



FOUR MOTORS FOR EUROPE

Working group on digital health and care

“Equity in a digital health and care system – Bridging social and digital divide in times of demographic change“

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Introduction

The demographic structure of the EU has been transforming over the last decades, which lead to the significant increase of the portion of elderly in the overall population. Indeed, in 2017, nearly 1/5 of EU inhabitants were aged 65 or more, with the median age being highest in Italy and Germany (45.9 years in both countries), as well as Spain (43.2 years) and France (41.2 years) (1). This trend is expected to continue in the future and therefore it is projected that the number of working-age people per one person aged 65 and above will decrease from 3.3 to 2 by 2070. Increased life expectancy is usually accompanied with chronic conditions (2), of which some develop because of physiological process of aging (3), while the rest is the outcome of the various risk factors (genetic, behavioural, environmental, etc.) (4). According to Brennan et al. (5), eight out of nine persons aged 65 and above suffer from one or more chronic diseases, which have negative impact on both quality of life and health care system. Along with that, multimorbidity increases significantly too, requiring more and better interprofessional and intersectoral patient coordination in order to prevent

¹ europa.eu [homepage on the Internet]. Brussels: European Commission [updated 2018 Oct 17; cited 2019 Jan 27]. Available from: https://ec.europa.eu/eurostat/statistics-explained/index.php/Population_structure_and_ageing

² Lunenfeld B, Stratton P. The clinical consequences of an ageing world and preventive strategies. *Best Pract Res Clin Obstet Gynaecol.* 2013;27(5):643-59.

³ Jaul E, Barron J. Age-Related Diseases and Clinical and Public Health Implications for the 85 Years Old and Over Population. *Front Public Health.* 2017;5:335. doi:10.3389/fpubh.2017.00335

⁴ Rappaport SM. Genetic Factors Are Not the Major Causes of Chronic Diseases. *PLoS One.* 2016;11(4):e0154387. doi:10.1371/journal.pone.0154387

⁵ Brennan P, Perola M, van Ommen GJ, Riboli E, European Cohort Consortium. Chronic disease research in Europe and the need for integrated population cohorts. *Eur J Epidemiol.* 2017;32(9):741-749.



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adverse events. More than half of the population between 50 and 64 have more than two, one third of women over 75 were shown to live with 5(!) or more coexisting diagnoses (6). The most prevalent chronic conditions among EU population are cardiovascular diseases, diabetes, cancer, chronic obstructive pulmonary diseases, mental conditions and musculoskeletal conditions (7). The World Health Organization Regional Office for Europe at the 66th session in 2016 proposed an Action Plan for the prevention and control of non-communicable diseases (NCDs) in the WHO European Region, with the aim to reduce morbidity and premature mortality rates of NCDs, the increase of the quality of life, the decrease of the burden of NCDs to health systems and to reduce inequity in health among member states (8).

European Commission guidelines and recommendations to manage chronicity

Knowing the multicausality of chronic conditions and acknowledging that most risk factors are modifiable and preventable, the majority of recommendations are focused on health promotion and disease prevention, on both individual and community level. To implement such programs, good strategic coordination between policy makers and health systems is vital, as well as unified surveillance, monitoring and evaluation in order to support care planning and achieve compatibility of research data (7, 9).

In July 2018, the European Commission established a Steering Group on Health Promotion, Disease Prevention and Management of NCDs with the aim to support member states to achieve the health targets of the Sustainable Development Goals. Based on available data, priorities were set and efforts to achieve these targets have been made in certain areas, such as mental health, cancer,

⁶ Uijen, v.d. Lisdonk. Multimorbidity in primary care: prevalence and trend over the last 20 years. *Eur J Gen Pract* 2008;14(1):28–32.

