

# Joint Statement on “Improving the employment of people with chronic diseases in Europe”

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## Framing paper

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### Preamble

*This paper presents the common position of stakeholders from the health, social and employment sectors in Europe on the issue of the employment of people with chronic diseases. It offers recommendations to EU and national policymakers to address the identified challenges. A standalone call to action summarises concrete policy asks to the European Commission and EU Member States in order to achieve improved participation of people with chronic diseases in the employment market; and the organisations behind this statement urge them to include the recommendations provided herewith in their actions to address chronic diseases but also their strategies on social equity and on employment, jobs and growth.*

*This framing paper and the associated call to action were developed by the European Chronic Disease Alliance (ECDA) in partnership with stakeholders and Members of the EU Health Policy Platform (a full list of contributing organisations is available at the end of the paper).*

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## Background

### a. The growing burden of chronic diseases in Europe

The prevalence of chronic diseases and disabling conditions has been growing in the EU and the wider European region over the past decades<sup>1</sup> due to an increasing ageing population. Globally, Europe has the highest burden of chronic diseases, which are responsible for 86% of all deaths<sup>2</sup> and a major cause of morbidity and disability estimated in disability-adjusted life-years (DALYs).

In Europe, the highest burden of chronic diseases comes from cardiovascular diseases (CVDs- heart disease and stroke), cancer, chronic respiratory diseases (chronic obstructive pulmonary disease (COPD) and asthma), diabetes, chronic kidney disease, chronic liver disease, and allergy, accounting for the premature death of more than 550 000 people of working age annually across the EU<sup>3</sup> – the loss of around 3.4 million potential productive life years<sup>4</sup>. Over one-third of the European population aged 15 years or older lives with a chronic disease and 23.5% of the working population in the EU suffer from a chronic illness, while two out of three people at retirement age have at least two chronic conditions<sup>5</sup>. The co-occurrence of two or more chronic conditions (multimorbidity) has become increasingly common in Europe<sup>6</sup>.

The burden of disabling conditions is also increasing in Europe. Rheumatic and Musculoskeletal Diseases (RMDs) alone affect 1 out of 4 Europeans and are the number one cause of disability and impairment, accounting for almost 30% of all disabled people in Europe<sup>7</sup>. 165 millions of Europeans are living with a brain or a mental health problem giving rise to a far higher level of disability, while mental health problems account for the second health disability in the workplace.

While the causes for some of these conditions are associated with ageing or genetic predispositions, other important determinants are socio-economic and lifestyle-related and, therefore, can be addressed by measures targeting the population at large. Social determinants of health where policy action can be taken include smoking, alcohol use, unhealthy diets, lack of physical activity; overweight/obesity and exposure to poor air quality. For instance, more than one in five adults in EU countries smoke every day, while another one in five adults report drinking heavily on a regular basis and one in six adults is obese<sup>8</sup>. In addition, despite a dedicated EU Strategy in place since 2007 and the ongoing EU Action Plan on Childhood Obesity 2014-2020, one-in-three children in the EU between the ages of six and nine is overweight or obese, while childhood obesity is a strong predictor of adult obesity. It is estimated that over 60% of children who are overweight before puberty will remain overweight in early adulthood<sup>9</sup>, a major risk factor for type 2 diabetes, cardiovascular diseases and many cancers.

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<sup>1</sup> Eurostat, 2010; Busse et al., 2010

<sup>2</sup> WHO high level Consultation. 2011 <http://www.euro.who.int/en/media-centre/events/events/2010/11/regional-high-level-consultation-on-noncommunicable-diseases>

<sup>3</sup> Busse R, Blümel M, Scheller-Kreinsen D, Zentner A. Tackling chronic disease in Europe - Strategies, interventions and challenges. World Health Organization 2010, on behalf of the European Observatory on Health Systems and Policies.

[http://www.euro.who.int/\\_data/assets/pdf\\_file/0008/96632/E93736.pdf](http://www.euro.who.int/_data/assets/pdf_file/0008/96632/E93736.pdf)

<sup>4</sup> OECD/EU (2016), Health at a Glance: Europe 2016 - State of Health in the EU Cycle, OECD Publishing, Paris. DOI:10.1787/9789264265592-en

<sup>5</sup> Europeans of retirement age: chronic diseases and economic activity. RIVM. December 2012

[http://ec.europa.eu/health/sites/health/files/major\\_chronic\\_diseases/docs/rivm\\_report\\_retirement\\_en.pdf](http://ec.europa.eu/health/sites/health/files/major_chronic_diseases/docs/rivm_report_retirement_en.pdf)

<sup>6</sup> Boyd & Fortin, 2010; Uijen & van der Lisdonk, 2008

<sup>7</sup> Global Burden of Diseases Study <http://www.thelancet.com/gbd>

<sup>8</sup> Idem source 4

<sup>9</sup> <http://www.euro.who.int/en/health-topics/noncommunicable-diseases/obesity/data-and-statistics>

Mental health problems can also be the precursors to other chronic diseases, consequences of them, or the result of interactive effects<sup>10</sup>. In particular, mental health problems (such as depression) often exacerbates unhealthy life styles including smoking, substance abuse, physical inactivity and insufficient sleep and increase the chance to suffer from chronic physical illnesses.

In addition, stigma and lack of public knowledge worsen the impact of the conditions on patients and families by preventing people from seeking treatment and causing social exclusion including on the labour market, while huge inequalities in access to care hamper efforts to reduce the burden of chronic diseases in Europe.

