical-issues-in-practice/The-ethical-issues-linked-to-the-use-of-assistive-technology-in-dementia-care>

the use of assistive technologies whose key principles could be extrapolated further for all older patients with chronic diseases.<sup>38</sup>

- Enabling and supporting patient involvement in *health technology assessment*, as this is essential to ensure that innovations are made accessible to all patients that need them.
- Encouraging public private partnerships in the area of ageing, for example through the Innovative Medicines Initiative at EU level. One particular area where industry needs to be engaged as a partner alongside decision makers, patients and healthcare providers is the identification of sustainable funding models that guarantee equitable access to good quality healthcare regardless of the patient's ability to pay.

## 7. Making meaningful patient involvement a reality

From the perspective of patients with chronic diseases, the current healthcare systems need to be re-organised to ensure they provide care that meets users' needs, is equitable and of high quality in the face of demographic ageing and the associated rise in chronic diseases. But in order to do this, patients and their representative organisations have to be involved in the design, development and implementation of new solutions.

Patient organisations are increasingly involved in dialogue and political discussions on all the above mentioned themes: 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 to support evidence-based decision making. Most organisations, however, lack resources. It can even be difficult to maintain a good website, a crucial tool to inform patients and the public. Patient organisations therefore need adequate support to build their organisational capacity to enable them to play their role as a link between the patient communities and decision-makers.

**EPF calls for a strategy at EU level to make meaningful patient involvement a reality, both in research and in all relevant policies and programmes. This strategy should encompass:**

- Engage patients collectively and pro-actively through patient organisations in policy decision-making to ensure that all policies and practices reflect patients' real life needs, preferences and capabilities.
- Take concrete action to support the functioning of patient organisations through appropriate institutional, structural and financial support mechanisms at EU and member state levels.
- An explicit commitment at EU and Member State level to implement and streamline good practices that exist as regards *patient involvement in research* in the next

<sup>38</sup> <http://www.alzheimer-europe.org/Ethics/Ethical-issues-in-practice/The-ethical-issues-linked-to-the-use-of-assistive-technology-in-dementia-care/An-ethical-framework-for-making-decisions-linked-to-the-use-of-AT>

programming period (2014-2020), based on available evidence of the benefits of patient involvement for research.<sup>39</sup>

- Encourage projects and initiatives that 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. Stakeholders, including researchers and patient organisations, should work together to provide structured process and outcome evaluation to demonstrate the added value of innovation, taking into account both economic and quality-of-life considerations.
- Develop a set of *patient-centred healthcare indicators to evaluate healthcare services and health policies*. 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. EPF will develop with its membership a position paper to define further what is patient-centred healthcare from the perspective of patients, in 2014.

## Conclusion

EPF is strongly committed to raising awareness of the needs of older patients at EU level, including in the European Innovation Partnership on Active and Healthy Ageing. EPF will monitor how actions that have been set in motion impact on older patients' rights and the degree to which they contribute to meeting their specific needs. Beyond this, we strongly believe that further actions and initiatives are needed, across policy areas, to advance the rights of older patients across Europe.



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Disclaimer: The content of this position paper reflects only the author's views and the Executive Agency is not responsible for any use that may be made of the information contained therein.

<sup>39</sup> The PatientPartner project identified some of the barriers for partnerships in clinical trials, as well as good practices; lessons from the RESPECT project (participation of children and their families in clinical trials) regarding ethics and empowerment could be applied to research in older persons, together with Alzheimer Europe's work addressing the ethical issues linked to the involvement of people with dementia in research. For further information please consult: <http://www.patientpartner-europe.eu/>

The VALUE+ project created targeted resources for patient organisations and project coordinators, as well as a set of policy recommendations to promote meaningful patient involvement in projects. <http://www.eu-patient.eu/whatwedo/Projects/EPF-led-EU-Projects/ValuePlus/>