

EPF comments on the preliminary opinion of the expert panel on Effective Ways of Investing in Health on ‘Access to health services in the European Union’

06/11/2015



1. Forward

The following paper is based on the European Patients' Forum's positions to date on access to healthcare and patient empowerment, and on the comments received through a consultation with our membership on the expert panel. The expert panel opinion was sent to EPF members and to the EPF Policy Advisory Group with a call for comments. The EPF comments were submitted to the expert panel on 6 November.

2. An introduction to access to health services in the European Union

Section on access, line 340: EPF strongly believes the principle of patient involvement outlined in the Council Conclusions is also highly relevant in access discussions, as it aims at ensuring care is patient-centred, that patients should be involved in their treatment, and that systems should be accountable and transparent.

Reference:

Council Conclusions on Common values and principles in European Union Health Systems, 2006
<http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=OJ:C:2006:146:0001:0003:EN:PDF>

3. Financial resources are linked to health need

General comment: Overall, EPF strongly agrees with the message provided in this chapter that healthcare spending should be linked to a population's needs. In our perspective, better spending on healthcare shouldn't always mean containing costs. In some cases, it may be necessary to spend the same amount, or even more – but to spend differently and spend better. Cutting healthcare budgets is counter-productive and will not contribute to the sustainability of health systems in the long run.

Specific comments:

3.1 SECTION 1.1. ENSURING AN ADEQUATE LEVEL OF SPENDING ON HEALTH

Policy response, line 1038: In our perspective, several other areas for recommendation need to be explored by the expert panel:

The first area is the value of low-tech innovation: the term “innovation” should be understood to include “low-tech”, or “simple” innovations. This would include the design of health and social care systems and how care is delivered. Innovation does not need to be expensive and it should be valued for its potential to improve quality of services, quality of care, and the quality of life: people-focused rather than technology-focused innovation. For example, the Operational plan of the European Innovation Partnership on Healthy and Active Ageing from 17 November 2011 acknowledges innovation in all its forms, whether technology, process, or social innovation.

References:

<http://www.eu-patient.eu/globalassets/policy/ageing/ageing-epf-response-integrated-final.pdf>

https://ec.europa.eu/research/innovation-union/pdf/active-healthy-ageing/steering-group/operational_plan.pdf

Another area where EPF would recommend further exploration is the lack of patient involvement in therapeutic innovation. In our perspective, this is an important obstacle to ensure investment in research that meet the needs of patients. Patient involvement in research has been shown to have various benefits including better direct applicability of the research to patients, integration of researchers’ theory expertise with patients’ real-world knowledge and experiences, balancing scientific excellence with social and cultural relevance, higher trust and acceptance of research results, and promotion of research results by patient organisations.

Recent documents such as the European Commission staff working paper SWD (2014) 216 final/2, the 2013 WHO report Priority Medicines for Europe and the World, reports from the Belgian EU presidency on Innovation and Solidarity, and the 2014 Council conclusions on Innovation for the benefit of patients (2014/C 438/06) all raised an important question: *what is valuable innovation, and how should it be adequately incentivised and rewarded?* In order to ensure that innovation that brings real value to patients and to society is encouraged, patient involvement needs to be adopted as a strategic approach and integrated across the entire innovation chain, starting with the setting of research priorities, which should be driven by patients’ identified needs. Developing a framework for patient involvement is a main recommendation in the WHO report.¹

¹ Kaplan et al., (2013) Priority Medicines for Europe and the World 2013 update, Chapter 8, “New approaches to promoting innovation”.

References:

Patient engagement in research: a systematic review, BMC Health Services Research 2014, 14:89
doi: 10.1186/1472-6963-14-89

<http://www.biomedcentral.com/1472-6963/14/89>

Brett J, Staniszewska S, Mockford C, Herron-Marx S, Hughes J, Tysall C, Suleman R. A systematic review of the impact of patient and public involvement on service users, researchers and communities. Patient. 2014;7(4):387-95. doi: 10.1007/s40271-014-0065-0.

<http://www.ncbi.nlm.nih.gov/pubmed/25034612>

Value + project: http://www.eu-patient.eu/globalassets/projects/valueplus/doc_epf_handbook.pdf

EPF also suggests further exploration of the role of patient-centred healthcare as a solution towards ensuring sustainability of healthcare while meeting the need of patients. Patient-centredness is increasingly recognised as a core component of high quality care. In addition, patient-centred care models have been shown to be cost-effective as well as to increase patient satisfaction and, often, clinical outcomes.