### **b. The current situation for people with chronic diseases on the employment market**

Beyond the direct costs of healthcare to treat people with chronic diseases, which amount to €700 billion in the EU<sup>11</sup>, workers with chronic conditions and employers incur indirect costs. For cardiovascular diseases alone, productivity losses are estimated at € 54 billion/year<sup>12</sup>. Evidence shows that chronic diseases have a significant impact on labour supply in terms of workforce participation, hours worked, job turnover and early retirement<sup>13</sup>. For individuals with chronic conditions, those diseases also mean barriers to employment and stigma, with consequences on wages, earnings and positions reached/level of seniority in an organisation<sup>14</sup>. Overall, they “depress wages, earnings and labour productivity, as well as increase early retirement, high job turnover and disability”<sup>15</sup>. It has been extensively observed that chronically ill employees have reduced employment prospects, as many of them experience difficulties either staying at work or returning to work after a long period of absence. The *Health at a Glance: Europe 2016* report<sup>16</sup> clearly shows the consequent impact on the labour market of chronic diseases. It also indicates that the employment rate of people who have one or more chronic condition, and particularly people aged 50-59, is much lower than for those who do not suffer from any disease. EU data show that the employment rate for people with limitations in work due to a longstanding health problem and/or a basic activity difficulty is lower for cardiovascular diseases, cancer, as well as people with diabetes related complications and respiratory diseases<sup>17</sup>. It can be suspected that the situation is as bad for people with stroke, mental health conditions, and chronic kidney disease, which are often later consequences of some of the conditions mentioned above<sup>18</sup>. For CVDs (including heart, blood pressure or circulatory problems), cancer and diabetes, the employment rate is less than 30%<sup>19</sup>.

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<sup>10</sup> WHO (2014), Integrating the response to mental disorders and other chronic diseases in health care systems.

<sup>11</sup> Economist Intelligence Unit, 2012

<sup>12</sup> Wilkins E, Wilson L, Wickramasinghe K, Bhatnagar P, Leal J, Luengo-Fernandez R, Burns R, Rayner M, Townsend N (2017). [European Cardiovascular Disease Statistics 2017](#). European Heart Network, Brussels.

<sup>13</sup> Idem source 3

<sup>14</sup> Idem source 4

<sup>15</sup> Idem source 13

<sup>16</sup> Idem source 4

<sup>17</sup> Eurostat, LFS ad hoc module 2011. Rate of employment per chronic disease category for persons with limitations in work due to LHPAD; both sexes, age group 20-64 years

<sup>18</sup> [Law MC et al, Hong Kong Journal of Nephrology \(2016\) 18, 11e14; Also Mauro JJC et al, Nefrologia 2012;32\(4\):439-45. And Imanishi et al, PLoS ONE 12\(3\): e0170731. 2017](#)

<sup>19</sup> Comparison of available strategies for professional integration and reintegration of persons with chronic diseases and mental health: Report based on five categories of social welfare models in Europe [http://www.path-ways.eu/wp-content/uploads/pathways\\_report\\_identify.pdf](http://www.path-ways.eu/wp-content/uploads/pathways_report_identify.pdf)

### **Case study - Health status of people with diabetes type 2 and impact on labour market participation**

The French GAZEL cohort study<sup>20</sup> on the “impact of diabetes on work cessation” found that patients with diabetes type 2 lost an estimated mean time of 1.1 year in the workforce between 35 and 60 years old. Compared with nondiabetic individuals, people with diabetes had significantly increased risks of transition from employment to disability, retirement and even death and overall a rapid decrease in the employment rate was observed.

Data<sup>21</sup> indicate that the impact of the condition for a 50-year old single man was significant, accounting for almost 3% of career lost in terms of years of working life<sup>22</sup>.

The European Commission notes that the example of the negative effects of diabetes type 2 provides evidence on the impact of prevention on labour market participation<sup>23</sup>.

According to the 2011 Eurostat<sup>24</sup> report on health and safety at work in Europe (1999-2007), prolonged sickness leave of one month or more is frequent among employed persons with circulatory problems, including heart disease or attack (29%) as well as stress, depression or anxiety (25%) and musculoskeletal problems (25%)<sup>25</sup>. In addition to the costs of days off work, 43% of patients with allergic rhinitis and asthma experience sleep disturbances and 39% have difficulty in falling asleep with negative impacts on social life, career and school performance. For their part, RMDs have a huge impact on work-related absences accounting for about 60% of all cases of permanent incapacity to work. Mental health problems are also associated with increased sickness absence recurrence and work impairment and studies find a significant correlation between mental health problems and non-re-employment rate<sup>26</sup>. People with epilepsy are more than twice as likely to be unemployed as the general population<sup>27</sup> though the proportion varies considerably between countries. 1 in 4 people with chronic pain report it has impacted their employment with an average loss of more than 3 weeks of work each year due to their pain<sup>28</sup>.

From the employer side, workers who present with chronic illnesses can generate challenges for managers who need to accommodate levels of attendance and ensure company growth. Yet, from the employee perspective, a majority of workers welcome the opportunity to contribute to society, value the status of employment and earning their salary, which reduces or eliminates their dependency on welfare/state benefits<sup>29</sup>.

In addition, it is also important to note the impact on the work participation of care givers for people with chronic sickness and disability<sup>30</sup>. A large number of people report that they have been voluntary

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<sup>20</sup> [http://www.hal.inserm.fr/file/index/docid/593506/filename/Diabetes\\_Care\\_May\\_2011.pdf](http://www.hal.inserm.fr/file/index/docid/593506/filename/Diabetes_Care_May_2011.pdf)

<sup>21</sup> Commission data for Poverty Rates, Life Expectancy, Population, GDP, labour market, healthcare expenditure. International Diabetes Federation (IDF) for Diabetes Type 2 epidemiology and direct medical cost, peer-reviewed journal publications for Quality of Life (QoL)

<sup>22</sup> European Commission Staff Working Document, Investing In Health, 2013

[https://ec.europa.eu/health/sites/health/files/strategy/docs/swd\\_investing\\_in\\_health.pdf](https://ec.europa.eu/health/sites/health/files/strategy/docs/swd_investing_in_health.pdf)

<sup>23</sup> <http://eur-lex.europa.eu/legal-content/EN/ALL/?uri=CELEX:52013SC0043>

<sup>24</sup> Eurostat, 2011 LFS ad hoc module ([hlth\\_dlm190](http://hlth.dlm190))

<sup>25</sup> [http://www.path-ways.eu/wp-content/uploads/pathways\\_report\\_identify.pdf](http://www.path-ways.eu/wp-content/uploads/pathways_report_identify.pdf)

<sup>26</sup> Nwaru et al. (2017)

<sup>27</sup> Clarke BM et al. Work beliefs and work status in epilepsy. *Epilepsy Behav.* 2006;9(1):119-25

