



# **BENCHMARKING ACCESS TO HEALTHCARE IN THE EU**

**Report of the  
Expert Panel on effective ways of  
investing in Health (EXPH)**

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## EXPERT PANEL ON EFFECTIVE WAYS OF INVESTING IN HEALTH

(EXPH)

### Opinion on Benchmarking Access to Healthcare in the EU

The EXPH adopted this opinion by written procedure on 13.12.2017 after public hearing on 11.10.2017

### About the **EX**pert Panel on effective ways of investing in Health (**EXPH**)

Sound and timely scientific advice is an essential requirement for the Commission to pursue modern, responsive and sustainable health systems. To this end, the Commission has set up a multidisciplinary and independent Expert Panel which provides advice on Effective Ways of Investing in Health (Commission Decision 2012/C 198/06).

The core element of the Expert Panel's mission is to provide the Commission with sound and independent advice in the form of opinions in response to questions (mandates) submitted by the Commission on matters related to health care modernisation, responsiveness, and sustainability. The advice does not bind the Commission.

The areas of competence of the Expert Panel include, and are not limited to, primary care, hospital care, pharmaceuticals, research and development, prevention and promotion, links with the social protection sector, cross-border issues, system financing, information systems and patient registers, health inequalities, etc.

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### SUMMARY

Faced with growing evidence that some groups within European Union Member States have been unable to achieve access to necessary healthcare, the European Union has committed to action to reduce levels of unmet need, most recently as an element of the European Pillar of Social Rights. In response, the Expert Panel on Effective Ways of Investing in Health has been requested to propose a series of quantitative and qualitative benchmarks for assessing progress in reducing unmet need for healthcare and to discuss means by which EU funds or other mechanisms might be used to improve access to healthcare.

A first step is to define need for healthcare. This is the ability to benefit from it, meaning that the individual in question has a condition that causes him or her to be in less than good health but also that there is a treatment available that can improve their health, whether curative, life-sustaining or enhancing, or merely palliative. While recognising that there may be clinical reasons, such as low levels of cost effectiveness, for denying treatment in the face of limited resources, treatment should never be withheld on moral grounds.

In practice, however, there are many challenges involved in measuring unmet need for particular interventions, precluding its routine use. Consequently, a pragmatic solution involves the use of survey data in which individuals are asked whether they have experienced a need for healthcare but were unable to obtain that care. These data are collected throughout the European Union annually in the Survey of Income and Living Conditions (EU-SILC), with subsidiary questions that ask about the reasons for unmet need. The report of the Panel recognises that this approach has a number of limitations, and also that there are other sources of data that provide insights into the extent to which you need for healthcare is being met, including comparative data on outcomes related to healthcare, but for the present, the EU-SILC data are the only timely and comparable source of information available across all Member States.

Using this measure, the Panel draws attention to persisting evidence of relatively high rates of unmet need in some Member States, and some groups within them.

The Panel notes that, consistent with the political objective of achieving convergence within the European Union, there is a strong argument for setting a target for unmet need that is close to that already achieved by the most privileged group within the best performing Member State. However, given the very differing starting positions, the Panel considers that this is, for the present time, unrealistic. It is beyond the scope of the Panel to propose a precise target for reduction in unmet need, given that this will require the commitment of financial and other resources. Instead, the Panel has proposed a mechanism for setting such a target. This involves setting a benchmark of the median value achieved by the best performing Member States, with the expectation that those Member States not yet achieving it should narrow the gap by a given percentage, which might be around 50%, over a defined period of time, which might be three years. Such a target would be ambitious, requiring a significantly faster rate of reduction and has been achieved in recent years in many Member States but, in our view, would be achievable.

The Panel was also asked to identify second level indicators. Taking a pragmatic approach, based on the availability of data, it proposes that this should follow the questions that are included in the EU-SILC data. These provide information on affordability, availability, and acceptability of health services. The Panel did, however, note the importance of developing additional sources of data that can be collected regularly to provide more detailed insights into the levels, patterns, and determinants of unmet need for healthcare across the European Union.

The Panel was requested to identify qualitative measures of unmet need. This is particularly challenging, given the many and diverse reasons for unmet need for

healthcare, both among and within Member States. The Panel was not convinced that a standard reporting system was appropriate. Rather, it was recommended that each Member State identify those groups that are most likely to be disadvantaged, according to factors such as age, gender, education, ethnicity, or employment status, analyse the appropriate data, and prepare a report on the level and pattern of unmet need among disadvantaged groups, accompanied by recommendations for action. The Panel also note the value of shadow reports produced by civil society organisations in other areas and encourages the production of such reports.

Finally, the Panel reviews the scope for using European Union funds to improve access to healthcare. It notes that, as the problems facing each Member State differ, as well as the extent to which each of them is eligible for different forms of support. However, it notes that there are many opportunities for using vehicles such as Structural Funds, research funds, and European Reference Networks.

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### 1. BACKGROUND

During the economic turbulence of recent years, it has become clear that some groups within society have been unable to obtain the healthcare they require. Longstanding barriers to access have been exacerbated by the financial crisis, stimulating an active debate in many parts of Europe about how to respond.

In 2015 the five Presidents' report set out a new direction for Europe, including a stronger focus on social performance (Juncker, Tusk et al. 2015). They made clear that Europe's ambition should be to earn what was termed a 'social triple A'. The current Commission has taken a series of actions on access to good-quality healthcare; the following are some of the most relevant examples:

- In the European Semester the Annual Growth Surveys, which set out the EU priorities to boost growth and job creation for the coming year, have increasingly acknowledged the importance of access to healthcare. This has given it greater importance and visibility in the European Semester process and in the resulting recommendations to Member States and has been accompanied by growing interest in inequalities more generally, but especially in health.
- The Expert Group on Health System Performance Assessment promotes discussions between EU Member States and international organisations on methodologies and tools to assess the performance of health systems; it has recently published a report on quality of healthcare (OECD 2016) and is expected to focus attention on access to care over the next year.
- The Expert Panel on Effective Ways of Investing in Health, in its opinion on access to health services of 2016, showed that rates of unmet need for health care was an increasing problem in the EU and set out options for how to maximise the added value of EU action on access to healthcare (Expert Panel on effective ways of investing in Health 2016).
- On 26 April 2017 the Commission presented its Communication and Recommendation on the European Pillar of Social Rights. It aims to serve as a compass for a renewed

process of both economic and social convergence, towards better living and working conditions. The Commission tabled also the proposal for an Interinstitutional Proclamation of the European Pillar of Social Rights to be adopted by the Commission, the Council, and the Parliament, which is expected to be adopted by the end of 2017.

- The principles and rights enshrined in the Pillar are structured around three categories: equal opportunities and access to the labour market, fair working conditions as well as social protection and inclusion. They focus on how to tackle new developments in the world of work and society at large so as to deliver on the promise of the Treaties of a highly competitive social market economy, aiming at full employment and social progress. One of the 20 principles of the Pillar is that everyone has the right to timely access affordable, preventative and curative care of good quality.
- The European Pillar of Social Rights is accompanied by a 'social scoreboard', which will monitor the implementation of the Pillar by tracking trends and performances across EU countries in 12 areas - one of which is healthcare (unmet need for medical care) - and will feed into the European Semester of economic policy coordination. The scoreboard will also serve to assess progress towards a social 'triple A' for the EU as a whole.

## **2. TERMS OF REFERENCE**

The Expert Panel on effective ways of investing in Health is requested to provide its views on Benchmarking Access to Healthcare by:

1. Proposing a quantitative benchmark/target on access to healthcare based on an indicator of unmet need for medical care. A target for the EU and a target, which can be adapted to the context of each Member State should be proposed;
2. Proposing a qualitative benchmark, based on principles and policy levers that can be operationalised, to improve access to healthcare in the EU Member States;
3. Discussing the possible utilisation of EU funds and/or other mechanisms to support the improvement of access to healthcare according to the benchmarks proposed.

### **3. OPINION**

#### **3.1. Context**

Although health, and especially health care, initially had only a limited presence in the European Treaties (McKee, Mossialos et al. 1996), this has expanded considerably over time, including, in the past decade, growing attention to access to health care (Greer, Hervey et al. 2013). In parallel, there have been a series of developments in the wider international arena, and particularly within the framework of the United Nations, in which Member States have stated their commitment to the right to health and access to care (Sridhar, McKee et al. 2015).

Within the European Union, the Council of Ministers agreed a set of common values and principles for EU health systems in 2006. One of these was access to good quality care. This right was subsequently enshrined in the Charter of Fundamental Rights (Article 35), which provided all EU citizens with a legal “right of access to preventive health care and the right to benefit from medical treatment under the conditions established by national laws and practices”.

In 2017, the European Commission set out proposals for a European Pillar of Social Rights (European Commission 2017). Containing 20 principles, this is intended to build on, and complement, the EU social “acquis”, guiding policies in a number of fields essential for well-functioning and fair labour markets and welfare systems within the participating Member States. The principles proposed do not replace existing rights, but offer a way to assess and, in future, more closely align the performance of national employment and social policies. The European Pillar for Social Rights was proclaimed by the Member States at the European Social Summit, which was held in Gothenburg, Sweden on 17 November 2017. The Pillar is the reference framework to screen the employment and social performance of participating Member States, to drive the process of reforms at national level and, more specifically, to serve as a compass for renewed convergence within the euro area. Principle 16 states that “Everyone has the right to

timely access to affordable, preventive and curative health care of good quality”, although this is a dilution of what was in an earlier draft, which included the words “and the need for healthcare shall not lead to poverty or financial strain”.

Finally, although the arrangements for providing health care are reserved to Member States by the Treaties, the European Union can play a role by facilitating the exchange of information. In pursuit of this goal, it has convened an Expert Group on Health System Performance Assessment, working with OECD, which is likely, in the near future, to pay particular attention to access to health care.

The rationale for including this right in the Charter reflects several considerations. The first is that all Member States have committed, within the United Nations system, to the progressive realisation of the right to health, as set out in the International Covenant on Economic, Social, and Cultural Rights (United Nations 1966). The Committee on Economic, Social, and Cultural Rights, the body charged with monitoring the Covenant, has subsequently interpreted this as creating a set of core principles, as follows:

*All states, no matter how poor, should offer a minimum core level of provision, which should include at least the following obligations:*

- *To ensure the right of access to health facilities, goods and services on a non-discriminatory basis, especially for vulnerable or marginalised groups;*
- *To provide essential drugs, as from time to time defined under the [World Health Organization] Action Programme on Essential Drugs;*
- *To ensure equitable distribution of all health facilities, goods and services [based on need];*
- *To adopt and implement a national public health strategy and plan of action, on the basis of epidemiological evidence, addressing the health concerns of the whole population.*

These principles have subsequently been incorporated into the Sustainable Development Goals, which once again, all Member States have committed to. Specifically, Goal 3.8

commits Member States 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” (UNDP 2015).

A second set of reasons are instrumental, related to the pursuit of the EU’s fundamental goals. Thus, it is now recognised that modern healthcare can do much to prolong life and to prevent disability and suffering, an objective that is implicit in the Treaty obligation to ensure that a high level of human health protection shall be ensured in all of the Union’s policies and activities. It is also accepted that health contributes to economic growth, through enhanced productivity and reduced losses from the workforce, and by avoiding the adverse economic consequences of catastrophic expenditure on healthcare (Suhrcke, McKee et al. 2005). Third, inequalities in health undermine progress in reducing social exclusion (Marmot, Friel et al. 2008).

There are also many reasons why it is in the interests of national governments to minimise unmet need. Thus, at least for now, European citizens, in opinion polls and through their choices at the ballot box, have expressed their support for the welfare state, including the provision of universal health care either by government, social partners or others, within a statutory framework (Missinne, Meuleman et al. 2013). It is also in the interests of those providing health care to minimise unmet need, as a failure to do so will often be more expensive in the long run, as illustrated by studies that have looked at the so called *ambulatory care sensitive conditions*, whereby failure to identify and treat conditions at an early stage allows them to progress and develop complications that require much more complex and costly treatment (Purdy, Griffin et al. 2009).

Taken together, these considerations create a clear justification for establishing a right to good quality care. However, the challenge then is how to operationalise this right, and in particular to determine how it should be defined, monitored, and where lacking, how it can be addressed. This is important because, for many reasons, it cannot be assumed that simply by making health care available all needs will be met. In particular, it is now well recognised that health care is subject to market failure (Arrow 2001); if viewed as a

tradable commodity health care in a free private market will not reach an equilibrium at a point that maximises health gain and social inclusion.

There are several reasons for this. First, need may not be translated into demand, with the most vulnerable in society often least able to express their need as demand. Second, many of the characteristics of a perfectly competitive market, such as symmetry of information between the patient and the health care provider, and the absence of externalities do not apply. These issues have given rise to what has been termed the *inverse care law*, which states that those in most need are least likely to have it met (Hart 1971).