References:

S Jayadevappa and S Chhatre (2011) "Patient-centred care – a conceptual model and review of the state of the art", Open Health Services and Policy Journal, 4, 15-25

K Parsi, CJ Chambers, AW Armstrong (2011), "Cost-effectiveness analysis of a patient-centered care model for management of psoriasis, J Am Acad Dermatol, Aug 9

LE Olsson, E Hansson, I Ekman, J Karlsson (2009) "A cost-effectiveness study of a patient-centred integrated care pathway", J Adv Nurs, Aug; 65(8):1626-35

3.2 SECTION 1.2. ENSURING THE DISTRIBUTION OF SPENDING MEETS REGIONAL HEALTH NEEDS

Line 1108: Another important policy response could be explored here: according to the European Commission 2007-2013 report, only 1.5 % of total Structural Funds are used for direct planned health sector investment. We suggest the structural funds should be part of the objective to ensure that spending meets regional and population health needs.

Reference:

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

4. Chapter 2: Service are affordable for everyone

General comment: All patients should have access to healthcare without suffering financial hardship. We concur with the assessment that lack of affordability is a major obstacle for access to healthcare. We also agree with the principle that access should be based on needs not means. In our view, affordability is linked to healthcare system financing and Member States have a responsibility to ensure their healthcare is provided at a fair and acceptable cost for patients. Affordability requires good governance, accountable, and timely and transparent systems of decision-making for pricing and reimbursement, where patients are meaningfully involved. It also requires early dialogue between health products developers, regulators, and health technology assessment bodies.

Specific comments:

4.1 SECTION 2.3. THE ROLE OF VHI IN ADDRESSING GAPS IN PUBLICLY FINANCED COVERAGE

Line 1607: Regarding the impact of private health insurance for patients, it is important to note that patients often face barriers to access these insurances. Common barriers for patients' access to these services include age and certain chronic diseases categorised as "pre-existing conditions". For example, in Italy chronic and recurrent diseases as well as mental illnesses are some of the conditions usually excluded from individual insurance policies. In the UK, long term chronic diseases are on the list of conditions usually excluded from voluntary health cover (moratorium underwriting). In EPF's perspective, these practices are discriminatory.

Reference:

Mossialos, E, S Thomson, and al. Voluntary health insurance in the European Union. World Health Organisation, 2004.

Policy response (line 1619): EPF would recommend taking into account the financial and human cost of chronic and long term conditions in discussions around healthcare financing and in defining what is affordable for the patient. The disease burden is compounded by specific vulnerabilities that patients and their families face due to illness, including dependence on timely access to safe, high quality healthcare and the needed support services; reduced or inability to work and the resulting loss of income and risk of poverty;

the direct and indirect costs of illness; and social discrimination and stigma. Chronic disease is often a direct cause of health inequalities for patients and their families.

- **Mental health:** The Operational Plan of the European Innovation Partnership on Active and Healthy Ageing states that depression affects 1 in 5 of older people living in the community and 2 in 5 living in care homes. Furthermore, mental health problems are often linked to physical chronic disorders, which have a major negative impact not only on quality of life but also on the costs of healthcare as well as costs to society outside the health sector.
- **Alzheimer's and dementias:** the annual direct and indirect costs of Alzheimer's and other dementia diseases are around €130 billion in the EU27 (€21,000 per patient). Over half of these costs (56%) are borne by informal care. The UN Political Declaration on NCD recognises dementias as a major chronic disease.
- **Parkinson's disease:** There are more than 1.2 million people living with Parkinson's in Europe and the incidence is forecast to double by 2030, primarily as a result of the ageing population. The estimated annual total cost of Parkinson's disease is €13.9 billion.
- **Musculo-skeletal disorders:** Chronic diseases such as rheumatoid arthritis and back pain prevent thousands of people from working across the EU, costing European economies up to €240 billion a year.
- **Rare diseases:** across the EU, approximately 7,000 rare diseases (defined as affecting not more than 5 per 10,000) are estimated to affect 6-8% of the population, equating to around 29 million people. Rare diseases are a significant public health issue and are recognised as an area where action at EU level has significant added value. This has resulted in a number of initiatives and programmes, such as European Reference Networks and Centres of Expertise, which may potentially be transferable to other types of chronic diseases.