<sup>28</sup> Breivik H et al. Survey of chronic pain in Europe: prevalence, impact on daily life, and treatment. *Eur J Pain.* 2006;10(4):287-333

<sup>29</sup> Promoting healthy work for workers with chronic illness: A guide to good practice - European Network for Workplace Health Promotion (ENWHP). [http://www.enwhp.org/uploads/media/ENWHP\\_Guide\\_PH\\_Work\\_final.pdf](http://www.enwhp.org/uploads/media/ENWHP_Guide_PH_Work_final.pdf)

<sup>30</sup> Oortwijn W, Nelissen E, Adamini S, van den Heuvel S, Geuskens G, Burdof L. Social determinants state of the art reviews - Health of people of working age - Full Report. (2011) European Commission Directorate General for Health and Consumers. Luxembourg. ISBN 978-92-79-18526-7

caregivers for family members with chronic conditions in the past year, which has limited their own work participation, productivity and opportunities for job advancement. For cardiovascular diseases the cost of informal care amounts to € 45 billion/year<sup>31</sup>. The results of a 2005 study<sup>32</sup> indicated that the proportion of caregivers aged 25-64 in the EU-25 was 5.5%, with variations from 0.5% in Luxembourg to 9.7% in Cyprus.

#### **Case study – Employment and professional reintegration issues for cancer survivors**

With the aim to examine the employment situation for cancer patients, a national study conducted in France in 2013 (the VICAN 2) highlighted the impact of cancer during the survivorship and rehabilitation period of patients and the inequalities on both the occupation rate and income two years after the first diagnosis of cancer<sup>33</sup>. The findings indicated that the poverty level of cancer patients at the diagnostic stage in 2010 was 6.9% more compared to the general population, and the gap worsened two years after diagnosis, in line with a deterioration of their professional situation. The study reports decreasing employment rates for cancer patients over their time with cancer and identifies the most vulnerable people, which include manual workers, the youngest and oldest workers, and workers with fixed term precarious working contracts. According to the data collected, 21.8% of cancer patients aged 18-57 years old lost their job right after being diagnosed, while 91.6% lost it 15 months after diagnosis, and they experienced a six-month longer waiting period before being employed again in comparison to the general population.

According to another study from 2014 conducted in the Netherlands<sup>34</sup>, the employability of cancer patients and survivors is the lowest among chronically-ill people in the country.

#### **c. The links between economics and the professional integration of people with chronic diseases**

Statistics clearly demonstrate that chronic diseases pose a serious societal problem in Europe<sup>35</sup>. The direct costs of care for chronic diseases coupled with lower employment rates of people living with chronic health problems generate loss for our economies. Chronic-illness can result in increased welfare payments for disability, sick leave, unemployment, or early retirement according to the specific situation of the person. Lower market participation is also associated with lower economic growth.

However, people with a well-managed chronic disease are able to work normal hours and many people affected by chronic illnesses can, if enabled to, work under flexible working times and adapted conditions, which allows them to be fully part of a country's workforce and economic growth. Along with further investment in prevention and targeted efforts among the working-age population, measures facilitating the entry/reintegration for people with disabilities to the labour market can bring significant economic and social benefits<sup>36</sup>. Addressing chronic illness and work issues has the potential to lead to stronger economic growth, higher employment rates and labour supply, and reduce public spending on state/disability benefits, while resulting in fewer demands on healthcare systems and increased productivity<sup>37</sup>. For instance, a study conducted through a cross-sectional retrospective analysis of data collected in France, Germany, Italy, Spain and the UK by several primary care physicians and pulmonologists found out that when comparing employed COPD patients with those "not in paid

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<sup>31</sup> Wilkins E, Wilson L, Wickramasinghe K, Bhatnagar P, Leal J, Luengo-Fernandez R, Burns R, Rayner M, Townsend N (2017). [European Cardiovascular Disease Statistics 2017](#). European Heart Network, Brussels.

<sup>32</sup> EU Labour Force Survey

<sup>33</sup> European Guide on Quality Improvement in Comprehensive Cancer Control, Chapter 7 Survivorship and rehabilitation. CanCon Joint Action. 2017. [https://cancercontrol.eu/archived/uploads/images/Guide/pdf/CanCon\\_Guide\\_FINAL\\_Web.pdf](https://cancercontrol.eu/archived/uploads/images/Guide/pdf/CanCon_Guide_FINAL_Web.pdf)

<sup>34</sup> Research "Profielacceptatie" <http://www.startfoundation.nl/profielacceptatie>

<sup>35</sup> Idem source 19

<sup>36</sup> Idem source 4

<sup>37</sup> Idem source 29

employment”, the employed group had lower frequency of exacerbations and lower incidence of co-morbidities, including anxiety and depression. Even though 27.3% of patients took up to ten and more days off work due to COPD, the real and perceived burden of COPD is lower in employed patients than those not in paid employment<sup>38</sup>.

In addition, a study commissioned by Randstad<sup>39</sup> suggests a potential shortfall of around 35 million workers, or about 15% of the total labour demand, by 2050. For this reason, it is important to ensure an inclusive labour market that can meet the future labour demand and contribute to sustainable growth. Such inclusive markets can become reality if every person of working age has the opportunity to take part in the labour market and is provided with adequate support.

Retaining the experience and knowledge of a worker with a chronic illness is essential to the business outcomes of a company and the overall economic productivity of a country. The ability to manage complex and chronic conditions brings important returns to individuals, employers and indeed society as a whole. In order to achieve inclusive and sustainable growth in the EU as targeted in the Europe 2020 Strategy, every person of working age should be given an opportunity to enter and remain in the labour market, including people with chronic diseases<sup>40</sup>. Ensuring the conditions for the employment of people with chronic diseases and disabilities also falls within a human rights-based approach to work and employment.

#### **d. The role of organisation and integration of care in managing chronic diseases and employment prospects**

Health at work is not just a socio-economic issue. In order to avail of the opportunities to access employment, people living with chronic diseases need earlier and accurate diagnosis as well as appropriate treatment and management. The organisation and delivery of healthcare plays an essential part in chronic disease management. Improved interaction between primary and specialist care<sup>41</sup> can result in better management of people with chronic diseases, generating a healthier workforce and, when needed, quicker (re) integration into the employment market.