The challenge of operationalising the concept of unmet need, which is in itself considerable given the many methodological issues involved, and which will be discussed later, is complicated further by the qualification in the Charter. Thus, reflecting the Treaty requirement that “Union action shall respect the responsibilities of the Member States for the definition of their health policy and for the organisation and delivery of health services and medical care, the right is to be interpreted “under the conditions established by national laws and practices”. In practice, this raises issues of entitlements to care and, specifically, who is considered to make up the population to whom the right applies. For some groups, this is uncontroversial, such as citizens resident in the Member State. For others, such as undocumented migrants, it is often highly contested (Legido-Quigley, Urdaneta et al. 2013, Hiam and Mckee 2016).

### **3.2. Why was this opinion requested?**

This opinion has been requested to support a process of benchmarking Member States, so it is appropriate to reflect on what this means. Benchmarking provides an opportunity for Member States to learn from experiences elsewhere, reflecting on progress made by others and how they have achieved it, offering scope for learning from different experiences, of both good and bad practice and, where possible, to adopt those that work, taking account of differences in context.



This has certain implications. It is not enough to collect information for the sake of it, especially as this requires considerable effort and investment in resources. This investment can only be justified if it leads to improvements. Thus, benchmarking requires that the collection of information on performance is accompanied by an understanding of what policies and processes are effective in bringing about improvements, what strategies can achieve the necessary changes in behaviour, and what characteristics of the healthcare environment facilitate or impede change.

Unfortunately, few health systems place a priority on organisational learning, so the same problems are often repeated in different settings. The exchange of ideas on how to improve established practices is rarely given the priority accorded to the introduction of new ones (World Health Organization 2008).

Benchmarking is a continuous process, which enables organisations to strive for and even surpass previously determined standard. In this context, it should not be considered as a means of ranking the performance of health systems, although comparative data on performance can be useful for many purposes. Rather it should be viewed as a systematic process of searching for best practices, innovative ideas, and effective operating procedures that lead to improved performance. This requires information, but also the motivation to change, encouraged by a supportive culture and knowledge of what works.

### **3.3. Defining need**

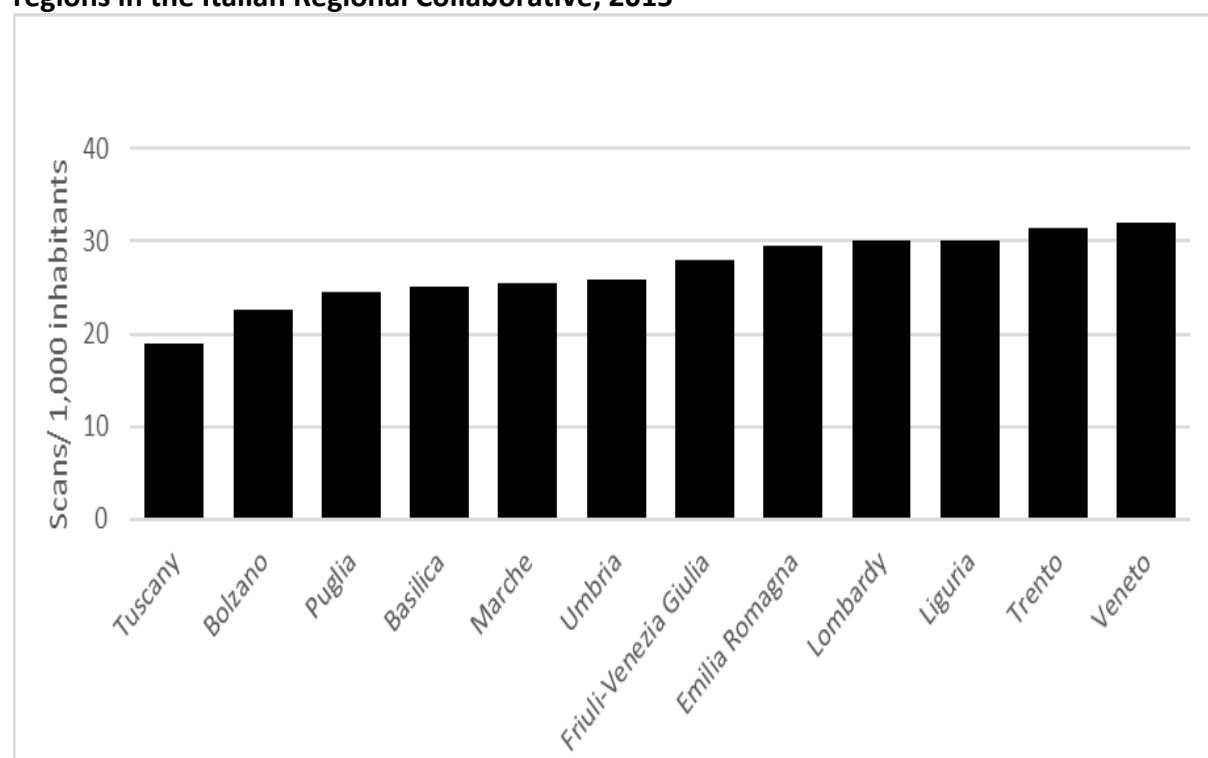
A useful starting point is to define the need for health care. One of the most widely used definitions is “the ability to benefit from health care” (Stevens and Gillam 1998). This has several obvious implications. First, an individual must have a condition that renders him or her in less than good health. Second, there must be a treatment available that can improve the health of the individual concerned. This need not necessarily mean that there are the means to cure their condition; it may instead be sufficient for there to be the means to alleviate their suffering. However, it also implies that there are no other

reasons why they might not benefit from care. For example, a treatment may be available that could extend life from 5 years to 10 years. However, if the individual concerned has a separate life-threatening illness, with a life expectancy measured in months, then they clearly do not have the ability to benefit from treatment. This does, however, raise more complicated issues. Thus, interventions requiring strict adherence to treatment or lifestyle modification may be questioned when, for whatever reason, the individual concerned is unable to adhere to the recommended treatment. The challenges lie in deciding where to set the boundaries. Thus, in some countries, nonurgent treatment is being denied to those who are smokers or who are obese. The issues raised are beyond the scope of this report, but do demand a wide-ranging public discussion. It is, however, the view of the Expert Panel that, while such decisions may be justifiable on clinical grounds, in that the condition or actions of the patient mean that the treatment is very likely to be ineffective (based on objective evidence), there is no case whatsoever for making them on moral grounds.

There is now extensive literature on how need for health care can be measured but, in brief, the task is often quite challenging. First, in many cases, the individual concerned may not realise that they need health care, as is the case with someone who has undiagnosed high blood pressure. Second, even when their condition is symptomatic, it may be necessary to undertake complex, and in some cases, painful or uncomfortable investigations to make a precise diagnosis, and therefore determine whether there is an effective treatment for the condition, and which, by extension, they have a need for. Third, there is the potential for supplier-induced demand, in which an individual may not actually need care, but is advised by a health worker that they do. This situation may arise where that health worker can profit from the administration of unnecessary treatment. The Scottish general practitioner Margaret McCartney has coined the term “patient paradox” when she realised that, at a time when she was struggling to obtain access to essential care for many of her patients from a National Health Service under severe financial pressure, she was being deluged with advertisements from private

companies offering screening and treatments that had no evidence of effectiveness (McCartney 2013). Another example comes from Italy. While patients in many Italian regions complain about unacceptable waiting times for diagnostic imaging services, in particular computerised tomography and magnetic resonance imaging (MRI) examinations, the use of these examinations is among the highest in the world, although there is substantial inter-regional variation (Figure 3-1).

**Figure 3-1** Variation in rates of musculoskeletal MRIs among those aged 65 or above in regions in the Italian Regional Collaborative, 2015



Source: Indicator calculated for a network of Italian Regions by the MeS-Lab (Sant'Anna School of Advanced Studies) – year 2015. These data are public available at the link <http://performance.sssup.it/netval/>

There are many reasons for variation on this scale (Wennberg 1999, Appleby, Raleigh et al. 2011), which may reflect overuse or underuse. It cannot be assumed that lower use equates to unmet need; there is clear evidence from many countries that some care is inappropriate. Well-known examples include the use of diagnostic tests (Kachalia, Berg et al. 2015) and elective procedures that yield little or no health gain (McKee, Whatling et al. 2005). Thus, it is important to undertake a comprehensive assessment of the

situation to put in place the most efficient strategies (Nutti and Vainieri 2012). What is necessary is to ensure that people who might benefit most from a service are those who are actually receiving it (Gray, Airoidi et al. 2017). It is important to recognize that what is portrayed as unmet need may, in some cases, reflect inappropriate expectations or supplier-induced demand, especially where those providing the service have financial incentives for over use. In this context, it is important to take account of the questionable ethics of the extensive marketing of many products of unproven effectiveness, including many alternative treatments, such as homeopathy (Shahvisi 2016).

Given these challenges, research on need for specific types of health care has, in general, been limited to a few conditions with certain characteristics. These characteristics are that the condition can be recognised accurately by the individual affected, that an effective treatment exists, and there are clear objective criteria for determining whether the individual concerned will benefit from treatment. Typically, research has looked at need for certain forms of non-urgent surgery. Studies of osteoarthritis of the hip (Wilcock 1979) and benign prostatic hypertrophy (Sanderson, Hunter et al. 1997) have first developed a symptom scale on which each potential patient can be placed. Clinical judgement, typically based on formal consensus development methods (Black, Murphy et al. 1999), identifies a point on the scale above which the individual is deemed to have an objective clinical need for treatment. The point selected on the scale reflects that at which point the net benefits of treatment outweigh the risks. The scale can then be used in a population-based survey to identify the number of individuals in the population who meet this clinically defined criterion for treatment. However, certain challenges arise. First, the individual may have other coexisting conditions that increase the risk of treatment. Second, some individuals who meet the criteria may, as result of personal preference, decline an invitation to be treated. Such individuals, while meeting the objective criteria, would be deemed not to

be in need of treatment. However, this approach is only practical in the context of epidemiological research studies.

While epidemiological needs assessment, as described in the previous paragraph, can provide valuable information in a defined population, international comparisons confront another problem in that the reference population may differ among countries. Thus, as the Charter of Fundamental Rights notes, the right to health care is granted under the conditions established by national laws and practice, and Member States with different resources can provide different standards for the acceptable level of care as long as this is done in a way that is non-discriminatory. What this means is that, in each Member State, entitlement to health care varies. In some, it is based on residence, for example in the National Health Service in the United Kingdom. In others, it is related to affiliation to an insurer. This insurer may be a private company or a sickness fund, and enrolment may be optional or compulsory. Entitlement to care is also often related to citizenship, and in particular to migration status. Thus, in many countries, undocumented migrants will be excluded. This problem extends to those who are entitled to care in some countries but who are unable to realise this entitlement because of problems in proving it. One of the best-known examples is the situation faced by Roma in several countries, who face major obstacles to obtaining the appropriate documentation to demonstrate their citizenship and entitlement to services (Kuhlbrandt, Footman et al. 2014, Arora, Kuhlbrandt et al. 2016). However, there are many other examples, such as migrants who, while entitled to care, struggle to establish it, or those with mental health problems who face similar challenges. For example, the MIPEX study confirms that access for irregular migrants is exceedingly poor, although a handful of countries have taken steps to improve it (International Organisation for Migration 2016). The EU's Minimum standards directive (2004/2011) is widely assumed to have mandated adequate health care for asylum seekers, but MIPEX shows that this is far from being the case. The most surprising finding concerns 'legal migrants' (primarily, those with a work permit): even for this group, coverage may be refused if they become unemployed or do not have

permission to stay for a sufficiently long period. Many receive inadequate information about their rights and are obliged or persuaded to take out expensive private health insurance, despite the fact that they may already be paying for health care through taxation.

These issues were discussed in detail in the Expert Panel's report on access to care (Expert Panel on effective ways of investing in Health 2016).

In practice, some of the technical challenges of measuring need, but not the political questions of who is covered, have been circumvented by adopting a simple, pragmatic approach, whereby individuals are asked whether they perceive themselves to have a need for health care, although this is not usually defined. They are then asked whether they have sought and obtained treatment for it. Those who have not obtained such treatment are considered to have unmet need for health care. While this approach is pragmatic, it has obvious conceptual limitations, as the preceding discussion shows. A key point is whether there can be unmet need for some types of health care with very small but positive benefits and with very high social costs of providing them, taking into account the "adequate" care qualification mentioned above. The notion of adequate care involves some judgement, which may include consideration of the scarcity of resources required to provide for small benefits of access to health care. Still, the current advantages, including availability, of self-reported measures of unmet need justify its use. The source of such data is discussed in the following section.

### **3.4. How is unmet need measured at a European level?**

The primary source of comparative data on unmet need for health care is the European Union Survey of Income and Living Conditions (EU-SILC). This survey has been undertaken annually, since 2005, in all Member States and the results formed the basis of many indicators in widely used databases (Arora, Karanikolos et al. 2015). The surveys ask respondents whether they have had a need for individual health services, defined as examination or treatment by a physician or equivalent professional, but has

not been met because of cost, distance, or waiting lists, with the same question asked about dental care (Box 3-1).

**Box 3-1      Questions on unmet need in EU-SILC (UK questionnaire)**

Was there any time in the last 12 months when, in your opinion, you personally needed a medical examination or treatment for a health problem but you did not receive it?

1. Yes

2. No

What was the main reason for not receiving the examination or treatment (the most recent time)?

