

# Taking Action – A Roadmap to Achieving Universal Health Coverage for All by 2030

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01/12/2017



## Contents

1. Introduction .....	3
1.1 How Universal Health Coverage relates to EPF's priorities .....	3
1.2 Past milestones of EPF's work on Access to Healthcare .....	4
2. Why this matters.....	4
2.1 A situational analysis.....	4
2.2 UN Sustainable Development Goals .....	7
3. About this Roadmap .....	8
3.1 Why we developed this Roadmap .....	8
3.2 How was this Roadmap developed? .....	8
3.3 Who is this Roadmap intended for? .....	9
3.4 How to use this Roadmap .....	9
4. Roadmap .....	9
4.1 Preamble .....	9
4.2 Concerns .....	12
4.3 Recommendations for Providing access to quality of care.....	13
4.4 Recommendations for Committing to sustainable investment in health.....	14
4.5 Recommendations for Encouraging affordability of healthcare products and services .....	15
4.6 Recommendations for Implementing access to a holistic range of health and related services.....	16
4.7 Recommendations for Ending discrimination and stigma .....	17
5. Towards an inclusive method of implementation .....	18
6. Conclusions .....	19
6.1 Roadmap conclusions .....	19
6.2 Monitoring and Accountability .....	19
6.3 Next Steps .....	21
References .....	22

## 1. Introduction

### 1.1 How Universal Health Coverage relates to EPF's priorities

Patients' access to healthcare is a long-standing priority for EPF and its membership, and is at the heart of the vision of the organisation.

Further to EPF's vision, two of EPF's strategic goals, described in our Strategic Plan 2014-2020, clearly highlight our priorities in this area.

**Vision:** All patients with chronic conditions in Europe have equal access to high quality, patient-centred health and related care.

**Healthcare Access and Quality:** To contribute to improvements in health systems that enable equitable access to sustainable and high-quality healthcare designed and delivered to meet patients' and informal carers' needs at all levels of care, embracing innovation in all its forms.

**Non-Discrimination:** To promote the development of EU and national policies that tackle discrimination faced by patients in health and social care as well as in domains like education and employment.

Disparities in access to healthcare have increased since the 2008 financial crisis in Europe. Access to care is affected by austerity policies, such as cuts in healthcare budgets and in insurance coverage, increased fees and co-payments, and cuts in social protection measures. Against a background of austerity measures, increased cost of treatment and medicines and falling healthcare spending in many Member States since 2009, inequalities have been made worse. All this comes at a time of even greater demand for healthcare and social support by Europe's ageing population.

EPF believes that every patient should have equitable access to person-centred high-quality health and social care and strives to eliminate disparities and barriers related to access and standards of care and health inequalities within the EU.

EPF supports the World Health Organisation's definition of Universal health coverage, where "everyone has access to quality health services that they need without risking financial hardship from paying for them."

EPF's 2017 thematic Campaign on Access to Healthcare for All<sup>1</sup> builds on our 2015-16 campaign on patient empowerment, which recognised that equity must go hand in hand with patient empowerment: to be an empowered patient, one first needs access to high-quality care. This requires political change to ensure the rights of all patients are respected, to fight the inequalities that persist in health across the EU, and to make health a priority in all policies at national and EU levels.

The EPF campaign calls on Member States and the EU to commit to a long-term vision where equity of access and universal health coverage is a reality for all patients in the EU – a target of the third UN Sustainable Development Goal on ensuring healthy lives<sup>2</sup>. In line with EPF's campaign, this Roadmap

sets out recommendations that decision-makers need to consider in order to achieve Universal health coverage for all by 2030.

The EU has played an important role in shaping the 2030 Agenda for sustainable development. EPF welcomes and recognises the European Commission's efforts, the European Parliament's engagement and the EU's commitment to the UN SDGs, as outlined in the November 2016 EC Communication<sup>3</sup>, 2017 EP Report on EU action for sustainability<sup>4</sup> and June 2017 Council Conclusions<sup>5</sup> respectively. This roadmap aims to support the European Commission's efforts and encourage further concrete action and collaboration with Member States.

## 1.2 Past milestones of EPF's work on Access to Healthcare

In 2008, EPF responded to the European Commission's consultation on the EU Health Strategy, framing our response around our vision of high-quality, equitable healthcare and our strategic goals on equity, empowerment and inclusion. The subsequent Communication titled "Solidarity in health: reducing health inequalities in the EU", failed to address the particular needs of patients or the importance of health literacy. EPF therefore welcomed the European Parliament's report on Reducing Health Inequalities in the EU, drafted in response to the Communication. Our 2010 policy paper succeeded when a patient perspective was included in the report: patients with chronic diseases are recognised as "a specific group suffering inequalities in diagnosis and care, social and other support services, and disadvantages including financial, employment, and social discrimination, whose needs should be addressed".<sup>6</sup>

In the next years, in our contribution to the Council of the European Union's reflection process on chronic diseases, EPF highlighted the need to tackle health inequalities. We co-organised a first Conference on health inequalities in the new Member State of Bulgaria, in Sofia in 2012 with our member, the National Patient Organisation (NPO). Further work was undertaken in subsequent years, including the establishment of the Patient Access Partnership (PACT)<sup>7</sup> and the inclusion of a new strategic goal on non-discrimination into EPF's Strategic Plan in 2014.

EPF's working group on access, comprised of EPF members, was formed in 2014 and has been instrumental in guiding this campaign and EPF's work on access since then. In 2015, the EPF together with the working group worked on defining access and recommendations on access indicators, resulting in the 2016 EPF position statement "Defining and measuring access to healthcare: the patients' perspective".<sup>8</sup> A survey on access to healthcare<sup>9</sup> followed in 2016 to provide strong evidence of patients' current situation across the EU, which has in turn informed the EPF campaign.