References - Key evidence in various diseases area:

- Dementia in Europe Yearbook, Alzheimer Europe, 2008, p.67-70.
- European Commission Communication on a European Initiative on Alzheimer's disease and other dementias (2009)
- Political Declaration of the High-level Meeting of the General Assembly on the Prevention and Control of Non-communicable Diseases (NCD), 19-20 September 2011, para. 18
- European Parliament resolution on Mental Health of 19 February 2009
- Consensus document on brain research, J. Olesen, M Baker, T Freund, M Di Luca, J Mendlewicz, I Regan, M Westphal -EBC – J Neurol Neurosurg Psychiatry, 2006.
- ER Dorsey et al "Projected number of people with Parkinson disease in the most populous nations, 2005 through 2030", Neurology 68(5) p.384-6 (30 January 2007).
- A Gustavsson et al, "Cost of disorders of the brain in Europe 2010", Eur Neuropsychopharmacol. 2011 Oct; 21(10)
- Fit for Work, EUROSTAT (2009). See <http://www.fitforworkeurope.eu/msd-backgroundunder.htm>

5. Chapter 3 Services are relevant, appropriate, and cost effective

General comment: EPF supports the recommendations related to providing stronger information to patients and to improving the training of healthcare professionals. We also agree with the assessment that healthcare spending needs to be cost effective. However, we have specific comments on some of the policy responses proposed by the expert panel opinion to achieve this goal.

Specific comments

Line 1703 to 1745: While EPF welcomes the emphasis of this chapter on appropriateness and relevance of services, for patients it raises a key question: who defines what is relevant, appropriate, and cost effective? In our perspective, these parameters should be defined with the patients as part of a patient-centred healthcare model. Patients can contribute directly to ensuring healthcare services are cost-effective and sustainable through patient empowerment. Patient empowerment is "a multi-dimensional process that helps people gain control over their own lives and increases their capacity to act on issues that they themselves define as important." Collective empowerment is "a process through which individuals and communities are able to express their needs, present their concerns, devise

strategies for involvement in decision-making, and take political, social, and cultural action to meet those needs.”² A key component for patient empowerment is health literacy. Well-informed, health-literate people are more discerning about their health, make more informed choices and decisions, and are more likely to seek earlier diagnosis and recover faster. Conversely, people with low health literacy have poorer self-management skills, higher hospitalisation rates, and more emergency visits. They have poorer overall health, and more inappropriate, less effective use of healthcare resources.³

References:

K Parsi, CJ Chambers, AW Armstrong (2011), “Cost-effectiveness analysis of a patient-centered care model for management of psoriasis, J Am Acad Dermatol, Aug 9

LE Olsson, E Hansson, I Ekman, J Karlsson (2009) “A cost-effectiveness study of a patient-centred integrated care pathway”, J Adv Nurs, Aug; 65(8):1626-35

WHO/Europe 2013, “Health literacy: the solid facts”

http://www.euro.who.int/_data/assets/pdf_file/0008/190655/e96854.pdf

Luttrell et al., “Understanding and operationalising empowerment”, Overseas Development Institute, Working Paper 308, November 2009

Line 1896: In the section entitled over-medicalisation (“disease mongering”), the expert opinion refers to two studies (Moynihan and Cassels 2005, Moynihan, Henry 2006). In our view, further evidence needs to be taken into account.

We agree that menopause is not a disease; however, it brings with it fluctuation of hormone levels which in turn change risk and protective factors for certain diseases in women. One example is cardiovascular diseases in women. Women are protected through their hormones from CVD, but once past menopause their risk increases. CVD is the main cause of death in women in all countries of Europe. CVD is still largely considered a male disease and some health systems fail to recognize the seriousness of CVD in women.

