

Defining and Measuring Access to Healthcare: the Patients' Perspective

Position Statement

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2 Introduction

2.1 BACKGROUND AND POLICY CONTEXT

Disparities in access to healthcare predate the financial crisis in Europe, but against a background of austerity measures and falling healthcare spending in many Member States since 2009, inequalities have been made worse.¹ Access to care is affected by austerity policies in response to the economic crisis, such as cuts in healthcare budgets and in insurance coverage, increased fees and co-payments, and cuts in social protection measures. All this comes at a time of even greater demand for healthcare and social support.

At the same time, healthcare systems are facing increasing demands as a result of demographic change. As the population ages, the number of patients with chronic diseases is growing. Many diseases become more prevalent with age and though some are preventable to some extent, others are not. Patients who developed a chronic disease at a younger age are also living longer, thanks to modern medical treatments. Patients with chronic diseases develop specific needs which the healthcare systems need to adapt to.

Health inequalities carry a significant economic as well as personal cost. In the current policy debate, the economic argument “health is wealth” is now widely accepted. Investment in health is an investment in our fundamental values, in social cohesion, and in economic development. Reducing health inequalities is crucial for the overall health and wealth of society.

In recent years there has been renewed focus at EU level on health inequalities and access through the following initiatives:

- The European Parliament motion for resolution on health inequalities in the EU, adopted in 2011, in which patients and older patients were recognised as a group with specific needs
- The European Commission report on health inequalities in 2013
- The European Commission communication “On effective, accessible and resilient health systems”, which highlighted that having a common methodology in the EU to monitor access would be an important step forward in tackling health inequalities
- The EU conference “Health in Europe, Making it Fairer” on 18 March 2014

¹ See OECD- health at a glance 2013 <http://www.oecd.org/els/health-systems/Health-at-a-Glance-2013.pdf> And Eurofound (2014), Access to healthcare in times of crisis, Publications Office of the European Union, Luxembourg. http://www.eurofound.europa.eu/sites/default/files/ef_publication/field_ef_document/ef1442en.pdf

- In 2014 the Commission set up an expert group on Health System Performance Assessment²
- The preliminary opinion of Expert Panel on Effective Ways of Investing in Health on “access to health services in the European Union” published in September 2015.³

In addition, over the last few years the European Semester has provided recommendations on healthcare from a financial perspective to several EU Member States. However no mechanism has been put in place yet to consult civil society on the recommendations, in particular to ensure access to healthcare and the cost of health inequalities are taken into account in this process when providing recommendations on health spending.⁴

2.2 EPF'S VISION ON ACCESS

Patients' access to healthcare is a key priority for the European Patients' Forum, as highlighted by the second goal of our strategic plan 2014-2020:

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.

Health equity is part of our core values: we believe every patient should have equitable access to patient-centred high-quality health and social care. We strive to fight the disparities existing within the EU in relation to access to and standards of care for chronic diseases and/or long-term conditions.

Breaking down access barriers was at the heart of the EPF campaign during the 2014 EU elections, aiming to ensure that EU institutions put this issue higher on the agenda for the new legislature (2014-2019).⁵

Access to healthcare is a basic human right and one of the fundamental principles of European health systems, together with safety, quality, and equity.⁶ Treatment should be accessible to every patient who needs it, not only to those who can pay. Regrettably, this is not a reality for all.

² http://ec.europa.eu/health/systems_performance_assessment/policy/expert_group/index_en.htm

³ http://ec.europa.eu/health/expert_panel/opinions/docs/010_access_healthcare_en.pdf

⁴ See more information on this in the joint EPF EPHA letter on the Mid-term review of Europe 2020:

http://www.eu-patient.eu/globalassets/news/joint_epha_epf_letter_final_eu2020.pdf

⁵ http://www.eu-patient.eu/globalassets/campaign-2014-eu-elections/epfmanifesto_backgroundpaper3_nov13.pdf

⁶ Access to healthcare is recognized as a right in the charter of fundamental rights of the European Union, and as a fundamental principle in the Council Conclusions on Common values and principles in European Union Health Systems.