## 2. Why this matters

### 2.1 A situational analysis

Healthcare should be accessible in a timely way to every patient who needs it, not only to those who can pay and regardless of gender, age, employment and residence status. Regrettably, this is not a reality for all. Disparities in access predate the 2008 financial crisis in Europe, but between 2009-2011 widespread austerity measures and falling healthcare spending in many Member States, contributed

to worsening inequalities. In the last few years the trend has been again towards growing spending on health, albeit at a lower level.<sup>10,11</sup>

Access to care can be affected by **restrictive policies**, such as cuts in healthcare budgets or in insurance coverage, increased fees or co-payments, and cuts in social protection measures. All this comes at a time of even greater demand for healthcare and social support as a consequent of Europe's ageing population.

Some countries have adopted **progressive policies and measures** to lower user charges, improve financial protection, in order to counter the negative impacts of austerity and to increase coverage.<sup>12</sup>

The **impact of chronic conditions** is well known. They account for up to 80% of healthcare costs in terms of premature deaths, healthy life years lost, and lost productivity.<sup>13</sup> At the same time, healthcare systems are facing increasing and complex demands as a result of **demographic change**. Many diseases are more prevalent with age and as the population ages, the number of patients with chronic conditions is increasing. Although some diseases are preventable to some extent, others are not and many chronic conditions affect people of all ages, including the young.<sup>14</sup> The impact of chronic illness is multi-faceted and includes negative impact on quality of life, education and employment.<sup>15</sup> Patients with chronic conditions and their families have been recognised as a group that is subject to specific vulnerabilities.<sup>16</sup> **Multimorbidity** is increasing at a significant rate and poses a particular burden on patients and their families, as well as specific challenges to healthcare delivery and organisation.<sup>17</sup> Patients with multiple conditions are even more vulnerable and at risk of barriers in accessing healthcare.<sup>18</sup>

Ensuring the future **sustainability of health systems** is key to realising the Europe 2020 goals of smart and inclusive growth.<sup>19</sup>

Over the last decade, the above-mentioned common challenges, have led to growing demand for healthcare and subsequent pressure on public budgets. Sustainability strategies should include reducing the burden on secondary care by strengthening **primary and community care**, which is accountable for 80% of seeking treatment.<sup>20</sup> Strong primary care systems are needed to provide continuous, comprehensive, and co-ordinated care for the whole population.<sup>21</sup>

Health is defined according to the World Health Organisation as "a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity". However, Europe currently lacks **inter-sectoral action and collaboration for health**, and a systematic **health in all policies** approach. For example, in employment there is a need to ensure that all workers, including those with chronic conditions and informal carers, benefit from working conditions that protect their health and provide complete coverage and effective access to healthcare. People with chronic conditions (including survivors, e.g. of cancer<sup>22</sup>) are often considered as a burden by employers and face difficulties in accessing or continuing employment. Due to social exclusion, unemployed patients are prone to health deterioration and increased need of medical attention.<sup>23</sup> In this respect, a society on its way to healthier ageing and sustainable healthcare systems demands a better-defined labour policy that takes into account the needs of people of all abilities and provides **more flexible and inclusive working arrangements**.

The Treaty of Lisbon<sup>24</sup> mandates the Union with ensuring a high level of protection for human health in all EU policies; investment in healthcare is recognised as a pre-requisite of economic growth and

social cohesion. Similarly, strong, efficient and well-run health systems are a key cornerstone of universal health coverage. **Access to healthcare is a basic human right**<sup>25</sup> and one of the fundamental principles of European health systems, together with safety, quality, and equity<sup>26</sup>. Timely, equitable access to appropriate, person-centred treatment, care and support is an investment in society. Eurobarometer surveys indicate that European citizens consistently identify health as a high EU priority.<sup>27</sup>

Yet, research provides evidence of the systematic failure of European health systems for many people currently living within the region, particularly people in situations of precarity, social isolation or vulnerability<sup>28</sup>. Persistent **inequities** undermine the EU's fundamental values and patients' rights, with an impact on social cohesion and economic growth.<sup>29</sup> The European Commission's Reflection Paper on the Social Dimension of Europe notes that half a million premature deaths could be avoided, not only by better prevention but also by more timely and effective healthcare.<sup>30</sup>

EPF's 2016 survey on access to healthcare<sup>31</sup> among other sources demonstrate that **health inequalities** within and between EU countries are increasing. Health inequalities carry a significant economic, societal as well as personal cost. In the current policy debate, the economic argument "health is wealth" is now widely accepted. Patients are reporting **financial hardship** as a result of healthcare costs which for many means reducing spending on some essential needs such as food or clothing, and/or postponing healthcare visits or treatment.<sup>32</sup> Postponing care can result in complications, hospitalisations and worse health outcomes and ultimately more costs for both patients and the healthcare system.

Despite the fact that health is a human right, in Europe people's ability to access health care is often conditioned on their right to reside. This means both third country nationals and EU nationals with precarious residence status are typically excluded from health coverage. Following the recent increase in the number of new arrivals to Europe's shores, attention has been given to the challenge of delivering health services to migrants in a humanitarian emergency context. However, less attention has been paid to the broader question of ensuring **adequate health services** in the longer term for the millions of **migrants** living and working in Europe.<sup>33</sup> Migrants often face obstacles in access, such as the lack of interpretation or cultural mediation services, difficulty navigating complex health systems, and insufficient cultural competency among health professionals. In addition, access to basic services, including health care, social support and housing, as well as to decent work, often depends on residence status. Precarious residence status therefore tends to lead to precarious living conditions. In most EU Member States, people who are undocumented have extremely limited access to health care, except in emergencies. When they do access care, they face the risk of being denounced to immigration authorities.<sup>34</sup> There is growing consensus that such exclusion is contrary to medical ethics<sup>35</sup> and broader public health goals<sup>36</sup> in addition to undermining social solidarity, trust in authorities and patients' health.<sup>37</sup>

In all countries, life expectancy is strongly influenced by **social determinants**, including factors such as employment, income, housing, length of education and ethnicity. In addition, factors that create health-related vulnerabilities include poor working and living conditions, precarious or irregular residence status, and exposure to violence or discrimination.<sup>38</sup> Investment in health is an investment in the EU's fundamental values, in social cohesion, and in economic development. Reducing health inequalities is crucial for the overall health, wealth and cohesion of society.