Regarding osteoporosis being a risk factor rather than a disease, we wish to refer to the report by the WHO scientific group on the assessment of osteoporosis at primary health care level which states that *“Following the publication of the report of a WHO Study Group meeting on Assessment of fracture risk and its application to screening for postmenopausal osteoporosis, osteoporosis has been recognized as an established and well-defined disease*

² Joint Action PaSQ (www.pasq.eu) definition, adapted from Luttrell et al., “Understanding and operationalising empowerment”, Overseas Development Institute, Working Paper 308, November 2009 and deepening our Understanding of Quality improvement in Europe (DUQuE); <http://www.duque.eu/>

³ WHO/Europe 2013, “Health literacy: the solid facts”.

that affects more than 75 million people in the United States, Europe and Japan (1). Osteoporosis causes more than 8.9 million fractures annually worldwide, of which more than 4.5 million occur in the Americas and Europe (Table 1.1). The lifetime risk for a wrist, hip or vertebral fracture has been estimated to be in the order of 30% to 40% in developed countries – in other words, very close to that for coronary heart disease. Osteoporosis is not only a major cause of fractures, it also ranks high among diseases that cause people to become bedridden with serious complications. These complications may be life-threatening in elderly people. In the Americas and Europe osteoporotic fractures account for 2.8 million disability-adjusted life years (DALYs) annually, somewhat more than accounted for by hypertension and rheumatoid arthritis (2), but less than diabetes mellitus or chronic obstructive pulmonary diseases (Fig. 1.1). “

We would recommend to the Expert Group to encourage health systems to address the need for prevention of age-related diseases early on in order to avoid, as in the case of osteoporosis, expensive hip fractures in older people, rather than focusing on “medicalisation” in this context. We agree with the WHO report that managing disabilities in an ageing society is a matter of prevention and care. In our view, it would be in the interest of the Expert Group to point out that in order to tackle the chronic disease burden in an ageing population, it is important for health systems to invest more in prevention and if possible, address risk factors early on to prevent chronic diseases from developing.

References:

<http://www.ehnheart.org/cvd-statistics.html>

WHO scientific group on the assessment of osteoporosis at primary health care level, Summary Meeting Report Brussels, Belgium, 5-7 May 2004 <http://www.who.int/chp/topics/Osteoporosis.pdf>

Women and Health, “Today's evidence, tomorrow's agenda 2009, WHO

Line 1964: The European Patients' Forum would like to emphasise that many HTA agencies do not involve patients in HTA Assessment or only involve patients in a very limited way. There is increasing evidence of the benefits of patient involvement in HTA. Patients experience and expertise are key in selecting patient relevant outcomes in the scoping phase of HTA, and in providing patient evidence during the HTA process. For example, patients can identify limitations in published research especially as regards patients' preference and quality of life. They can share their experience with current available treatment options and experience with new options, as well as the impact of disease on quality of life.

Therefore it is not only important to support uptake of HTA informed decisions, but also to improve HTA processes in the EU.

References:

Facey K, Boivin A, Gracia J et al. Patients' perspectives in HTA: a route to robust evidence and fair deliberation. *Int J Tech Ass in Health Care*. 2010;26:334-340

Patient involvement in Health Technology Assessment in Europe: Results of EPF Survey, 2013 - <http://www.eu-patient.eu/globalassets/projects/hta/hta-epf-final-report2013.pdf>

Line 1974: Effective patient decision aids should be more widely applied and shared, but they are one part of the process of shared decision-making. Health professionals should be trained in shared decision-making, including communication skills and use of decision aids. Evidence indicates that when patients are meaningfully involved in the decision process, this results in better health outcomes, better patient experience and potentially lower costs as patients often choose less interventionist approaches to treatment.

References:

Stacey et al. (2014) "Decision aids for people facing health treatment or screening decisions" Cochrane review. <http://onlinelibrary.wiley.com/doi/10.1002/14651858.CD001431.pub4/abstract>

"Video as patient decision support" Report on a study carried out in collaboration among the Department of Orthopaedic Surgery at Gentofte Hospital, the foundation Trygfonden, Danish Regions and the Danish Society for Patient Safety. May 2014. <http://patientsikkerhed.dk/media/7658/PatientDecisionSupport%20kopi.pdf>

Coulter A, Parsons S and Askham J (2008) "Where are the patients in decision-making about their own care?" WHO Policy brief.

6. Chapter 4 Well-equipped facilities are within easy reach

General comment: In EPF's perspective, availability of services is a key dimension of access. Therefore, we welcome the focus and key recommendations of this chapter.

Specific comment:

Line 2027: Another example is the issue of "medical deserts" in France: these are areas where there is a lack of healthcare professionals. When this issue is not actively addressed, "medical deserts" become a form of discrimination for patients living in such areas.