1. Could not afford to (too expensive)

2. Waiting time

3. Could not take time because of work, care for children or for others

4. Too far to travel/no means of transportation

5. Fear of doctor/hospitals/examination/ treatment

6. Wanted to wait and see if problem got better on its own

7. Didn't know any good doctor or specialist

8. Other reasons

Note: The first part of this question is in the process of being changed (see below)

Like all surveys, however, the data are subject to certain limitations. First, the sample size is relatively small, limiting scope for sub-group analysis, especially when the sample is already reduced by limiting it to those who report need for health care. Second, EU-SILC data are not fully representative of the population. Specifically, they exclude the institutionalised population, such as those living in health and social care institutions. They also tend to exclude those who are homeless. Both groups are likely to have worse health (and worse access) than the general population. Moreover, while it is intuitive that those who are homeless also have high levels of unmet need, there is also cause for concern that, in some countries, those who are in long-term care may also lack appropriate treatment and, as a result, experience unmet need. Further problems relate

to other institutionalised populations, such as prisoners, who often have particular health needs and are also excluded from surveys. Importantly, the surveys do not provide specific information on unmet need for mental health services or for social care, with the latter a particular problem in countries where much of the care provided for people with dementia is in the social care sector. The data also fail to capture most irregular migrants, with those without a valid residence permit unlikely to participate in it. Moreover, even among those that do have a permit may become irregular due to their permit losing its validity. Children under 16 are also excluded. This is especially important in relation to migrant children, as many migrant children in Europe lack adequate entitlement to care (Østergaard, Norredam et al. 2017). There are also problems of comparability as the questions and the means of data collection are not exactly the same in every country. Another problem is that the question, as asked, provides an upper bound on unmet needs. This can become problematic when developing targets (Box 3-2).

### **Box 3-2 Challenges in interpreting the EU-SILC question on unmet need**

We begin with two different people:

Person A: felt the need to obtain health services 3 times in a year and actually accessed them on 2 of the 3 occasions so the answer to a question about any episode of need that was not satisfied is “yes”.

Person B: the need to obtain health services on one occasion but did not access them, so again the answer is “yes”.

If calculated in terms of episodes of need, these two people have 4 of which 2 are unmet, so unmet need should be 50%.

If calculated in terms of people having at least one episode of not having access, there is 100% unmet need.

Then, person C is added, with 2 episodes of need for health services, both of which lead to care. If measured as people, the unmet need is 66%, while if measured as in episodes it is  $2/6 = 33\%$ .



The question is, however, in the process of being changed. The new version will be in two parts, as follows:

A. Was there any time during the past 12 months when, in your opinion, you personally needed a medical examination or treatment for a health problem?

1. Yes
2. No

B. (only for those answering Yes):

Did you have a medical examination or treatment each time you needed it?

1. Yes
2. No

Use code -2 for "not applicable" if the answer to A was No.

Asking the question like this allows the percentage of the whole population with no health needs to be calculated (state of health), as well as the percentage of those with needs who had them met (access). The answer to the old question can also be reconstructed. According to Eurostat, the change should be introduced in all countries in the 2017 reference year, this will not be known for sure until 2019. This does, however, mean that data from the years 2015, when the first countries started to use the new question, and 2017, when it should be fully implemented, may not be fully comparable.

Even with the new question, it is not possible to distinguish between unmet need for first contact and for subsequent care. Need for the latter may not be met when waiting lists for interventions are long and people are treated outside a clinically acceptable time window, when patients receive less care than required, for example through premature discharge or failure to provide necessary treatment, when patients are kept in hospital inappropriately because there is no space in social care or other more appropriate settings, or when informal care inappropriately replaces formal care because of an absence of the latter. Thus, although comparative data on unmet need at European level

are routinely collected, there are some concerns about their validity, coverage, and meaning.

An alternative approach to measuring need through health outcomes is to use self-reported health measures, where each individual in a survey is asked to rate her health as, for example, very good, good, bad, very bad. This information is also available in EU-SILC but suffers from the major limitation of saying nothing about whether the poor health is due to unmet need for health care.

Another approach is to infer the extent of health need by looking at health outcomes. There are several approaches to assessing population health outcomes. The one used most often in assessing the contribution of health care involves variants on the theme of mortality amenable to health care, or avoidable mortality (Nolte and McKee 2011). A variety of versions are used by different organisations, including the OECD, the Commonwealth Fund in the USA, and the NHS in England. The most recent iteration has been developed by the Institute of Health Metrics at the University of Washington (GBD 2015 Healthcare Access and Quality Collaborators 2017). This goes beyond previous approaches by standardising for risk factors in a population and by creating a frontier quantifying what a country might expect to achieve given its level of development. Summary results of the most recent analysis are shown in Table 3-1. The HAQI scores are on a scale from 0 to 100, with higher scores indicating better performance. The frontier is calculated as what could be expected based on a combination of national income, level of education, and fertility. As can be seen, most Member States achieve or exceed what would be predicted but not all do.

**Table 3-1 Health Access and Quality Index scores for EU Member States, 2015**

Member State	HAQI	HAQI Frontier	Difference
Austria	88.2 (87.3-89.0)	90.0	1.8
Belgium	87.9 (86.8-88.8)	89.6	1.8
Bulgaria	71.4 (69.6-73.1)	84.8	13.5
Croatia	81.6 (80.5-82.7)	82.9	1.2
Cyprus	85.3 (84.2-86.4)	89.5	4.2
Czech Republic	84.8 (83.9-85.7)	90.2	5.3
Denmark	85.7 (84.7-86.7)	90.9	5.2
Estonia	81.4 (80.1-82.6)	88.3	6.9

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Finland	89.6 (88.6-90.5)	90.2	0.6
France	87.9 (86.9-88.9)	86.7	--
Germany	86.4 (85.4-87.3)	90.6	4.3
Greece	87.0 (86.1-87.9)	85.9	--
Hungary	79.6 (78.2-81.0)	87.6	8.0
Ireland	88.4 (87.5-89.3)	90.0	1.6
Italy	88.7 (87.8-89.6)	88.1	--
Latvia	77.7 (76.3-79.3)	88.4	10.6
Lithuania	76.6 (75.5-77.9)	87.0	10.4
Luxembourg	89.3 (88.4-90.2)	90.9	1.6
Malta	85.1 (84.0-86.1)	84.5	--
Netherlands	89.5 (88.6-90.4)	90.3	0.8
Poland	79.6 (78.2-81.0)	88.8	9.2
Portugal	84.5 (83.6-85.5)	80.5	--
Romania	74.4 (72.7-76.0)	84.0	9.6
Slovakia	78.6 (77.3-79.9)	88.5	9.9
Slovenia	87.4 (86.5-88.4)	88.0	0.6
Spain	89.6 (88.8-90.3)	85.7	--
Sweden	90.5 (89.6-91.4)	90.2	--
United Kingdom	84.6 (83.8-85.4)	90.3	5.7

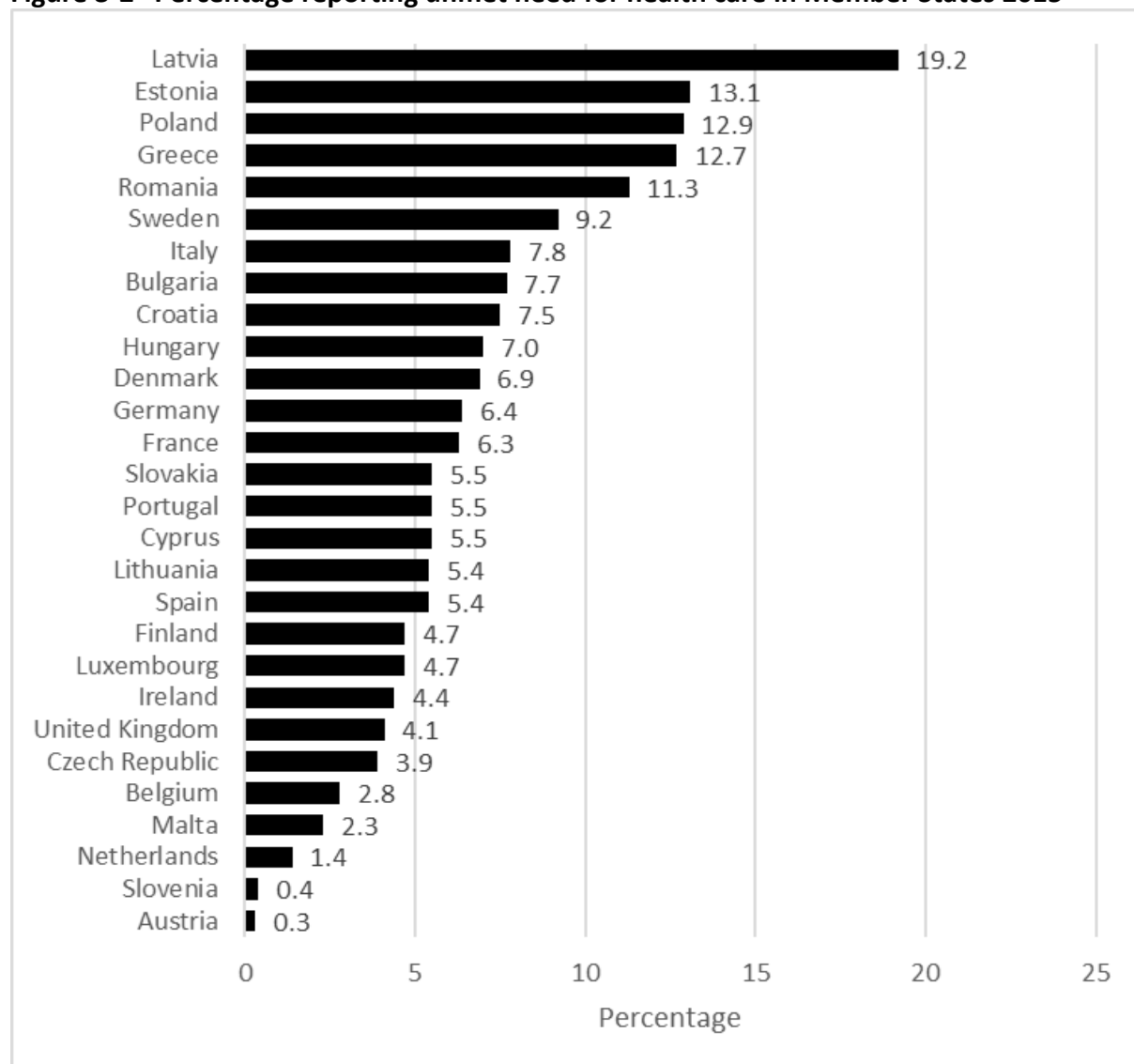
Source: (GBD 2015 Healthcare Access and Quality Collaborators 2017)

In summary, while the formal definition of need for health care, and consequently the level of unmet need in a population is clearly defined, there are major challenges in operationalising a measure of it. These relate to definition of the population that is included, achieving a representative sample of the population, and creating a practical but verifiable definition of unmet need. We are also not aware of alternative surveys which measure unmet need with the same degree of EU country coverage, which limits the scope for alternative indicators in the short run.

### 3.5. Trends in unmet need in Europe

Trends in unmet need for health care were described in detail in the expert panel's previous report on access to health services (Expert Panel on effective ways of investing in Health 2016). These have been updated and are shown in Figure 3-2. In brief, there are large variations in the percentage of people reporting unmet need for health care among those needing a medical examination or treatment, varying from under 1%, in countries Austria and Slovenia, to over 19% in Latvia.

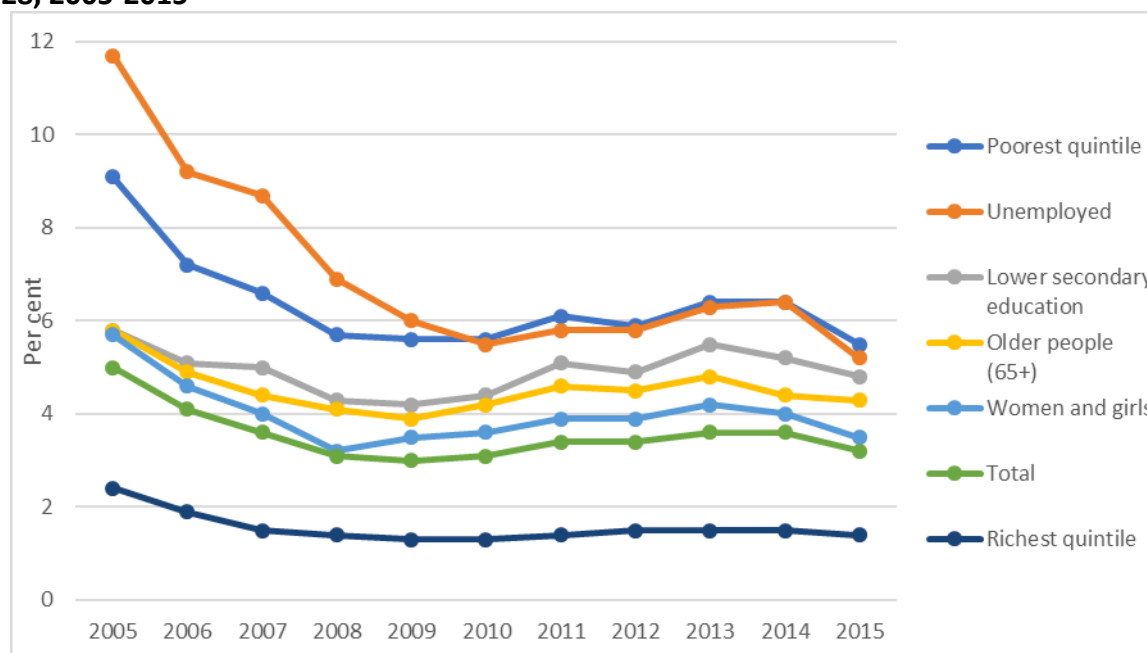
Figure 3-2 Percentage reporting unmet need for health care in Member States 2015



Source: Calculated from EU-SILC data

Overall, the percentage of people reporting unmet need for health care has fallen substantially from 2005 until 2010, after which it began to increase, possibly due to the change in financial climate (Reeves, McKee et al. 2015), although the most recent trend indicates some recovery. When disaggregated, there are very large differences according to the characteristics of respondents, in particular by socioeconomic status, as shown in Figure 3-3, which is an updated version of a figure in the previous report.