Primary care is particularly important for prevention and diagnosis, but also in shared follow-up and survivorship care. Besides contact with secondary care specialists, chronic disease patients already have multiple interactions with their family doctor and other primary care professionals during and after treatment. In addition to the general practitioner, the primary care team should include psychosocial professionals (psychologists, social workers, counsellors, etc.), community nurses, pharmacists, physiotherapists, occupational specialists from a range of professions. Such a team contributes to optimal outcomes and fostering re-integration in the labour market<sup>42</sup> alongside patient organisations which play

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<sup>38</sup> Miguel Roman Rodriguez, Mark Small, Steve. Fermer, James Bailey, Robert Wood., Antje –H. Fink-Wagner. Real World Burden of COPD: Employed vs Not in Paid Employment Patients. Journal of Health and Productivity (JHP) Volume 7, Number 1 December 2013 [http://www.ihpm.org/pdf/jhp\\_V7\\_N1\\_2014.pdf](http://www.ihpm.org/pdf/jhp_V7_N1_2014.pdf)

<sup>39</sup> Berkhout et al., 2012

<sup>40</sup> Participation To Healthy Workplaces And inclusive Strategies in the Work Sector, Pathways Project. Deliverable number 4.1. Report on the comparison of the available strategies for professional integration and reintegration of persons with chronic diseases and mental health issues based on five categories of social welfare models in Europe. [http://www.path-ways.eu/wp-content/uploads/pathways\\_report\\_identify.pdf](http://www.path-ways.eu/wp-content/uploads/pathways_report_identify.pdf)

<sup>41</sup> For more information on primary and specialist care, see WHO Framework for professionals and administrative development of general practice/family medicine in Europe. Copenhagen: World Health Organisation Regional office for Europe, 1998

<sup>42</sup> ECCO Position Statement: Integrated Cancer Care: Bringing Primary Care and Secondary Care Together : [http://www.ecco-org.eu/~media/Documents/ECCO-sections/Policy/Positions-and-publications/2017/ECCO\\_Position\\_Statement\\_Integrated\\_Cancer\\_Care.pdf?la=en](http://www.ecco-org.eu/~media/Documents/ECCO-sections/Policy/Positions-and-publications/2017/ECCO_Position_Statement_Integrated_Cancer_Care.pdf?la=en)

an important role in assisting patients and their relatives in the care pathway and getting back to work or maintaining a work life.

Indeed, areas where primary care is solicited by chronic disease patients may include the management of treatment side effects and of psycho-social events - which are also of primary importance for a successful re-integration into daily life including into employment. More recently, the need to include other professionals, such as dieticians, motivational coaches or experts in physical activity in the multidisciplinary team has been highlighted in order to improve patients' lifestyle behaviours and reduce mortality rates. As the first point of contact for chronic disease patients and survivors, it is essential that primary care professionals have an understanding of the issues faced and the capacity to deliver high quality care to address these specific needs. In turn, this requires mechanisms of knowledge-sharing and an enabling culture of communication between primary and secondary care professionals, or a degree of what can be referred to as "integration of care"<sup>43</sup>.

In cancer as an example, important reasons for improved integration of primary and specialist care during and after treatment include symptom control and management of toxicities to avoid emergency department visits and hospital admissions, but also to potentially better manage everyday life and return-to-work. Management of cancer patients with concurrent mental health problems and other multi-morbidities are also part of the integration model, to foster quality of life and address the psycho-social dimensions, both conducive to a re-integration into society and employment as explained above<sup>44</sup>.

A number of required elements can be identified to establish successful integration of care:<sup>45</sup> patient centricity; multidisciplinary team based approach; pre-defined coordination of the total care process; clearly defined roles and responsibilities; good communication among all care providers; adequate education, clear guidelines/protocols on management/follow-up care; rapid access back to secondary care; and adequate IT systems.

Time of delivery of care should also take into account work and travel constraints whenever possible for people with chronic conditions and the care itself should integrate all evidence-based innovation, such as in eHealth, to better accommodate a patient still in the labour market. This would support both the employers and the patient-employee efforts to remain at work.

Widespread and improved integrated care may help reduce the impact of the disease and support people with chronic diseases successfully managing their condition in their everyday life, in accordance with their health status, including living a normal working life, returning to/retaining work when appropriate. All levels of care - from primary care to specialised interventions care are important and should interact as part of the treatment pathway for a person with a chronic condition to foster staying in, integration or reintegration in the labour market. Rehabilitation programmes including therapy, medical treatment and psycho-social support are key in supporting patients in managing their conditions, including in terms of work life. As multifaceted and multidisciplinary interventions, they improve functional capacity, recovery and psychological well-being of individuals, although the efficiency of some multidisciplinary programs is still unclear in terms of integration and reintegration of people with chronic health conditions in specific pilot interventions conducted<sup>46</sup>. As an example, pulmonary or cardiac and stroke rehabilitation programmes help prevent recurrence, improve functional capacity, recovery and psychological well-being<sup>47</sup>.

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<sup>43</sup> Idem source 42

<sup>44</sup> Idem source 42

<sup>45</sup> Idem source 42

<sup>46</sup> "Evaluate effectiveness integration and reintegration to work strategies for persons with chronic diseases and mental disorders in Europe" report [http://www.path-ways.eu/wp-content/uploads/pathways\\_report\\_evaluate.pdf](http://www.path-ways.eu/wp-content/uploads/pathways_report_evaluate.pdf)

<sup>47</sup> Cardiac and Stroke Rehabilitation - a European Heart Network paper. 2013

In economic terms, extensive evidence indicates that rehabilitation programmes are cost effective. For instance, for cardiac rehabilitation, studies show that compared to no cardiac rehabilitation, cardiac rehabilitation programmes result in an incremental cost-effectiveness ratio of about €9 000 per quality adjusted life year (QALY)<sup>48</sup>. In addition, rehabilitation programmes are cost-saving: it is widely accepted that a direct economic consequence for public finances of absence of rehabilitation is an increase in hospital stays and medication<sup>49</sup>.