More information on our work on access can be found here: <http://www.eu-patient.eu/whatwedo/Policy/access-to-healthcare/>

2.3 WHY IS A DEFINITION OF ACCESS NEEDED FROM THE PATIENTS' PERSPECTIVE?

The given picture of access to healthcare through existing indicators often fails to reflect the experience of patients and to give a comprehensive picture. Access is a multi-dimensional concept and currently there is not one universally accepted definition.

Patients diagnosed with chronic diseases and long-term conditions are in a vulnerable position due to the effects of the illness itself, which are often very serious and disabling. These effects also have a physical, psychological, and emotional impact on the person, their family, and their immediate environment. Patients are dependent on having timely access to safe, high quality, integrated, and continuous healthcare, and other related support services.

Patients are more frequently in contact with the healthcare system and have expertise on gaps and barriers in accessing healthcare. They often have a global perspective from primary to secondary health and social care, encompassing their needs for various services and healthcare products. Patient organisations have collective expertise in identifying access barriers and good practices.

Therefore, it is crucial that decision makers and researchers, when designing or adopting indicators, take into account the patients' perspective on what access to healthcare means.

In order to encourage the definition of more accurate indicators that reflect the experience of EU patients, we believe it is important to arrive at a common definition of access which identifies the dimensions of access to healthcare that are crucial to patients.

A patient-led definition is essential in order to set objectives to improve access to healthcare in the EU that are relevant to patients who are affected and bear the cost of health inequalities and access barriers.

This paper is also supporting the European Patients' Forum contribution to the Patient Access Partnership's (PACT) work on a definition of access as well as on indicators. The Patient Access Partnership is a patient-led network which was co-founded by EPF and NPO (the National Patient Organisation of Bulgaria) and brings together the patients, the public health community, industry, and policy-makers to move forward on solutions to access that really work for patients and address the current barriers and inequities.⁷

⁷ <http://www.eupatientaccess.eu/>

Objective of this position paper:

- To provide a patient-led perspective on what access to healthcare means to decision makers and other health stakeholders, including academia
- To foster change in the way access is measured in the EU (whether at EU level or in Member States) and ultimately contribute to the setting of appropriate EU policies to tackle access barriers
- To contribute a patients' perspective to current EU debates on access and indicators, including to the Patient Access Partnership work on indicators.

2.4 CONSULTATION PROCESS

The first draft of this paper was developed with input from the EPF access working group.⁸ Following this, it has undergone two rounds of consultation by the EPF membership in 2015.

3 Definition of Access: the patients' perspective

3.1 THE DEFINITION

A detailed definition of access was provided by Penchansky and Thomas (1981) and subsequently readapted by the Patient Access Partnership (PACT).⁹ This definition is based on 5 As - Adequate, Accessible, Affordable, Appropriate, and Available - as the defining aspects of access.

The EPF access working group discussed this definition, adapted it, and specified further the meaning of each of the 5 As' definitions in order to better reflect the patients' perspective and to clarify areas which were subject to interpretation.

⁸ The EPF access working group contributes to shaping EPF's vision and activities in this area from the patients' perspective. It will also strengthen the evidence base on health inequalities and access. More information at: <http://www.eu-patient.eu/About-EPF/structure/epf-working-groups/>

⁹ Penchansky R, Thomas JW "The concept of access: definition and relationship to consumer satisfaction" Med Care. 1981 Feb; 19(2):127-40. <http://www.ncbi.nlm.nih.gov/pubmed/7206846/>
Patient access partnership (PACT)definition: http://www.eupatientaccess.eu/page.php?i_id=19

Available¹⁰: Healthcare, including specialised services and every service conducive to good quality health care, should be available to all patients. Patients need to have access to health care in their country, as the primary responsibility for access is national. This includes responsibilities at regional, local, and hospital level. The European Union also has responsibilities in terms of access, for example encouraging universal access, building more cooperation for quality care and research¹¹, and for cross border healthcare. Availability also means that the necessary resources are available for health at national and EU level. Healthcare supply and resources (for example medicines, equipment, healthcare professionals...) should be sufficient and the necessary infrastructures and organisation to provide suitable care should be in place. Existing EU funds such as the Structural and Investment Funds should be used in greater measure and more effectively for health purposes.¹²

