# Health inequalities and eHealth

# Report of the eHealth Stakeholder Group

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# **Executive summary**

Health inequalities is a cross-cutting policy area that has received increased attention at European, national and international levels in recent years. While thus far the focus has been predominantly on the links between the social determinants of health and the barriers of the traditional health system, a growing number of EU documents are establishing the relationship between eHealth and health inequalities. This includes the European Commission's eHealth Action Plan 2012-2020, several actions enshrined in the Digital Agenda for Europe, and the eHealth Task Force Report.

Avoidable health inequalities are multifaceted and include several dimensions including problems experienced at individual, professional and health system level. For patients and members of vulnerable groups, 'eHealth inequalities' comprises, *inter alia*, concerns over access and affordability of technology, its usability and appropriateness, as well as over digital health literacy. In the professional realm, eHealth technologies are situated in a shifting health system and wider cultural environment struggling to cope with competing resource demands and complex demographic and disease-specific challenges, which are also changing the roles of health professionals. In order for the European health workforce to reap the many potential benefits of eHealth and integrate it successfully into day-to-day clinical practice, continuous investment, nurture and training will be required.

### The goals of this report are as follows:

- To provide the European Commission (DG CONNECT) with comprehensive stakeholder input as to why it is crucial to pay close attention to the link between health inequalities and eHealth, and ensure that this is explicit in eHealth and related policy discussions;
- To present a snapshot of how 'eHealth inequalities' are being addressed and tackled across Europe at policy and industry level, including tailored solutions for non-traditional end users and health providers;
- To provide key references, stimulate a dialogue and encourage future research and discussion at European level on 'eHealth inequalities'.

Taking a holistic approach, this report examines a number of obstacles experienced by various categories of people whose participation in eHealth is either not guaranteed or who require special attention if solutions are to be implemented in a fair, inclusive way. The report takes into account the needs of both those who provide and/or manage health and social services, and the individuals who receive them.

Based on the report findings, the **eHealth Stakeholder Group** suggests the following recommendations:

- 1. Improve access to eHealth and involve all stakeholders
- 2. Accommodate diverse needs and reduce technological pressure
- 3. Improve digital health literacy
- 4. Integrate eHealth into overall health and social care system policy
- 5. Evaluate the impact of eHealth solutions and build up an evidence base
- 6. Give specific consideration to empowering patients with disabilities / specific diseases
- 7. Consider financial subsidies for the purchase of eHealth equipment / ICT access

# 1. Introduction

Health inequalities is an area which has not yet been sufficiently examined in the context of eHealth despite the latter's important potential for delivering more equitable care. Apart from mapping out eHealth's envisaged contributions to the delivery of more personalised, efficient and citizen-centric healthcare, the European Commission's eHealth Action Plan 2012-2020 states that eHealth is to play a central part in facilitating ''socio-economic inclusion and equality, quality of life and patient empowerment through greater transparency, access to services and information and the use of social media for health."

Technological progress steadily manifests itself in innovative eHealth solutions that offer new ways for individuals, including members of vulnerable groups, to actively participate in the management and monitoring of their own health. It will also assist health professionals collaborate more efficiently with each other and with their patients – thereby also contributing to better public health.

On the other hand, the speed of change, the costs involved in accessing and upgrading the required hardware/software and devices and various barriers related to, inter alia, insufficient knowledge, skills and literacy, lack of user-friendliness and doubts over the meaningfulness of information can also create new health inequalities.

"Every European Digital", the aspiration of European Vice-President for the Digital Agenda, Neelie Kroes is still a long way off, not least given the pronounced differences in wealth, technology deployment and acceptance both between and within Member States (MS).

But the problem is much wider than merely the impact of technology on the health outcomes of individual patient-consumers. New health inequalities also arise, *inter alia*, as a result of incoherent planning and uneven infrastructures, ongoing interoperability and operational problems, differences between countries and regions regarding the cost, procurement and availability of ICT for health system managers and healthcare professionals, as well as lack of involvement of users in the design process.

Hence eHealth inequalities are complex and multifaceted (including individual, institutional and political dimensions), amplified by the fact that priorities are rarely aligned at European, national, regional and local level. The ultimate risk is that the flaws of the traditional health system will be reflected and potentially even aggravated online. This would deepen the rift between socio-economic groups, in particular between the well-to-do and educated and those who, for whatever reason, experience difficulty navigating Information and Communication Technology (ICT)-enabled environments and consequently have less information and fewer quality services at their disposal.

Although the 'digital divide' appears to be narrowing slowly but steadily as far as access to technology is concerned, at least in the richer MS and thanks to mobile devices, the *knowledge gap* between proficient and inept users is becoming ever wider, thereby '*lending support to the hypothesis that information technology is creating a new social inequality, rather than levelling out social discrepancies*". In other words, it is not so much a question of access but of *how* the Internet is used.

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<sup>&</sup>lt;sup>1</sup> COM(2012) 736 final, "eHealth Action Plan 2012-2020 – Innovative healthcare for the 21st century"

<sup>&</sup>lt;sup>2</sup> Efrat Neter and Esther Brainin (2012), "eHealth Literacy: Extendig the Digital Divide to the Realm of Health Information", Journal of Medical Internet Research, Vol. 14, No 1.

<sup>&</sup>lt;sup>3</sup> See JRC-IPTS paper, <a href="http://ipts.jrc.ec.europa.eu/publications/pub.cfm?id=6180">http://ipts.jrc.ec.europa.eu/publications/pub.cfm?id=6180</a>

Such a two-tier scenario not only runs counter to the EU's common values and rights as enshrined in the Charter of Fundamental Rights of the European Union<sup>4</sup>, and those underpinning the EU health systems – amongst them, universality, equity and solidarity -, it would also be highly unsustainable in economic terms for health systems already under intense pressure to perform better.<sup>5</sup>

Against this background, the eHealth Stakeholder Group<sup>6</sup> set up a dedicated subgroup to explore how eHealth solutions can **help overcome health inequalities and benefit users in a meaningful way.** The present report includes a number of policy recommendations based on the insights and experiences of experts from civil society, public administration and industry who were asked to share relevant examples of how 'eHealth inequalities' are tackled at national or regional level<sup>7</sup>.

Moreover, the members of the subgroup were asked to consult their own networks, composed mainly of national member organisations to obtain information from the MS. Further information and references were collected via a non-systematic literature review including academic and grey literature, as well as desk research on relevant European, national and regional websites.

# 2. Health inequalities on- and offline

The WHO defines health inequalities as 'differences in health status or in the distribution of health determinants between different population groups." Moreover, as the WHO points out, "it is important to distinguish between inequality in health and inequity. Some health inequalities are attributable to biological variations or free choice and others are attributable to the external environment and conditions mainly outside the control of the individuals concerned. In the first case it may be impossible or ethically or ideologically unacceptable to change the health determinants and so the health inequalities are unavoidable. In the second, the uneven distribution may be unnecessary and avoidable as well as unjust and unfair, so that the resulting health inequalities also lead to inequity in health."

A number of European documents and initiatives address health inequalities or stress the importance of solidarity in health (see Annexes I and II), the most recent being a European Commission Staff Working Paper<sup>8</sup> and the EU-funded report "Health inequalities in the EU" led by Sir Michael Marmot. A European Parliament resolution states that, crucially, 'health inequalities are not only the result of a host of economic, environmental and lifestyle-related factors, but also of problems relating to access to healthcare". Clearly, such disparities exist in all MS and the effect on health status is that people in lower educational and income groups, as well as vulnerable groups, usually experience higher rates of illness and (co)morbidity, as they tend to lead less healthy lifestyles with higher consumption rates of tobacco, alcohol, and junk food, insufficient levels of physical exercise, etc. The problem is amplified by lack of medical attention and guidance due to health professional shortages, especially in rural and peripheral areas and in the poorer EU MS. Moreover, members of vulnerable groups are still subject to discrimination across Europe and the quality of care they receive often depends on the attitudes of the individuals who treat them, coupled with deep-rooted institutional and cultural barriers.

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<sup>&</sup>lt;sup>4</sup> The EU Charter of Fundamental Rights (2010/C83/02) became legally binding with the entry into force of the Lisbon Treaty.

<sup>&</sup>lt;sup>5</sup> European Parliament Resolution 2010/2089(INI) on reducing health inequalities in the EU estimates that economic losses linked to health inequalities amount to about 1.4% of GDP.

 $<sup>\</sup>underline{\textbf{6}} \ \textbf{For more information see} \ \underline{\textbf{https://ec.europa.eu/digital-agenda/en/news/ehealth-stakeholder-group-members}}$ 

<sup>&</sup>lt;sup>7</sup> The examples collected are neither based on a comprehensive mapping exercise nor are they the outcome of an in-depth research process. Some of the information may be incomplete or out of date.

<sup>&</sup>lt;sup>8</sup> SWD(2013) 328 final, Report on health inequalities in the European Union.

<sup>&</sup>lt;sup>9</sup> See <a href="http://ec.europa.eu/health/social\_determinants/docs/healthinequalitiesineu\_2013\_en.pdf">http://ec.europa.eu/health/social\_determinants/docs/healthinequalitiesineu\_2013\_en.pdf</a>

<sup>&</sup>lt;sup>10</sup> See European Parliament Resolution 2010/2089(INI), article P.

If seen in this light, the potential of eHealth to improve access for vulnerable groups and, ultimately, contribute to a *reduction* in health inequalities is enormous. For those who have access to and confidently utilise eHealth tools including the growing array of mobile communication and/or monitoring devices designed to increase patient safety and comfort, it opens up a whole new way of interacting with healthcare. In particular, eHealth can enhance and intensify contacts between patients and professionals (e.g. consultations over Skype, dedicated Q&A sessions with experts on disease-specific and other trustworthy websites, various types of teleconsultations<sup>11</sup>, etc.). It also offers a convenient way to communicate anonymously about sensitive health issues, which may be too embarrassing or culturally sensitive to discuss in a face-to-face situation. From a public health perspective, eHealth also allows reaching out to specific groups of patients, e.g. individuals prone to alcohol use disorders, and can potentially curb addictive behaviours in a cost-effective and customised way.<sup>12</sup>

Health inequalities thus describes a constantly evolving notion whose translation into the eHealth context requires us to take into account the social determinants of health, the nature and characteristics of health systems (including economic governance structures), but also additional factors specifically related to the use of technology, the status quo of infrastructures and networks, as well as the individual competences required in order to search, retrieve, interpret and act upon online information effectively - skills that, in combination, constitute eHealth literacy (see below).

Recognising that "the digitally illiterate are missing out on social and economic opportunities and on easy access to online public services that can save time and money", pillar VI of the Digital Agenda for Europe (DAE)<sup>13</sup> stresses the need for education and training in e-skills to improve employment, equal opportunities and inclusion. In light of the fact that up to 30% of Europeans have never used the Internet, the DAE foresees thirteen specific actions to be taken at EU and national level, from "helping disabled people to access more content" to "proposing EU-wide indicators" and "implementing digital literacy policies in the MS" (see Annex II).

One of the most palpable consequences of health inequalities remains the difference in life expectancy at birth between different socioeconomic groups in Europe, which is about 12 years for men and 8 years for women. This can be even more pronounced between different MS and regions, or even between city neighbourhoods. Compounding the problem is the fact that Europe is becoming older and more diverse due to demographic shifts, coupled with a rise in chronic diseases and a host of ageing- and lifestyle-related conditions. Recent austerity measures have demonstrated that the weakest suffer the most from the effects of an economic downturn as they are the first to be excluded from healthcare provision.

Yet patients' expectations are rising for health systems to be able to manage these complex challenges, and they anticipate the application of state-of-the-art technology for offering increasingly personalised healthcare as a result of scientific advances. Simultaneously, there are also growing demands on patients to take more responsibility for their own health as they obtain more information and become active participants in managing their conditions.

Stakeholders including policy-makers at EU, national and international level, civil society organisations representing end user interests<sup>15</sup> and the ICT/telecoms industry, are becoming more aware of the

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<sup>&</sup>lt;sup>11</sup> For an overview of different types of teleconsultations conducted in Finland, See Jaatinen, P., Forström, J. and Loula, P. (2002)

<sup>&#</sup>x27;Teleconsultations: who uses them and how?', *Journal of Telemedicine and Telecare*, December 1, 2002 vol. 8, no. 6 319-324 Smit, F. et al. (2011), 'Modeling the Cost-Effectiveness of Health Care Systems for Alcohol Use Disorders: How Implementation of

eHealth Interventions Improves Cost-Effectiveness', *Journal of Medical Internet Research,* 2011 Jul-Sep; 13(3): e56. 