**e. Existing policy frameworks and good practices in the management of the employment of people with chronic diseases and measures or pathways to improve their care and optimise employment prospects and working conditions**

National policy and legislative frameworks relative to the employment of people with chronic diseases are disparate across EU countries. In most cases, national policies do not necessarily address chronic illnesses specifically nor the specific needs of patients with highly cyclic conditions where periods of normal life (e.g. during remission) and periods of frailty (e.g. during treatment cycles) alternate and do not address the needs of caregivers either. However, they provide overarching frameworks which can promote inclusion or reintegration policies for people with chronic diseases<sup>50</sup>, and such policies are often part of broader policies and strategies. The EU-funded PATHWAYS project<sup>51</sup> provided a map of existing policies, systems and services facilitating the inclusion of persons with chronic diseases in the labour market. Amongst its findings were that many countries provide assistance in this regard in the context of policies targeted at broader groups, in particular in the scope of strategies for persons with disabilities.

Indeed, in a number of Member States, chronic diseases fall under the “disability” category: in the UK for instance, the 2010 Equality Act<sup>52</sup> introduced a new definition of “disability”, under which people are “disabled not by their impairment, but by the barriers to participation that they experience”; and many chronic diseases fall within the definition of a disability within the Act.

Specific definitions and references to chronic diseases which include the employment perspective are observable in some EU countries, including Germany, Finland and Portugal<sup>53</sup>. In other countries, the concept of chronic diseases in an employment context is taken into consideration in the scope of regulation against discrimination, as the (Dutch Act on Equal Treatment) on the Grounds of Disability or Chronic Illness<sup>54</sup> or the above mentioned UK Equality Act. These legislative frameworks contain rules that protect employees against discrimination in the workplace, including people affected by disabilities and longstanding health conditions and employers have the responsibility to make the necessary work adaptations to enable effective participation in work of people who are disabled and chronically ill<sup>55</sup>.

In the case of the Dutch Act, improved provisions would be needed to successfully facilitate the return to work of chronically-ill people, including cancer patients and cancer survivors; as it has been observed that a high number of workers who have cancer become unemployed and many stay unemployed until reaching retirement-age.

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<sup>48</sup> Idem source 47

<sup>49</sup> Idem source 47

<sup>50</sup> Idem source 40

<sup>51</sup> Idem source 40

<sup>52</sup> <http://www.legislation.gov.uk/ukpga/2010/15/contents>

<sup>53</sup> Employment opportunities for people with chronic diseases. European Observatory of Working Life. November 2014. <https://www.eurofound.europa.eu/observatories/eurwork/comparative-information/employment-opportunities-for-people-with-chronic-diseases>

<sup>54</sup> Act on equal treatment on the grounds of disability or chronic illness (Stb. 2003, 206)

<http://mensenrechten.nl/sites/default/files/2013-05-08.Legislation%20Equal%20Treatment.pdf>

<sup>55</sup> Idem source 53

The UK Equality Act requires that employers make “reasonable adjustments” in the workplace to prevent employees from “being treated less favourably than others for reasons related to their disability or progressive condition”. Under this regulation, employers are under a legal duty to provide support for workers with chronic illnesses and take steps to remove, reduce or prevent obstacles that may face a disabled worker, and this also applies to job applicants. Conditions covered by the Act are “physical or mental impairments that have more than a minor or trivial long-term adverse effect on a person’s ability to carry out normal day-to-day activities”.

In Italy, a 2003 regulation<sup>56</sup> provides for the right of cancer patients active in the private sector to switch to part-time positions while under treatment, and to revert to full-time work from the moment it becomes possible. The legislation was extended to workers in the public sector in 2007<sup>57</sup>. The same law provides caregivers of cancer patients priority for part-time applications “as long as there are positions available”.

#### **Case study - The UK “Workplace Wellbeing Charter”**

As part of the Health, Work and Wellbeing’ initiative of the UK Government aimed at protecting and improving the health and well-being of working age people, Expert Adviser on Health and Work to the Department of Health and Public Health England Professor Dame Carol Black launched the Workplace Wellbeing Charter<sup>58</sup>. The Charter is a voluntary self-assessment scheme that can be used by any public, private or voluntary sector organisation. It provides employers with a clear guide on how to make workplaces a supportive and productive environment in which employees can flourish and self-assess their work against defined benchmarks specific to the different types of businesses. By signing up to the Charter, employers demonstrate that they adhere to a set of minimum standards to promote good, safe and healthy work. According to the website dedicated to the initiative, over 1000 employers have committed themselves since 2009, and are using the standards to “ensure a holistic approach to health and wellbeing in the workplace”.

Additionally, different organisations have developed guidelines to help employers adopt a positive strategy in managing disability related issues in the workplace, such as the International Labour Organization (ILO) Code of Practice on managing disability in the workplace<sup>59</sup>.

A conference on the topic of “Working with a Chronic Illness” held in Brussels in 2013 at the initiative of the European Network for Workplace Health Promotion provided a series of ten policy recommendations on managing chronic illnesses in the workplace to politicians, employer organisations and unions at EU and national levels<sup>60</sup>. The conference called for a shift of the paradigm from reduced performance to retaining current and future working ability and focus on the abilities and resources of the individual and not only on limitations or restrictions.

Other recent initiatives from EU stakeholders specifically addressed the topic of reintegration to work including in the context of cancer survivorship and provided recommendations to this aim.

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<sup>56</sup> decree-law n° 276/2003, article 46, as amendment of decree-law n° 61/2000, article 12 bis

<sup>57</sup> law n° 247/2007, article 1, subsection 44

<sup>58</sup> The Workplace Wellbeing Charter, Self-Assessment Standards, Public Health England

<http://www.wellbeingcharter.org.uk/media/Dropbox/Charter%20standards.pdf>

<sup>59</sup> International Labour Organisation. February 2002 [http://www.ilo.org/skills/pubs/WCMS\\_103324/lang--en/index.htm?ssSourceSiteId=empent](http://www.ilo.org/skills/pubs/WCMS_103324/lang--en/index.htm?ssSourceSiteId=empent)

<sup>60</sup> 2013 Declaration on Workplace Health Practices for Employees with Chronic Illness

[http://www.enwhp.org/uploads/media/Layman\\_article\\_PH\\_Work\\_conference\\_22-23\\_october.pdf](http://www.enwhp.org/uploads/media/Layman_article_PH_Work_conference_22-23_october.pdf)