Reference:

“ Démographie médicale: repartition des médecins sur le territoire: Enjeux pour l'accès aux soins et la sécurité des usagers » by the Collectif Interassociatif sur la Santé

http://www.leciss.org/sites/default/files/101117_DOSSIER_DesertsMedicaux_Cahier1.pdf

7. Chapter 5 There are enough health workers, with the right skills, in the right place

General comment: In EPF's perspective, an efficient public health workforce, equipped with the right skills and with sufficient capacity to carry out activities effectively, is essential for the quality, safety, and accessibility of healthcare throughout the EU. While we support the recommendations and policy responses proposed in this chapter, EPF strongly believes that patients can play a key role in identifying healthcare service needs, including the appropriate skills and competences needed for high-quality healthcare. Patients live with their condition every day, learn to manage it, and to navigate the health system to get the care they need. Therefore, they should be involved in developing training schemes for healthcare professionals.

Specific comments:

Line 2429: A key issue which EPF believes needs to be further addressed by the expert panel is the need for healthcare professionals to receive adequate training and have the right skills to support patients in the management of chronic diseases, including multimorbidities. In our perspective, healthcare professionals have a key role to play in supporting patients' health literacy and their participation in shared decision-making. This is essential for both access to care and quality of care. The EMPATHIE study explored the role of healthcare professionals in patient empowerment; a key finding was that attitudes and lack of skills form a major barrier to patients' empowerment and involvement in the healthcare context. An overwhelming majority of the stakeholders consulted agreed that it would be feasible to establish a set of core skills for patient-centred care at EU level. This skill set would be based on a needs assessment from the patient perspective, which could be used as a basis for a transferable core training curriculum. (EMPATHIE WP4 survey and interview results, not in the public domain).

References:

Coulter A, Parsons S and Askham J (2008) "Where are the patients in decision-making about their own care?" WHO Policy brief

<http://www.who.int/management/general/decisionmaking/WhereArePatientsinDecisionMaking.pdf>

EMPATHiE (Empowering patients in the management of chronic diseases) final summary report, 30 September 2014 http://ec.europa.eu/health/patient_safety/docs/empathie_frep_en.pdf

Policy response, line 2469: The feasibility of developing a non-disease-specific core set of skills and attitudes (competences) for patient-centred care, including communication and listening skills, adapting to different health literacy needs, shared decision-making and other ways to involve patients, should be explored at EU level, including a needs assessment from the patient perspective. This could add value to the development and updating of educational curricula in the Member States.

8. Chapter 6: Quality medicines and medical devices are available at fair prices

General comment: EPF welcomes and echoes the call to change the process for funding and reward of innovation, and for more transparency on cost of Research and Development. We also agree with the need to collect further data on use of medicines and medical devices. We believe that more transparency and accountability is needed in pricing and reimbursement decisions on medicines. However, we also believe that in order to assess accurately the value of innovation, involvement of patients is essential, as their perspective of what is valuable is often different from that of medical professionals, researchers, or industry. Patient involvement in HTA processes is also essential to achieve that goal.

Specific comments:

8.1 SECTION 6.1 MEDICINES

Line 2527: While the opinion supports the uptake of cost-utility analysis, it is important to also acknowledge the potential limitations of QALYs and DALYs that have been raised in literature. For example, the limits in accounting for all the benefits of a health intervention or accounting for the fact that different patients may have different preferences as regards outcomes should be explored. HTA should consider a wide range of evidence including patient evidence.

References:

Sarah J. Whitehead and Shehzad Ali, Health outcomes in economic evaluation: the QALY and utilities Br Med Bull (2010) 96 (1): 5-21. doi: 10.1093/bmb/ldq033 First published online: October 29, 2010 <http://bmb.oxfordjournals.org/content/96/1/5.full>

Michael Drummond, Rosanna Tarricone, Aleksandra Torbica, Assessing the Added Value of Health Technologies: Reconciling Different Perspectives, Value in Health Volume 16, Issue 1, Supplement, January–February 2013, Pages S7–S13
<http://www.sciencedirect.com/science/article/pii/S1098301512041587>

Line 2581: While we agree with the assessment that the issue of pricing is essential, for patients the affordability of medicines also depends on reimbursement decisions.

Line 2695: EPF agrees that adherence is a major issue. However, rather than blaming patients, adherence needs to be tackled by developing more concordant prescribing through shared decision-making, and better multi-disciplinary patient support for self-management and medicine use, especially in cases of multiple chronic conditions and polypharmacy.