<sup>9</sup> COM(2010)0245 final, "A Digital Agenda for Europe"

<sup>&</sup>lt;sup>14</sup> European Commission Press Release (Sep 2013). Available at <a href="http://europa.eu/rapid/press-release\_IP-13-823">http://europa.eu/rapid/press-release\_IP-13-823</a> en.htm?locale=en

<sup>15</sup> EPHA Charter for Health Equity (October 2011), available at www.epha.org/a/4338

problem and a number of initiatives are currently underway to solve technical, legal and data transfer issues in order to improve access to eHealth. Notably, the 2009 Council Conclusions recognised "the need for further political leadership and to integrate eHealth into health policy in order to develop eHealth services on the basis on public health needs". 16 In response, partnerships are being formed to take a more inclusive view, build confidence, and ultimately increase uptake and acceptance.

The key question is thus how to turn eHealth into an enabler as part of sustainable and inclusive health systems that can alleviate existing health inequalities without being in competition with other healthcare needs.<sup>17</sup> In order to get there, more concrete evidence of the impact of eHealth on end users, as well as thorough evaluation of eHealth implementations at national and regional level, is urgently required, while at the same time keeping in mind that health is a human right for all.

# 3. Integrating eHealth into health systems

The best eHealth strategies have little value if they are not integrated into the overall health system of the country or region in question. Separating 'health' and 'eHealth' inevitably means that on- and offline healthcare objectives neither match each other nor acknowledge their reciprocity. Moreover, it makes eHealth prone to be steered by actors from outside the health sector.

Increased complexity means there is a manifest need for health systems to provide stratified services to meet the exigencies of an ever more diverse population with different levels of education, exposure to technology and health knowledge. This implies that funding must not only focus on technological innovation - at present the main driver for health investments - but also on social innovation to ensure that all people in Europe can benefit from quality healthcare services.

One of the problems is the disjointed and ephemeral nature in which eHealth inequalities are being addressed (if they are dealt with at all) across Europe. The project implemented by more 'eHealth ready' regions and MS may not always be transferable 'best practices', be it due to divergences in access (in many parts of Europe, neither hospitals / clinics nor general practitioners have reliable Internet access) or because the socio-economic context is incompatible. More importantly, if eHealth remains at the margin of health policymaking, there is a risk that its progress will be technology-driven rather than based on end users' needs, favouring economic over social objectives.

It is thus important to consider needs and priorities at all levels and ensure they are being tackled in harmony by national, regional and local policy and implementation actors. This is essential for developing a long-term perspective and ensuring continuity of action. Legislative and regulatory frameworks need to support the various layers of eHealth without scope for loopholes, especially given the convergence of technology, and similarities between eHealth, medical devices, and other health tools. In addition, business models must be supportive of investments in innovation for social inclusion

In short, integration of eHealth into health systems as a prerequisite for tackling inequalities involves strategic thinking, planning (including effects on organisational cultures and work routines, patient-health professional relationships, patient rights, etc.), standardisation, education and training, and interplay between providers, policy makers, and users, to name but a few of the challenges. The experience of

<sup>&</sup>lt;sup>16</sup> Council Conclusions on Safe and efficient healthcare through eHealth, 1 December 2009, http://www.consilium.europa.eu/uedocs/cms\_data/docs/pressdata/en/lsa/111613.pdf

M. Kosińska & S. Marschang, 'e-fit for purpose', Public Service Review, March 2013.

such EU-wide projects as epSOS18 and ReNEWING HeALTH19 should help inform an evidenced-based way forward.

# 4. National and regional differences in eHealth deployment

There are enormous differences in eHealth deployment at national, regional and local level in Europe, and the October 2013 European Council Conclusions urge that the digital gap amongst Member States should be reduced so that Europe's digital economy which also includes eHealth services, can flourish.<sup>20</sup>

Access is obviously the most decisive barrier for effective eHealth use; according to the most recent Eurobarometer survey<sup>21</sup>, there is a significant gap between MS when it comes to broadband Internet access at home, with 86% of Dutch households reporting access compared to 48% in Romania and 46% in Greece. Overall, people living in the richer MS tend to have more ubiquitous and faster Internet access. Roughly one half of Europeans (49%) can access the Internet through their mobile phones, with widespread availability in Sweden (71%) whereas mobile Internet is still emerging in Bulgaria (20%) and Portugal (26%). It is also noteworthy that across all MS, mobile access tends to be complimentary to access at home, hence its diffusion has not yet made much tangible difference to disadvantaged groups who primarily use mobile phones for core functions (e.g. making calls, texting, gaming) rather than for sophisticated online information searches.

Just as importantly, inequalities also permeate the 'supply-side' functions, e.g. use of ICT by GPs and in hospitals. While in some countries and regions it is common for GP practices to have their own websites that provide patients with condition-specific health information, health status updates and the possibility to re-order medicines, this is not the case in most MS where most of healthcare still takes place offline.

Differences are also marked at policy level. Although all EU countries have developed an eHealth vision or action plan, only few (e.g., some Nordic / Baltic States, parts of the United Kingdom) have well-defined and comprehensive strategies in place linking up national, regional and municipal stakeholders and are 'mature' enough to incorporate health inequalities as part of amelioration strategies. In contrast, in the majority of MS eHealth implementation still centres on the introduction of Electronic Health Records (EHR) and e-Prescription, with only minor effects (but future opportunities) on mitigating health inequalities. Ongoing debates over data protection and privacy, as well as over health system priorities, hinder the uptake of eHealth both in economically strong MS (e.g., Germany) and in the poorer MS where austerity measures continue to restrict the scope of action.

Besides, capacities and know-how for managing European Structural Funds (ESF), which can be exploited for eHealth projects, differ between MS. It is likely that insufficient use in countries like Romania and Bulgaria points to a much bigger problem, namely incoherent overall health system structures and lack of understanding about creating synergies between eHealth and other health system priorities.

<sup>&</sup>lt;sup>18</sup> epSOS aims to design, build and evaluate a service infrastructure that demonstrates cross-border interoperability between electronic health record systems in Europe. For more information see <a href="http://www.epsos.eu/home/about-epsos.html">http://www.epsos.eu/home/about-epsos.html</a>

<sup>&</sup>lt;sup>19</sup> ReNEWING HeALTH aims at implementing large-scale real-life test beds for the validation and subsequent evaluation of innovative telemedicine services using a patient-centred approach and a common rigorous assessment methodology. For more information see <a href="http://www.renewinghealth.eu/en/overview">http://www.renewinghealth.eu/en/overview</a>

European Council Conclusions, 24/25 October 2013 (EUCO 169/13)

<sup>&</sup>lt;sup>21</sup> Special Eurobarometer 396 (2013), "eCommunications Household Survey". Available at <a href="http://ec.europa.eu/digital-agenda/en/news/special-eurobarometer-396-e-communications-household-survey">http://ec.europa.eu/digital-agenda/en/news/special-eurobarometer-396-e-communications-household-survey</a>

The overall uncoordinated, fragmented and sometimes haphazard nature of eHealth implementation in Europe also calls attention to the fact that it requires successful coordination with other policies that impact on health (e.g. social policy, housing), and those that directly or indirectly determine its scope (including cyber security, patients' rights, medical devices, research and development, etc.). The Article 14 network set up under the Directive on patients' rights in cross-border healthcare is tasked with identifying and solving a number of these challenges, and the 2013 Declaration by the Irish Presidency calls for the development of 'eHealth ecosystems' to fuel national and cross-border projects, and identify legal constraints that hold back mobile health technologies.

# 5. The literacy challenge

Digital health literacy, also called eHealth literacy, has been described as "a set of skills and knowledge that are essential for productive interactions with technology-based health tools". 22 The key words productive interaction - imply that it is situated in a wider literacy environment that encompasses basic literacy (as an essential prerequisite to successfully enter, capture and read information), health literacy (in terms of being able to locate, understand, contextualise and interpret health information) and digital literacy (the precondition for using computers and mobile devices in a skilful and effective way). In other words, the mere ability to go online is not sufficient to be eHealth literate, and even regular Internet users display very different competency levels when it comes to handling issue-specific content such as health information.

More closely defined as "the ability to seek, find, understand, and appraise health information from electronic sources and apply the knowledge gained to addressing or solving a health problem "23, eHealth literacy thus places high demands on users as it involves making use of multiple competences simultaneously, including cognitive and behavioural, that can only be developed through regular practice.<sup>24</sup>

However, many eHealth tools neglect the different demands they exert on individuals' skills and knowledge. In many cases, the dominant assumption is that users are a rather homogenous group with similar needs, comparable means and equivalent competences. In reality though, people's level of eHealth literacy is shaped by many environmental and societal factors, such as differential access to eHealth tools.25

That even basic literacy skills such as reading, writing and numeracy represent an obstacle for many people in Europe is often overlooked in the quest to gain cost efficiencies by moving certain health functions online. In 2013, more than one million (one in five 15-year-olds), as well as over 75 million adult Europeans lack basic reading and writing skills.<sup>26</sup> In addition, a survey undertaken in the UK suggests

<sup>&</sup>lt;sup>22</sup> Chan, Connie and Kaufman, David (2011), "A Framework for Characterizing eHealth Literacy Demands and Barriers". Journal of Medical Internet Research, Vol. 13, No 4.

<sup>&</sup>lt;sup>23</sup> Norman, C. and Skinner, H. (2006) "eHealth literacy: Essential skills for consumer health in a networked world". Journal of

Medical Internet Research, Vol 8, no 2.

24 Norman & Skinner discuss various models of eHealth literacy, describing competencies such as media literacy, computer literacy,

<sup>&</sup>lt;sup>26</sup> See European Commission website, 'Focus on literacy', http://ec.europa.eu/education/focus/literacy\_en.htm

that many Europeans lack basic online skills in order to perform simple tasks whether at home or at work.<sup>27</sup>

Many individuals have difficulty using computers; in 2012, one quarter of Europeans had never used the Internet at all<sup>28</sup>, although the ubiquity of smartphones is likely to close this gap somewhat. This is important because familiarity with eHealth technologies, e.g. with the format, design, content and operational mode of websites, reduces confusion and increases the ability to perform. The 2013 European Council Conclusions recall that, due to a lack of digital skills in Europe, many jobs in the digital economy cannot be filled. Hence they call for integration of digital skills at all stages and levels of education and training, from the earliest stages to continuing education.<sup>29</sup>

Two additional impediments exist in the context of eHealth: one is posed by the specific requirements of health literacy, the other by the need for information to be meaningful, especially where it is aimed at non-traditional ICT users. Generally speaking, addressing specific access and usability problems experienced by vulnerable groups also holds less interest for industry since investments in minority needs do not promise high returns.

Health literacy is an increasingly discussed concept at EU level. According to the HLS-EU Consortium definition, it is "linked to literacy and entails people's knowledge, motivation and competencies to access, understand, appraise, and apply health information in order to make judgments and take decisions in everyday life concerning healthcare, disease prevention and health promotion to maintain or improve quality of life during the life course". 30 It begins with the ability to understand terminology and medical jargon that can be found on health websites and that many people are not familiar with. It is even more important in order for individuals to comprehend the nature and source of the information they access, its meaning (which is likely to be different depending on health status) and, most importantly, how this information can help making beneficial health decisions. Online health information comes from a range of sources both official (government portals, authorised commercial actors, etc.) and unofficial (unauthorised commercial actors, informal patient communities, interest groups, etc.) and therefore it is difficult for people to interpret whether it is trustworthy and factual. Evaluating online information represents a health literacy test as incorrect assessments or misunderstandings can provoke harmful behaviours which could be avoided if the information is being communicated and explained by qualified health professionals.