**Affordability of healthcare**, particularly of **medicines**, has become an urgent priority for patients and policy-makers, as EU Member States are concerned about the impact of new medicines on their healthcare spending. Key trends that indicate serious failures in the current system include the rising prices of some new medicines; pockets of unethical business practices; and the emergence of exceptional therapies where the usual cost-effectiveness logic as applied by health technology assessment no longer works (e.g. for Hepatitis C and rare diseases).<sup>39</sup> The results of a European Commission analysis of the impact of existing industry incentives on medicines prices and access, expected for 2018, will have important policy implications.<sup>40</sup> By the same token, generic and biosimilar medicines are becoming increasingly available and are providing more therapeutic choices for patients and more affordable prices of medicines.

**Waste** in the healthcare system is also a threat to sustainable access. According to a recent OECD report, a considerable part of health spending makes little to no contribution to improving people's health and in some cases even results in worse outcomes.<sup>41</sup> In this respect, improving patient safety will be a key strategy; effective implementation of **integrated, person-centred care models** will also play an important role in providing services that are of better quality, more responsive and appropriate to the needs of individuals and communities, and ultimately more sustainable.<sup>42</sup>

**Transparency** of decision-making and of the quality of healthcare is a prerequisite to ensure **accountability of the health system** to its users. "Greater accountability can lead to better priority setting, and incentivise improvement initiatives across the health system"<sup>43</sup>. Furthermore, the development of effective, accountable and transparent institutions is a target of the 16<sup>th</sup> UN SDG.<sup>44</sup>

## 2.2 UN Sustainable Development Goals

In September 2015, the 17 Sustainable Development Goals (SDGs) of the 2030 Agenda for Sustainable Development were adopted by world leaders. Over the next fifteen years, countries are committed to mobilise efforts to end all forms of poverty, fight inequalities and tackle climate change, while ensuring that no one is left behind. The new goals follow on from the UN Millennium Development Goals (UN MDGs) adopted in 2000 and call for action by all countries, poor, rich and middle-income to promote prosperity while protecting the planet. The UN SDGs recognise that ending poverty must go hand-in-hand with strategies that build economic growth and addresses a range of social needs, including education, **health**, social protection and employment, while tackling climate change and environmental protection. While the SDGs are not legally binding, governments are expected to take ownership and establish national frameworks for the achievement of the 17 Goals.<sup>45</sup>

As a sub-target of the third UN SDG to "ensure healthy lives and promote well-being for all at all ages", EU Member States have committed to achieving universal health coverage by 2030, including financial risk protection, access to quality essential health-care services and access to safe, effective, quality and affordable essential medicines and vaccines for all. The European Commission has also committed itself to implementing the 2030 Agenda while supporting EU Member States in this task.

In line with WHO Europe, EPF believes that an important paradigm shift is required to reach the SDG targets. The Roadmap for health and sustainable development, published in September 2017, calls for a particular focus on "governance and inter-sectoral action for health; leaving no one behind; the alignment of national development and health policies, as well as policy coherence across multiple SDGs; and on the means of implementation", with the latter including partnerships, sustainable financing, research and innovation, and enhanced monitoring and accountability.<sup>46</sup>



EPF believes that achieving universal health coverage is fundamental to the achievement of the other health and wellbeing-related targets, such as reducing premature mortality, as well as the attainment of all other sustainable development goals and targets related to reduced inequalities, gender equality and elimination of poverty. Health can thus be regarded as a cross-cutting dimension of the UN SDGs.

### 3. About this Roadmap

#### 3.1 Why we developed this Roadmap

This Roadmap to Achieving Universal Health Coverage for All by 2030 has been developed by the European Patients' Forum in the context of our 2017 Campaign on Access to Healthcare for All. EPF's campaign calls on Member States and the EU to commit to a long-term vision where equity of access and universal health coverage is a reality for all patients in the EU.

This Roadmap aims to raise awareness of the gaps and barriers patients face in accessing healthcare, to elevate health on the political agenda of the EU and Member States, and to foster more EU cooperation to improve access to healthcare.

The Roadmap identifies the challenges that need to be addressed and proposes political steps and actions that EU decision-makers and

Member States need to take in order to achieve universal health coverage for all patients in the EU by 2030. This Roadmap also aims to contribute to the European Commission's mid-2018 strategy for the SDGs and the implementation of the 2030 Agenda for sustainable development.



The safety and **quality of healthcare** in the EU is unequal, and key aspects of patient centered healthcare are not implemented



There is a lack of appropriate resources being **efficiently invested** in healthcare



Too many patients in the EU are confronted to **financial hardship** as a result of healthcare costs



Organisational changes are needed to ensure the package of services covered by the healthcare system is tailored to the needs of patients and to promote better **coordination of care**



A majority of patients and informal carers are reporting **experience of stigma** while seeking or receiving healthcare

#### 3.2 How was this Roadmap developed?

The outstanding challenges and related recommendations that follow have been developed on the basis of EPF's definition of *Access*<sup>47</sup> which defines the 5 key aspects of access – *Adequacy*, *Accessibility*, *Affordability*, *Appropriateness*, and *Availability* – in order to better reflect the patients' perspective.

This Roadmap was developed in dialogue with EPF's membership and the wider health community, based on an inclusive working process. EPF's internal working group on access to healthcare<sup>48</sup> has supported the development of this Roadmap by providing valuable contributions throughout its advancement. Furthermore, the Roadmap has undergone extensive consultation with the wider EPF membership, board and secretariat, Members of the European Parliament<sup>49</sup> championing the five goals of the campaign and civil society organisations representing a number of groups vulnerable to



social exclusion in order to ensure that their specific needs and potential barriers to access are clearly set out.

### 3.3 Who is this Roadmap intended for?

This Roadmap is intended mainly for EU and Member State decision and policy-makers. The Roadmap serves as a guide to patients' concerns, unmet needs and outstanding challenges, and recommends actions to achieve universal health coverage for all.