⁷ Busse R, Bluemel M, Scheller-Kreisen D, Zentner A. Tackling chronic disease in Europe [monograph on the Internet]. Copenhagen: WHO Regional Office for Europe; 2010 [cited 2019 Jan 27]. Available from: http://www.euro.who.int/_data/assets/pdf_file/0008/96632/E93736.pdf

⁸ WHO Regional Committee for Europe. Action plan for the prevention and control of noncommunicable diseases in the WHO European Region [monograph on the Internet]. Copenhagen: WHO Regional Office for Europe; 2016 [cited 2019 Jan 27]. Available from: http://www.euro.who.int/_data/assets/pdf_file/0011/315398/66wd11e_NCDActionPlan_160522.pdf?ua=1

⁹ [alliancechronicdiseases.org](http://www.alliancechronicdiseases.org) [homepage on the Internet]. Brussels: European Chronic Disease Alliance; [cited 2019 Jan 27]. Available from: <http://www.alliancechronicdiseases.org/home/>



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nutrition and physical activity, as well as in rare diseases (10). The Steering Group on its first formal meeting discussed the importance of reliable health data as a support for decision-making and chose mental health to be a priority area for best practices and screening of implementable research results in 2019 (11). Later the same year, the Steering Group at the extraordinary meeting emphasized the importance of the Innovative Medicines Initiative, which was formed to facilitate collaboration of public and private sector to promote research-based development of models that improve patients' access to personalized medicine. Such practices are especially important for areas where patients' medical needs are not met (12). In the area of mental disorders the attempt had been made in terms of diagnostic criteria (13).

How States responded to EC recommendations

According to the Companion Report 2017, The State of Health in the EU, there are still disparities among member states in the quality of health data and thus its comparability, regarding the portion of people with unmet medical needs, the amount of health budget spent on the prevention, as well as inequities among various population groups. Strengthening of multi-disciplinary primary health care, with increased patient involvement and patient centred data might support to tackle the epidemic of chronic diseases (14).

¹⁰ ec.europa.eu [homepage on the Internet]. Brussels: European Commission [updated 2019 Jan 24; cited 2019 Jan 27]. Available from: https://ec.europa.eu/health/non_communicable_diseases/steeringgroup_promotionprevention_en

¹¹ European Commission Directorate General for Health and Food Safety. First formal meeting of the Steering Group on Health Promotion, Disease Prevention and Management of Non-Communicable Diseases; 2018 6 November [cited 2019 Jan 27]. Available from: https://ec.europa.eu/health/sites/health/files/non_communicable_diseases/docs/ev_20181106_flash_en.pdf

¹² European Commission Directorate-general for health and food safety. Extraordinary meeting of the Steering Group on Health Promotion, Disease Prevention and Management of Non-Communicable Diseases; 2018 4 December [cited 2019 Jan 27]. Available from: https://ec.europa.eu/health/sites/health/files/non_communicable_diseases/docs/ev_20180928_note_en.pdf

¹³ Steinley D, Lane SP, Sher KJ. Determining optimal diagnostic criteria through chronicity and comorbidity. In *Silico Pharmacol*. 2016; 4: 1. doi: 10.1186/s40203-016-0015-8

¹⁴ European Commission. State of health in the EU. Companion Report 2017 [monograph on the Internet]. Luxembourg: Publications Office of the European Union; 2017 [cited 2019 Jan 27]. Available from: https://ec.europa.eu/health/sites/health/files/state/docs/2017_companion_en.pdf



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Despite the fact that estimated 50 million people in the EU live with more than one chronic disease, there is a lack of strategies or policies on integrated care for people with multimorbidity, neither on national or regional level, usually strategies are disease specific. However, there are local and regional programs for improvement of care of patients with multimorbidity in 25 EU member states, with the common goals of better patient involvement and multidisciplinary approach (15).

Another promising example for comprehensive patient management is The Social Impact of Pain, a platform that was initiated based on the French White Book, with a comprehensive approach for chronic pain management (16). Since the burden of pain is very high in Europe (approximately 150 million people have reported pain that lasted more than three months) (17) and this condition is usually accompanied with chronic conditions (18), there are policies addressing this issue (Article 8 (5) by the EU Directive on the application of patients' rights in cross-border healthcare (2011/24/EU).