A study undertaken in Israel found that individuals deemed 'highly eHealth literate' searched for significantly more health information than those with low eHealth literacy, regardless of the type of content, i.e. social, service-related, or therapy-related. Highly literate individuals used more search strategies and scrutinised information more carefully, thereby benefiting more from the information, both cognitively and instrumentally, including better interaction with physicians.<sup>31</sup>

Finally, the importance of meaningfulness of health information in an increasingly diverse Europe must not be underestimated. Many MS have growing migrant populations with origins within and outside of Europe and speaking a host of languages. For a number of reasons, many 'new Europeans' are not fluent in the main language(s) of the country they live in, yet content on most websites and portals reflects

<sup>&</sup>lt;sup>27</sup> BBC news "Millions in UK lack basic online skills", 8 Nov 2012, http://www.bbc.co.uk/news/technology-20236708

<sup>&</sup>lt;sup>28</sup> Eurostat, "Internet use in households and by individuals in 2012". Available at

http://epp.eurostat.ec.europa.eu/cache/ITY\_OFFPUB/KS-SF-12-050/EN/KS-SF-12-050-EN.PDF

European Council Conclusions, 24/25 October 2013 (EUCO 169/13), p.5.

<sup>30</sup> Sorensen K et al. (2012), Health literacy and public health: A systematic review and integration of definitions and models. BMC Public Health 12:80 doi:10.1186/1471-2458-12-80

<sup>&</sup>lt;sup>31</sup> Neter, E. and Brainin, E. (2012). "eHealth Literacy: Extending the Digital Divide to the Realm of Health Information". Journal of Medical Internet Research, Jan-Feb. 14(1):e19.

traditional notions of how 'Europeans' appear and speak. The specific health needs of linguistic, religious and ethnic minorities are rarely addressed in a manner and language that befits the purpose. Taking stock of diversity, including tailored services and training in a variety of languages to existing and emerging communities, is thus key for ensuring eHealth inclusion. This represents an immense challenge, also given the millions of undocumented migrants living in Europe who are often excluded from the health system.

# 6. Common problems experienced by non-traditional eHealth users

There are a number of challenges experienced by members of disadvantaged groups and other nontraditional ICT users. In this context it is important bearing in mind that individuals facing multiple exclusion - e.g., ethnic minority and disabled, 50+ and unemployed, female and sans papiers experience health inequalities more severely, making them particularly vulnerable for abuse and exploitation yet harder to reach out to.

Several issues affecting some of the most important categories of non-traditional eHealth users are outlined below. Although a number of initiatives encourage their online inclusion, few exist specifically in the domain of eHealth.

### People with disease-specific conditions

Disease-specific patient populations encounter very diverse problems regarding the use of ICT, depending on the nature of their condition but also on the progress of the disease.

It has been shown that diabetes is particularly suitable as a model for eHealth solutions for chronic disease care given the integral role of self-monitoring in the management of diabetes types 1 and 2. The conversion of mobile phones and medical devices is proving valuable in this context given the number of tasks (e.g., monitoring glucose levels, sending alerts, providing health information, personalised care) that can be performed.<sup>32</sup> Similar patient benefits have been shown to apply for those with COPD. asthma and chronic heart failure.

The EC-funded Renewing Health project<sup>33</sup> involves 9 of the most advanced European regions in the implementation of health-related ICT services, especially regarding service solutions at local level for telemonitoring and treatment of chronic diseases including diabetes, COPD and cardiovascular. eHealth is a tool for giving patients a central role in the management of their own diseases, fine-tuning the choice and dosage of medications, promoting compliance to treatment, and helping healthcare professionals to detect early signs of worsening in the monitored pathologies. The aim is to integrate these solutions at regional level, with a view to scaling up at national and European levels.

At health institutional level, select hospitals such as Sotiria in Athens (2009 winner of the European Commission's elnclusion award) have incorporated eHealth ICT into clinical practice in order to develop home and community-based, health and social integrated care and chronic care management. Both patients and carers make use of technology (TV, real-time video, stationary or mobile wearable devices), which can improve quality of life for chronic disease patients and older people.

<sup>32 &#</sup>x27;Diabetes and mobile health'. Presentation by João M. Valente Nabais (International Diabetes Federation Europe) at GSMA Mobile 360 Series conference, Brussels, 5 September 2013

<sup>3</sup> See http://www.renewinghealth.eu/en/overview

Disease-specific patient communities combining websites with other opportunities for social interaction on- and offline are also very important for patients as they allow for the exchange of first-hand information and discussions about treatments, which is not only reassuring for newly diagnosed patients wishing to learn more about how to live with their condition on a day-to-day basis. The feeling of 'community' can also help alleviate depression and other mental health problems.

### ii. Older people and children

Older people as patients should not be seen as a homogenous group. They might be patients in day care centres, hospitals, residential homes, at home, or in other environments. Their conditions might also differ a lot, the specific case of dementia being a case in point and one of the major challenges when it comes to eHealth and health inequalities. It should also be kept in mind that older people might themselves be carers of their spouses or older parents.

Although Internet use is still pretty low amongst older people compared to the rest of the population, especially in the 75+ age group<sup>34</sup>, it would appear likely that more and more older people will be online as the baby boomers and subsequent generations are retiring. Older people often feel isolated, and the older they get, the more they tend to depend on medical and social care without family support structures.<sup>35</sup>. Being able to use the Internet can be life-transforming and improve quality of life for seniors who possess the know-how to navigate it. Internet based social media (e.g. Facebook. Twitter or blogs) provide a chance to connect with people around the world and share experiences, emotions and problems related to ageing, caregiving and common health conditions older people are facing.

The Strategic Implementation Plan of the European Innovation Partnership on Healthy and Active Ageing (EIP on AHA)<sup>36</sup> is the best example at EU level for creating intersectoral networks in order to tackle ageing-related problems via innovative ICT solutions for building up patient empowerment and health literacy, including projects in the areas of independent living (e.g., ambient assisted solutions and domotics), remote monitoring of chronic diseases, treatment adherence and falls prevention.

Children on the other hand are particularly vulnerable to messages that might stimulate them to adopt unhealthy behaviours such as drinking, smoking or eating junk food. As every new generation spends ever more time online, there is need to support eHealth solutions early in education, and much scope to develop eHealth solutions that emphasise the importance of prevention and health promotion from an early age and throughout the life course. Given that youngsters have a remarkable ability to adapt to new technology and integrate it into their lives, it is equally important that health content addresses their specific needs and concerns, and that the tools are engaging and have pedagogic value.

## iii. People with disabilities

For people with disabilities – whether these manifest themselves in a physical, cognitive or another way – the issue of eAccessibility is key and represents the first barrier that can greatly enhance health inequalities. People with disabilities have a particularly hard time as they are often overlooked in the design of new technology, both regarding tools and content. Due to their impairment, the notion of them being proficient ICT users is often sidelined, although a number of innovations allow even severely

<sup>34</sup> Special Eurobarometer 396 (2013), pp. 33-34

<sup>&</sup>lt;sup>35</sup> Stroetmann, V. et al. "The attitudes, expectations and needs of elderly people in relation to e-health applications: results from a European survey". Journal of Telemedicine and Telecare, Vol. 8 (Suppl.2), pp. 82-84.

<sup>&</sup>lt;sup>36</sup> COM/2012/083 final, "Taking forward the Strategic Implementation Plan of the EIP on AHA"

disabled people to claim their space in the public sphere and improve quality of life. For example, features such as voice-generated content are of help to those who cannot physically operate computers (e.g., due to missing limbs) and to the visually impaired, whereas special 'lip reading' software can assist the hearing impaired.

A study undertaken in 2006 found that only 3 per cent of public websites complied with the minimum web accessibility standards and guidelines, hindering access to web content and services for people with disabilities who comprise about 15% of the EU population.<sup>37</sup> Since then this percentage has probably risen, however most public websites have not changed their approach. Moreover, the visually or hearing impaired miss out on most of the information that is provided electronically, including video content.

A recent UK report on health inequalities and people with learning disabilities<sup>38</sup> demonstrated that the latter make a significant contribution to overall health inequalities. As a high risk group, they are more prone to a variety of conditions and diseases including sensory and physical impairments, respiratory diseases, endocrine disorders, epilepsy, osteoporosis, dementia, falls injuries, etc. The combination of both learning related problems and condition-specific disadvantages means that the needs of such individuals are particularly complex, both regarding use of technology and being able to understand context. This also points at the need for targeted health education initiatives and specialised training for health professionals and carers who can promote healthy behaviours and prevention.

#### iv. People with mental illness

For people who are mentally challenged (whether this is due to a cognitive, developmental, learning or other impairment) online inclusion is an even bigger issue since the notion of them becoming proficient ICT users often remains contested. Face-to-face contact and personal attention play a central role in the treatment process and meeting their special needs. There are also specific concerns related to patient confidentiality, consent, data protection, accuracy of information, etc. It must however not be forgotten that they are people like everybody else.

A Joint Action on Mental Health and Well-being<sup>39</sup> was launched in February 2013 involving 24 Member States and three associated countries. Its work focuses on issues to improve health inequalities, including, for example, action against depression using eHealth solutions.

One example of how people who are mentally ill can be brought online, the Dutch WAI-NOT website<sup>40</sup> provides accessible content that can be used in special education schools and help young people to improve their quality of life through ICT. The use of pictograms makes it possible to write e-mails, and information content such as news is audio supported and also translated into pictograms.

It has also been found that online 'e-therapy' can be an effective tool as interpersonal trust can be effectively established via ICT<sup>41</sup>, however this is more likely to benefit individuals otherwise able to function normally.

<sup>&</sup>lt;sup>37</sup> Waterova, I. and Tveit, L. (2012). 'Digital local agenda: bridging the digital divide'. Transforming Government People, process and policy, Vol. 6, No.4

<sup>&</sup>lt;sup>38</sup> See Emerson, E. et al (2012, "Health inequalities & people with learning disabilities in the UK:2012", available at <a href="http://www.improvinghealthandlives.org.uk/securefiles/140117">http://www.improvinghealthandlives.org.uk/securefiles/140117</a> 1420//IHAL%202012-11%20Health%20Inequalities r1.pdf

Note that n the UK, the term learning disabilities goes beyond problems experienced in educational settings; instead, it describes "a significant general impairment in intellectual functioning that is acquired during childhood". This differs from the American definition.

<sup>39</sup> Joint Action on Mental Health and Wellbeing, <a href="http://www.mentalhealthandwellbeing.eu/">http://www.mentalhealthandwellbeing.eu/</a>

<sup>&</sup>lt;sup>40</sup> See WAI-NOT website, <a href="http://www.wai-not.org/?q=en">http://www.wai-not.org/?q=en</a>

<sup>. .</sup> 

<sup>&</sup>lt;sup>41</sup> Postel, de Haan & De Jong 'E-Therapy for Mental Health Problems: A Systematic Review', <a href="https://www.myptsd.com/c/gallery/pdf/1-35.pdf">https://www.myptsd.com/c/gallery/pdf/1-35.pdf</a>

### v. Next of kin and informal caregivers

In an ageing Europe, next of kin play an increasing role in looking after family members no longer able to care for themselves and who cannot afford care facilities or prefer staying at home. In addition to relatives, housebound individuals often rely on other types of informal carers who could be neighbours, volunteers, migrant workers, etc. Many of these are female, without conventional health training, and not infrequently they are working for very low pay. These important yet largely unrecognised members of the informal health workforce tend to work in isolation in the sense that they are often not linked to health professionals within the system. Yet they are dealing with chronic conditions and difficult-to-manage diseases such as dementia, stroke disease, Parkinsonism and other chronic neurodegenerative conditions. Moreover, they play an important role in medication management, monitoring vital signs, falls prevention and ensuring regular and healthy nutrition.

In terms of eHealth, family and informal carers draw attention to the diversity of personal contexts and conditions health is situated in, rebutting a 'one size fits all' approach to eHealth. While some caregivers appreciate the opportunities afforded by ICT as it allows them to connect directly and in real-time with peers and health professionals, others worry about the depersonalisation of healthcare or are not in a position to learn new technologies, e.g. because skill acquisition competes with day-to-day care tasks or because of hurdles pertaining to access, language, isolation, and lack of support.

Another issue in this context is related to the importance of user/patient control, privacy, data protection and consent. Whether accessing EHRs or e-monitoring devices, the issue of consent becomes particularly thorny when proxies act on behalf of patients in informal arrangements.