Adequate: Adequacy refers to quality of care. Care should be constantly adapted to the needs of patients. To this end, ongoing dialogue between individual patients and their healthcare team is essential. Appropriate informed consent procedures need to be in place to ensure patients are informed and involved in decisions regarding their care. It requires patient involvement at individual level through shared decision making and adequate mechanisms to capture patients' feedback and at collective level in health policy decision making. Standard of care or good clinical practices are available for some diseases and can be a good indicators of adequacy.¹³

Accessible: From the patients' perspective, this means that treatment is accessible throughout all stages of their care, from preventive/health promotion services and early diagnosis through all treatments, including non-medical support. Geographical circumstances should not be barriers to access.¹⁴ It encompasses access to information: patients should have clear information on what care and support is available, as well as the standards in place. Care should be accessible in a timely way. Patient involvement in healthcare policies and decision making is also a prerequisite to ensure care is fair and accessible for all.

¹⁰ The definition of the PACT states "whether services are available in the first place" and refer to physical and timely availability.

¹¹ For example with specific responsibilities in the field of rare diseases

¹² According to the European Commission 2007-2013 report, 1.5 % of total Structural Funds only are used for direct planned health sector investment

http://ec.europa.eu/health/health_structural_funds/docs/watson_report.pdf

¹³ However it is important to note that clinical guidelines can sometimes be restricted and not include alternative therapies.

¹⁴ Examples of such circumstances include living in remote areas, medical deserts, small and isolated countries or regions.

Appropriate¹⁵: Service should be relevant to the health needs of different populations or groups, as healthcare needs to be inclusive. EPF has developed specific recommendations to make healthcare more inclusive for all patients in its paper “Healthcare for all: tackling discrimination”.¹⁶

Affordable: Affordable means that people can access healthcare services without suffering financial hardship¹⁷. Affordability is both an issue at individual level for the patient (direct cost/out of pocket payment), and at system level. Affordability is not just a question of money but also of the personal or “human” costs. Chronic conditions have psychosocial impacts. Illness impacts people’s quality of life, education, employment, and integration into society. The financial and human cost of chronic and long-term condition needs to be taken into account in discussions around healthcare financing and in defining what is affordable for the patient. National healthcare systems need to finance equitable healthcare at an acceptable and fair cost for the patient. As “acceptable” and “fair” are subjective criteria (they mean different things for different stakeholders), affordability requires good governance, accountable, and timely and transparent systems of decision making for pricing and reimbursement, where patients are meaningfully involved. It requires early dialogue between health products¹⁸ developers, regulators, and health technology assessment bodies.¹⁹

3.2 ACCESS TO WHAT HEALTHCARE?

Patients need access to the whole continuum of care, in a life course approach. This should encompass prevention (primary, secondary, and tertiary), diagnosis, disease management, and palliative care.

Patients with a chronic disease need a **holistic approach** to their healthcare. As defined by World health Organization (WHO), “Health is a state of complete physical, mental and social well-being and not merely the absence of disease”²⁰. Holistic means access to psychological support and encompasses affordable access to other services, for example dental and oral health. There is a strong interlink between mental health and physical health (both for patients with mental health conditions who develop physical conditions and conversely) yet this link is not always addressed by health policies, and mental health services are not

¹⁵ Appropriateness also refers to the quality of meeting the need of various groups in the PACT definition.

¹⁶ <http://www.eu-patient.eu/globalassets/policy/anti-discrimination/epf-position-discrimination-jan2015.pdf>

¹⁷ This part of the definition from the PACT was kept in the EPF definition.

¹⁸ Including medicines, medical devices and other health technologies

¹⁹ In this definition, we consider affordability from the patients’ perspective. While we are aware affordability for healthcare system is an important question, this is not in the scope of this paper.

²⁰ Preamble to the Constitution of the World Health Organization

always accessible and affordable.²¹ It also means taking into account multiple aspects in any patients' chronic disease management, including nutrition.²² Multidisciplinary, integrated care is necessary to diagnose and suitably manage many chronic conditions.

Patients need access to healthcare services in the widest sense, including access to other **services in connection with their personal health**: they require access to public healthcare services²³, to social care services, community care, and support. They need health to be taken into account in various area of their daily life, such as patient-friendly educational systems and workplaces.