The challenge for (in) formal care givers in rural areas

Caring for the beloved ones is a challenging but also a very rewarding task (19, 20). Nevertheless, more than 70 % of informal caregivers report a strong or even very strong burden (21, 22), since

¹⁵ van der Heide I, Snoeijs S, Melchiorre MG et al. Innovating care for people with multiple chronic conditions in Europe (ICARE4EU) [monograph on the Internet]. Utrecht: NIVEL; 2015 [cited 2019 Jan 27]. Available from: http://www.icare4eu.org/pdf/State-of-the-Art_report_ICARE4EU.pdf

¹⁶ SIP. Thematic Network on the Societal Impact of Pain. Framing Paper .Version 5; 2018 Nov 5 [cited 2019 Jan 27]. Available from: https://ec.europa.eu/health/sites/health/files/policies/docs/ev_20181112_co07_en.pdf

¹⁷ Eccleston C, Wells C, Morlion, B. European Pain Management. Oxford, UK: Oxford University Press, 2017. ISBN: 9780198785750

¹⁸ Barnett K, Mercer SW, Norbury M, et al. Epidemiology of multimorbidity and implications for healthcare, research, and medical education: a cross-sectional study. Lancet. 2012; 380:37–43

¹⁹ Nowossadeck S, Engstler H, Klaus K. Pflege und Unterstützung durch Angehörige. Report Altersdaten 01/2016. Deutsches Zentrum für Altersfragen: Berlin; 2016

²⁰ Wetzstein M, Rommel A, Lange C. Pflegende Angehörige. Deutschlands größter Pflegedienst. GBE kompakt. 2015; 3:1-11.

²¹ Helscher V, Kirchen-Peter, S, Nock, L. Pflege in den eigenen vier Wänden: Zeitaufwand und Kosten. Dusseldorf: Hans-Böckler-Stiftung; 2017.

²² continentale.de [homepage on the Internet]. Dortmund: Continentale Versicherungsverbund; [cited 2019 Jan 25]. Available from: <https://www.continentale.de/-/pressemitteilung-2016-geschaeftergebnisse>



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more than half of them have to take care of their family members every single day – one third reports a care-load of 5 hours and more per day. According to a report by the German health insurance DAK (23), every second informal caregiver suffers from mental stress (i.e. depression, burnout). 43 % provide the care giving on top of a regular occupation, which causes additional pressure, especially for those who live in rural areas and have to commute a lot to work, but also to health practitioners/ health centers etc.

In 2015, almost one quarter (22.8 %) of the EU-28 population was living in rural areas, half of them over 60 years old. Thus, a predominant topic of concern is caregiving for rural elders, since the support network in the rural context is fragile also due to a lack of medical workforce and oftentimes infrastructure, and the prevalence of informal care networks.

Today's tele-health and -care approaches are promising to offer considerable enhancement of service delivery in rural and other underserved communities. Technology-based delivery methods, such as videophone clinics or skill training, and one- and two-way interactive computer networks, are envisioned as contributors for improving rural residents' access to services, individualizing rural health care, increasing rural health practitioners' continuing education opportunities, and improving quality and cost-efficiency of care.

Similarly, informal care can profit substantially of telehealth applications (i.e. monitoring, tele-consultation and -coaching). The challenges of actually providing informal caregiving have been attributed to: the level of intensity and physical intimacy required to provide care, the amount of burden, distress, and role strain that care engenders for the caregiver, and, the skill required to master care tasks. Although interventions and support services for older family carers exist, there is still a need for more effective ways of supporting them. Telehealth can especially alleviate the burden of informal caregivers by tele-coaching as well as supporting communication and surveillance of elderly.

Moreover, the studies carried out so far indicate that new digital solutions must be accompanied by sufficient services. It is therefore necessary to rethink home support, with a real combination of human help and digital solutions, with real integration of “digital data” in caregivers' process or procedures.

²³ Kordt M. DAK-Gesundheitsreport 2015; 2015 [cited 2019 Jan 25]. Available from: <https://www.dak.de/dak/download/vollstaendiger-bundesweiter-gesundheitsreport-2015-1585948.pdf>



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“Four Motors for Europe” contribution for social and welfare innovation

“Four Motors for Europe” is a long-lasting cooperation between the Regions of Baden-Württemberg (Germany), Catalonia (Spain), Lombardia (Italy) and Auvergne-Rhône-Alpes (France). Since its beginning in 1988, the goal of this cooperation has been to contribute to both the internationalization of the regions and to promote the role of the regions in Europe and within the European institutions. The agreement was to have the four regions cooperate in a long-term relationship in the fields of science, research, education, environment, culture, and other sectors.

The strategy developed by the Four Motors in the recent years has focused on the reinforcement of the competitiveness in economy, sciences and technologies of the four regions, in this particular context of global interdependence and economic crisis. We would like to extend this focus on social aspects as well in order to foster technological and social innovations in the area of health and care, where not only will most future jobs emerge, but also productivity, economic growth and well-being for our citizens.