For these reasons it is important to involve civil society organizations representing families and caregivers to ensure that their specific needs are considered in eHealth development, e.g. it is possible that they will benefit more from low-tech solutions that can be easily integrated into busy routines. Research undertaken by the European Commission's Joint Research Centre identified that carers' needs are multifaceted, including support for care coordination (e.g. solutions for improving quality of care provided at home), personal support for the carers themselves (e.g. stress support, connecting with peers, improving quality of life, engaging with NGOs), and facilitating their participation in society (e.g. information and training resources about caring, language training), but also technologies that allow patients to be less dependent on them so caregivers can benefit from better working conditions. 42

Targeted and tailored awareness-raising, education and training appears to be essential given that carers possess differential skills and competences that make them more or less inclined to benefit from eHealth. It will be important to gather more evidence on the use of ICT amongst next of kin / informal carers and to carefully assess the impact of technology on their activities.

# vi. Geographical exclusion

For populations living in rural, disadvantaged or peripheral areas, infrastructure represents a particularly acute challenge given that some areas, especially parts of Eastern Europe, trail behind regarding technology diffusion, and broadband access in particular. While prices are falling, they also depend on competition between ICT service providers, which in rural and peripheral parts of Europe is very low.

<sup>&</sup>lt;sup>42</sup> 'Can ICTs support carers? Facts, opportunities and challenges ahead'. Presentation by James Stewart & Clara Centeno (Joint Ressearch Centre Institute for Prospective Technological Studies), Eurocarers 2011, 6 May 2011.

Moreover, in some areas healthcare services are simply not provided (although due to health professional shortages caused by out-migration), which makes eHealth a crucial tool to reach patients and monitor their conditions, though it does not make it a replacement solution for health professional shortages.

On the other hand, eHealth is especially powerful for users in remote areas since ICT-enabled technologies build bridges between individuals and institutions, thereby helping people overcome their isolation. This is even more important for people suffering from health conditions who otherwise may not be able to spend much time outside of their homes. The possibilities for, *inter alia*, accessing health information, engaging in video conferences with health professionals, and using audiovisual aids are numerous and they all work to reduce health inequalities. The findings of the Chain of Trust survey analysis make reference to patients living in underserved areas, with a majority of patient respondents (75%) indicating that telehealth can improve access to healthcare for patients in areas affected by geographical exclusion. Moreover, if technology is readily available, it can also bring economic benefits to patients due to decreased travel costs and fewer days off work.

The role of community institutions as meeting places and learning spaces, such as public libraries or drop-in centres, must also not be underestimated as often they are the only locations where non-traditional ICT user groups can receive access and training. In Poland, elnclusion has been furthered by a programme for providing local libraries with multimedia equipment and internet access. Assistance is given primarily to seniors and free-of-charge. Librarians enjoy a high level of trust, which is conducive to learning, and users value the friendly atmosphere.

# vii. People who have had less educational opportunities

Individuals or population groups with little formal education may find it particularly hard to master the skills they need to use eHealth tools effectively. This is only partly due to insufficient literacy: most eHealth solutions are designed for people who already possess a much broader set of 'health skills' – including awareness, attention, ambition and self-discipline – to use new technologies for better health outcomes. These capabilities are 'by-products' of formal education; they describe cognitive and behavioural habits learnt and adapted from peers in particular social contexts from an early age. New technology thus enhances already existing skills, which makes eHealth particularly attractive and amenable to the educated - and potentially impenetrable for the unschooled.

For this reason 'rejection' of eHealth does not necessarily need to be linked to lack of interest or self-confidence due to insufficient literacy or intelligence, but it also has to do with the aptitude to grasp its overall purpose and logic given the multiplicity of information online. This means that eHealth products need to be designed so that the wider deficiencies experienced by individuals are taken into account.

In addition, individuals with low levels of health literacy may be tempted to purchase medicines online from unauthorised sources in the erroneous belief that this form of procuring medicines constitutes a form of 'eHealth'. Others may be tempted to bypass their regular prescribers either due to the lower costs offered online or because they are embarrassed to seek advice about a particular health condition. Given the undisputable convenience of eHealth, an unintended consequence could thus be that it might potentially compound the general reluctance and tardiness of some people, especially men, to discuss their health with qualified health professionals given that so much information is available on the Internet,

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<sup>&</sup>lt;sup>43</sup> Chain of Trust - Analysis of the Online Survey (2012), p.57. Available at <a href="http://www.eu-patient.eu/Documents/Projects/ChainOfTrust/CoT\_WP4\_Survey%20Analysis\_FINAL\_31%2003%2012.pdf">http://www.eu-patient.eu/Documents/Projects/ChainOfTrust/CoT\_WP4\_Survey%20Analysis\_FINAL\_31%2003%2012.pdf</a>

smartphone apps, etc.

# viii. Individuals affected by poverty and unemployment

Poverty and unemployment can have a devastating effect on physical (including the adoption of unhealthy eating habits and harmful behaviours such as alcoholism or drug use) and mental health, at worst leading to depression and even suicide. They can also trigger social exclusion and homelessness, with terrible consequences for families and individuals.

People in this category are amongst the most difficult to reach as many have 'given up' in the sense that they suffer from very low self-esteem or have no motivation left to develop or upgrade ICT skills. Even if they do have access, eHealth is not a priority given the focus on day-to-day survival.

That said, targeted training programmes have successfully converted prison inmates into IT experts, and tailored 'eHealth literacy' support can help raise interest in disadvantaged communities. While there are few specific programmes targeting the poor, some MS including the United Kingdom, offer networks of community-level training centres for digital inclusion to help non-traditional IT users navigate the online world. Outreach activities by UK Online Centres also include special programmes in unusual locations frequented by people unable to afford home technology, e.g. pubs, cafes and launderettes, as well as centres targeting the unemployed and disabled. This has helped make IT more accessible and combat misconceptions associated with formal learning. The impact of the work is significant as often users quickly progress to using government websites and accessing learning and employment opportunities.

Experience from developing and emerging economies has shown how mHealth in particular can help reduce inequalities based on economic status, gender or geography as various health information campaigns have successfully been carried out by SMS to save infants' lives (e.g. in Bangladesh) and for family planning, which could also be of interest for geographically isolated communities or socially excluded groups living in segregated areas in Europe.

### ix. Migrants and ethnic minorities

Vulnerable migrants and ethnic minorities are more affected by ill-health; not infrequently, risk factors are related to legal status, which determines access to health and social services. Other risk factors include poverty, social exclusion, discrimination, language barriers, administrative and cultural barriers, lack of information about health and health system functioning, the epidemiologic profile of the country of origin and the conditions of the migration. Refugees and undocumented migrants are particularly vulnerable and may be more likely to suffer from specific diseases or disorders acquired en route to Europe. 45

There are too many migrant communities and ethnic minorities living in Europe in order to label this a coherent category or make blanket statements about their ICT use. For example, young irregular migrants from Asia and the Middle East habitually use texting to keep family members (or traffickers) informed of their whereabouts, and mobiles have become an important tools for problem solving and expressing 'affect', <sup>46</sup> Yet there are parts of Europe in which minorities are so marginalised (e.g. some Roma communities) that they live without basic amenities like running water. That said, poorer people

<sup>&</sup>lt;sup>44</sup> See <a href="http://www.ukonlinecentres.com/">http://www.ukonlinecentres.com/</a>

<sup>&</sup>lt;sup>45</sup> Compare Specifications attached to the Invitation to tender n°EAHC/2013/Health/03 concerning training packages for health professionals to improve access and quality of health services for migrants and ethnic minorities, including the Roma, p.4 <sup>46</sup> Harney, N. (2012). "Precarity, affect and problem solving with mobile phones by Asylum Seekers, Refugees and Migrants in Naples, Italy". Journal of Refugee Studies, Vol. 26, No 4.

often prioritise the acquisition of technology – especially mobile phones - as they combine many functions (telephone, video, Internet, games, chat, etc.) that in the past needed to be purchased separately, and their multi-functionality enables mobility and migration, as well as 'integration' into mainstream society. Thanks to their size, relative affordability, and flexible contracts mobile phones have thus become essential tools, there are however stark differences in access and utilisation marked by gender, age, and education.

Generally speaking, similar obstacles exist for migrants and minorities as for other categories of potential eHealth users: the mere fact that individuals have access does not mean they are proficient users. This is amplified by the lack of foreign language options on most national websites providing health information, where in addition to the national language(s) at best there is information in English (as the most common lingua franca), sometimes also in widespread migrant languages such as Turkish or Arabic. However, the 'new Europeans' hail from a whole range of countries, many of which more linguistically diverse than Europe. In order for them to understand health information, there needs to be more content in other languages. Moreover, given the dominance of English online, many Europeans are not even able to find relevant information in their own language and thus rely on unfamiliar sources in a language they are not fluent in. This raises questions over who decides on content as English-language sources and research enjoy an enhanced status.

Regarding the meaningfulness of information, many migrants are not used to the format, style and 'candidness' of information found on European websites, which may not fit their own cultural or religious values. Community-specific questions and sensitive problems also need addressing (e.g. female genital mutilation) since such practices also take place in Europe, especially as migrant communities grow to become more self-sufficient.

Even long-time residents or citizens cannot be expected to be 'empowered agents' since language competency requires time, effort and practice. While some solutions offer voice-generated content and operate largely via pictograms and videos, this is usually not enough to motivate people as most information is still predicated on the traditional literacy skills of reading and writing.

# x. Individuals wishing to 'opt out'

Another aspect commonly ignored is that individual attitudes towards technology differ, not only at individual level but between entire regions and countries. For example, while in some countries (e.g. Nordic / Baltic countries, UK) people tend to be generally convinced of the democratic value of new technology, fears over data security, online monitoring and potential infringements on privacy are taken very seriously in other places, e.g. in Germany in light of the recent PRISM scandal.

According to the 2013 Eurobarometer household survey, of those EU citizens who did not have Internet access, the majority declared having 'no interest' in it, revealing that ICT is not important to all Europeans. Never before have there been so many technologies in parallel, and the typical household has different generations of technologies, digital and non-digital, side by side. Many people feel it is becoming increasingly burdensome and costly to keep up with technological advances and skills, and they deplore that technology has eradicated the boundary between private and professional lives, making people more occupied throughout the day. Others find it a hassle to constantly create separate accounts and passwords for every new service offered online.

<sup>&</sup>lt;sup>47</sup> Special Eurobarometer 396 (2013), "eCommunications Household Survey". Available at <a href="http://ec.europa.eu/digital-agenda/en/news/special-eurobarometer-396-e-communications-household-survey">http://ec.europa.eu/digital-agenda/en/news/special-eurobarometer-396-e-communications-household-survey</a>

The (mainly negative) health impacts of increased reliance on ICT covering all aspects of our lives have been widely explored, but what has not been discussed much is what will happen to people who do not wish to be a part of the information highway or those who regard the onslaught of ICT-enabled solutions as a form of 'coercion'. While the reasons for individual non-compliance with technological norms are diverse, the general trend towards online service provision, including eHealth, means that potentially fewer services will be offered face-to-face, thereby implicitly forcing people to 'go digital'. Another consequence is that documents available in hard copy are increasingly disseminated only electronically, hence taking for granted that people own personal computers or mobile devices. The poor and excluded, as well as technophobes, are thus potentially forced to pay extra for information others are able to see and print at home.

# 7. Health provider issues

As principal users of eHealth who, on a daily basis, enter, analyse and update patient information and share their knowledge and skills with their peers at institutional and even cross-border level, health professionals are as much affected by eHealth disparities as patients. New technology is disruptive by nature, and it usually takes years to understand its impact on day-to-day tasks, processes and routines. Health managers need time to evaluate the overall impact on clinical practice in order to make informed investment decisions.

If put into action wisely, eHealth can produce potential benefits for health professionals both by creating better working conditions (e.g. facilitating work and mobility in a cross-border context) and by improving efficiency (e.g., avoiding duplication of tests and procedures, and medication errors).<sup>48</sup>

Regarding specifically the use of telehealth services as a component of eHealth, amongst those healthcare professionals who responded to the *Chain of Trust* survey, specialist doctors and GPs were the most frequently engaged in telehealth, which they used for various tasks including analysing clinical data providing health assistance, and monitoring vital parameters of patients, Pharmacists used telehealth less and for different purposes, e.g. health promotion and education. Overall however, the majority of health professionals stated they were either 'not very familiar' or 'not familiar' with telehealth services, which hints at the relatively low availability of telehealth and/or eHealth at European workplaces, which is also the main reason for non-use. Amongst users however, almost half (44%) had received training on telehealth in the past three years and overall health professionals rate their experience with telehealth as positive (82%). Moreover, regular users expressed fewer concerns about their own and patients' competence to use this technology than non-users. <sup>49</sup>

The vast differences in eHealth deployment amongst MS health systems demonstrates that health professionals' work is situated in specific national and regional contexts that determine IT infrastructures and attitudes. In turn, this creates different work flows and determines the choices health professionals are able to make about patients' treatment options, as well as the information and tools they have at their disposal for public health activities like prevention and health promotion.