Access to **healthcare products and innovation**, whether medicines, technologies, or medical devices, must be taken into account. This includes access to research and ensuring clinical trials are accessible to patients. The right frameworks also need to be in place to allow for off-label use and compassionate use of medicines when necessary. In addition, ensuring that eHealth, mHealth, and personalised medicine are developed with equity of access and patients' needs at their core is fundamental for the future of healthcare.

Patients need access to various **supporting tools and services**: access to peer support is essential and patient organisations play an important role here. Patients need access to information and support to enable them to achieve an appropriate level of health literacy, as well as tools and resources for self-help and self-care. Furthermore, patients need to be involved in decision making regarding policies that affect access to healthcare.

Having a **choice** about the management of chronic and long-term conditions as part of shared decision making with healthcare professionals is a key element. Though there is often the perception that patients' demands would result in additional costs and treatment, literature shows that patients' demands are usually appropriate and can often result in less treatment rather than more. For example, a recent study showed that cancer patients rarely ask for unnecessary tests or treatments.²⁴ Shared decision-making can lead to patients choosing less invasive therapeutic options – one of the largest systematic reviews on the topic shows that use of decision aids led to fewer patients choosing elective surgery, and fewer opting for certain screening tests.²⁵

²¹ See for example N.Roman "Dividing the inseparable: The link between physical and mental health in the EU's second Health Programme", thesis in Maastricht University. http://www.mhe-sme.org/fileadmin/Position_papers/Study_on_the_interlink_between_mental_and_physical_health_July_20_14.pdf

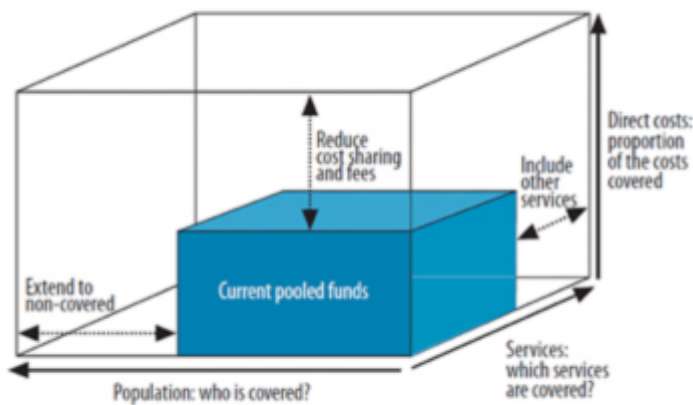
²² http://www.eu-patient.eu/globalassets/press/pressreleases/patient_perspectives_on_nutrition_.pdf

²³ This refers to publicly funded healthcare services, by contrast with private healthcare which refers to services not provided by the government.

²⁴ <http://oncology.jamanetwork.com/article.aspx?articleid=2108852>

²⁵ http://www.cochrane.org/CD001431/COMMUN_decision-aids-to-help-people-who-are-facing-health-treatment-or-screening-decisions

3.3 UNIVERSAL, EQUITABLE HEALTH COVERAGE



In EPF’s perspective, in order to achieve universal healthcare coverage, patients should be the first concern in healthcare.

The concept of universal health coverage, defined and promoted by the WHO, is often used as a measure of success for access to healthcare. In 2005, all WHO Member States made

Figure 1: Source World Health Organization 2013, *The world health report 2013: research for universal health coverage*.

the commitment to achieve universal health coverage.²⁶ The UN sustainable development goal 3 on healthy alive also set as a target to “achieve universal health coverage, 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” within the horizon of 2030.²⁷

In 2014, the European Commission declared in its Communication on effective, accessible resilient health systems that “Healthcare coverage is universal or almost universal in all Member States; however, some people from disadvantaged backgrounds are still excluded from adequate health coverage.”²⁸ Experiences of patient organisations in the EU, across disease areas, show that barriers to access are not exclusively affecting populations from disadvantaged groups, and that barriers are present in wealthier countries as well.

Three dimensions have to be taken into account to truly achieve universal health coverage:

- **Who is covered:** in EPF’s perspective, this should include all patients in the EU, including undocumented migrants
- **What services are covered:** as detailed in part 2.2 of this paper, in EPF’s perspective patients need access to a wide range of services
- **The proportion of costs covered:** this is another key component in the current context where many patients are faced with increased co-payments.