**Figure 3-3 Share of people reporting unmet need for health care due to cost, travel distance, and waiting list by income, age, gender, education and employment status, EU 28, 2005-2015**



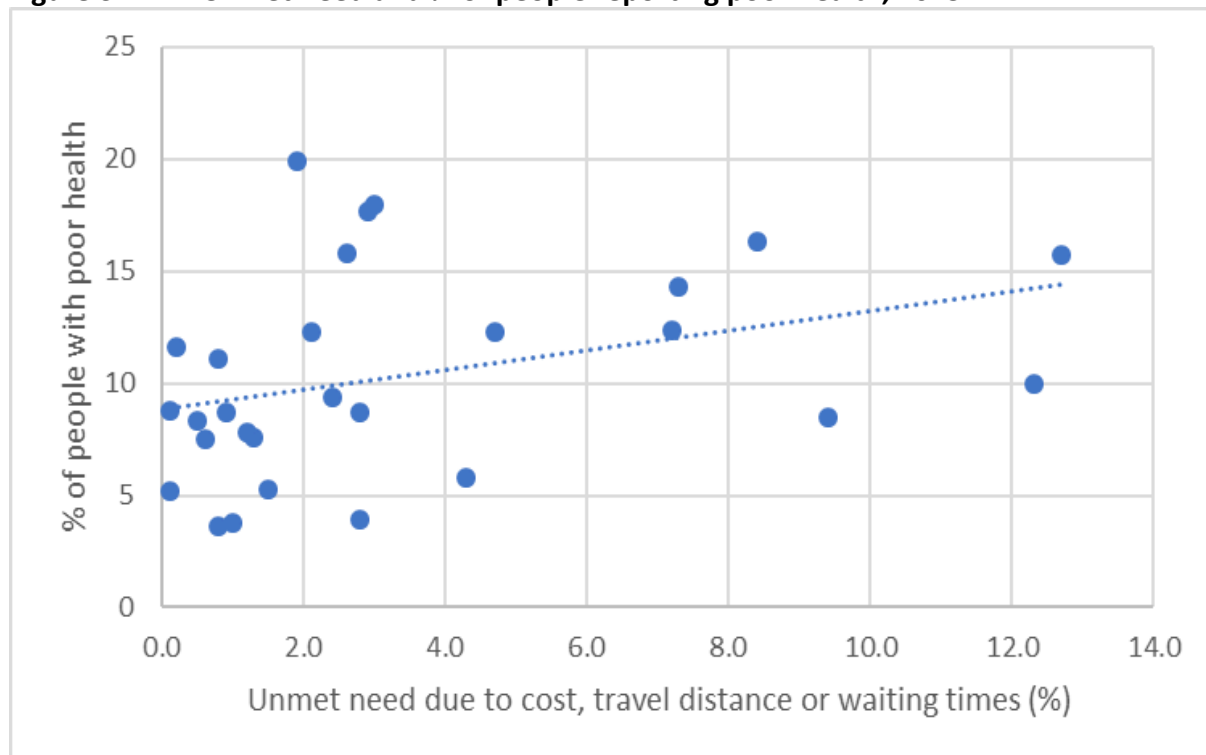
Source: Calculated from EU-SILC data

Thus, in 2015, the percentage of those in the richest quintile reporting unmet need was below 2% while in the poorest quintile it was over 5%. Rates of unmet need are about 50% higher among people aged over 65 and among the overall population, are slightly higher among females than males, and substantially higher among those with less education or who are unemployed. The changes over time have had a substantial impact on European citizens. One study estimated that, in 2013, an extra 1.5 million people experienced unmet need compared to 2008, although with the earlier rate of decline had continued, the gap would be 7.3 million people (Reeves, McKee et al. 2015). The poor were most affected: the increase in unmet need after 2010 was approximately 6 times larger among those in the poorest quintile compared to those in the richest quintile.

A number of studies have been undertaken in individual countries to understand the factors underlying these changes (Kentikelenis, Karanikolos et al. 2014, Karanikolos, Gordeev et al. 2016, Legido-Quigley, Karanikolos et al. 2016). These vary, but include introduction or increases in co-payments and reduced access to facilities, either through limited opening hours or closures, necessitating longer travel distances.

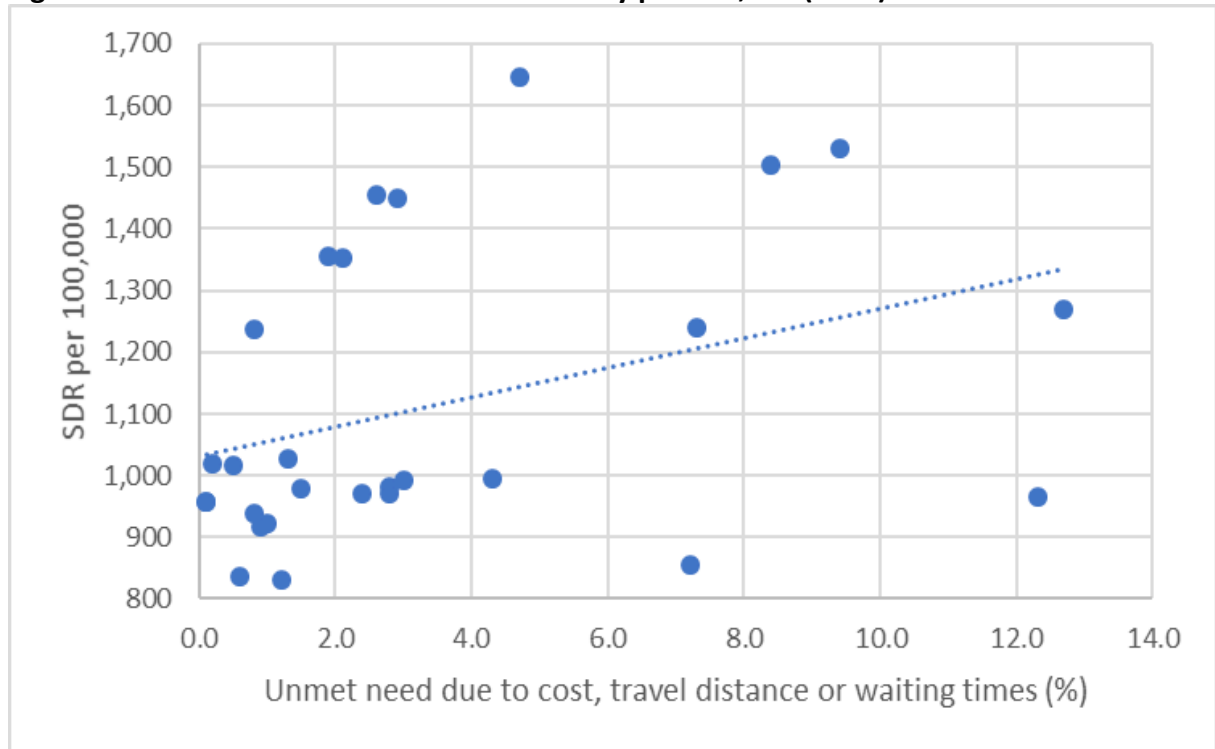
It would be expected that, for given supply of services, unmet need will be higher when need is higher. In figures 3-4 and 3-5 it can be seen that there is a tendency, albeit weak, for there to be greater unmet need in countries where more people report poor health or where the overall mortality rate is higher.

**Figure 3-4 Unmet need and % of people reporting poor health, 2015**



Source: calculated from statistics compiled by EUROSTAT and EU-SILC data

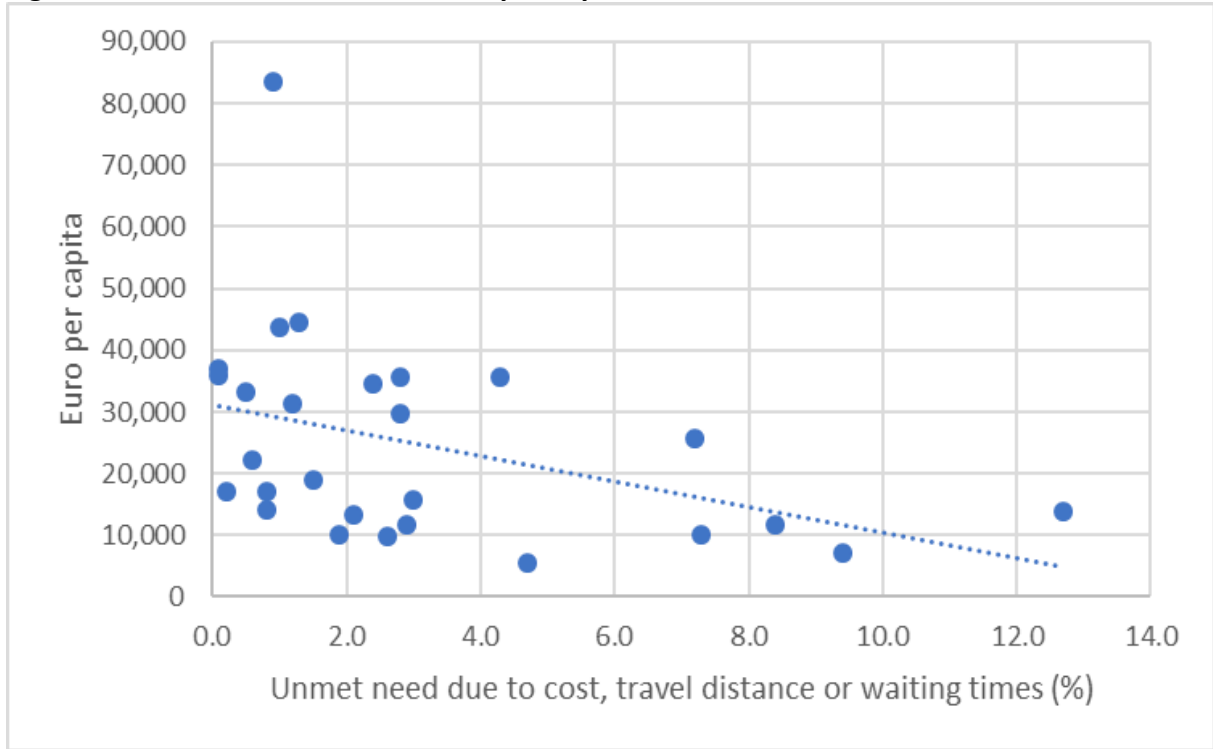
Figure 3-5 Unmet need and total mortality per 100,000 (2014)