At EU level, chronic diseases are mentioned in health policy, but provisions regarding the promotion and support of the employment of people with chronic diseases or preventing exclusion from the labour market are to a large extent part of broader policy frameworks. These include frameworks related to the employment of people with disabilities, such as the European Disability Strategy 2010-2020, the EU Strategic Framework on Health and Safety at Work 2014-2020 as well as frameworks on inclusion and anti-discrimination or general EU strategies on growth, which target the employment of all. While these do not specifically support people with chronic diseases, they provide overarching frameworks for integration or reintegration of all people within the labour market. The EU Disability Strategy 2010-2020 promotes the employment of disabled people with the aim to increase their participation in the labour market. The Europe 2020 Strategy: “Europe 2020: the European Union strategy for growth and employment” aims at employment activation and inclusion in the labour market for all<sup>61</sup>. Health initiatives related to the strategy include the “Agenda for new skills and jobs”, which calls for adopting targeted approaches for vulnerable workers, including older workers, disabled people and people with mental health issues<sup>62</sup>.

For its part, the EU Strategic Framework on Health and Safety at Work 2014-2020 specifically mentions support in recruitment and return to work of people with chronic diseases. It promotes the implementation of integrated employment measures such as individualised support, counselling, guidance, and access to general and vocational education and training, and encourages Member States to build on the European Social Fund and other European Structural and Investment Funds to financially support actions related to occupational health and safety<sup>63</sup>.

According to Eurostat data<sup>64</sup>, only 5.2% of employed people, limited in their work capabilities because of a longstanding health problem and/or a basic activity difficulty, report to use special working arrangements, while 24.2% of the non-employed ones specify that those would be needed to return to work.

Some initiatives and policy schemes exist across Europe to protect and promote employment activation policies for people with chronic diseases; and while in recent years a number of steps have been taken to encourage the inclusion or reintegration of workers with chronic diseases on the labour market, much remains to be done to effectively ensure similar opportunities for workers with and without chronic illnesses.

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<sup>61</sup> Idem source 40

<sup>62</sup> Idem source 61

<sup>63</sup> Idem source 61

<sup>64</sup> Eurostat, 2011 LFS ad hoc module ([hlth\\_dlm190](#))

## Priorities for Action at EU and national levels

The growing prevalence of chronic diseases and their impact on productivity and labour market participation demonstrate the urgency to minimise the impact the illnesses have on businesses and people and call for greater awareness of the need for comprehensive policies and strategies for the (re)integration of persons with chronic conditions on the employment market. While chronic diseases are the main causes of longstanding health problems in the working-age population<sup>65</sup> the gaps observed in the current policy response in terms of health promotion and disease prevention, management and care but also in relation to the way our socio- economic models are designed need to be addressed to provide comparable levels of employment opportunities for people living with and without chronic conditions in Europe and to defend the rights of people who are already working with a chronic disease.

### 1. Investing in the prevention of chronic diseases to fight the epidemic

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Among the preventable risk factors of many chronic diseases, four main health determinants (tobacco use, unhealthy diets, alcohol use and physical inactivity) must be addressed robustly. Health promotion and disease prevention, including initiatives and measures at the workplace, play a major role in driving lifestyle changes with respect to these risk factors. Modifiable factors such as stress and other negative emotions (anxiety), which have an impact on ill-being and chronic diseases, should also be tackled with increased actions to prevent them at workplace level. Social determinants of health (including exposure to indoor and outdoor air pollution or harmful chemicals), health inequalities, and poverty also have to be addressed to fully prevent the increase in chronic diseases in Europe. It has been extensively demonstrated that investing in prevention is cost-effective and reduces not only costs of care -including high long-term treatment costs-, ensuring the sustainability of our health systems, but also indirect costs for our societies and individual businesses related to absenteeism, presentism or prolonged sick leaves. According to estimates, interventions that promote prevention could help save billions of Euros a year. For instance, a National Institute for Health and Care Excellence (NICE) analysis of the cost effectiveness of various interventions that informed public health guidance published between 2006 and 2010 found that 15% were cost saving and 70.5% were cost effective<sup>66</sup>. Other data suggest that halving cardiovascular events for England and Wales alone would result in discounted savings in healthcare costs of approximately £14 billion a year<sup>67</sup>. A limited change, such as bringing the inhabitants in Germany to use the recommended quantities of salt, sugar and fat, would result in 2.1 billion of savings per year and per 10 million people on health care costs for chronic diseases<sup>68</sup>.

Investing in the childhood and adolescent years is key to preventing ill health later in life and numerous studies have highlighted the critical importance of preventive action in early childhood to reduce the risk of developing chronic diseases<sup>69</sup>. Yet, the OECD estimates that on average only 3% of total health expenditure (for all age groups) in OECD countries including EU Member States goes towards population-wide public prevention while 97% of health expenses are presently spent on treatment<sup>70</sup>.

Broad and coherent strategies with a “health-in-all-policies” approach are needed to address the many socio-economic determinants of health and risk factors that are leading to many chronic diseases and

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<sup>65</sup> Idem source 30

<sup>66</sup> National Institute for Health and Care Excellence (2013) Judging whether public health interventions offer value for money. London: National Institute for Health and Care Excellence

<sup>67</sup> National Institute for Health and Clinical Excellence (NICE),UK; public health guidance 25 - June 2010

<sup>68</sup> Meier et al, PlosOne, 10: e0135990; 2015

<sup>69</sup> McQueen, D. V. (2013). Global handbook on noncommunicable diseases and health promotion (pp. 337-342). New York, NY: Springer; Demaio, A. R., Nielsen, K. K., Tersbøl, B. P., Kallestrup, P., & Meyrowitsch, D. W. (2014); Primary Health Care: a strategic framework for the prevention and control of chronic noncommunicable disease. Global health action, 7

<sup>70</sup> Together for Health: A Strategic Approach for the EU 2008-2013, White paper, European Commission, COM(2007) 630 final

premature deaths<sup>71</sup>, and prevent chronic diseases among the working-age population, alongside measures to support the employment or return-to-work of people affected by chronic diseases.