²⁶ World Health Organization 2013, the world health report 2013: research for universal health coverage.

²⁷ <http://www.un.org/sustainabledevelopment/health/>

²⁸ http://ec.europa.eu/health/healthcare/docs/com2014_215_final_en.pdf

The International Association for Patient Organizations has defined seven principles of universal, equitable healthcare which EPF strongly supports:²⁹

- Accessibility
- Patient-centredness and equity
- Choice and empowerment
- Quality
- Partnership and collaboration
- Sustainability and the value of healthcare
- Accountability and transparency

4 Measurement of access: current approach at EU level and gaps

Various indicators are currently used at EU level to measure and monitor access and health inequalities in the EU.

A key indicator is “**the self-perceived unmet medical needs**” item in the EU SILC instrument which gives information on living conditions in the EU.³⁰ Participants of the EU SILC survey are asked whether they had unmet medical needs over the past 12 months. This indicator provides information on barriers to access including prices, waiting lists, and problems related to physical access (distance and lack of means for transportation). However this data has some limitations - for example, it doesn't give specific information on access for vulnerable groups, including patients with chronic or long-term conditions.

Another way access and health inequalities are measured and monitored in the EU is through the **OECD health statistics**³¹, which are published annually. Some examples of the indicators include:

- Health insurance coverage for a core set of services
- Waiting times
- Out-of-pocket expenditure on health as a percentage of total expenditure on health.

The **Eurobarometer** provides other indicators on obstacles that impact access, for example corruption in healthcare. This includes indicators on bribery and additional payments (informal payments).³²

²⁹https://www.iapo.org.uk/sites/default/files/files/UHC_principles.pdf

³⁰<http://ec.europa.eu/eurostat/web/microdata/european-union-statistics-on-income-and-living-conditions>

³¹<http://www.oecd.org/els/health-systems/health-data.htm>

³²http://ec.europa.eu/public_opinion/archives/ebs/ebs_397_en.pdf, p85-95

The **Expert Panel on Effective Ways of Investing in Health** provided further details of indicators used at EU level and flagged several other limitations in its opinion on access to health services. These included the fact that the indicators don't always cover all Member States and that they cannot be broken down by subgroups.³³ EPF provided input to the consultation.³⁴

There is an important and comprehensive body of indicators in the EU regarding health inequalities that arise from social and health determinants, as illustrated by the **European Commission report on health inequalities**.³⁵ Examples of indicators include comparisons of life expectancy and mortality rates across EU Member States, indicators for major health determinants (e.g. percentage of male and female individual who smoke, employment data), or self-reporting of poor health.

In addition, the **European Health Consumer Index** (EHCI) produced annually by the company Health Consumer Powerhouse, provides information on equity of healthcare systems and on accessibility (access to primary care doctors, access to specialists).³⁶ However, some indicators of the index have limitations - for example, the EHCI draws conclusions on equity of healthcare solely based on the share of public spending in total healthcare spending. There is no indicator related to co-payments. Moreover, the accessibility indicator is based on a limited number of items (for example, cancer therapy is chosen as the unique case study). While it is a recognised benchmark and can provide a good general overview on healthcare, the conclusions of the EHCI do not always match with the experience of patients regarding access or the impact of the crisis.

But from the patients' perspective, some key areas of access are not addressed by existing indicators:

- Specific information on access to healthcare and other connected services for patients with chronic, long-term conditions is lacking: as chronic conditions are considered a key challenge for all EU healthcare systems, more indicators geared toward measuring access to quality chronic disease care and management are needed

³³ Expert Panel on effective ways of investing in health preliminary opinion "Access to health services in the European Union", September 2015. See page 109 for the summary of the limitation of indicators and Annex 3 page 139-142 for a list of indicators used by the EU

³⁴ <http://www.eu-patient.eu/globalassets/policy/access/epf-comments-on-expert-panel-opinion-on-access---final.pdf>

³⁵ http://ec.europa.eu/health/social_determinants/docs/healthinequalitiesineu_2013_en.pdf