Source: calculated from statistics compiled by EUROSTAT and EU-SILC data

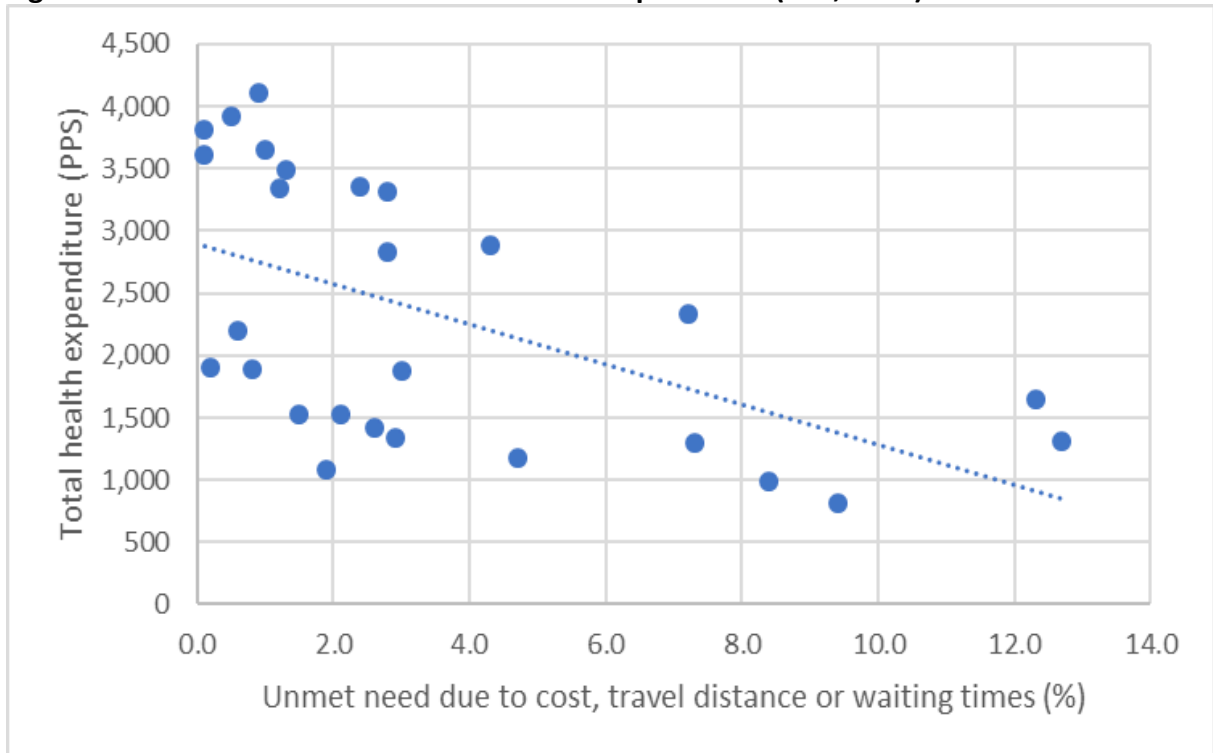
It would also be expected that, for a given level of need, unmet need will be lower in systems with more resources devoted to health care. In figures 3-6 and 3-7 we show that unmet need tends to be lower in wealthier countries and those that spend a greater proportion of national income on health (spending involves prices and costs of resources, meaning that for the same physical resources and care provided, different prices across countries may imply different spending levels; adjusting for this aspect will likely not change the picture).

Figure 3-6 Unmet need and GDP per capita, 2013



Source: calculated from statistics compiled by EUROSTAT and EU-SILC data

Figure 3-7 Unmet need and Total Health Expenditure (PPS, 2014)



Source: calculated from statistics compiled by EUROSTAT and EU-SILC data



### **3.6. Reasons for unmet need**

There is an extensive body of literature on the reasons for unmet need for health care, much of which was summarised in the Expert Panel's previous opinion on access to care. These can be illustrated with reference to two systematic reviews examining barriers to the receipt of effective care for hypertension (Maimaris, Paty et al. 2013, Khatib, Schwalm et al. 2014). These identified barriers at several levels, summarised in the previous report of the Expert Panel on access to care as:

*"Access is a multi-dimensional issue. Barriers to access can be found at the level of individuals, health service providers and the health system. Access is also affected by public policy beyond the health system – especially fiscal policy, but also social protection, education, employment, transport and regional development policy. Survey data suggest that financial barriers are the largest single driver of unmet need for health care in the European Union."*

Thus, the extent to which a condition is regarded as 'abnormal' and requiring treatment varies, reflecting cultural norms and expectations. The decision to seek treatment may be influenced by the opportunity cost of doing so, for example where someone must travel long distances or will lose income if they take time off work. Some individuals may not be aware that there is a treatment available for their condition. Finally, the decision to seek care often requires recourse to financial resources, a supportive social network of family, friends and informal carers, access to transport, and information about how to navigate the system. Other barriers exist in health facilities and in interactions with health workers. These include lack of knowledge by health workers, inaccessibility of the facilities, and lack of equipment or supplies. A final set of barriers act at the level of the health system, including the overall level of funding, availability of prepayment mechanisms, such as insurance coverage, the services covered, and mechanisms to ensure that appropriate services are available in each community.

### **3.7. Proposal for an overall target**

Pragmatically, any target to reduce unmet need must be obtainable from existing sources. In practice, this means the EU-SILC, which is the only survey covering dimensions of unmet need for all EU countries, notwithstanding its limitations. However, this begs the question of what the target should be.

Given that Member States have already subscribed to the right to health care, the implication should be that the adequate level of unmet need should be zero, or close to it. It does not mean that all needs should be met whatever the cost of providing that health care. There is clearly an opportunity cost to providing any care. In a system with constrained resources, it is necessary to set priorities that take account of both the cost and the benefit of intervening, although this should be done in a way that is transparent, using processes that ensure that the bodies involved are accountable to those whose care they are responsible for. This is a complex and contested area, involving both technical and political considerations, and goes far beyond what can be addressed in this report.

For the present purposes, what is important to note is that several countries have reduced rates to under 1%. The International Covenant established the principle of progressive realisation (Sridhar, McKee et al. 2015), which would imply that a Member State could set as a target a higher figure initially, but subject to periodic revisions consistent with progress over time. However, this would mean that several Member States will already have achieved this target.

### **3.8. Proposal for national targets**

The terms of reference for this report asked for both a target for the EU as a whole, and a target that can be adapted to the context of each Member State. Our approach was informed by the SMART mnemonic, widely used in setting targets (Doran 1981). This proposes that targets should be:

- Specific – they should target a specific area for improvement;

- Measurable – they can be quantified, or at least there should be indicators of progress;
- Assignable – responsibility for achieving them should be specified;
- Realistic – results can realistically be achieved, given available resources;
- Time-related – the time to achieve the result(s) should be specified.

In this case, several of these elements are prespecified. Thus, the target relates to unmet need for healthcare, which is measured by using data from the EU-SILC surveys. Legally and politically, the target is assumed by the Member States, although how they further assign responsibilities is a matter for them under the principle of subsidiarity. The remaining questions relate to levels of achievement and timings that are realistic.

Given the long-established principle of adopting policies that move towards convergence within the EU, there is a strong argument for setting a target that is in the vicinity of that already achieved by the most privileged group in the best performing Member State (i.e. below 1% in 2013). However, recognising the different starting positions of each Member State, it seems reasonable to argue that individual national targets should be set that are challenging but achievable improvements on what has already been attained (Vainieri, Vola et al. 2016). If a 1% target is agreed, then the timing by which it should be achieved will need to be considered. However, this will clearly need appropriate resources, the allocation of which is a fundamentally political issue at the national level. For this reason, it is beyond the remit of this Expert Panel to set a date for this target to be achieved. However, it should be sufficiently ambitious. An extrapolation of trends on the weighted EU average between 2005 and 2015 suggest that, without further actions, this will only be achieved in 2052. It seems reasonable to suggest that a reasonable target might be within about 10 years. This would be challenging but achievable. To bring the unweighted EU average rate below 1% by 2025 would require the rate of decline to be 2.3 times faster than it has been between 2005 and 2015. Clearly,

progress against the required performance would be monitored regularly in the intervening period.

As to the national targets, again, it is ultimately a political decision as to where the target should be set. After detailed discussion, we believe that the following approach could be appropriate, on the basis of considerations of feasibility, simplicity, and data availability. This envisages that the initial target would be defined as the median value achieved by the best performing tercile of Member States (this could also be the best performing quartile or quintile – the choice will make little difference). Given the intrinsic variability associated with the small numbers in the surveys, we propose that this should be averaged over several years (between 3 and 5). This means that some Member States will already have achieved this target, but most would not have. Recognising that it may be more difficult for those further from the target to make progress, we propose that each would be expected to close the gap between its current performance, averaged over 3 years, and the target by certain percentage over a defined period of time. We propose that this percentage might reasonably be 50% and the time period three years, while recognising that the precise figures will be subject to political agreement.

This approach is set out mathematically in Box 3-3. The benchmark figure is defined as the median value obtained in countries in the lowest tercile of unmet need. To allow for fluctuations related to sampling, this is averaged across the three most recent years for which data are available for all countries (2013-15). Each country's level of unmet need in 2015 is then calculated. In some cases, this causes a country in the best performing tercile over the past three years to be above the benchmark if its reported performance has deteriorated. Those countries exceeding the benchmark are then given a target of reducing the gap between the score in 2015 and the benchmark by 50%. This would allow every Member State to have a specific target that is both challenging and fair. The implications for each Member State are shown in Figure 3-8.

**Box 3-3 Possible formula for generating target for unmet need**

We denote  $TG_t$  as the overall target (across all EU member states) in period  $t$ , and  $UN_{it}$  as unmet need of country  $i$  in period  $t$ , defined as the percentage of people reporting unmet need for health care among those needing a medical examination or treatment.

Then, we can write the target for country  $i$  in period  $t$ ,  $TG_{it}$ , as a function of the same country unmet need and the overall target:

$$TG_{it} = \max(TG_t, TG_t + (x\%) * (UN_{it} - TG_t))$$

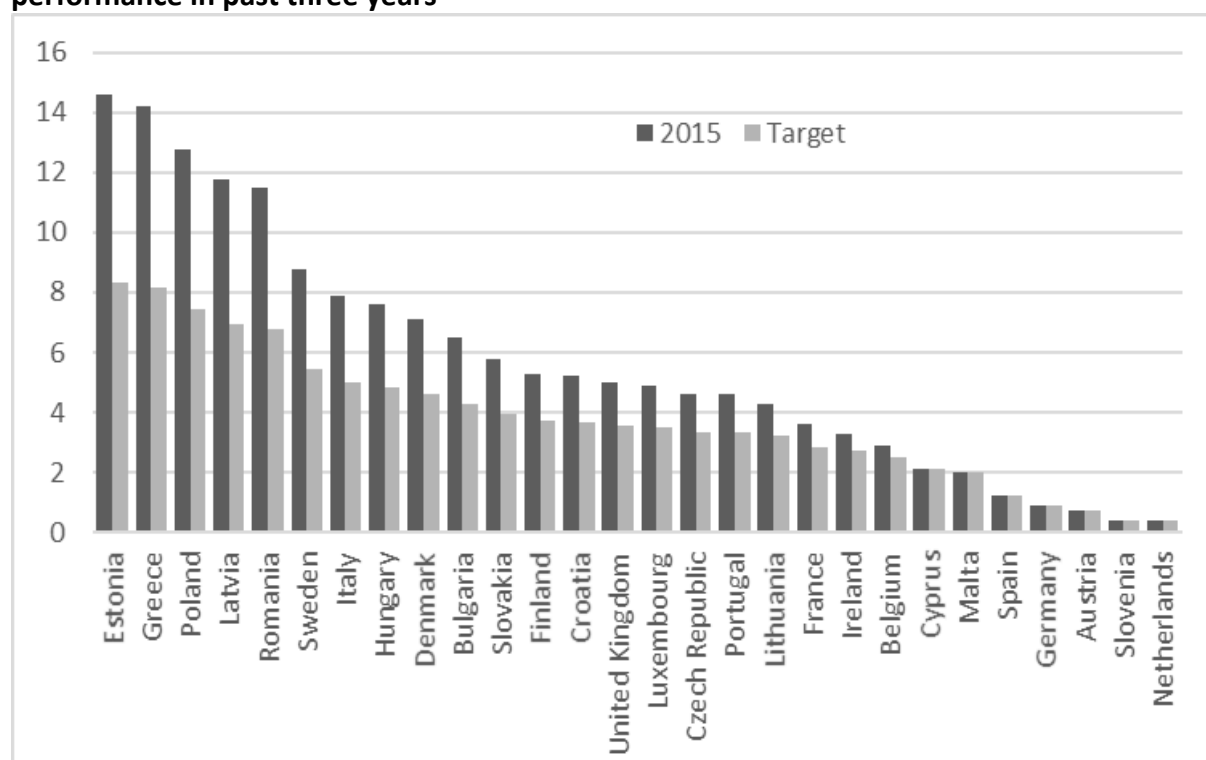
where  $x\%$  is the adjustment parameter required to close the gap between unmet need in country  $i$  in period  $t$  in  $k$  years (e.g. 50% of the gap in 5 years, 40% of the gap in 4 years etc.).

The overall target could be computed as a function of the unmet need across all countries in the previous years. Suppose for example that we use the median unmet need averaged across the three previous years. Then,

$$TG_t = \frac{1}{3} \sum_{t-3}^{t-1} (\text{median } UN_{it} \mid i \text{ in } I)$$

where  $I$  is the reference set of EU countries.

**Figure 3-8** Gap between level of unmet need in 2015 and benchmark based on best performance in past three years



Source: calculated from EU-SILC statistics

A note of caution is, however, required. The small size of the samples must be taken into account, in that confidence intervals will have to be computed to assess the extent to which unmet need is statistically different from a reference category (which could be mean or median unmet need in all Member States or in a group with low unmet need or a previous level of unmet need in the Member State concerned), though this would require a regression based approach. A single (final) target for all countries means that there are no differences in countries that justify a principle of target differentiation.

### **3.9. Inequalities within Member States**

The scenarios above refer to overall levels of attainment within a Member State, yet as noted above, an even greater problem is the degree of variation within them, on grounds of age, gender, education, employment status, and potentially many other factors. Thus, a second question to be addressed is the extent to which overall national targets should

be supplemented by those examining inequalities between groups, defined in various ways.