While the organisation of healthcare is a national competence, the EU has a key role to play to improve access to healthcare for patients and to ensure the right to health stated in the EU charter of fundamental rights is implemented. Health is absolutely and unequivocally a core business of the EU, a view shared by the vast majority of EU citizens<sup>50</sup>. In light of the 2030 Agenda for sustainable development, there has never been a stronger case, or a more vital moment for Europe to work together to protect our health, and for this reason it is essential that this is not only to be maintained, but actually enhanced. Health protection and improvement is a great success story of the European Union and by facilitating closer cooperation, the EU has saved countless citizens' lives and contributed to their improvement.<sup>51</sup> For these reasons, we are confident and encourage the EU to continue to deliver results that make a tangible difference in the daily lives of its citizens and thus re-establish people's trust in its institutions.

### 3.4 How to use this Roadmap

EPF invites EU and Member State decision-makers to consider this roadmap and its recommendations when developing related policies and UN SDG implementation strategies, and to ensure a collaborative policy-making process with the involvement of civil society, including patient organisations.

We also invite other health stakeholders, such as organisations representing the whole range of healthcare professions, healthcare managers, industry sectors and civil society, to make use of the Roadmap in their work and consider their role in implementing relevant recommendations.

EPF will use this roadmap as a reference document for all our future activities on access to health. As we advance, this roadmap will be refined and realigned as needed and may be updated as and when we feel necessary together with our membership.

Furthermore, we invite our members to use it when advocating for improved patient access to high-quality health and related care to national policy-makers. A factsheet giving a snapshot of this Roadmap has also been developed as a tool for advocacy activities. We invite our members to use, share and disseminate the Roadmap and factsheet within their memberships.

## 4. Roadmap

### 4.1 Preamble

The European Patients' Forum:

1. RECALLS the Constitution of the World Health Organization<sup>52</sup> and its principle that “**health is a state of complete physical, mental and social well-being** and not merely the absence of disease or infirmity”;
2. RECALLS the 2000 Charter of Fundamental Rights of the EU<sup>53</sup>, which states that “Everyone has the right of access to preventive health care and the **right to benefit from medical treatment** under the conditions established by national laws and practices” (Article 35) and **prohibits discrimination** (Article 21);
3. RECALLS the UN Committee on Economic, Social and Cultural Rights General Comment No. 14 (2010) on the **right to health**<sup>54</sup>, which asserts that “[e]very human being is entitled to the enjoyment of the highest attainable standard of health conducive to living a life in dignity”;
4. RECALLS article 25 of the 2006 UN Convention on the Rights of Persons living with Disabilities<sup>55</sup>, which states that “persons with disabilities have the right to the enjoyment of the **highest attainable standard of health without discrimination** on the basis of disability”;
5. RECALLS article 168 of the Treaty of Lisbon<sup>56</sup>, which states that “**A high level of human health protection** shall be ensured in the definition and implementation of all Union policies and activities”, highlighting the scope within the Treaty to act;
6. RECALLS the UN 2030 Agenda for Sustainable Development (2015)<sup>57</sup>, which upholds **universal health coverage** as the key to sustainable health systems and reduction of health inequalities and ENCOURAGES civil partnership to address health challenges as an indivisible component of social, environmental and economic policies (2015);
7. RECALLS the 2013 Council conclusions on the “**Reflection process on modern, responsive and sustainable health systems**”<sup>58</sup>, which acknowledge the role of health for economic prosperity, highlight the importance of solidarity and access to universal health care, and encourage the endorsement of a “**health in all policies**” approach;
8. RECALLS the 2014 Council conclusions on the **economic crisis and healthcare**<sup>59</sup>, which call on Member States to **strengthen collaboration** and information exchange to improve access to quality healthcare services;
9. RECALLS the 2017 Commission Communication on establishing the **European Pillar of Social Rights**<sup>60</sup>, the 2017 Commission Recommendation on the European Pillar of Social Rights<sup>61</sup> and in particular the latter’s **Principle 16 on Health care**, which states that “Everyone has the right to timely access to affordable, preventive and curative health care of good quality”, expressing the EU commitment to put access at the core of the European social model;
10. RECALLS the 2014 Commission Communication on effective, accessible and resilient health systems<sup>62</sup> on the need for implementing EU-wide mechanism and methodology for **assessing, measuring and monitoring access** to reduce health inequalities;

11. RECALLS the 2016 Commission Communication on the Next steps for a sustainable European future: European action for sustainability<sup>63</sup>, which outlines a strategic approach for achieving **sustainable development** in Europe;
12. RECALLS the 2016 Council conclusions on EPC-Commission Joint Report on health care and long-term care in the EU<sup>64</sup> and the resulting joint report<sup>65</sup> on the challenges to **universal health care and long-term care services** in the context of an ageing society with proposals to address these through (1) governance reforms to improve evidence collection, accountability and administrative efficiency; (2) promotion of financial sustainability, and (3) strengthening structural efficiency, competition and transparency;
13. RECALLS the 2017 Council conclusions on A sustainable European future: The EU response to the 2030 Agenda for Sustainable Development<sup>66</sup>, which affirm the willingness of the EU Member States to implement the 2030 Agenda in close cooperation with partners and other stakeholders, urging the Commission “to elaborate, by mid-2018, an **implementation strategy** outlining timelines, objectives and concrete measures to reflect the 2030 Agenda in all relevant EU internal and external policies”;
14. RECALLS points 48 and 49 of the Resolution on the European Semester for economic policy coordination: Annual Growth Survey 2016<sup>67</sup>, which “Stresses the importance of being able to provide **equal access to healthcare services for all citizens**”;
15. REITERATES that the 2017 Annual Growth Survey outlines universal access to cost-effective public health and healthcare services as a key priority for reducing **health inequalities**<sup>68</sup>;
16. NOTES the recommendations of the 2017 Report of the Expert Group on Health Systems Performance Assessment<sup>69</sup> on the need to address inequity in access through country-tailored approach for measurement and assessment of the level of **integrated care delivery** to better serve the needs of patients and improve the health-related outcomes as per country-specific goals, values and needs;
17. RECALLS the 2017 Council conclusions on Encouraging Member States-driven Voluntary Cooperation between Health Systems<sup>70</sup>, encouraging Member States to explore the development of areas of **voluntary cooperation** to improve affordability, improve access to health technologies and increase the efficiency of health systems to ensure better outcomes for patients;
18. HIGHLIGHTS that public expenditure on health in the EU28 is approximately 8.7% of GDP and 15% of all **public expenditure**, with a projected increase of 0,9% p.p. of GDP by 2060 due to improved life expectancy but also increased co-morbidity and chronic disease burden<sup>71</sup>;
19. RECALLS that health is an indivisible component of **economic sustainability and growth**<sup>72</sup>;
20. RECALLS article 4.3 of the UN Convention on the Rights of Persons living with Disabilities (UN CRP), which states that “In the development and implementation of legislation and policies to