³⁶ See for example the 2014 report:

http://www.healthpowerhouse.com/files/EHCI_2014/EHCI_2014_report.pdf

- There is a lack of specific information on groups that are vulnerable to discrimination in healthcare and health inequalities³⁷
- There are no patient-centred indicators on access that are developed with patients, to measure dimensions that patients have themselves defined as relevant.³⁸

5 Recommendations for indicators on access

1. Indicators and studies should be developed taking into account the dimensions and components of access highlighted by the definition in this paper.
2. While there is a good body of research on health inequalities in the European Union, it tends to focus on health determinants and prevention. Further indicators on access to healthcare services and support for chronic and long-term disease management are needed in order to truly reflect and ultimately improve the situation of patients.
3. Researchers should assess the impact of health inequalities and access barriers in other areas of a patient's life, including employment.
4. To achieve a truly patient-centred healthcare system, patients and their organisations must be involved in defining indicators on access and health system performance assessment. More research should be encouraged in this area, notably through EU funds such as the public health programmes. Patient organisations should be involved meaningfully in these projects, according to existing good practices/recommendations.³⁹
5. The absence of common definitions for terms, such as chronic diseases or disability, is an obstacle to having comparable data across Europe. We believe the European Commission has a role to play in ensuring collaboration towards providing inclusive common definitions of these terms.
6. For disease areas that have agreed standards of good clinical practice, these standards should be considered as key components to measure the "appropriate"

³⁷ We identify many of these groups in EPF position paper on discrimination in healthcare: http://www.eu-patient.eu/globalassets/policy/anti-discrimination/epf-position-discrimination-jan2015_final.pdf

The European Parliament has also identified specific groups in its motion for resolution on health inequalities ³⁸ <http://iapo.org.uk/sites/default/files/files/IAPO%20Patient-Centred%20Healthcare%20Indicators%20Review.pdf>, p 4. The report notes that there are many indicators on access, but that "The majority of the literature discussed in the results did not demonstrate patient involvement in the development of these indicators"

³⁹ The Value+ project has developed one model of meaningful patient involvement in projects, along with recommendations and practical tools to support this, although others exist in specific disease areas. See for example the outcomes of the FP7 project PatientPartner (www.patientpartner-europe.eu) and the PHP project Value+ (www.eu-patient.eu/Initatives-Policy/Projects/EPF-led-EU-Projects/ValuePlus)

dimension of access. Standards should be developed with the involvement of patient organisations to ensure that they consider treatment alternatives that have added value from a patients' perspective.

7. Various groups have been identified at EU level as particularly vulnerable to health inequalities, including patients with chronic conditions.⁴⁰ Specific groups who are vulnerable to discrimination in healthcare are well-identified as well. Data collected through indicators should enable Member States to monitor the situation of these groups as to access to healthcare.
8. Indicators and policy recommendations on informal payments should take into account the perspective of patients. Indeed in some countries, informal payments have been formalised into items that patients pay for legally but that do not correspond to any extra service or bring added value to patients' care. These forms of legalised informal payments are an obstacle to affordability of healthcare.
9. As recommended in the Riga Roadmap⁴¹, we call on the EU to:
 - Develop common tools to measure access, monitor outcomes, and assess performance in the health sector as part of the European Semester evaluation, including a tool to measure patients' experience in a way that reflects their needs and priorities
 - Develop tools and a common approach to measurement of patient/person-centredness as a key aspect of quality of healthcare under the EU Health System Performance Assessment framework.

6 Conclusion

Access is a high priority for the European Patients' Forum and we are committed to work in partnership with the EU institutions and stakeholders to realise our vision, which is that all patients with chronic and/or lifelong conditions in the EU have access to high quality, patient-centred equitable health and social care.

⁴⁰ The European Parliament as identified disadvantaged migrant groups and people belonging to ethnic minorities, children and adolescents, people with disabilities, with a special focus on mental illness, patients diagnosed with chronic diseases or conditions, older people, people living in poverty, and people affected by alcoholism and drug addiction as vulnerable.

T;<http://www.europarl.europa.eu/sides/getDoc.do?type=REPORT&reference=A7-2011-0032&language=EN>

⁴¹ The Riga roadmap is available at: <http://rigahealthconference2015.eu/wp-content/uploads/2015/08/Riga-roadmap-download-FINAL.pdf>



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