The groups that are disadvantaged will vary among countries, reflecting differences in ethnic mix, history, and much else. Thus, it seems appropriate that the different types of inequities in access on which attention is focussed should take account of national context, with reporting of a range of quantitative and qualitative assessments as appropriate. Thus, while gender is likely to be of interest everywhere, it may be important to consider issues such as age, rural habitation, or specific ethnicities only in some settings. This has certain implications. A comprehensive strategy to reduce unmet need must understand the nature of disadvantage in each country and devise strategies that explicitly seek to address it. This will often require bespoke systems of data collection, coupled with a detailed understanding of the cultural issues involved in health-seeking behaviour. This national approach is consistent with the accumulated literature on targets points to a need to avoid a top-down approach when setting them (Wismar, McKee et al. 2008). Ideally, each country will recognise the importance of making progress in reducing inequities in unmet need and will set a plan which is compatible with its other priorities, and also with a recognition of the limitations of the data. Even for countries currently meeting the eventual target set, its monitoring is relevant to detect and act early on future deviations. It may also help to fine tune policies.

### **3.10. Second level indicators**

As noted above, there are many reasons why some individuals, and some groups within populations experience greater levels of unmet need than others. These issues were explored in considerable detail in the Expert Panel's previous report on access to care (Expert Panel on effective ways of investing in Health 2016). They followed three broad categories: affordability, availability (and accessibility) and acceptability (user experience). Each, in turn, is separated into three further headings. Thus, affordability can be ensured by having financial resources that are linked to health need, services

that are affordable for everyone, and ensuring those services are relevant, appropriate, and cost-effective. Availability encompasses accessibility to acceptable, well-equipped facilities within easy reach and adequate provision of health services, staffed by health workers with the right skills in the right place, who have access to quality medicines and devices are available at fair prices.

These categories suggest several second level indicators, each of which can help to explain overall levels of unmet need in a country. However, for these purposes, it is necessary to make a decision about how parsimonious such a set of indicators should be. Thus, it could be argued that a very large number of existing measures have some relationship to need for health care and the extent to which it is met, such as the share of national income being spent on health or the numbers of health workers per head of population. However, in all of these cases, the relationship is somewhat indirect, and in many cases, the key issue is the distribution rather than the absolute level in a country. Consequently, it is suggested that the secondary indicators be few in number. While it is not necessarily desirable for indicators to be driven entirely by availability of data, there is, however, an argument for seeking to make them congruent with existing data, to the extent possible. In this context, the key consideration is the categorisation of reasons for unmet need in the EU-SILC data. Respondents are given three options, with unmet need being attributed to cost, travel distance, or waiting lists. These map nicely onto the three broad categories identified in the Expert Panel's earlier report. Thus, cost equates to affordability, travel distance captures aspects of availability, and waiting time is a key dimension of user experience. The Expert Panel believes that all of these are important and should be monitored at a European level, although the importance on individual measures will vary among Member States depending on the progress they have made previously and what still needs to be done. We will now consider each of these in turn.

Before doing so, it is however, necessary to reflect upon the point at which need is considered to have been met. For the patient, this is relatively straightforward, as it is the point at which the condition is cured or symptoms alleviated, even if the ultimate



outcome is death. However, there are enormous practical difficulties in operationalising this for routine measurement. Instead, it is more usual to define needed as having been met when the patient has made first contact with the health system. It is, however, fully recognised that this is a very incomplete, and arguably irrelevant measure of met need, even more so at a time when interactions with health system are assuming many non-traditional forms, including via the Internet.

This is an issue that will require further consideration. Thus, the growth of chronic disease and multi-morbidity means that many patients will be on a prolonged journey through the health system, and for them, the crucial question will be the extent to which their needs are met at each point on that journey. The challenges are often exacerbated for those with mental health or social care needs. It is not clear, however, how this can easily be addressed in a consistent way using survey data. There is potential to use administrative data on regular contacts with patients at all levels of care for the purpose of following the patients' journey within the health care system, at least in systems where there are unique personal identifiers that are used consistently.

A related issue is the quality of care that is provided. This also raises the issue of asymmetry of information. Thus, a patient may have achieved access to a health professional who will provide reassurance that they either do not need treatment or the treatment they are provided with is adequate, yet in practice that treatment is far from adequate. The patient may consider that their need has been met even though it has not been.

### **3.10.1. Affordability**

The episodic nature of health care, whereby most people require care only occasionally, but when they do, it may be extremely expensive, is quite different from consumption of other goods, such as food. Consequently, a comprehensive picture of affordability involves an understanding of how much is spent regularly to ensure access to care, for example through insurance premia, how much is paid for each episode of care, for

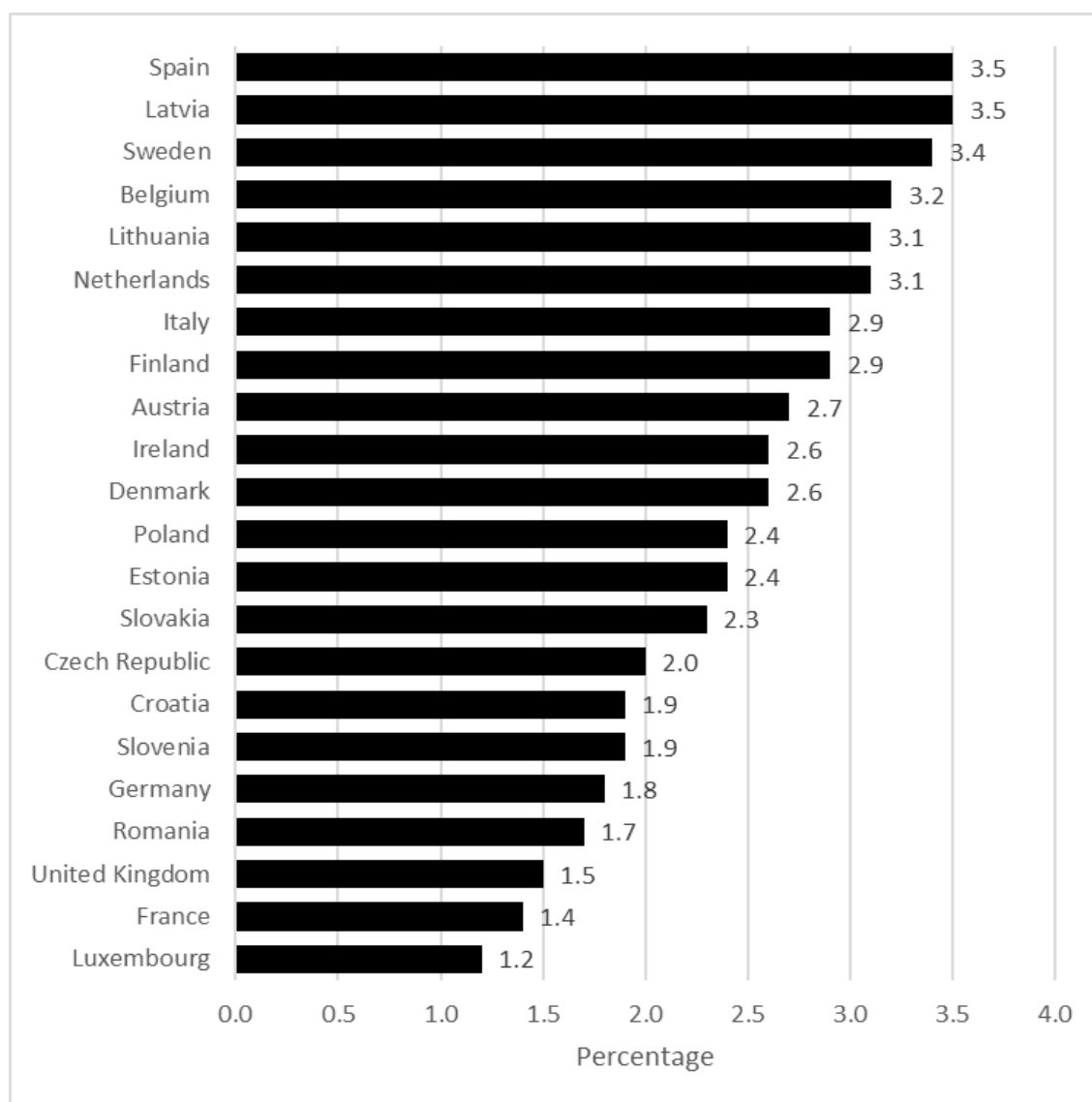
example, payments for consultations or medicines, and the economic impact of severe illness, usually measured as catastrophic expenditure. Some of these measures are, to some extent, measurable and, in some cases, are already incorporated in routine statistics.

There are, however, substantial problems with all of them. First, the amount paid for health care may be concealed within overall taxation. Given that government revenues in countries with national health services are derived from many different sources, it is not simply a matter of taking the share of expenditure for health as a fraction of, for example, income tax. Moreover, in countries with universal coverage, those who are unable to afford regular payments for health care will usually receive additional support through the welfare system. However, for the present purposes, the very existence of a prepayment system will increase the probability that a need will be met. Consequently, it is reasonable to focus attention on the other elements of expenditure on healthcare.

Co-payments are similarly complex. Often, they vary, according to the type of service provided or the medicines received. There are very frequent exemptions. Thus, in Portugal, where there have been considerable changes in the co-payment regime in recent years, the net result is quite complex because of the extent to which exemptions for some have compensated for higher payments by others (Legido-Quigley, Karanikolos et al. 2016).

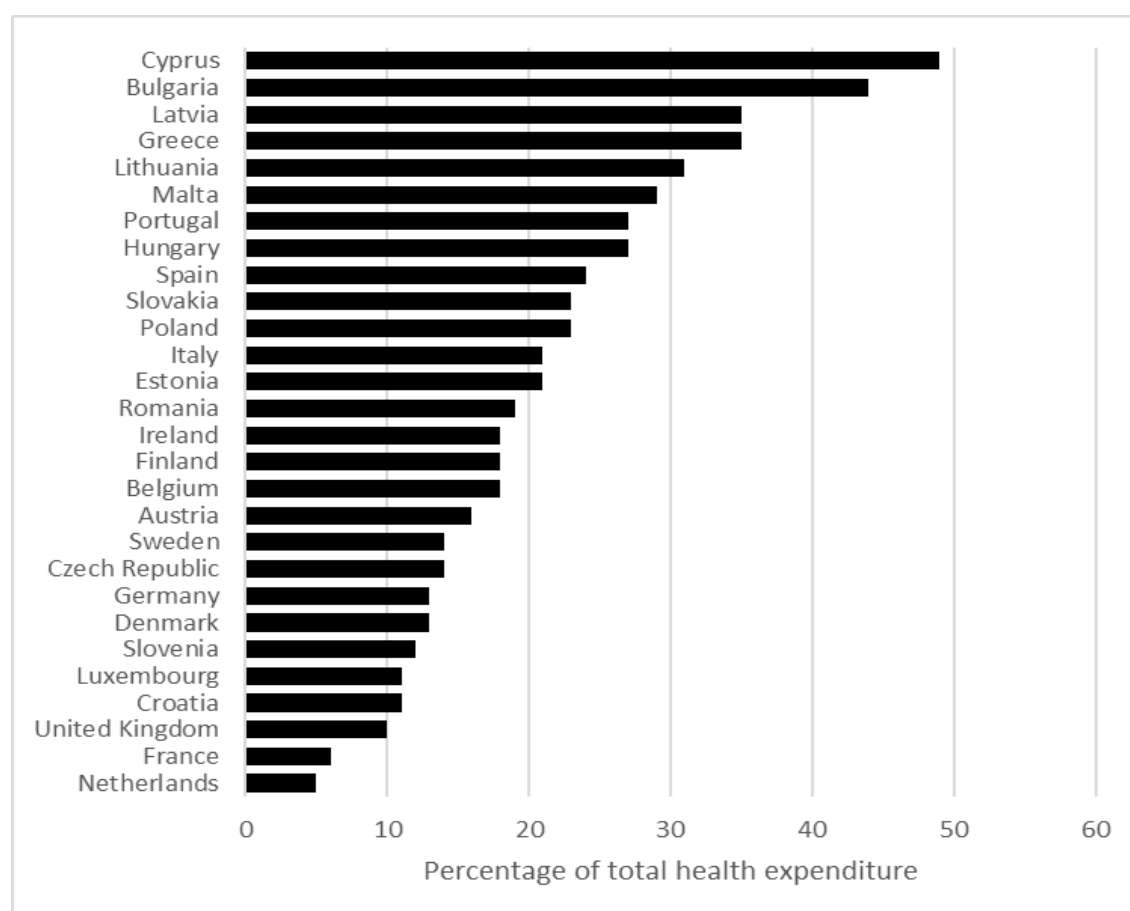
The OECD define household out-of-pocket expenditure on health as comprising expenditures borne directly by a patient where insurance does not cover the full cost of the health good or service. They include cost-sharing, self-medication and other expenditure paid directly by private households. In some countries, estimations of informal payments to health care providers are also included. Using this definition, the figures for 2015 range from 6.8% of total household expenditure in France to 41.6% in Latvia (Figure 3.9).