Reference:

EPF position paper “adherence and concordance” (March 2015) http://www.eu-patient.eu/globalassets/policy/adherence-compliance-concordance/adherence-paper-final-rev_external.pdf

Line 2791: In our perspective, transparency in national authorities’ decisions on pricing and reimbursement should also be required. Transparent and objectively verifiable criteria are needed, as well as good governance and accountability.

Policy response, line 2842: Good practices in adherence support based on concordance, and involving pharmacists and nurses, as well as doctors, should be identified, implemented, and integrated into the care pathway. The platform of the Innovation Partnership on Active and Healthy Ageing could be used to develop and share good practices.

8.2 SECTION 6.2 MEDICAL DEVICES

Line 2899: The practice of reprocessing and reusing single use devices can pose safety issues (problem of inadequate cleaning and decontamination, potential for healthcare acquired

infections); therefore we would recommend caution in promoting reprocessing as a means to improve access. Reprocessing should only be allowed with appropriate frameworks and procedures in place to ensure patients safety.

References:

http://ec.europa.eu/health/scientific_committees/emerging/docs/scenihr_o_027.pdf

Outcome of the first public consultation on the reprocessing of medical devices, synthesis report, European Commission: http://ec.europa.eu/health/medical-devices/files/guide-stds-directives/synthesis_en.pdf

Line 2967: Patient involvement in procurement may also improve the process. Evidence exists in the field of haemophilia for coagulation factor concentrates: countries that hold a centralised tender with a legal framework where patients and physicians are meaningfully involved, purchase the same medicinal products for a cheaper price compared to countries where all of these conditions are not met.

Reference:

B. O'Mahony, D. Noone ,and L. Prihodova, Survey of coagulation factor concentrates tender and procurement procedures in 38 European Countries Haemophilia Volume 21, Issue 4, pages 436–443, July 2015

Line 2990: EPF recognises that eHealth has the potential to improve patients' access but we also note that in some cases technology is developed without adequate focus on the needs of end-users. Therefore, when encouraging cooperation on development of eHealth technologies we believe a strong emphasis should be placed on end-users involvement (including patients), to ensure these technologies meet the needs of patients.

Reference:

Josip Car and al, The Impact of eHealth on the Quality & Safety of Healthcare, A Systemic Overview & Synthesis of the Literature, Report for the NHS Connecting for Health Evaluation Programme, March 2008, p380 <https://www1.imperial.ac.uk/resources/32956FFC-BD76-47B7-94D2-FFAC56979B74/>

9. Chapter 7 People can use services when they need them

General comments: The European Patients' Forum welcomes the recommendations on timely access and waiting times in this chapter, as these are often cited as important obstacles for patients. In a survey carried out in the new member states, 49 percent of respondents felt that waiting times had worsened since joining the EU.

Specific comments:

Line 3222: Another key issue that needs to be further explored for patients' timely access to treatment is that of screening and diagnosis. Early diagnosis, followed by timely treatment, is crucial to ensure good health outcomes and quality of life for patients. Early diagnosis and timely treatment also helps patients avoid deterioration and complications that require complex medical interventions that burden both the patient and the healthcare system.

10. Chapter 8: Services are acceptable to everyone

General comment: EPF strongly welcomes the focus on acceptability (but see note below) of services for everyone, and on user experience. In our perspective, this is an essential dimension of access. But in our perspective, ensuring that services meet patients' needs requires more than carrying out user experience surveys; it requires the use of qualitative research to dig "behind the numbers". Patient involvement in the design of healthcare services is also needed. Only the patient sees his/her whole journey through the healthcare system, so involving patients in the designing of healthcare systems results in services that meet the real needs of patients. The right methodology is crucial: patient experience is not limited to patient satisfaction surveys and it serves as a signal to what is occurring (both good and bad) in the system. So there is realisable value in involving patients in the assessment, planning, designing, implementation, continuous evaluation, and improvement of healthcare systems. In practical terms, this means involving patients' organisations (repositories of multiple individual patient experiences) at the policy and provider levels. Continuity is also vital: one-off consultations are unlikely to achieve the necessary systemic changes.

A note on terminology: The EPF internal working group on patient empowerment, comprising patient representatives, discussed the concept of acceptability in a recent meeting and unanimously preferred the terms "patient-centred" or "person-centred" to the word "acceptable". We note also that at WHO (2006) the term is actually "acceptable/patient-centred" and refers to "health care which takes into account the

preferences and aspirations of individual service users and the cultures of their communities”.