Some key concerns of health providers are identified below.

<sup>&</sup>lt;sup>48</sup> CPME Statement on the eHealth Action Plan 2012-2020,

http://cpme.dyndns.org:591/Adopted/2013/CPME\_AD\_Brd\_27042013\_017\_Final\_EN\_eHealthActionPlan.pdf http://cpme.dyndns.org:591/Adopted/2013/CPME\_AD\_Brd\_27042013\_017\_Final\_EN\_eHealthActionPlan.pdf http://www.eu-

Chain of Trust – Analysis of the Online Survey, pp. 42-48 and pp. 118-121, available at <a href="http://www.eu-patient.eu/Documents/Projects/ChainOfTrust/CoT\_WP4\_Survey%20Analysis\_FINAL\_31%2003%2012.pdf">http://www.eu-patient.eu/Documents/Projects/ChainOfTrust/CoT\_WP4\_Survey%20Analysis\_FINAL\_31%2003%2012.pdf</a>

#### i. Horizon scanning

Due to the ongoing economic crisis, most health professionals across Europe are subject to budget cuts and, especially in Southern and Eastern European countries, to austerity measures following its effects. As a number of surveys have shown, severe cuts in spending and reduction of posts has occurred as a result of recent reforms, which have deteriorated working conditions and require health professionals to do more with fewer resources at their disposal. From the analysis and recommendations set out in the European Federation of Nurses Associations (EFN) report "Caring in Crisis: the impact on the financial crisis on nurses" on sequences of the economic downturn are: unemployment, less job security, constraints in resources, increased workload and reduction in high qualified personnel. Furthermore, closely linked to their will and ethical commitment to deliver care, health professionals continue to deliver the same care to a larger number of patients, in spite of their much increased workload, at the expense of their own health and well-being. This is leading to increased stress and burnout, and an overall lack of safety for the public and for health professionals themselves. Quality and safety are in a deep crisis as a result of the current policies of cutbacks that do not take sufficiently into account the necessary reform in terms of actual governance.<sup>51</sup> When empowering good existing practices in designing safe and healthy workplaces, local and cost-effective initiatives reduce the high costs of work related accidents and diseases for social security systems while increasing the well-being of all workers, including health professionals.

In times of austerity, health and safety protection is often seen as a soft target and an area that can be cut back without generating any immediate consequences. However, it is essential that the economic case for investment in good health and safety standards at an organisational, national and EU wide level is an integral element of the reform. It is also important to establish synergies with other policies such as those relating to the environment, public health, social policy, active ageing and the provision of healthcare. Next to these, gender should also become more prominent in the design of the health system reform. It is therefore essential to consider those gender sensitivities that will have an impact on helping designing the new health system reform.

Moreover, despite the ongoing efforts to emerge from the crisis and design reforms, important policy challenges remain. For example, youth unemployment is at a worryingly high level. Therefore, boosting productivity and investing in education through structural reforms is crucial. Additionally, more attention has to be paid to public sector reform – which needs more flexibility - and to investing in research and development (R&D). Health systems are undergoing a paradigm shift that requires flexibility, investment in education and more research in order to move the focus from treatment to prevention and health promotion.

At the same time, it is crucial that the welfare state is safeguarded and modernised to protect health professionals and the public; this needs to take into account the pillars of universal access and solidarity, which need to be ensured through measures including combating misuse of services and corruption.

Adding new technologies, such as eHealth services, in a climate of crisis and uncertainty could lead to

<sup>&</sup>lt;sup>50</sup> EFN Report on "Caring in Crisis – the Impact of the Financial Crisis on Nurses and Nursing", June 2012, available at <a href="http://www.efnweb.be/wp-content/uploads/2012/05/EFN-Report-on-the-Impact-of-the-Financial-Crisis-on-Nurses-and-Nursing-January-2012-rev-June-2012-24-06-2012.pdf">http://www.efnweb.be/wp-content/uploads/2012/05/EFN-Report-on-the-Impact-of-the-Financial-Crisis-on-Nurses-and-Nursing-January-2012-rev-June-2012-24-06-2012.pdf</a>

<sup>&</sup>lt;sup>51</sup> Aiken L., Clarke S., Sloane D., Sochalski J. and Silber JH. 'Hospital nurse staffing and patient mortality, nurse burnout, and job dissatisfaction'. *JAMA* 2002; 288(16):1987-1993.

detrimental effects if no resources are available for health professionals' education and for properly integrating these technologies into busy daily work schedules. Therefore, investment in upscaling health professionals' skills becomes key when designing the health sector reform. A key overarching concern is that the EU health workforce needs to be provided with both generic and more specific skills and competencies to deliver high quality and safe care to patients and other healthcare users. There is a tendency in the eHealth community to immediately look at specially skilled IT 'managers', however the professional and skill mix oriented approach recommends focusing more on upscaling the continuum of care of the health workforce.

eHealth specialists argue that the eHealth field is populated by many types of professionals but the EU health workforce, i.e. those who deliver services to and care for people, is primarily composed of health professionals, of which the nursing workforce is the largest occupational group. For instance, as regards nurses, Directive 2013/55/EU on the recognition of professional qualifications sets the requirements for registered nurses in the EU and emphasises the need for polyvalence. Therefore, within the context of austerity and health system reform, there is no need to develop IT specialists within the health workforce but an urgent need for polyvalent health professionals with both general and specific competences in different fields. Again to cite the example of nurses, next to the registered nurse three other categories are framing the nursing care continuum: healthcare assistants, specialist nurses and advanced nurse practitioners. It is important that these four categories have a good understanding of the generic eHealth skills needed to support health system reform.

In this regard, a clearly defined and health IT literate workforce is a necessary basis for eHealth solutions and services to be part of the integrated care model in Europe. In addition, gender issues needs to be taken into account when designing eHealth services and new ICT tools, which need to be user and gender friendly. Interestingly, parallel activity is being undertaken under the aegis of the EU-US Transatlantic eHealth Cooperation Roadmap and the EU-US Memorandum of Understanding on cooperation surrounding health-related ICTs that addresses transatlantic workforce issues. Under this framework, the EU and US are working together to determine and plan the eHealth competences needed to fully utilise technology's potential to enhance health professionals' expertise and performance.

### ii. Access

A study undertaken by the European Commission in 2008<sup>52</sup> showed that, on average, only 66% of GPs used computers during consultations (11% in Poland and 8% in Lithuania as opposed to almost full use in Finland), although tablets and other mobile devices are continually increasing the percentage. For these, national percentages varied from 100% in Finland to 8% in Italy. In addition, electronic communication and exchange of data between hospitals and GPs occurred, on average, in only 20% of cases, with data varying from 76% in Denmark to 0% in Romania, indicating there is still a long way to go before professional use of ICT becomes the norm. It is thus important to bear in mind that a two-tier EU approach to eHealth priorities like EHRs could further increase this gap.

Coupled with the access of clinical practitioners to ICT is their own frequency of use, competence and confidence in using new technology.

To return to the issue of access, this is also linked to the cost of the technologies. eHealth often involves high research and development costs, which should not be reflected in the final price of the service or

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<sup>&</sup>lt;sup>52</sup> Empiria / European Commission (2008), "Benchmarking ICT use among General Practitioners in Europe". Available at <a href="http://www.rcc.gov.pt/SiteCollectionDocuments/ICT\_Europe\_final\_report08.pdf">http://www.rcc.gov.pt/SiteCollectionDocuments/ICT\_Europe\_final\_report08.pdf</a>

technology. Notably in MS where physicians exercise in free practices as opposed to being employed, the costs will be borne by them in addition to sick funds and patients. In times of financial crisis, cost implications and sustainable provision of eHealth are all the more important.<sup>53</sup>

### iii. Lack of focus / specific eHealth strategies

eHealth designates a vast area that potentially includes all of health. Its scope and often ad hoc, project-based implementation can be overwhelming. This is especially the case when eHealth strategies are developed as separate entities. They must be realistic in terms of what can be achieved as overly ambitious targets cannot be realised when basic parameters regarding acceptance, interoperability, coherence and skills are not in place. National eHealth strategies, as have been developed in many EU countries, are a step in the right direction, but without cross-sectoral networks and partnerships (public-private-third sector) and clearly defined responsibilities of all actors at different levels (vision, investment, implementation), they represent merely a drop in the ocean. The creation of regional or municipal eHealth bodies can be beneficial to move forward the strategy.

Consequently, there needs to be a clear focus on what aims eHealth is supposed to achieve or complement: if health inequalities are to be addressed, this needs to be unambiguously stated in strategies and supported by 'action plans' and activities that go beyond the domain of health and link in with education and social services. Even at European level, the link between eHealth policy and health inequalities policies remains weak: even the eHAP 2012-2020 and the 2013 Report on health inequalities in the EU barely refer to it.

As the experience of the Nordic countries has shown, eHealth inclusion can be more easily realised in places where eHealth readiness is high; to give an example, in Denmark, there is a long history of databases and health registries<sup>54</sup>, the overall health system is marked by transparency and openness, and the responsibility of service delivery is generally close to the end user, thereby making eHealth more acceptable to users.

#### iv. Interoperability and Standardisation

Lack of interoperability at semantic, technical and system level, is clearly one of the biggest contributing factors to eHealth inequalities between health providers and, by extension, MS. This is a problem not only in new MS still catching up, but also for older MS where different generations of systems and devices are deployed simultaneously. Too often they cannot 'speak to each other', sometimes even within the same institution or department.

It is thus vital to ensure that disparate eHealth solutions are linked to each other and able to share data (e.g., management systems, health information portals, various solutions used in healthcare institutions that store medical/patient data) as otherwise they will not create synergies, amplify health inequalities between regions and municipalities, and impede long-term cost savings. Likewise, health managers must consider information governance challenges and interoperability standards.

The continuous increase in devices within medical information systems produces a large amount of heterogenic clinical information which must be integrated and correctly stored in order to decrease

<sup>54</sup> Danish Ministry of Health (2012), "eHealth in Denmark – eHealth as a part of a coherent Danish health care system"

<sup>&</sup>lt;sup>53</sup> CPME Statement on the eHealth Action Plan 2012-2020

healthcare costs. Using universally recognised standards of information and knowledge transmission and storage can facilitate the development of innovative eHealth solution.

The implementation of national and (eventually) EU-wide technical standards is another prerequisite for tackling 'eHealth inequalities' since currently there are also big differences between countries in this area.

### v. Market fragmentation

eHealth solutions are mainly designed and provided by the private sector. Given the big growth potential of the EU market – especially in MS where markets still need to be consolidated – a hosts of different providers and products are competing with each other, which can stimulate innovation.

But market fragmentation can also hinder innovation. For example, telecommunication operators are struggling to develop EU-wide strategies. Since spectrum is allocated at national level, where delays and auctioning processes are common, the provision of adequate 4G system-based mobile connections has been hindered, thereby restricting Europeans' ability to use their smartphones, laptops and tablets in many regions. <sup>55</sup>

# vi. Different work protocols

While new technology has the potential to foster better patient – health professional relationships by freeing up time, and offer higher quality services (e.g., due to better knowledge of patient histories) and improved continuity of care, the flip side of eHealth is that, without integration into work protocols, it can create additional work by adding 'data entry' responsibilities to busy schedules. This is particularly the case where paper and electronic records are kept side by side and no specific times are allocated for electronic communication, whether for responding to colleagues' requests or for direct communication with patients, which is becoming more common as the latter are increasingly regarded as active partners in the treatment process. Hence eHealth can divert attention from core tasks.