Figure 3-9 Out-of-pocket expenditure as a share of final household consumption



Source: OECD

**Figure 3-10 Out-of-pocket expenditure as a share of total health expenditure**



Source: OECD

The interpretation of out-of-pocket payments can be problematic. For example, an individual with private health insurance who visits a specialist several times will have their needs met but may incur high out-of-pocket payments (as will also be the case when significant user charges exist in a publicly funded National Health Service). In contrast, an individual who never visits a doctor will have zero out-of-pocket payments but, if ill, may have a high level of unmet need. Out-of-pocket payments are the result of very different institutional arrangements in terms of public-private mix on both funding and provision. There is also the issue of informal payments, some of which may take the form of gifts of things that cannot easily be monetarised (Gaal, Belli et al. 2006). There are also large differences in the elements that make up out-of-pocket payments. For example, data from 2014 show that the share contributed by spending on pharmaceuticals ranges from 16% in Luxembourg to 75% in Romania (OECD 2016).

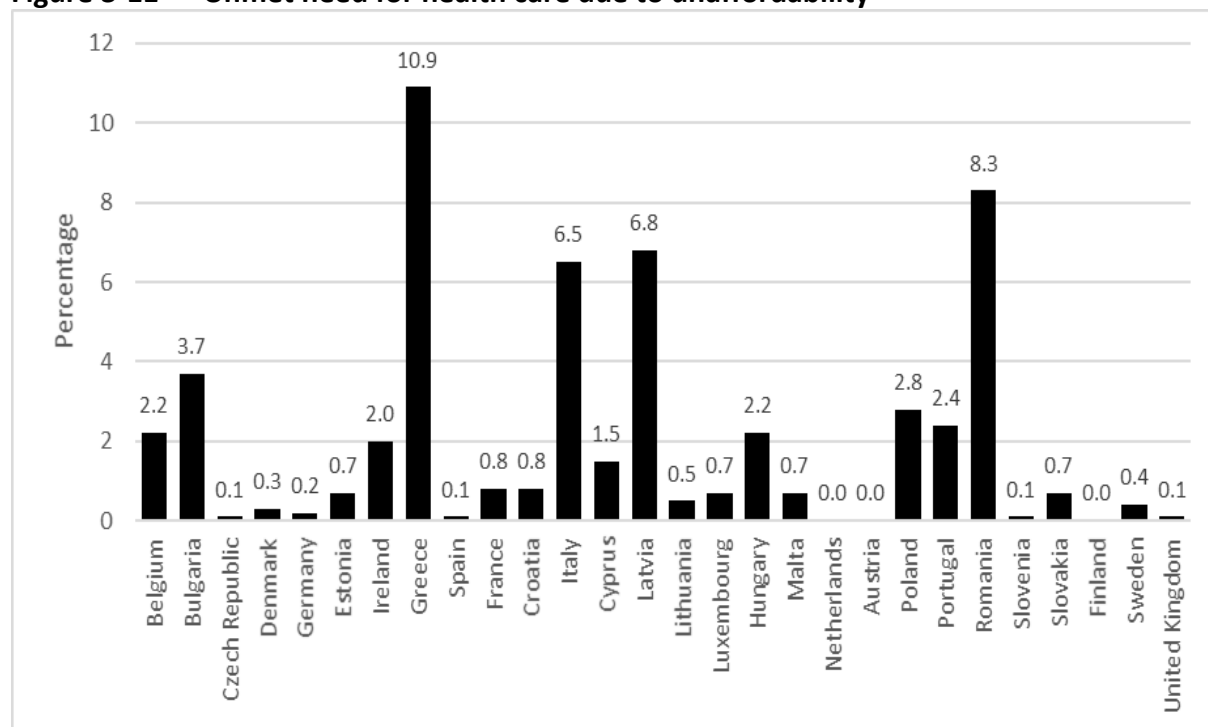
Thus, they represent a useful indicator but only if combined with a good understanding of the diverse institutional settings in which they originate.

The third element is catastrophic expenditure. Yet, although this measure is often used in international comparisons, it is more problematic than is sometimes recognised (Xu 2005). First, survey questions vary in asking about different periods in which catastrophic expenditure occurs, with some using a period as short as one week but others up to one year. Second, surveys typically miss those households that forgo treatment because it is unaffordable, thereby avoiding what would otherwise be catastrophic expenditure. Third, although less directly relevant here, illness incurs costs other than direct monetary ones, for example through loss of earnings. Nevertheless, the share of catastrophic out-of-pocket payments in household consumption can be considered as a means to reveal limitations in access to healthcare due the financial hardship resulting from out of pocket payments.

In practice, data on catastrophic expenditure are not routinely available in all Member States. They are usually derived from family budget surveys, typically collected every five years, although with inconsistencies across countries. If used, a number of alternative definitions would need to be explored (e.g. payment as ratio of non-food expenditure, income or wealth).

We suggest that affordability as a potential cause of unmet need should be addressed through i) the EU-SILC data which ask about whether unmet need was due affordability; and ii) out-of-pocket payments combined with a clear description of the institutional arrangements that pertain and differences in how the data are collected in each member State. Figure 3-10 illustrates the potential for using the EU-SILC data, showing the percentage of respondents reporting unmet need for health care in 2015 due to unaffordability by Member State.

Figure 3-11 Unmet need for health care due to unaffordability



Source: calculated from EU-SILC data

### 3.10.2. Availability & Accessibility

Availability relates to the existence of facilities that provide services that can meet the needs of potential patients. Again, this is potentially extremely complicated, as patients with complex needs will require highly specialised facilities. Consequently, pragmatically, it seems reasonable to consider availability as the existence of facilities meeting some basic level of provision, such as primary care clinics. Availability has several dimensions, spatial, temporal, and formal. Thus, there is a well-known gravity effect, whereby rates of attendance at health facilities fall off markedly with increasing distance. This is a non-linear relationship, approximating to the well-known adverse square law, although there is some variation according to the nature of the needs being met (McKee, Gleadhill et al. 1990, Jordan, Roderick et al. 2004). However, to complicate matters, distance can be measured in several ways. These measures range from the simple straight line between the patient’s home and a facility, the so-called crow fly distance, to travel time, which varies according to the means of transport available to the individual. Thus, a facility that may appear close for someone with their own car may be relatively inaccessible for

someone dependent on public transport, while in some remote areas, as in Finnish Lapland, it may be quicker to fly to the capital than to drive to the nearest tertiary hospital. It should also be noted that, in some cases, people may be willing to trade what they perceived to be the advantages of living in a remote rural area for access to healthcare. However, this highlights the need for information on unmet need to be interpreted in the light of evidence on the travel distances of the population from major settlements in some countries. A further complication relates to the starting point for the potential patient. Individuals live their life in complex spaces, encompassing home, work, and leisure locations. A facility that is close to them at one point in the day may be distant at another (e.g. while the individual is at work). Conversely, a facility close to where they live may yet be inaccessible at night if it is only open during working hours. This leads onto the next point.

The temporal dimension relates to when the facility is open. Thus, in Greece, reductions in opening hours of clinics were associated with a significant increase in unmet need for care (Kentikelenis, Karanikolos et al. 2014).

Opening hours should ideally relate to when services are needed, so while emergency care facilities should be open twenty-four hours a day, routine clinics need not be.

The formal dimension relates to the extent to which services are open only to those with particular characteristics. This may be insurance status, occupation, or some other parameter. This may be relevant for some groups such as homeless people, the long-term unemployed, undocumented migrants, people with severe and chronic mental disorders, and people with disabilities.

Measuring the number of facilities across countries is unlikely to be a good measure of a cause of unmet need. A smaller number of large facilities might provide higher quality if they benefit of scale and scope economies, and learning-by-doing effects due to larger volumes, although the literature on the relationship between hospital volume and outcome is complex (McKee and Healy 2002). There are also definitional issues to obtain meaningful comparisons of facilities availability across countries. It is also necessary to

take account of appropriateness, as not all facilities will be able to offer care for every health need.

Availability could also be captured by a measure of the comprehensiveness of the basket of health services covered in each Member State, but such measures are likely to be multidimensional and difficult to quantify, making it challenging to and collapse them into a single measure (Schreyogg, Stargardt et al. 2005).

We, therefore, suggest that availability as a potential cause of unmet need should be addressed through the EU-SILC data, as these ask about whether unmet need was due to availability. Other existing proxies from existing data collections at member country level (e.g. OECD Health at a glance) could be used (e.g. beds per capita) but are an imperfect measure of availability (thus, hospital beds per capita become less meaningful due to increases in day surgery and ambulatory care).

### **3.10.3. User experience**

User experience is also a multidimensional construct. It is subject to numerous biases and is time dependent. Thus, a service perceived as unacceptable immediately after it was received may be reassessed more favourably later, and vice versa. It covers all aspects of the care provided, including both clinical interventions and what might be described as customer experience, such as the extent to which the patient is welcomed to the facility, the quality of the facility, encompassing such issues as ease of navigation around it, comfort, choice and quality of food, and facilities for friends as well as relatives. It also includes the extent to which patients' preferences are taken into account. This is especially challenging. While there is a growing consensus that the decision to intervene should be taken jointly by the patient and their health provider, or increasingly, multidisciplinary team of providers, based on the provision of appropriate information, there are also some patients that would prefer that the choice be taken for them. Clearly, it is important that all those involved in such decisions find the right balance.



Methods to evaluate user experience have been developed and implemented, such as the “friends and family” test in the NHS in England. This asks patients whether they would recommend a health facility to their friends or family. It draws on the use of this question in surveys of hotels, restaurants, and the like. From the outset, this measure faced considerable criticism because of the obvious difference between healthcare and use of leisure facilities. Subsequent research has shown that it has many flaws, with responses differing by age, gender, and mode of administration, while in practice, it can be difficult to obtain satisfactory response rates (Sizmur, Graham et al. 2015).

These considerations make it challenging to operationalise the concept of user experience. However, it can be considered as equating to the measure of responsiveness used in the 2000 World Health Report (World Health Organization 2000). This had several elements, falling into two broad categories. The first category related to respect for persons, including respect for the dignity of the person, confidentiality, and autonomy to participate in choices about one’s health. The second was client orientation, which included prompt attention, communities of adequate quality, including cleanliness, access to social support networks, and choice of provider. All of these factors could, in theory, impact on whether need is met. Thus, a service that is extremely unresponsive will act as a deterrent to potential patients, making it more likely that their need will be unmet. The previous report of the Expert Panel on access to health services noted that:

*“People need to be willing to use available services, and when they use health services, their experience should be as positive as possible because user experience shapes expectations and can influence health care-seeking behaviour in the future. Services that fail to be acceptable to people are likely to be under used, with negative implications for health, efficiency in the use of health system resources and equity in use.” (Expert Panel on effective ways of investing in Health 2016)*

As noted above, the one aspect that is already asked about in the EU-SILC data is prompt attention, or the extent to which need is unmet because of long waiting lists.

However, there may be a case for requesting that additional questions be included in future waves of the EU-SILC questionnaires.

We, therefore, suggest that user experience as a potential cause of unmet need should be addressed through the EU-SILC data which ask about whether unmet need was due waiting time, which could be further complemented or validated from OECD data collection on waiting times from administrative data (Siciliani, Moran et al. 2014). Care is required in defining the indicator. In a health system, there may be several waiting times: waiting time for a first appointment, waiting time after receiving a decision to undertake surgery, the sum of all relevant waiting times (as restricting access to primary care helps waiting times for surgery as less people reach that stage), etc.

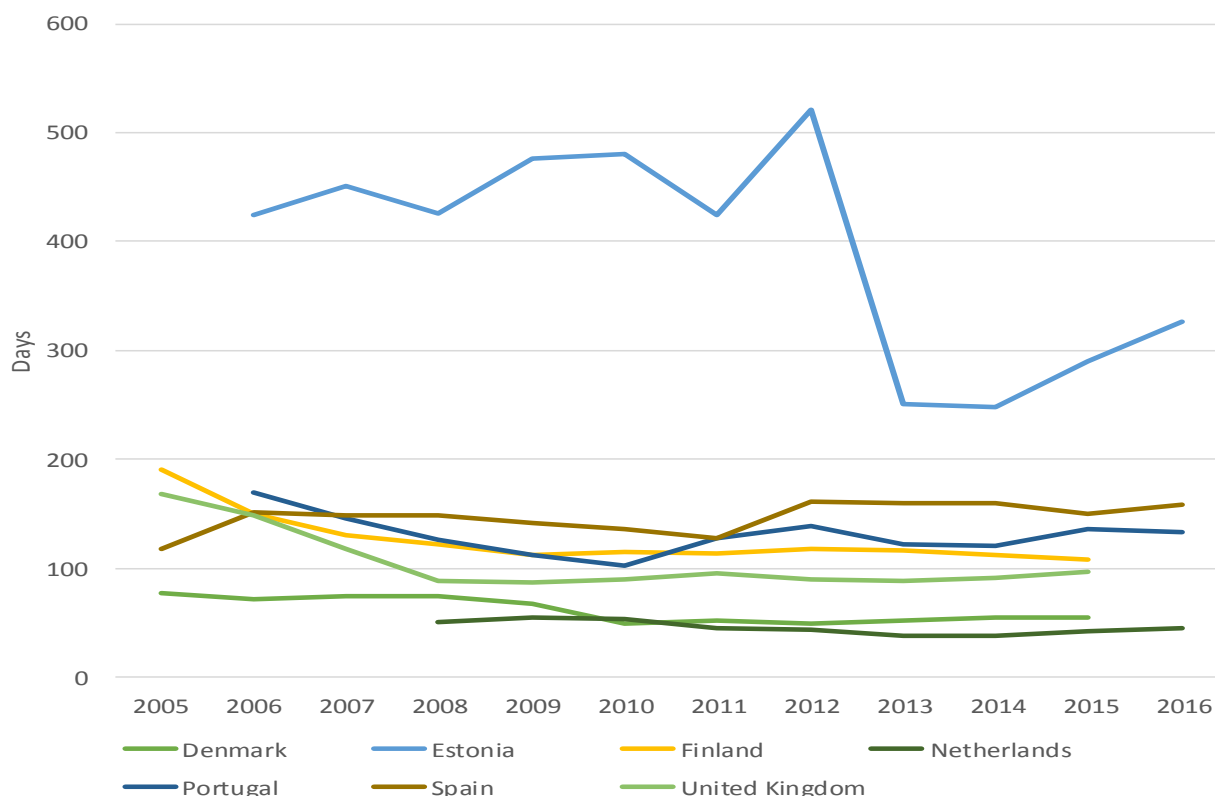
### **Box 3-4      Waiting times for non-emergency treatments across the EU**

Waiting times for non-emergency treatments (such as hip replacement, knee replacement, and cataract surgery) have been reducing in the recent years in some countries.