References:

Minutes of the EPF empowerment working group of the meeting of 29 April 2015 (unpublished)

Quality of care : a process for making strategic choices in health systems. WHO, 2006.

http://www.who.int/management/quality/assurance/QualityCare_B.Def.pdf

Patient Empowerment conference report, European Patients’ Forum, pp18-20 <http://www.eu-patient.eu/globalassets/campaign-patient-empowerment/pe-conference-report.pdf>

11. Access for Roma, undocumented migrants and people with mental health problems

General comment: EPF strongly welcomes the focus of this part of the report on underserved population groups. We concur with many of the policy responses proposed. EPF had made recommendations in this area in our position paper on discrimination in healthcare, which was published in 2014. In line 3811, the report suggests “user involvement in the design and provision of accessible services” and we believe this is crucial to ensure healthcare responds to the need of different groups and would recommend that this should be part of the policy responses. We also welcome the reference to intersectionality as a report by the EU Fundamental Rights Agency has demonstrated that multiple discrimination is an important issue.

It is important to note that recent research has also looked at the cost of exclusion of undocumented migrants from healthcare.

References:

“Cost of exclusion from healthcare: the case of migrants in an irregular situation”, European Union Agency for Fundamental Rights, 2015 http://fra.europa.eu/sites/default/files/fra_uploads/fra-2015-cost-healthcare_en.pdf

European Union Agency for Fundamental Rights “Inequalities and multiple discrimination in access to and quality of healthcare”, March 2013 http://fra.europa.eu/sites/default/files/inequalities-discriminationhealthcare_en.pdf

Healthcare for all” European Patients’ Forum position paper on Discrimination in healthcare, December 2014
http://www.eu-patient.eu/globalassets/policy/anti-discrimination/epf-position-discrimination-jan2015_final.pdf

FEANTSA, “Health and Well-being for All – Holistic Health Services for People Who Are Homeless” 2013,
<http://www.feantsa.org/spip.php?rubrique24&lang=en>

12. Ensuring equitable access: EU and Member State responsibilities and responses

General comment: EPF concurs with the assessment that the EU has a crucial supporting role to play in improving access to healthcare. We have also identified that there is a strong need for new indicators to better monitor access. Our experience is that the experience of patients is not always reflected by current indicators. For example, this was very visible regarding indicators on the consequences of the financial crisis.

In our perspective, to improve the quality of monitoring of access, and ultimately of policy responses to access issues, patient-centred indicators are needed. Patients with chronic and long term conditions 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 care, encompassing their needs for various services and healthcare products. Patient organisations have collective expertise in identifying access issues and good practices. Therefore, it is crucial that decision makers and researchers, when designing or adopting indicators, take into account the patients’ perspectives on what access to healthcare is. A key study in this area is the International Alliance of Patients’ Organizations’ patient-centred healthcare indicators review, which concluded that many indicators on patient-centred healthcare did not involve patient involvement. As a result, these indicators do not consider several aspects of patient-centredness or healthcare that are crucial to patients.

Reference:

International Alliance of Patients’ Organizations’, Patient-centred Healthcare Indicator Review:
<http://iapo.org.uk/sites/default/files/files/IAPO%20Patient-Centred%20Healthcare%20Indicators%20Review.pdf>

Line 4291: Indicators should be developed to measure patients' experiences in a way that reflects their needs and priorities.

13. Other comments

As regards other policy responses to improve access, we would like to refer to the Riga Roadmap. The Roadmap was adopted following the conference “Universal Health: Investing in Health and Wellbeing for All”, held in Riga on 28-29 June 2015 and building on the Vilnius Declaration of November 2013, which called for action in the areas of health promotion and disease prevention; universal access to high-quality people-centred health services; and ensuring health systems are evidence-based and grounded in common European values of solidarity, high quality and equity. The signatories of the Roadmap are the European Patient’s Forum (EPF), the European Generic and Biosimilar medicines Association (EGA), the European Federation of Pharmaceutical Industries and Associations (EFPIA) and the European Public Health Alliance (EPHA). The Roadmap sets out key objectives and actions to realise the principles of promotion, prevention, protection and participation in European health systems, and many of its recommendations are highly relevant to this paper.

Reference:

<http://rigahealthconference2015.eu/wp-content/uploads/2015/08/Riga-Roadmap-download-FINAL.pdf>