Active patient involvement as a result of better information can also be disruptive since it unsettles established hierarchies and etiquettes. It would potentially require more time for health professionals to communicate, clarify and explain medical issues patients may have read about online. While some physicians are thus wary of empowered patients, others rejoice in the time-saving capabilities of ICT, e.g. tablets allowing them to record information and patient feedback 'on the go'.

Nonetheless, while eHealth can work to reduce errors and create better task division and overview of responsibilities, healthcare IT can also generate other types of errors related to erroneous input and retrieval by health professionals, or by those in charge of 'interpreting' the information. <sup>56</sup>

Hence one of the recommendations of the *Chain of Trust* project final report highlights that "training on eHealth- and telehealth related knowledge and skills should be included in the health professionals' undergraduate and postgraduate curricula and also be part of Continuing Professional Development programmes according to different professional needs"<sup>57</sup>.

<sup>&</sup>lt;sup>55</sup> EC Press Release (IP/13/742), "Connected continent? Three-quarters have no 4G access!", 25 July 2013

<sup>&</sup>lt;sup>56</sup> Ash, Joan, Berg, M. & Coiera, E. "Some unintended consequences of information technology in health care: The nature of patient care information system-related errors"

<sup>57</sup> Chain of trust final report: http://www.eu-patient.eu/Documents/Projects/ChainOfTrust/EPF-report-web.pdf

# 8. The role of regional and local authorities

Local authorities, as key implementers of eHealth initiatives and, as the administrative authority that is closest to residents, they have a particularly important role to play in the planning, financing, management and diffusion of eHealth solutions, especially when it comes to inclusiveness. It is important that experiences made at local or regional level are shared and scaled up, especially given the experiences of integrated services at local level.

This is particularly relevant in MS where healthcare provision is decentralised, or where sub-populations and marginalised groups are concentrated in specific areas. Moreover, the effects of ICT, e.g. regarding interoperability, capacities, training and information needs, employment or social issues, can be most clearly observed at local level and it is important that the lessons learnt inform national policy.

The Digital Local Area (DLA) is an example of a strategic elnclusion instrument to support eGovernment planning by local governments in regional areas in order to build networks with public and private stakeholders and create a commonly agreed strategy for ICT use and inclusion, in line with the real needs of a given region.<sup>58</sup>

In Sweden, in order for county councils' and regions' eHealth collaboration to be run effectively with clear goals and continuity, consensus is needed on the focus, scope and financing of the work. The Center for eHealth<sup>59</sup> has the mandate of creating the long-term conditions necessary for developing and introducing nationwide use of IT in a decentralised health system. The work comprises new citizens' services and support for health and social care provision, a national technical infrastructure and common regulatory frameworks and standards. These joint eHealth solutions will improve accessibility of information, quality and patient safety.

# 9. Industry solutions

As in other areas of the economy, industry should produce technologies addressing the real needs of consumers and taking into account social inclusion objectives. While the pace of technology has increased dramatically over the last decade, and different groups living side by side (e.g., based on age, gender or origin) are accustomed to different technologies (e.g., radio, TV, laptops, smartphones), increasing convergence opens up new doors for providing tailored solutions.

In times of intense market fragmentation, competition, and – to an extent - saturation, only the most innovative and user-friendly solutions will survive. Hence it is in industry's interest to provide technologies that have mass appeal and yet are flexible enough to address specific needs. The elnclusion awards of 2012 and 2008 have demonstrated the business potential of niche products, and global telecoms players with health expertise are in the process of developing products offering customisation for marginalised groups.

Below are some of the most important technologies able to reach specific users in effective ways.

<sup>&</sup>lt;sup>58</sup> Waterova, I. and Tveit, L. (2012). "Digital local agenda: bridging the digital divide". Transforming Government People, process and policy, Vol. 6, No.4

<sup>59</sup> http://www.cehis.se/en

### i. mHealth 'apps'

Mobile health (mHealth) describes a subset of eHealth. It comprises health services delivered through mobile phones, tablets or personal digital assistants for the benefit of individual users, however its scope is much wider as it also includes health system pillars such as health call centres / help lines, mobile telemedicine, emergency services, and remote monitoring.

As stated in the 2012-2020 eHealth Action Plan, mHealth applications 'are blurring the distinction between the traditional provision of clinical care by physicians, and the self-administration of care and wellbeing." It is the latter element and the convergence of new technologies that are driving the IT and telecoms sector to invest in and pilot a range of tools (e.g. text messages for hospital appointment reminders, tools for surveys, data collection and public health campaigns) and especially smartphone health 'apps' which combine features of popular pastimes such as computer games with health-specific content. Many mHealth apps fall into the category of 'wellness' and allow individuals to monitor their health behaviours, improve fitness levels, or obtain condition-specific information. Other solutions facilitate treatment compliance, manage health conditions and diseases (e.g., obesity, diabetes), family planning, contribute to reducing drug shortages, etc. The 2012 European mHealth Directory lists over 250 apps fulfilling a host of functions, some of which extremely basic (e.g. 'toilet finder') others geared towards specific health conditions, especially chronic diseases.

In addition, mHealth has been used primarily in developing and emerging markets for a range of other functions, from collecting population-specific data to storing information in databases. Hence there is potential to expand its use for public health functions like prevention and epidemiological surveillance. However, given that these technologies are currently driven by the private sector, there is no public governance structure in place, leaving consumers vulnerable in case information is misinterpreted.

Although the market for wireless technology is still finding focus and maturity, it is a hotbed of innovation with great potential for reaching out to vulnerable groups who may be more comfortable in non-hierarchical environments and using non-traditional modes of communication. Mobile phones are arguably more democratic in orientation than computers (whether desktop or laptop based) or tablets given that they are compact, multifunctional (texting, music, camera, e-mail, social media, video, GPS, etc.), comparatively affordable, and already widespread including in poor and remote areas. Hence much of the innovation potential is being realised in Asia and Africa, where mobile phones are often the only available mode of communication and the only 'health tool', aided by a strong culture of oral communication.

Similarly in Europe, members of vulnerable groups and minorities, especially younger people, habitually use mobile phones in spite of the fact that they may not be 'literate' in the conventional sense. New technologies challenge traditional literacy skills by allowing users to creatively adapt them to their abilities, e.g. phonetically based texting languages, use of icons and pictograms, voice-generated commands, video content, etc. thereby opening up new possibilities for engagement. Novel competencies are being developed and popularised in this way, which eventually become mainstream.

As for the attraction of health specific 'apps', the majority of these are still designed for the general (i.e., fairly literate) public and not customised enough to be of relevance to vulnerable groups. That said, there is a great potential to target society's weakest, e.g. by relying less on the written word and more on

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<sup>60 2012-2020</sup> eHealth Action Plan, p.9

pictorial and voice content. Of particular importance is the usability and relevance of technology, including embedding in local context and providing different language / communication options. They could also meet niche needs such as health information for undocumented migrants.

In 2014, the European Commission will release a Green Paper on mHealth in recognition of the fact that more clarity is required on legal, categorisation and other issues related to mHealth in order for various stakeholders including network operators, manufacturers, software developers and healthcare professionals to make full use of the opportunities afforded.

It is important to be aware of the potential risks implied by the use of mHealth. These include issues of data protection; consent of the people whose data is being used for secondary research purposes; and the crucial role played by healthcare professionals in explaining and interpreting the medical information contained in these apps. Also, by combining features of treatment and communication, it is often unclear which legislation applies.<sup>61</sup> It has been argued that for mHealth policies to work effectively, they '*'need to be complemented by standards, architectures, and solid partnerships*".<sup>62</sup>

#### ii. Games for health

While ICT-enabled gaming and health does not normally conjure up a perfect match, and time spent in front of the computer, TV, games console or smartphone screen tends to have an overall negative effect on physical and mental health given the lack of physical activity and the repetitive and sometimes violent nature of games, an increasing number of apps and health games aims to promote health, e.g. by making people more aware of the benefits of good nutrition and sports.

Games falling into the category of 'exergaming' are designed to stimulate physical activity at home - whether biking, dancing or football – in a fun, participative way that can be enjoyed in the comfort of one's living room. These games rely on users' physical movements and may contribute to increased awareness about exercise and its importance, albeit for a relatively affluent niche market that can afford to follow, purchase (and eventually discard) health trends. However, there is potential to enlarge this segment as part of the eHealth/mHealth expansion.

# iii. Social media

In addition, social media play an increasing complementing role in contextualizing information found online. While arguably we live in a hyper connected world in which people – both seriously and playfully negotiate and choreograph their identities as much online as they do offline, social media have captured people's desire for instantaneous communication-at-a-distance. Since many people tend to have less time in the 'real world', social ties and professional contacts online are being maintained online as the line between the private and the professional blurs. Hence popular social media outlets (e.g., Facebook, Twitter, blogs) allow for both superficial and deep engagement, depending on their users' preferences and communication habits.

With regards to eHealth, a number of specialized patient spaces and groups exist that can help individuals to understand their conditions in a supportive environment. Many newly diagnosed patients find this particularly useful as they would like to obtain honest information from their peers who have already gone through similar processes of adaptation. Young people from all backgrounds, including

<sup>&</sup>lt;sup>61</sup> EPHA Briefing on mobile health (mHealth), available at www.epha.org/a/5568, Sep 2013.

<sup>&</sup>lt;sup>62</sup> WHO Global Observatory for eHealth series, Vol 3 (2011), "mHealth – New horizons for health through mobile technologies"

migrants, also habitually update their social media profiles to keep each other informed of their whereabouts and share information about their conditions and/or experiences.

However, social media augment the risks for patients to be badly informed or misled by what they read on the Internet, and hence it is important to underline the necessity of consulting healthcare professionals to discuss this information. Some blogs for example are more inclined to provoke stress about one's condition rather than to reassure, and often patients erroneously believe that they suffer from a condition they do not have. Thus, patient empowerment should not be understood as self-diagnosis but as something that can be gained from an effective patient-doctor relationship.

### iv. Low-level applications

Low-tech and social innovation tools must not be forgotten as care staff working in health institutions, but also many of the informal carers looking after patients at home, do not necessarily have access to, or know how to use, more sophisticated eHealth solutions. Yet they are faced with the same decisions and require the same quality information in order to do their jobs.

For them, low-level solutions such as easy-to-use mobile phones with basic texting and Internet functions, which would ideally be free of charge, can make a difference. It would also be beneficial to have accessible remote monitoring technology in case incidents occur when individuals are not at their workplace, which would also allow them to communicate more quickly with health professionals. ICT can also build communities of carers where these do not exist offline, taking off the pressure of working in isolation.

The website of the US Caregiver Action Network, the country's leading family caregiver organisation, provides an overview of the many solutions that can potentially make life easier for caregivers.<sup>63</sup>

# 10. Good practice examples: eHealth policies and health inequalities

Although health inequalities now feature more prominently on the EU political agenda, little work has been done so far to specifically resolve their emergence in online health contexts, and most of the existing eHealth strategies refer to them implicitly rather than containing specific actions to reduce them. Some examples include the following:

**Sweden** is one of the few countries where health inequalities are an integral part of a national eHealth strategy in spite of the fact that no explicit reference is contained in the document. That said, the focus of National eHealth - the latest phase of the document, which updates the Swedish strategy - is firmly on 'deployment, use and benefit', with tangible benefits envisaged for individuals (whether in their role as citizen, patient, end-user and close relative/friend), health and social care staff, as well as decision-makers in all care services. By taking a holistic view, the Swedish government emphasises that 'the introduction and use of new technology should no longer be seen merely as 'technological development' but as a process that enables and accelerates quality improvement within the healthcare and social services in order to better be able to meet individual needs and expectations'. Adapting the strategy to the needs of all users – including municipalities, country councils, private and third sector practitioners – seeks to bring improvements throughout the entire care sector which, it is hoped, will ultimately translate

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<sup>&</sup>lt;sup>63</sup> See www.caregiveraction.org

into better health outcomes for individuals. Particularly notable amongst the strategy's action areas are the provisions on "eServices for accessibility and empowerment" for individuals (e.g., <a href="www.umo.se">www.umo.se</a>, a website functioning as a youth clinic that provides relevant information and anonymous advice on sexual health, relationships, drugs, etc. to young people aged 13-25) and on "usable and accessible information" providing decision support for staff.