implement the present Convention, and in other decision-making processes concerning issues relating to persons with disabilities, States Parties shall **closely consult with and actively involve persons with disabilities**, including children with disabilities, through their **representative organizations**”<sup>73</sup>;

21. RECALLS the International Alliance of Patients’ Organizations’ Declaration on Patient-Centred Healthcare<sup>74</sup> and its principle on **patient involvement in health policy**, and EMPHASISES that the principle of involvement outlined in the UN CRP above should apply to patients also (in formulating policies and practices that concern patients).

## 4.2 Concerns

Note that the concerns and recommendations of this roadmap are not listed in any particular order.

Whilst recognising the efforts of the European Union to address pertinent healthcare challenges, the European Patients’ Forum nonetheless EXPRESSES CONCERN that:

1. **Underfunded healthcare services, insufficient and/or inadequate investment** are detrimental to timely access to quality care and health outcomes.
2. Too many patients in the EU are confronted with **financial hardship** as a result of healthcare costs, leading to increased health inequalities.<sup>75</sup> **Unaffordability of healthcare**, particularly of some **medicines**, has become an urgent priority for patients and carers.
3. There are persistent **multi-dimensional barriers to access** for patients across the EU at individual, provider and health system level.<sup>76</sup> Reasons behind high levels of reported unmet need and unequal experiences include but are not limited to unaffordable medicines and services, out-of-pocket payments, waiting times, geographical distance, fragmented care pathways, lack of coordination, corruption, inadequate use of healthcare budgets, lack of patient centeredness, socio-economic and cultural factors with considerable disparities in access within and across Member States.<sup>77, 78</sup> Patients also report paradoxical situations where healthcare is affordable but not in a timely way, and where appropriate care, diagnosis or appropriate medication is not available in their country. This shows that while affordability is essential, other components of access are also indispensable.<sup>79</sup>
4. The **safety and quality** of healthcare in the EU is **unequal**, and key aspects of patient-centred healthcare are not implemented.<sup>80</sup>
5. Patients and informal carers are reporting experiences of **stigma and discrimination** on the grounds of health status or other while seeking or receiving healthcare. This can result in some patients avoiding contact with the healthcare system, which can lead to delayed diagnosis and/or treatment and worse health outcomes. Stigma is a particularly important access barrier for some vulnerable groups, such as people who are homeless. Discrimination exacerbates health inequalities by placing some groups or individuals at a systematic disadvantage.

6. Achieving the ambitious SDG 3 target places high demands on the health workforce and requires substantive and strategic investments. Sufficient, motivated and well-trained health workers is a fundamental feature of universal health coverage. Many Member States are facing critical workforce shortages, and it is estimated that by 2020 there will be a shortage of 1 million health professionals in the EU.<sup>81</sup> The frontline workforce is overburdened, with nurses for example struggling with increasing administration and complex caring tasks. This means less time spent with patients, which can jeopardise the quality of care and patient safety. Shortages, which are due to a variety of factors, pose a significant challenge for EU Member States in view of the growing need for care.<sup>82, 83</sup>
7. According to recent estimates, on average 20% of health spending in OECD countries may be **inefficient or wasteful**.<sup>84</sup> Identifying and tackling genuinely wasteful and/or redundant spending, should be done at national, regional or local level and with the meaningful involvement of patients, and is one avenue to pursue towards quality of care and achieving universal health coverage.
8. In order to meet the needs of an **ageing population**, further consideration should be given to care for older people, including more community support and an enhanced role for nurses and other caregivers who play a crucial role in improving the quality of life of older people.
9. Patients with chronic conditions and their informal carers experience severe difficulties in accessing and remaining in employment. The resulting social exclusion often leads to health deterioration and increased need of medical attention.<sup>85</sup> An intrinsic and coherent **inter-sectoral collaboration and action for health** as well as the **political will** of systematically adhering to a **health in all policies** approach is also lacking.
10. Against this background, whereas it is evident that EU Member States face common problems in health which need common, collaborative action at EU level, the recent Commission White Paper on the Future of Europe<sup>86</sup> instead provided scenarios which envision a limited or no visible role or future **EU cooperation in the field of healthcare**. This is also contrary to the expectations of citizens.<sup>87</sup>

### 4.3 Recommendations for Providing access to quality of care

The European Patients' Forum URGES the EU institutions and Member States to recognise that patients everywhere in the EU, regardless of which country they live in or their country of origin, have the right to **equitable access to high-quality care**. Thus, we encourage policy-makers and the civil society to undertake actions to:

- Promote and implement **high-quality and appropriate care**, according to relevant standards, guidelines and best practices, as a means to improve health outcomes, patient experience, efficiency and effectiveness of health systems and as an intrinsic value in all future healthcare reforms;
- Recognise and provide **person-centred, holistic, integrated and participatory care and support** to patients with chronic conditions as a key aspect of healthcare quality;

- Support and empower **healthcare professionals** to provide high-quality care through adequate investment in **resources, education and training**;
- Ensure **public provision** of essential services so that patients do not have to rely on private provision;
- Ensure that **timeliness**, including timely and accurate diagnosis, is considered a vital dimension of quality of care<sup>88</sup>;
- Perform **health outcomes measurement**, including patient-reported outcomes (PROMs) and patient experience (PREMs) as a tool to support optimal use of resources and improve quality of care whilst enhancing value for money<sup>89, 90</sup>;
- Foster better **cooperation and interaction** between health care providers (e.g. hospitals, insurances, ...) and users of the health care system (patients) to ensure high-quality care;
- Encourage Member States to define and adopt a patient-centred **definition of access to quality care**, considering best practice and the patients' perspective, in order to ensure comparability of data<sup>91</sup>.