Europe must invest in social and technological innovations to implement smart, scalable and sustainable solutions that will overcome above-mentioned challenges. There have been already a lot of inventions and small-scale pilots developed. However, an integrated and holistic up-scale of these solutions is still missing. The four highly industrialized and research-oriented Four Motors regions will join forces, exchange knowledge and work closely together on the implementation of solutions for a sustainable future of our health and care systems – and for the benefit of the European citizens. It deserves to appreciate how all the regions part of the “Four Motors for Europe” have been involved in the “The European Innovation Partnership in Active and Healthy Ageing (EIP on AHA)” initiative and awarded the prize as a Reference Site.

“Four Motors for Europe”: common strategies for demographic change

Welfare states like Italy, France, Spain and Germany are particularly affected by demographic challenges. Traditionally the family has to cover most of the chronic and care work. Almost $\frac{3}{4}$ of the care work is done by family members and other informal care givers (24). This is already causing severe challenges for the (informal) care givers (mainly women), especially those living in rural areas. Here, rural informal caregivers are known to report feelings of social isolation and stress.

²⁴ Courtin E, Jemai N, Mossialos E. Mapping support policies for informal carers across the European Union. Health Policy. 2014;118(1):84-94. doi: 10.1016/j.healthpol.2014.07.013.



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Therefore, the transnational and interregional Four Motors for Europe-network is committed to the question: *How can social and technological innovations help this growing number of people in Auvergne-Rhône-Alpes, Baden-Württemberg, Catalonia and Lombardia?*

Under the presidency of Baden-Württemberg, a new working group on “Equity in a digital health and care system – Bridging social and digital divide in times of demographic change” was set up by the Four Motors network to collaborate more intensively on this topic (meetings, workshops, conferences, research consortia etc.).

Together, the working group is committed to improve the transregional social, digital and research infrastructure as well as the quality of service for citizens, patients and employees of the health- and care-system, exploring the need and potential for (digital) health innovation and healthcare in the regions, especially in rural areas and set-up a large-scale deployment of social and technological innovation. These approaches must be “systemic”, with a focus on both public policies (to be articulated with private services) and a focus on territorial organizations. The longitudinal measurement of impact and effectiveness of these innovations in order to improve evidence-based policy-making should be a priority.

The transregional cooperation pillars are based on the effective integration of prevention, long-term- and social care (personalized medicine approaches) into healthcare services and systems to the benefit of patients and citizens, supporting the life of informal care givers and empowering citizens. The focus should also be put on prevention and the shift of perspectives to a person-centred care process. Support to guide people through the system should be improved. In order to emphasise their own responsibility, health literacy needs to be strengthened to enable people to take care of themselves

Results achieved – and next steps

Four successful workshops on “Equity in a digital health and care system – Bridging social and digital divide in times of demographic change” have been organized by the State of Baden-Württemberg during its Presidency. Coordinated by Lombardy region, the Four Motors for Europe have been also participating to the European Commission call on SC1-BHC-25-2019 (Demonstration pilots for implementation of personalised medicine in healthcare) with a project aimed to demonstrate the benefit for citizens and healthcare systems of specific personalized medicine approaches in real life healthcare settings, and the call DT-TDS-01-2019 (IA Innovation action) aimed at piloting an indoor and outdoor interoperable smart living solution, supporting the ageing population at risk of cognitive impairment.



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The Four Motors for Europe are interested in the development of a sustainable and trustful collaboration leveraging the transnational working group. Therefore, it is committed to meet regularly (twice a year) to discuss at technical and political level the themes connected to Digitalization of Health and Care, with a special focus on supporting the life of informal care givers.

In order to include further outstanding expertise on board, there is an ongoing process to extend the working-group with already associated Four Motors partners like Flanders or Wales. The strengthening of the dialogue with EU institutions (EIP AHA, Reference Sites) and the collaboration with other regions (i.e. CORAL, ECHA, EUREGHA) represents a priority. Finally, Four Motors is committed to publicly inform the civil society about group activities as well as on existing and streamlined good practices.



Baden-Württemberg



Generalitat de Catalunya



**Regione
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