Such disease prevention and health promotion measures are needed to halt the rise in the incidence of chronic diseases in Europe and will bring positive impact to our economies: in addition to bringing improvements in the health status of people with chronic diseases, preventive action will enable to reduce the burden of these conditions on our economies, while currently 70-80% of healthcare costs are spent on chronic diseases in Europe<sup>72 73</sup>. Ultimately, prevention measures promoting healthier lifestyles will impact on the well-being and quality of life of all Europeans.

In addition, further efforts need to be placed in investing in checking the effectiveness of existing prevention programmes. Research efforts have been already conducted in a number of areas to prevent chronic diseases, though it is not clear if all prevention programs are similarly effective and few of them have included outcome measures to check their efficacy<sup>74</sup>. Effectiveness assessments of existing prevention programmes shall consider the context and evaluate actions based on the situation and circumstances in which they have been carried out (geographical level, cultural considerations) to ensure that country/context tailored actions are performed where necessary.

## **2. Improving the integration of primary and specialist care to strengthen chronic disease rehabilitation, recovery and employment**

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Firstly, earlier detection of chronic diseases should be enhanced to effectively reduce the burden of the conditions. To this aim, strengthening integrated primary and secondary care should be a priority.

Integrated primary and specialist care should also be reinforced to ensure comprehensive care for people with chronic illnesses, according to their needs. Support services for employment activation should be integrated within the care pathway, and legislative provisions should promote such an integration. Patients' treatment plans should include a return-to-work and work retention component, which should be part of an integrated care supply and be discussed early on in the care trajectory with the involvement of the patient.

The following approaches to improve the integration of care should be considered<sup>75</sup>:

- IT solutions can address problems of communication and information transfer between healthcare providers in the primary and secondary care settings as well as with employment settings (e.g occupational medicine). Patients' access to their healthcare records can also facilitate access to all relevant healthcare providers.
- The active engagement of patients and patient organisations is essential in achieving sustainable high quality healthcare. Integrated models of care must result in an improvement for patients as a result of their active participation, including disease self-management with a guided plan and approach decided together with the treating doctor.
- More research into integration during treatment is needed

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<sup>71</sup> Idem source 4

<sup>72</sup> Economist Intelligence Unit, 2012

<sup>73</sup> Providing policy recommendations for combating preventable chronic diseases in Europe is a core mission of the ECDA. See ECDA position papers on how Europe can better address the various chronic disease risk factors for more information: <http://www.alliancechronicdiseases.org/policy-papers/>

<sup>74</sup> Borschmann, R., et al 2014

<sup>75</sup> Those were initially identified for integrated cancer care but are of relevance to chronic diseases and multi-morbid conditions. Idem source 42

- Various integration models have to be designed, and each healthcare system needs to take into account all the variables to adapt to its specificities. Member States should rethink their national health systems and translate a holistic approach to health into policy and practice.
- Education is a key area to drive progress: undergraduate and postgraduate training of healthcare professionals should ensure proper understanding of the importance to work in teams. Trainings should also include communication modules and educate on the importance of patient's expectations throughout the entire pathway.
- Integration of care requires a cohesive and collaborative effort, on the part of healthcare providers and researchers but also on the part of stakeholders actively involved in the organisation of care, such as policy makers, executive agencies, education/training organisers and providers, and patients. It requires a pre-defined coordination of the total care process. Policy and organisational commitments are needed to implement such change.

In particular, improving and further developing the implementation of rehabilitation programmes should be seen as an investment in health, rather than an expense, as these programmes are cost-saving and cost-effective<sup>76 77</sup> (see above). Every eligible patient should be given the opportunity to participate in rehabilitation programmes, regardless of age, gender, socio-economic status or place of living and not being discriminated against because of his condition. Health professionals should be provided with the necessary information to refer patients to specific employment support services to facilitate a quicker return-to-work and sustainability of work in good health with or after a chronic disease.

Accurate, earlier diagnosis and appropriate management are necessary to enable those with chronic conditions to optimise the social acquis. Improving Europe-wide access to healthcare is also an important part of supporting employment and economic productivity amongst patients and carers.

### **3. Putting in place adequate policy frameworks and financial and non-financial incentives to support the employment, return-to-work or retention at work of people with chronic diseases**

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It is important to have adequate strategies in place at a policy level and within companies - from small and medium-sized enterprises (SMEs) to large companies - to facilitate the employment and professional (re) integration of people with chronic diseases, including self-employed people. To improve their participation in the labour market and support them remaining part of the workforce, different initiatives can be envisioned, according to the person's capabilities, health needs and condition: workplace retention or return-to work after a period of absence due to a chronic illness.

At a national policy level, financial and non-financial incentives can be set up to encourage employers to hire or retain in employment persons with chronic conditions. Such initiatives include wage subsidies, tax incentives, preferential treatment in awarding public contracts etc, and can build on corporate social responsibility or workforce components of a company's corporate and operational strategies.

#### Workplace retention

Workplace retention aims to keep a person with a chronic condition in work as much as his/her health status allows. Workers in such situations have not yet experienced a (long-term) absence or sick-leave from work but are at risk of dropping out of the labour market because of their chronic illness. Workplace retention is promoted via initiatives and policies which focus on retaining a person's current employment,

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<sup>76</sup> Cardiac and Stroke Rehabilitation - a European Heart Network paper. 2013

<sup>77</sup> EU-OSHA Rehabilitation and return to work after cancer <https://osha.europa.eu/en/tools-and-publications/publications/rehabilitation-and-return-work-after-cancer-literature-review/view>

according to his/her capabilities. While in some cases - such as degenerative chronic illnesses - work can only be an option for a limited period of time, timely and appropriate workplace retention policies and initiatives are fundamental to avoid that employees with chronic conditions move out of employment when their condition deteriorates or continues.

### Return to work

Return to work initiatives aim to ease the reintegration in professional life 1) of persons out of employment resulting from a prior/ongoing condition or 2) after a sick-leave – which can be a long-term leave – due to one's chronic condition. Workers in such a situation may be cancer survivors, cardiac patients after rehabilitation or transplant recipients of a variety of organs and in those cases, initiatives and policies shall be linked with rehabilitation and reintegration programmes. Evidence shows that return-to-work initiatives play a vital role in maintaining or improving the health status and can even contribute to recovery, reducing the risk of a long-term disability in a worker with a chronic illness<sup>78</sup>.