#### 4.4 Recommendations for Committing to sustainable investment in health

The European Patients' Forum URGES the EU institutions and Member States to commit to **invest sustainably in healthcare** based on outcomes and added value. Thus, we encourage policy-makers and the civil society to undertake actions to:

- Ensure sustainable investment in healthcare services and the health workforce in all Member States, **avoiding unwarranted cuts** in the healthcare budget (that result in financial hardship) and ensuring **adequate resources are employed appropriately**;
- Engage in **efficient health spending** - including investment in an effective health workforce which will in turn help increase the economy's production assets, productivity, while optimising the 'social dividend' by enabling people to remain healthy and active for longer, and limiting future costs of treating preventable diseases;
- Invest in the **healthcare workforce** to ensure sufficient personnel, resources and capacity to provide high-quality, person-centred healthcare;
- Secure an **increased budget for EU-level health collaboration** in the next **Multiannual Financial Framework (MFF)** with additional resources for the EU health programme to ensure the EU fulfils its health-related commitments emanating from the SDGs;
- Enhance the profile of health in Cohesion policy – linking **European structural and investment funds (ESIF)** to health status of the regions;
- Continue efforts to feature recommendations focusing on health access and quality of care more prominently in the **European Semester process**;<sup>92</sup> whilst proposing more significant and meaningful health and long-term care-related country-specific recommendations for Members States with more unmet needs and unequal patient experience in accessing healthcare;
- Adopt more **inclusive stakeholder involvement** and **improved consultative processes** in the European Semester process both at EU and national level;
- Invest in **effective health promotion** and **prevention measures** and **early detection** such as cost-effective screening programmes and invest the thus freed resources into improving the quality and accessibility of the healthcare system;



- Secure **long-term sustainable investment** in health promotion and prevention, and quality primary and long-term care provision for all patients, to foster inclusive and healthy societies which take advantage of enhanced employability, productivity and economic growth;
- Improve the ethical collection, interoperability, accessibility and comparability of decision-relevant health **data**, appropriately disaggregated (e.g. by age and gender), including **real-world data**, for result-oriented policy solutions which include processes for patient prioritised outcomes on disease management;
- Invest in evidence-based **chronic disease management programmes**, including self-management support and **integrated care**, in order to maximise patients' quality of life, reduce the disease burden, encourage concordance and optimise the use of healthcare resources;
- Carry out a **solid assessment of the efficiency and effectiveness** of spending in order to increase the return on health investments.”<sup>93</sup> In this respect, health technology assessment (HTA) procedures may contribute through the reassessment of existing technologies to support disinvestment of obsolete and ineffective ones;
- Develop a **labour policy** that considers the specific vulnerabilities of patients with chronic conditions and informal carers ensuring them **equal opportunities** to employment, adequate and flexible working conditions, and reasonable accommodation<sup>94</sup>;
- Invest in **housing support** for homeless patients, especially those being discharged from hospital after an intervention, through social prescribing, to ensure better health outcomes and fewer readmissions, according to EU best practices, which have been proved to result in 70% reduced hospitalisation costs<sup>95 96 97</sup>;
- Identify, with the involvement of patients and civil society, where corruption is an access barrier, and put in place appropriate policy responses to **tackle corruption** and appropriate sanctions; monitor corruption in healthcare, through appropriate indicators defined with stakeholders, including patients' organisations, while raising awareness on the evidence needed to report such practices;
- Address and tackle **inefficiencies and genuine waste in health systems**, including (low value or outdated) clinical care, overly bureaucratic management structures and ensure effective operational governance to accurately identify “waste”, by pinpointing what matters most for patients and to ensure **meaningful and systematic patient involvement** across the process;
- Ensure **transparency of healthcare decision-making** in order to make health systems accountable to their users, to support patient choice and to enable them to assess how – and how effectively – resources are being used and ensure that patients have access to comprehensive, unbiased and easily understandable **information** about the quality of care and its outcomes.

#### 4.5 Recommendations for Encouraging affordability of healthcare products and services

The European Patients' Forum URGES Member States and the healthcare industry to ensure the delivery of healthcare products and services that are **affordable for all**. Thus, we encourage policy-makers and the civil society to undertake actions to:

- Ensure an **adequate** level of **spending on health**;

- Ensure that **financial resources** and the distribution of spending on health reflects a country's **health needs** at national and sub-national levels, to ensure equal access to health care and reduce inequalities;
- As part of an overall approach to meaningful patient engagement in the life cycle of medicines, **involve patients in value assessment, pricing and reimbursement decision-making** in order to eliminate discrepancies between patients' unmet needs and what therapies are made available and reimbursed;
- Apply **health technology assessment** (HTA) procedures **more systematically**, with the involvement of patients as users of health services, to ensure healthcare expenditure is allocated to high-quality services and products for all patients/citizens;
- Ensure **transparency** with regards to pricing and reimbursement decisions and the basket of care covered by healthcare systems and insurances;
- Ensure that patients are effectively protected from **financial hardship** as a result of healthcare costs, including by limiting co-payments and ensuring full coverage of products and services needed;
- Make greater use of **pharmacists' competences** and patient-focused community pharmacy services to optimise the use of medicines, achieve better health outcomes and reduce the overall cost of health care;
- Ensure appropriate coverage for currently **undiagnosed, chronic and long-term conditions** including rare diseases and work together with patients' organisations to identify these unmet needs, whilst delivering awareness campaigns on diagnosis, mis-diagnosis and undiagnosed chronic and long-term conditions;
- Ensure that affordability of healthcare products and services is not negatively affected by **corruption**, with zero tolerance policies and sanctions;
- Explore **innovative solutions** for the **pricing of new healthcare technologies**, such as personalised medicines and advanced therapies, reflecting patients' needs and the different economic situations of EU Member States.