People living in **Denmark** can access the national, patient-centric e-Health portal called <a href="www.sundhed.dk">www.sundhed.dk</a>, which enables direct communication between health professionals, patients and their families, and provides an overview of relevant, secure and up-to-date healthcare information for residents. What makes the portal exemplary is its scope in terms of functions (e.g. booking appointments, past treatments and diagnoses, disease- and issue specific forums and chat rooms, etc.) openness and inclusiveness. The user-friendly interface, comprehensiveness of services and overall utility – including active patient involvement through user-generated content - has made the portal an indispensable part of the Danish health system (albeit amongst a comparatively IT literate national population), and its ease of use and relevance has also succeeded to close the age gap.

It is also of note that Danish hospitals provide interpretation services via video conferencing, which is particularly useful for migrants unfamiliar with Danish medical culture and treatments.

A similar government portal has also been introduced in **Malta**, although it is still less interactive and more data-focused. The site is secured by the Government's electronic identity (e-ID) system, so the service is available to all those who have a Maltese e-ID and their e-ID delegates.

**Estonia** is one of the countries where, based on its positive experience with eGovernment solutions put into place in the late 1990s, elements of eHealth were pioneered (although implementation delays meant that ideas explored in 2002 only took concrete shape in 2008). Nonetheless the Estonian approach to eHealth demonstrates that a high level of political commitment – notably, President Toomas Hendrik Ilves was nominated Chair of the eHealth Task Force – combined with multi-stakeholder consensus can produce an 'e-ready' society. However, Estonia is also relatively small and homogenous which has facilitated the diffusion of electronic health services.

The **United Kingdom** is one of the frontrunners of elnclusion initiatives, with services and projects that might facilitate user experience with eHealth in all four countries (England, Scotland, Wales and Northern Ireland). For example, the Carers Direct Helpline provides round-the-clock information, advice and support for carers both formal and informal, coupled with targeted web-based information for carers provided by the National Health Service (NHS). In line with the UK's multicultural and community policies, there are also many ICT and other health promotion and training programmes that target the unemployed, elderly, and specific patient and ethnic communities throughout Britain and Northern Ireland.

The **Scottish** *eHealth Strategy 2008-2011*<sup>66</sup> listed eHealth's contributions to NHS Scotland's strategic aims and in line with the "Better health, better care" Action Plan, which emphasised the importance of tackling health inequalities. The eHealth Strategy mentions 'anticipatory care through screening and health checks' as an area where eHealth can make a contribution, and it also mentions the ability to record ethnicity details and better capabilities to select sub-sets of the population according to defined

<sup>&</sup>lt;sup>64</sup> 'eHealth in Estonia'. Presentation by Ivi Normet, Ministry of Social Affairs.

<sup>&</sup>lt;sup>65</sup> For more information, see <a href="http://www.nhs.uk/carersdirect/Pages/CarersDirectHome.aspx">http://www.nhs.uk/carersdirect/Pages/CarersDirectHome.aspx</a>

<sup>66</sup> NHS Scotland, "eHealth Strategy 2008-2011", available at http://www.scot.nhs.uk/eHealth%20Strategy%202008-11%20final.pdf

criteria for screening' as being advantageous. eHealth support is also foreseen in areas such as education, self-care, and support for carers. The document recognises the importance of successful local projects for national benefit and of the 'eHealth workforce', hence making it one of the most wide-reaching documents of its time.

**Ireland's** new *eHealth strategy* has been devised in response to the challenges identified in the eHealth Task Force report and it lists amongst the benefits of eHealth to Ireland 'empowered patients', 'access', and 'public health'. While it draws on the experiences made with eHealth in Europe and beyond, and aims to create a healthy 'ecosystem' for eHealth in Ireland, the document makes however no explicit mention of health inequalities (although the reduction of these is implied).

Various **Spanish** (autonomous) regions have taken a lead in eHealth, including offering services to specific categories of vulnerable groups and patient communities. The power of technology and of health literacy is being recognised across the country, and regional health plans such as the fourth *Plan Andaluz de Salud*<sup>67</sup>, while not expressly discussing health inequalities, clearly emphasise the importance of enhancing knowledge of and integration of technology 'with sustainable criteria" for improving the health of the population. In other words, ICT skills and health literacy are viewed as a public good that can help overcome health inequalities. Similar approaches are also taken in **Italy** (e.g. the region of Emilia Romagna) and in other EU countries.

<sup>&</sup>lt;sup>67</sup> Junta de Andalucia (2012), available at <a href="http://www.juntadeandalucia.es/presidencia/portavoz/resources/files/2013/11/27/1385555102219IV\_PAS\_v9.pdf">http://www.juntadeandalucia.es/presidencia/portavoz/resources/files/2013/11/27/1385555102219IV\_PAS\_v9.pdf</a>

# 11. Recommendations

As Michael Marmot has stated, ''A debate about how to close the health gap has to be a debate about what sort of society people want''. <sup>68</sup> Reducing health inequalities in Europe is ultimately a question of social justice and solidarity, something that merits an EU-wide reflection process as technology, including eHealth, can unite as much as it can divide people.

While the differences in the technologies people have access to might not appear to be quite so severe yet, the gulf between those who are comfortable and 'literate' to effectively use and process ever-more ICT-enabled content, and those who remain partially or fully excluded from it, is becoming wider - even if more people are making the transition to the Internet. When crucial areas such as health are increasingly being managed online, it will be indispensable to reflect on who designs, selects and purchases eHealth solutions, and for whose benefit. Already there is a sense of waning social cohesion as European patients/consumers increasingly draw on individualised online content that, at best, is being shared with like-minded social media networks. The debate over eHealth requires focus to ensure that quality and user-centric solutions can gain ground, acceptance and trust.

Based on the information compiled in this Report, the EHSG subgroup on eHealth and health inequalities proposes the following recommendations in support of inclusive, responsible and caring eHealth policies which are user- and not technology-driven:

# 11.1 Improve access and involve all stakeholders

For eHealth solutions to become widely accepted, and increase take-up by non-traditional and vulnerable user groups, it is important for them to be as accessible, affordable and user-centric as possible. This means that various categories of end users have to be an integral part of the design, evaluation and follow-up during the whole lifecycle of technologies so that particular challenges experienced by specific user groups can be understood and rectified.

Health information accessible in various online environments - from websites to mHealth apps to social media and electronic health records - should be provided in a language and with a layout which is easy to understand, also for people with special needs (e.g. older people, people with disabilities). When implementing large-scale eHealth systems, adequate consideration should be given to the needs of vulnerable groups such as children, migrants or people with mental and other disabilities.

There is in parallel a need for cultural change whereby information contained on websites should be checked by the patient with their doctor, and not taken for granted. More interactive features, e.g. built into telemedicine systems, would also allow individuals to confirm their understandings with healthcare professionals and could thus help sustain a strong patient-health professional relationship.

Moreover, it is important to address mounting concerns over data protection and privacy as they can be inhibitors to patients and health professionals alike.

Access is also conditional upon regulatory clarity. Identifying the potentially significant role of self- and co-regulation in the context of the Digital Agenda for Europe, the European Commission has examined Principles for Better Self- and Co- regulation<sup>69</sup> and set up a Community of Practice<sup>70</sup> to engage

<sup>&</sup>lt;sup>68</sup> Michael Marmot, Fair Society, Healthy Lives - Marmot Review, 2010

<sup>&</sup>lt;sup>69</sup> See <a href="https://ec.europa.eu/digital-agenda/en/node/66112">https://ec.europa.eu/digital-agenda/en/node/66112</a>

<sup>&</sup>lt;sup>70</sup> See <a href="https://ec.europa.eu/digital-agenda/en/content/cop-agora">https://ec.europa.eu/digital-agenda/en/content/cop-agora</a>

stakeholders in a dialogue on best practices. In any case, an appropriate regulatory framework, addressing the changing needs and conditions in ICT, is paramount for ensuring the protection of citizens and fostering innovation.

### 11.2 Accommodate diverse needs and reduce technological pressure

Providing patients with additional tools to be more actively involved in the decisions regarding their health and increasing awareness of the benefits and the opportunities of eHealth is of vital importance. Developing tailored solutions for accommodating the needs of specific population groups, health professionals and carers working in diverse institutional and non-institutional settings, and that can adapt and respond to specific national, regional and local circumstances will be particularly crucial. Since Europe is only becoming more diverse, it will be necessary to create sufficient incentives for industry to come up with solutions for underserved patients and communities.

The important thing is that end users need to see what concrete benefits eHealth can bring to their lives in order for deployment to become routine. Only customary utilisation will increase mutual trust and build up (self-) confidence and user skills amongst all stakeholders. At the same time, while users' knowledge and familiarity with eHealth will develop gradually and over time, patients and individuals must not be expected to have acquired knowledge gains or be held responsible for failing to do so, especially in the transition to personalised medicine.

It is however equally important to not overestimate the potential gains of eHealth and concede that, in all likelihood, it is *inevitable* that some individuals and population groups will not be able or willing to (for all the different reasons mentioned above) be part of the project. All technology-enhanced services are by nature dynamic, which means they inherently demand constant upgrading of hard- and software, associated devices, and user skills. The *Chain of Trust* project findings reveal that usability is relative and needs to be assessed on an ongoing basis.

Given the pace of innovation in ICT and telecommunications, it is likely that some people will continue to be able to afford and use technologies that others will never attain. Rather than trying to create a level playing field between individuals and regions, it might thus be advantageous to focus eHealth innovation on where it matters the most (e.g., technologies enabling cross-border and remote interventions and consultations, mobile monitoring devices to help treat specific diseases or conditions) instead of creating implicit pressure for people to become owners of technologies as a precondition for successful participation in eHealth as 'empowered' patient-consumers.

### 11.3 Improve digital health literacy and ensure user education at all levels

Individuals only feel empowered if they are able to use eHealth tools confidently. Since eHealth literacy comprises a whole set of different literacies, there is a growing need to educate and train individuals in all of these elements, especially members of vulnerable and at-risk groups. At a minimum, confident eHealth use entails the ability to effectively perform common eHealth tasks, and to understand how these activities can support health decision-making and disease management. In this context it is particularly important to consider specific personal circumstances, social processes and institutional environments that shape people's ability to be online and their Internet use.<sup>71</sup>

In addition, there also need to be more focused information campaigns and training activities directed at the general public since average literacy levels in all categories tend to be low, and digital health literacy

<sup>&</sup>lt;sup>71</sup> Efrat Neter and Esther Brainin (2012), "eHealth Literacy: Extendig the Digital Divide to the Realm of Health Information", Journal of Medical Internet Research, Vol. 14, No 1.

is a blurry notion for most people. There is a lack of understanding of what it entails and how it can add value, and there is even less information on common solutions and issues in a cross-border context, combined with concerns over data protection and confidentiality. Moreover, developing digital health literacy is a constantly evolving process due to advances in hardware and software, and new mobile devices entering the market, hence training needs to be complemented by upgrading of skills.

Health education in schools and other settings, from childhood through to continuing education, must be emphasised as a primary issue so that future generations become confident users of eHealth regardless of background, personal characteristics and social status. It is also a fundamental necessity that technology is integrated into daily work and study routines and that all users are proficient in fulfilling their respective tasks.

In order to gain the trust of health professionals, they must be educated and trained about the nature and purpose of the equipment. In this respect, knowledge needs to be gained on how to influence cognitive, physical or literacy barriers on workflow and outcomes of using health records. With the growing introduction of ICT services in all phases of the care process, health professionals' responsibilities are greater than ever. Therefore, there is a need to educate health professionals to make adequate use of these technological innovations, without affecting the health professional/patient relationship.

## 11.4 Integrate eHealth into overall health and social care system policy

So far eHealth policy is being developed at the margins of overall health and social policy, which does not make sense given technology's central role for future healthcare delivery in Europe. It also does not make sense to exclude eHealth from research into health inequalities and from national or regional health strategies.

The health system should be firmly focused on the needs of end users such as those of patients and health professionals / managers providing the services. Hence, all measures should be put in place to allow the health record to move together with the patient, to enable health professionals to communicate remotely with each other and with patients, and to facilitate the development of health information services based on evidence gathered from all members of society including vulnerable groups. The provision of these services must also be included in reimbursement policies to ensure that everybody can benefit from eHealth.

The issue of integration between social and healthcare services is a key component. Although challenging, it should not be overlooked in this reflection since it can bring significant added value to citizens and patients in providing better continuity of care.