At a policy level, measures should be taken to ensure that business models adapt to meet the growing demand for reintegrating workers with chronic diseases linked to their increased prevalence in the work-age population. As an example of such measures, around 2000 reintegration agencies have been established in the Netherlands<sup>79</sup> to support return-to-work and help people with chronic diseases find a job that is suited to their situation and abilities. Support from health authorities, in addition to the help offered by health professionals, is among factors facilitating the return-to-work of a chronically-ill person<sup>80</sup>.

The Annual Survey Report on Absence Management (2013) in the UK suggests that after several adjustments by some employers to help employees return to work after a period of absence and minor changes to working hours, more than 70% of employers reported a positive impact on employee motivation and employee engagement.

At a company level, retention at work, return to work and employment can be facilitated by the development of work-life programmes, which aim to create “a flexible and supportive work-place environment that helps employees balance their personal and professional lives”<sup>81</sup>. Such programmes include financial assistance or caregiving support. Other mechanisms in terms of structural adaptation include proactive work arrangements (e.g teleworking, job sharing/sharing responsibilities for tasks, sabbaticals – paid or unpaid leaves at recurring intervals), flexible working hours policies (working part-time, compressed work weeks – working full time in a reduced number of days – or flexitime, whereby employees vary the duration and timing of the workday within limits set by management), and worksite adjustments such as frequent breaks, slower work paces when possible. These may help workers better self-manage their chronic condition and for instance combine doctors' appointments with work schedule, while being productive and meeting business objectives and expectations.

Such mechanisms and programmes may in some cases be limited due to the type of employer or job, but should be considered to facilitate work retention/activation for people with chronic diseases, and fit with their health status, physical or cognitive capability during working times. These flexible arrangements and

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<sup>78</sup> Idem source 29

<sup>79</sup> Return to work coaching services for people with a chronic disease by certified “experts by experience”: the Netherlands. Case Study. EU-OSHA

<sup>80</sup> Dekkers-Sánchez P.M. (2013). Work ability assessments of employees on long term sick leave in Insurance Medicine (Doctoral Dissertation). Amsterdam: University of Amsterdam

<sup>81</sup> Ihara E. Workers affected by chronic conditions: how can workplace policies and programs help? Georgetown University, Health Policy Institute. Issue Brief Number 7, June 2004

adaptations may have to be tailored to the needs and specificities of the situation, as needs vary across EU countries<sup>82</sup> and should ideally be co-produced in partnership with people with lived experience.

Company strategies should also outline a management plan/disability management plan for workers with chronic conditions and provide details on the person(s) responsible for managing sick leave and accompanying the worker throughout his/her career pathway. Such plans keep the worker engaged in the workplace and productive, or help ill workers return to work as soon as possible and have a strong impact on the workers' morale and dedication.

In addition, training and reskilling schemes can enable workers to expand their capabilities and skills and adapt to their changing health situation by changing positions or moving to other areas of business better suited to their needs. While management styles differ between companies, training programmes should be encouraged and access to tailored training, seminars or workshops for workers with chronic diseases should be part of the company's programme for the professional development of the staff, as they have the potential to be considerable sources of support for chronically-ill workers.

Finally, chronically-ill workers and workers caring for a family member with a chronic disease may have to cope with mounting stress of balancing work and personal life demands. Nowadays, an increasing number of companies provide support in the form of stress management seminars for employees and those could include a component addressing the specific needs of people with chronic diseases or carers. Many patient organisations also offer a variety of support mechanisms, e.g. support helplines, experience sharing between patients and carers, "care for the carer" seminars to avoid stress and burn-out in people who are carers of a patient and the main income source of the family.

#### **4. Ensuring appropriate training of employers on the issue of chronic diseases and working conditions and promoting chronic disease awareness at the work place**

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Adapted human resource management and increasing health awareness in addition to ensuring employee involvement and promoting empowerment are fundamental to a sustainable working environment in a company and to its growth.

Appropriate training about chronic diseases for human resources managers, business managers and executive teams should provide them with the tools to harmonise workers' abilities and availability with the needs and functioning of the business. For instance, several studies indicate that employers/line-managers need to be provided with training, support, and resources to help them facilitate employment and job retention of employees diagnosed with cancer<sup>83</sup>.

Furthermore, chronic disease, musculoskeletal and mental health awareness at the workplace in general should allow a proper understanding of the condition in the work environment and facilitate effective team support and team work.

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<sup>82</sup> Findings from a survey conducted in the scope of the PATHWAYS project indicated that while flexible work arrangements were mainly very useful and were in general perceived as very helpful by people with chronic diseases, the need for these adaptations ranged considerably across EU countries.

<sup>83</sup> J Occup Rehabil. 2010 Dec;20(4):435-42. doi: 10.1007/s10926-009-9197-9.

## Annexes

### Annex 1 – List of contributing organisations to the production of this document

- European Chronic Disease Alliance (ECDA):

The European Academy of Allergy and Clinical Immunology (EAACI)

The European Association for the Study of the Liver (EASL)

The European COPD Coalition (ECC)

The European CanCer Organisation (ECCO)

The European Heart Network (EHN)

The European Kidney Health Alliance (EKHA)

The European Respiratory Society (ERS)

The European Society of Cardiology (ESC)

The European Society of Hypertension (ESH)

The European Society for Medical Oncology (ESMO)

The International Diabetes Federation European Region (IDF Europe)

- PATHWAYS project consortium
- Association of European Cancer Leagues (ECL)
- British Medical Association (BMA)
- European Association of Service Providers for Persons with Disabilities (EASPD)
- European Brain Council (EBC)
- European Cancer Patient Coalition (ECPC)
- EuroHealthNet
- European Federation of Allergy and Airways Diseases Patients' Association (EFA)
- European Federation of Neurological Associations (EFNA)
- European League Against Rheumatism (EULAR)
- European Organisation for Research and Treatment of Cancer (EORTC)
- European Psychiatric Association (EPA)
- International Psycho-Oncology Society (IPOS)
- Mental Health Europe
- Standing Committee of European Doctors (CPME)

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