#### 4.6 Recommendations for Implementing access to a holistic range of health and related services

The European Patients' Forum URGES the EU institutions and Member States to enhance cooperation and undertake measures to improve **holistic health systems performance and access** to health and related care for patients. Thus, we encourage policy-makers and the civil society to undertake actions to:

- Implement **inter-sectoral action for health**, meaning collaboration between the health sector and other sectors, such as social, labour, economic and environmental sectors to eliminate inconsistencies, damageable competition and address policies and actions affecting health outcomes undertaken by sectors outside the health sector;
- Promote **prevention** policies which encourage healthy and active ageing to reduce chronic conditions prevalence and co-morbidities;
- Promote access to **universal healthcare** for all as a framework, priority and intrinsic value to future EU policies;

- Assess and promote **research** on how the effective coordination between systems generates more effective and efficient health coverage and systems;
- Improve **collaboration** within the healthcare system and among health care professionals, which has been shown to improve timely diagnosis and health outcomes;
- Develop comprehensive policies in a spirit of EU-wide cooperation to enhance the potential of **healthcare professionals** in specialist and primary care settings (including nurses, community pharmacists and allied professions) through appropriate training (including human rights' training) and incentives to optimize the continuum of care and improve accountability for patients' outcomes;
- Improve cross-sectoral collaboration and interoperability to enable the sharing of **complete patient information** for effective care;
- Identify what individual patients' needs are in order to tailor the basket of care appropriately (including physiotherapy, psychotherapy, dental care, etc.);
- Promote a **patient-centred** approach to structural and operational **reforms** of healthcare systems towards **integrated care** delivery, designed to best serve the needs of patients throughout the care pathway, including better healthcare provision for patients with complex needs through multidisciplinary collaboration;
- Ensure a holistic and **integrated care approach** to health and social services' structure at the system, financing and service delivery levels to enable patient groups including vulnerable groups to collaborate more systematically on health issues;
- Implement **organisational changes** and **innovative care solutions** (e.g. case management), including a more practical approach to health workforce planning, to improve patient centeredness of care and promote better coordination of care;
- Improve effectiveness of integrated care solutions through the adoption and widespread implementation of **digital technology** and eHealth to improve the evidence base for healthcare management and policy actions.

#### 4.7 Recommendations for Ending discrimination and stigma

The European Patients' Forum URGES the EU institutions and Member States to **end the discrimination and stigma** that patients face and make sure that no population is excluded. Thus, we encourage policy-makers and the civil society to undertake actions to:

- Ensure that the **right to equal treatment in healthcare**, regardless of any factor that could lead to discrimination, be truly implemented in healthcare;
- Ensure persons with chronic conditions are **protected from direct or indirect discrimination** on the basis of health status, similarly to persons with disabilities and **replicate best-practice and health status provisions** currently existing in non-discrimination law of some Member States<sup>98</sup> across the EU and at EU level;
- Reform laws and policies that restrict the **right to health care based on residence status**, and that punish the provision of humanitarian and other forms of assistance to people who are undocumented; and create firewalls that protect the confidentiality and privacy of all patients, by prohibiting the sharing of information between the health sector and immigration enforcement, without express consent of the patient;
- Step up actions to **raise awareness of discrimination** in the area of healthcare and of good practices that exist to tackle it;

- Ensure the **right to respect and to dignity in healthcare facilities** by integrating fundamental rights and non-discrimination principles in the training of healthcare professionals and improve their ability to provide informed, quality, appropriate care to culturally- and linguistically-diverse communities;
- Ensure the **right to information (about health rights and care) and support** by putting in place an action plan on **health literacy** for patients and their carers, with a focus on ensuring patients have access to high quality information in accessible formats;
- Facilitate access to the healthcare system by ensuring the **needs of all users are met**, e.g. by offering intercultural mediation, medical interpretation and sign language, and appropriate **social and psychological accompaniment** and support for vulnerable persons;
- Eliminate barriers to **programme adherence**, often experienced by patients in severe exclusion (e.g. chronic homelessness and Roma) who face difficulties in bonding with public services in general, and need additional support to understand treatment pathways and recall appointments, for example;
- Ensure that the disabling consequences of health conditions are **recognised** by formal disability assessment systems, and that patients with chronic conditions receive **adequate support** in a social protection and employment context, and recognition of their rights.

## 5. Towards an inclusive method of implementation

With this roadmap, EPF emphasises the importance and need to establish an inclusive and collaborative working process for the implementation of the UN SDGs in general and in particular the universal health coverage sub-target of the UN SDG on health.

This roadmap invites EU and Member States' policy and decision-makers to explore collaboration opportunities with other health stakeholders. Furthermore, EPF calls on future EU and national SDG implementation strategies to be developed in concert with the health community and to incorporate and reflect health aspects in all priority actions. This reflects the unequivocal interdependency between social, economic and environmental policies all of which are in one way or another, linked to health, which in turn improve access and health systems' performance. Consequently, greater and better access will also in turn reflect positively on the labour market, social inclusion and economic growth.

A successful sustainable development agenda requires partnerships between governments, civil society, academia and the private sector. UN SDG 17 – Partnerships for the goals - encourages such inclusive partnerships built upon principles and values, a shared vision, and shared goals that place people and the planet at the centre.

## 6. Conclusions

### 6.1 Roadmap conclusions

“Universal health coverage is a human right”. This was a welcome statement from the Director General of the World Health Organization, Dr Tedros Adhanom Ghebreyesus.<sup>99</sup> The EU and its national governments need to take urgent action to respond to unacceptable gaps, barriers and unmet access the healthcare needs faced by patients in Europe.