Furthermore, with both patients and health professionals becoming more mobile within and between MS, developing clear and practicable interoperability standards is essential. It is therefore urgent to enable the sharing of health information between different healthcare settings and systems provided that they guarantee a sufficient level of data protection. An adequate legal framework and networked infrastructures should be built to cover the entire continuum of care.

### 11.5 Evaluate the impact of eHealth solutions and build up evidence base

The 2011 WHO Global eHealth Evaluation Meeting's Call to Action neatly sums up the fundamental dilemma stating that "to improve health and reduce health inequalities, rigorous evaluation of eHealth is necessary to generate evidence and promote the appropriate integration and use of technologies". 72

Thus, eHealth investments and implementations must be guided by evidence-based decision-making processes or else eHealth runs risk of diverting resources from other health and social care areas which are potentially more effective in improving health outcomes, or types of non-technological innovation that can facilitate collaboration between health professionals.

**11.6 Give specific consideration to empowering patients with disabilities and/or specific diseases**Patients with physical / mental disabilities and/or specific diseases must be a priority for eHealth educational interventions aiming to improve eHealth use, literacy and skills.

In the case of severe learning disability, which can lead to a variety of treatable and long-term conditions, a relative or health professional should be available to assist the individual patient in using eHealth ICT tools whenever necessary.

### 11.7 Offer financial subsidies for the purchase of eHealth equipment / ICT access

Wealth remains the primary inequality when it comes to accessing and using new technology. As the cost of established technologies and services decreases, new ones are being introduced that target affluent patients/consumers.

In particular, the equipment required for using eHealth effectively is expensive. Many patients with disabilities and from disadvantaged backgrounds are in a bad economic situation and they cannot afford to buy computers, new generation smartphones or special medical devices. While experiences with financial incentives are mixed, national health authorities and social security administrations could consider offering such patients appropriate eHealth tools either as a donation or via financial subsidies that would allow them to purchase everything necessary to manage their conditions more effectively through eHealth technology.

Moreover, access needs to be affordable for everybody and of the same high speed and quality across the Continent, to avoid that people living in geographically isolated areas or deprived urban neighbourhoods are not falling behind.

There also needs to be more clarity over reimbursement decisions pertaining to the use of eHealth services to ensure that economically weaker groups are able to take advantage of them.

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<sup>&</sup>lt;sup>72</sup> Call to Action on Global eHealth Evaluation, Consensus Statement of the WHO Global eHealth Evaluation Meeting, Bellagio, September 2011.

# **ANNEX I**

# Available studies and material on health inequalities of interest in the eHealth context

a) Communications, reports, studies and surveys conducted by EU Institutions

### **European Commission**

- "Health inequalities in the EU Final report of a Consortium led by Sir Michael Marmot" (2013) http://ec.europa.eu/health/social\_determinants/docs/healthinequalitiesineu\_2013\_en.pdf
- "Commission Staff Working Document: Report on health inequalities in the European Union" (2013)
  - http://ec.europa.eu/health/social\_determinants/docs/report\_healthinequalities\_swd\_2013\_328\_en\_.pdf
- "Towards Social Investment for Growth and Cohesion including implementing the European Social Fund 2014-2020"
  - http://ec.europa.eu/social/main.jsp?catId=89&langId=en&newsId=1807&moreDocuments=yes &tableName=news
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# **European Parliament**

Resolution on reducing health inequalities in the EU (2011)
 <a href="http://www.europarl.europa.eu/sides/getDoc.do?type=REPORT&reference=A7-2011-0032&language=EN">http://www.europarl.europa.eu/sides/getDoc.do?type=REPORT&reference=A7-2011-0032&language=EN</a>

## **Council of the European Union**

- Council Conclusions on Equity and Health in All Policies: Solidarity in Health (2010) http://www.consilium.europa.eu/uedocs/cms\_Data/docs/pressdata/en/lsa/114994.pdf
- Council Conclusions on Safe and efficient healthcare through eHealth (2009)
   <a href="http://www.consilium.europa.eu/uedocs/cms\_data/docs/pressdata/en/lsa/111613.pdf">http://www.consilium.europa.eu/uedocs/cms\_data/docs/pressdata/en/lsa/111613.pdf</a>

# b) Studies and report from other Institutions

- UCL/Institute of Health Equity reports and information, <a href="http://www.instituteofhealthequity.org/">http://www.instituteofhealthequity.org/</a>
- Health First Europe, "E-QUALITY IN E-HEALTH: Stakeholders' reflections on adressing e-health challenges at the European level", <a href="http://www.healthfirsteurope.org/uploads/Modules/Newsroom/HFE-EqualityInE-health\_BROCH\_LayA\_V23\_spreads-2.pdf">http://www.healthfirsteurope.org/uploads/Modules/Newsroom/HFE-EqualityInE-health\_BROCH\_LayA\_V23\_spreads-2.pdf</a>
- WHO, "How health systems can address health inequities through improved use of Structural Funds", <a href="http://www.euro.who.int/">http://www.euro.who.int/</a> <a href="https://data/assets/pdf">data/assets/pdf</a> <a href="file/0007/129868/e94606.pdf">file/0007/129868/e94606.pdf</a>

### c) Position papers of stakeholders (health inequalities)

- EPHA European Charter for Health Equity (2011)
- EPHA Briefing on Health inequalities (2010)
- CPME Position on Health Inequalities (2011)
- EPF positions on health inequalities, <a href="http://www.eu-patient.eu/whatwedo/Policy/Health-inequalities/">http://www.eu-patient.eu/whatwedo/Policy/Health-inequalities/</a>

# **ANNEX II**

# Select EU initiatives and projects considering eHealth inequalities

## I) eHealth Action Plan 2012-2020 (Dec 2012)

- Development of skills and digital health literacy
- Leveraging European Regional Development Fund (ERDF) for large scale deployment of innovative tools, with a particular attention to improving equal access to services

# II) Digital Agenda for Europe – Key actions

DAE Pillar VI: Enhancing digital literacy, skills and inclusion (Actions 57-68)

- Action 57: "Prioritise digital literacy & competences for the European Social Fund"
- Action 61: "Educate consumers on the new media"
- Action 62: "EU-wide indicators of digital literacy"
- Action 64: "Ensure the accessibility of public sector websites"
- Action 65: "Helping disabled people to access content"
- Action 66: "MS to implement digital literacy policies"

DAE Pillar VII: ICT-enabled benefits for EU society

- Action 75: "Give Europeans secure online access to their medical health data and achieve widespread telemedicine deployment"
- Action 77: "Foster EU-wide standards, interoperability testing and certification of eHealth"

DAE Pillar IV: Fast and ultra-fast Internet access

- Action ?: " Europe needs download rates of 30 Mbps for all of its citizens and at least 50% of European households subscribing to internet connections above 100 Mbps by 2020."

### III) eHealth Task Force Report (May 2012)

#### Lever 5 "Include everyone"

"Service providers need to be aware that there may be sub-groups of the population that are outside the reach of eHealth tools (...) These 'vulnerable communities' and their needs need to be accommodated, because if not carefully planned, eHealth could disenfranchise rather than empower" (p 14).

### • Recommendation III: "Support health literacy"

"In eHealth (...) education efforts have focused on professionals but missed the opportunity to empower patients/citizens. Health literacy efforts should begin in school."

# • Recommendation V: "Re-orient EU funding and policies"

"The majority of public funding (...) has been invested in centralised, large-scale, top-down solutions. These have failed to address and integrate the user experience sufficiently. The next phase should see investment in tools that citizens can use to support their wellbeing and manage their lives."

### IV) The European eHealth Governance Initiative

The eHealth Governance Initiative is working to establish a governance structure for eHealth within Europe in order to ensure continuity of healthcare both at home and across borders. It is achieving this through the development of strategies, priorities, recommendations and guidelines designed to deliver eHealth in Europe in a co-ordinated way. This work involves all stakeholders but especially patients and health professionals.

The Initiative seeks a strong coordinated political leadership and the integration of eHealth into national health policies. It achieves this through its links to the Article 14 eHealth Network that brings together

national authorities responsible for eHealth on a voluntary basis to work on common orientations in this area and to promote an interoperable and sustainable eHealth implementation across Europe.

The eHealth Network was established by Article 14(2) of Directive 2011/24/EU and it was considered desirable, in order to achieve coordination, coherence and consistency and to avoid duplication, that the eHealth Governance Initiative should operate within the framework of the Network and the objectives assigned to it.

More information is available at <a href="http://www.ehgi.eu/default.aspx">http://www.ehgi.eu/default.aspx</a>

## V) Sustains project

SUSTAINS comprises a rich basket of services based on giving citizens online access to their EHR. The services proposed have been distilled from the experience of regions which have already pioneered such access. The SUSTAINS Consortium is composed of regions in the EU leading in the area of innovation in services for citizens, and a number of user and professional associations all equally committed to the implementation of key action 13 of the Digital Agenda for Europe. Regions will share their experiences and achievements to speed up the implementation of the SUSTAINS basket of services in a representative cross-section of EU regions. Patient empowerment is high on the agenda of the Consortium, together with great care in addressing the concerns of the professionals in what could be seen as a revolution in the patient-health professional relationship. Legal and ethical issues associated with online access by citizens to their EHR will be thoroughly explored, and lessons will be drawn from 11 pilots in 9 EU countries and disseminated to facilitate the implementation of similar services by other regions. <a href="http://sustainsproject.eu/">http://sustainsproject.eu/</a>

# VI) Chain of Trust

The "Chain of Trust" project (Jan 2011-13), led by EPF and co-funded by the Public Health Programme of the European Union managed by the EAHC, had the overall objective of assessing the perspective of the main end users of telehealth services across the EU to see whether and how views have evolved since the initial deployment of telehealth and what barriers there still are to building confidence in and acceptance of this innovative type of services.

The final report and project recommendations are available at <a href="http://www.eu-patient.eu/Documents/Projects/ChainOfTrust/EPF-report-web.pdf">http://www.eu-patient.eu/Documents/Projects/ChainOfTrust/EPF-report-web.pdf</a>

### VII) ReNEWING HeALTH

ReNEWING HeALTH aims at implementing large-scale real-life test beds for the validation and subsequent evaluation of innovative telemedicine services using a patient-centred approach and a common rigorous assessment methodology. For more information see <a href="http://www.renewinghealth.eu/en/">http://www.renewinghealth.eu/en/</a>

### VIII) EPSOS

epSOS aims to design, build and evaluate a service infrastructure that demonstrates cross-border interoperability between electronic health record systems in Europe. http://www.epsos.eu/home.html

### IX) European Portal for Action on Health Inequalities

This website includes information and outcomes of various key initiatives including Equity Action - the Joint Action on Health Inequalities. More information on the partners and the JA's aims is available at <a href="http://eurohealthnet.eu/research/joint-action-health-inequalities">http://eurohealthnet.eu/research/joint-action-health-inequalities</a>

The European Portal for Action on Health Inequalities is available at <a href="http://www.health-inequalities.eu/HEALTHEQUITY/EN/home/">http://www.health-inequalities.eu/HEALTHEQUITY/EN/home/</a>

### X) e-Inclusion policy

e-Inclusion aims to achieve that "no one is left behind" in enjoying the benefits of ICT. e-Inclusion means both inclusive ICT and the use of ICT to achieve wider inclusion objectives. It focuses on participation of all individuals and communities in all aspects of the information society. e-Inclusion policy, therefore, aims at reducing gaps in ICT usage and promoting the use of ICT to overcome exclusion, and improve economic performance, employment opportunities, quality of life, social participation and cohesion.

e-inclusion features prominently in the DAE. Under Pillar 6 the Commission proposes a series of measures to promote take-up of digital technologies by potentially disadvantaged groups, such as elderly, less-literate, low-income persons. Improving access for people with a disability is another of the policy actions set by the Digital Agenda. An important part of the e-inclusion agenda is also tacking demographic ageing with the help of ICT: a better quality of life for the elderly, reduced cost of care, business opportunities in the "silver economy". Under Pillar 7 (ICT-enabled benefits for EU society) the Commission will reinforce the Ambient Assisted Living (AAL) Joint Programme to allow older people and persons with disabilities to live independently and be active in society.

e-Inclusion is closely related to European policies on social inclusion, education and culture, regional development, innovation, industry and internal market.