This Roadmap demonstrates that a fundamental change in Europe’s approach to healthcare access is required to reach the UN SDGs and achieve Universal health coverage for all by 2030 and ultimately significantly improve quality of life and care of patients with long-term chronic conditions, reduced mobility and dependent on care.

EPF’s Roadmap illustrates that a particular focus on the following over-arching principles are required in order to achieve universal health coverage for all by 2030:

- ✓ The right to health
- ✓ Leaving no one behind
- ✓ Person-centredness
- ✓ Inter-sectoral action for health
- ✓ Integrated care
- ✓ Open dialogue with all relevant stakeholders, including patients
- ✓ Adequate and sustainable investment in healthcare and the health workforce
- ✓ Transparency on the cost of healthcare
- ✓ Respecting quality of care standards and their upward convergence
- ✓ Alignment of national development, social and health policies
- ✓ Policy coherence across SDGs
- ✓ Sufficient means for SDG implementation
- ✓ Enhanced SDG monitoring and accountability
- ✓ Paradigm shift driven by political will and social solidarity

Health is a fundament of Europe’s wealth and is absolutely and unequivocally core business for the EU. In light of the 2030 Agenda for sustainable development, there has never been a stronger case, or a more vital moment for Europe to work together to protect our health, and for this reason it is essential that this is not only maintained, but continuously improved. Health protection and improvement is a great success story of the European Union and closer cooperation and collaboration between member states will empower and equip countries with the necessary tools and peer support to achieve EPF’s vision of a Europe where all patients with chronic conditions have equal access to high quality, patient-centred health and related care.

### 6.2 Monitoring and Accountability

A robust follow-up and review mechanism for the **implementation of the new 2030 Agenda for Sustainable Development** will require a solid framework of indicators and statistical data to monitor progress, inform policy and ensure accountability of all stakeholders.

Tracking progress on the UN SDGs requires the collection, processing, analysis and dissemination of decision-relevant data. Member States have recognized the crucial role of strengthened data collection and capacity-building and committed to addressing the data gap, and where possible, global monitoring should be based on comparable and standardized national data obtained through well-established reporting mechanisms.

The launch of The Sustainable Development Goals Report 2017<sup>100</sup> is accompanied by the launch of the Global SDG Indicators Database<sup>101</sup>, which presents country level data and global and regional aggregates compiled through the UN System and other international organizations. However, some key areas of access are not adequately measured and addressed by existing indicators. With respect to SDG 3, the EU SDG indicator set largely relies on Eurostat data and indicators.<sup>102</sup> EPF calls on Eurostat to **expand the indicators on universal health coverage indicators**, using those that depict the various components of universal health coverage, including out-of-pocket expenditure on health care, health care coverage, indicators geared to measuring access to quality chronic condition care and management, specific information on groups that are vulnerable to discrimination in healthcare and health inequalities and patient-centred indicators on access, taking into account EPF's recommendations for indicators on access,<sup>103</sup> in addition to the self-reported unmet need for medical examination and care indicator already identified.

EPF calls for accurate and **transparent monitoring and reporting** and emphasises the proactive and fundamental role of civil society in ensuring that monitoring measures reflects the needs that are considered by patients to be essential in attaining universal health coverage.

The 2030 Agenda makes some important references to **state-citizen accountability**, participation, and respecting human rights, committing to engage in a participatory and transparent follow-up and review framework. EPF calls for improved monitoring of access to healthcare and more country-specific monitoring of challenges and ways to address them.

Governments have the primary responsibility for follow-up and review, at the national, regional and global levels, in relation to the progress made in implementing the Goals and targets over the coming fifteen years.<sup>104</sup>

Follow-up and review processes will be voluntary and country-led, considering different national realities. The outcome from national level processes will be the foundation for reviews at regional and global levels, given that the global review will be primarily based on national official data sources.

As national ownership is key to achieving sustainable development, EPF urges its members, particularly national umbrella patient organisations, to engage with their governments, holding them accountable. EPF also invites members to collaborate with patient groups and health organisations across disease areas in organising national parliamentary meetings.

At European level, EPF will engage as a member of **SDG Watch Europe**<sup>105</sup>, an EU-level, cross-sectoral CSO alliance of NGOs whose goal is to hold governments to account for the implementation of the 2030 Agenda for Sustainable Development.



### 6.3 Next Steps

Equity of access will continue to be a high priority for EPF subsequent to our 2017 campaign on universal health coverage for all.

Building on our definition of “access” (2016), we will continue to contribute to the development and implementation of policies and strategies that maximise access and reduce health inequalities across the EU.

EPF will support the 2030 Agenda focusing primarily on the UN SDG to ensure healthy lives and promote well-being for all at all ages, engaging in related initiatives and building on the outcomes of our 2017 campaign, aiming to contribute to the European Commission’s mid-2018 strategy for the UN SDGs and the implementation of the 2030 Agenda.

EPF aims to elevate the priority of health at EU level, by increasing collaborative work with the health community and Institutions, reinforcing the role of health and its cross sectoral importance in the framework of the SDGs.

EPF will use this roadmap as a reference document for all our activities on access to health.

To review the progress made in reaching the actions proposed by our Roadmap, EPF will organise three events between now and 2030. With 10 years to go till the 2030 goal, EPF will organise a conference on Universal health coverage in 2020, in follow-up to the 2017 Campaign, to review multi-stakeholder progress. In 2025, EPF will organise a countdown meeting and political review of the implementation of the UN SDGs and in 2030, EPF will organise a satellite event to mark what has been achieved in Europe and to showcase accomplishments. These milestones will be an opportunity to review progress made, highlight achievements, sustain momentum, encourage further action, identify gaps and actions that are lagging behind and re-focus efforts as needed.

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This Roadmap received funding under an operating grant from the European Union's Health Programme (2014-2020). The content of this Roadmap represents the views of the author only and is his/her sole responsibility; it cannot be considered to reflect the views of the European Commission and/or the Consumers, Health and Food Executive Agency or any other body of the European Union. The European Commission and the Agency do not accept any responsibility for use that may be made of the information it contains.