Figure 3-12 provides the inpatient median waiting times for hip replacement (from addition to the list to treatment by a specialist) over the period 2005-2015 across 15 countries. The United Kingdom and Finland have experienced significant reductions in waiting times between 2002 and 2010 by combining maximum waiting time guarantees with sanctions for failure to fulfil the guarantee (Siciliani, Moran et al. 2014).

The data are from administrative sources and are representative of large populations of patients receiving a specific non-emergency treatment. Countries differ in key reported indicators. For example, some countries report the mean waiting times, while others only the median. Moreover, some countries report the waiting time of patients "on the list" at a point in time (e.g. every quarter), while others report the waiting time of patients who have been "treated" in a given year (as in the figure below); these will give different representations of the waiting time phenomenon (Dixon and Siciliani 2009).

**Figure 3-12 Median waiting time (from specialist assessment to treatment) for hip replacement**



Source: OECD Health Statistics (2016)

### 3.10.4. Inequalities & Inequities

As will be clear from the preceding discussion, to be relevant, measures of unmet need should capture both the absolute level and distribution within a population. There are different approaches to measuring inequalities. The first is a simple mathematical approach, looking at the degree of dispersion of a measure without any presupposition as to the underlying reasons. There are a number of statistical approaches, such as the sum of differences between all pairs of variables or the sum of absolute differences from the mean value (z-score). This approach has the advantage of being applicable in all settings but the limitation that it says little about the reason for the degree of dispersion. The second involves pre-specifying those characteristics of subgroups within the population associated with differences in unmet need. Reflecting the findings presented above, these are likely to include age, gender, income, and education, as well as, almost certainly, ethnicity. The difficulty arises when conducting international comparisons.

Other than age, gender, and education, few are consistently collected across countries. Moreover, the characteristics of interest may vary from one country to another. Thus, language or ethnicity may be of particular interest in one country but much less so in another. A further problem arises as some of the categories may be quite heterogeneous. Thus, some standard employment groupings may include people with quite different experiences. Ethnicity is particularly problematic. Thus, there may be considerable differences in the experiences of individuals from groups of neighbouring countries, as is the case with Indians, Pakistanis and Bangladeshis in the United Kingdom. Certain statistical problems may arise if the relative size of the categories varies greatly. Thus, where two categories of people form the top and bottom 2% of the distribution in a population, the distance between them will inevitably be much wider than in a country where they form the top and bottom 20%. A further problem relates to the issue of intersectionality, or the interaction between variables such as gender and ethnicity or religion (Bauer 2014).

There are number of approaches in the literature measuring inequalities in health and healthcare utilisation (Wagstaff and Van Doorslaer 2000) that can be usefully adapted to the context of unmet need. To measure absolute inequalities within each country and compare across countries an approach based on the Lorenz curve could be used, plotting unmet need (ranked in increasing order) against the cumulative proportion of unmet need. This approach has been used for example to measure health inequalities (as measured by mortality or self-reported health). A regression-based approach could be used to decompose the inequalities as a function of different determinants.

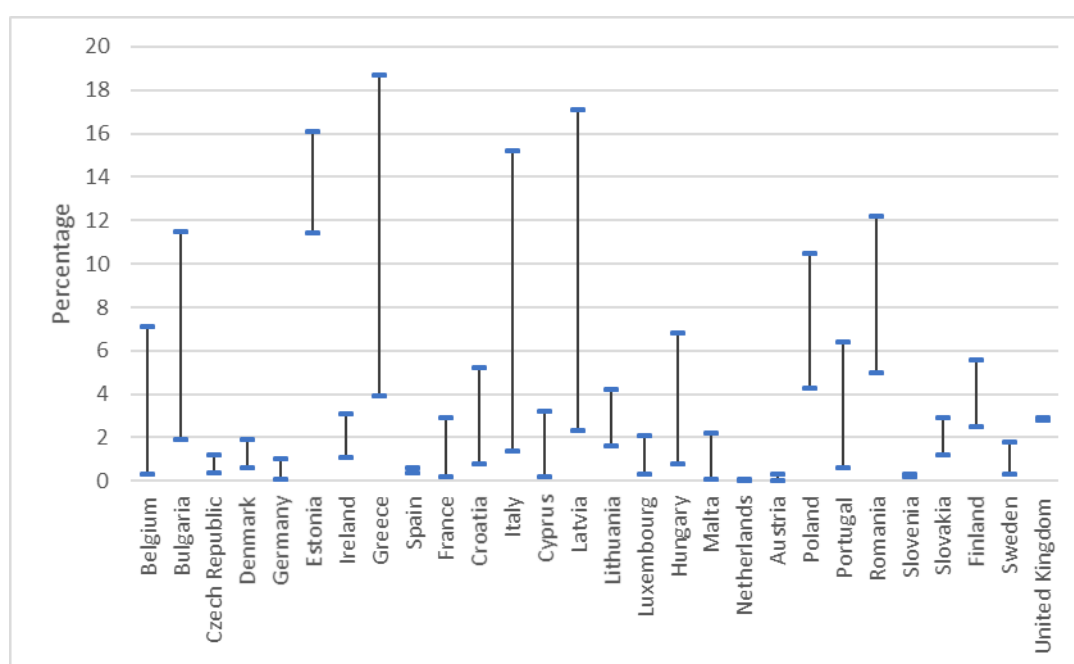
An alternative approach is to measure inequalities in unmet need along a specific dimension (e.g., socioeconomic status). An approach based on the concentration curve could be employed, which plots socio-economic status in increasing order against the cumulative proportion of unmet need. A curve above the diagonal would suggest that individuals with low socio-economic status have a higher share of unmet need. A regression-based approach could be used to measure and test for the presence of socio-

economic inequalities in unmet need. In its simplest formulation, this would involve regressing unmet need against socioeconomic status either for each country or for all countries (interacting socioeconomic status with country dummies). This regression approach would also give the option of taking account of certain variables (e.g., age and gender), providing a measure of socio-economic inequalities in unmet need which controls for populations characteristics. In contrast to the evidence on socio-economic inequalities in utilisation, it is not necessary to control for need (most often proxied by self-reported health) since this is already encompassed in the concept of unmet need (though the approach only holds if different individuals within and across countries perceive unmet need in the same way, which may not necessarily be the case). If unmet need is perceived differently, the inclusion of objective measure of need, e.g. morbidity or mortality may alleviate the problem but may suffer from reverse causality bias with unmet need affecting mortality and morbidity. The regression approach requires a more sophisticated analysis than is required if only collecting statistics and making them available. An unresolved issue is who will be responsible for producing such regression analysis.

The evidence has generally focused on inequalities (differences) or inequities (differences that are unfair) in either health or utilisation (health care). The focus on unmet need is different since it blends both aspects of health, with poorer health increasing unmet need, and utilisation, with better access to healthcare reducing unmet need. The distinction between fair and unfair inequalities however remains. For example, countries differ in the public-private insurance mix, with some countries having duplicative private health insurance (e.g. in Italy, Spain and the UK) with patients with private health insurance being able to get treatment after shorter waits and able to choose their doctor. Some might argue that differences in unmet need by socioeconomic status due to richer individuals holding voluntary private health insurance is not considered unfair, even while agreeing that differences in unmet need by socioeconomic status within a National Health Service is unfair.

We suggest that these approaches are explored in future work. Meanwhile, descriptive statistics of unmet need as experienced by certain groups, whose characteristics should be subject to political discussion, can be reported for a range of dimensions and for each Member State (so that for each dimension Member States can be compared along key dimensions of inequalities). The scale of inequalities is illustrated in Figure 3-11, which takes one of the simplest analyses, disaggregating individuals by income quintile.

**Figure 3-13 Percentage of respondents reporting unmet need due to care being too expensive, too far to travel, or long waiting list, by income quintile (2015)**



Note: In each case the poorest income quintile is the highest value and the richest is the lowest

Source: calculated from EU-SILC data

It should also be noted that inequalities may be higher in countries where unmet need is higher, and may reduce when the overall level of unmet need is reduced. An alternative indicator is to produce simple inequality indices which standardise for the level of unmet need (e.g. the coefficient of variation).

### **3.11. Proposals for additional data collection**

The EU-SILC data have many strengths, especially that they already exist and have done for over a decade, providing a meaningful baseline against which to assess future developments. However, as described previously, they also have many weaknesses, including their restricted coverage, especially of some groups who are most vulnerable to unmet need, and their relatively few variables that can shed light on the nature and reasons for unmet need. Consequently, we consider it necessary to make proposals for investment in additional data sources that can inform policy and practice in the future. These fall into three categories. The first include those resources that already exist in one or more Member States but could, with additional resources, be extended to all. Among them is the Survey of Health, Ageing and Retirement in Europe (SHARE). This collects detailed data on many aspects of the lives of participants aged 50 and over in several Member States and has been an invaluable resource for understanding the health needs of ageing populations. As an example, SHARE data from France and Ireland were used to compare the extent to which formal and informal care substituted for each other (Gannon and Davin 2010).

The second include those that are already in place in all Member States but which could be strengthened. The most obvious example is the EU-SILC, which contains few questions related to health need. While recognising the constraints imposed by participant fatigue, we propose a review of the variables currently collected to identify a small number of additional variables that could inform the quest to reduce unmet need. In particular, it will be important to improve the availability of data on mental health, and on unmet need for care of those with mental disorders. Another priority is to enhance mechanisms for collecting data on the most marginalised populations, groups whose characteristics will differ among countries, but who are often excluded from surveys, including, as already noted, the EU-SILC.

The third category includes resources that do not currently exist or do so only in an *ad hoc* form. These might include the regular use of studies of so-called tracer conditions,

for which the experience of patients captures the many potential barriers to accessing and achieving continuity of care. This has previously been applied mainly in middle income countries, using conditions such as diabetes (Balabanova, McKee et al. 2009, Kuhlbrandt, Balabanova et al. 2014) and hypertension (Risso-Gill, Balabanova et al. 2015), but could be adapted to use in European countries.

### **3.12. Policies to reduce unmet need**

Logically, these policies should follow the framework already set out, in that they should address affordability, availability, and user experience. This would suggest that we review briefly the evidence on out-of-pocket payments and unmet need.

#### **3.12.1. Affordability**

The Expert Panel's previous report noted the existence of variation in the benefits package in different Member States. It seems likely that these differences could contribute to differences in unmet need, for example where a particular service is excluded from the benefit package.

That report also looked at user charges, noting how these also varied among Member States. There were three reasons for applying user charges. The first is to limit access to health care as a means to contain public spending on health, even though this may transfer costs to the individual. The second is to direct patients towards more cost-effective services, and the third to raise revenue for the health system. As was noted, there was little evidence to support any of these and the lack of a strong evidence base for user charges was noted. It seems reasonable to argue, on the basis of the available evidence, that user charges should, wherever possible, be eliminated for several reasons. First, they often cost as much to collect as they raise in revenue. Second, they are often highly regressive, and measures to reduce this, such as exemptions, create significant complications in operating the system. Third, they do not differentiate between necessary and unnecessary care in deterrent effect. There is, however, one possible exception. This is that they could be used to influence behaviour where the



patient is faced with a choice as to how or where to obtain care. Thus, a charge may sometimes be appropriate to deter patients from buying unnecessary drugs or encourage patients to attend primary care facilities rather than direct attendance at specialist facilities. However, even here, it is important to look at the reasons why patients go to a less appropriate setting, which may reflect geographical, temporal, or other barriers to accessing primary care. A related, but more difficult issue is that of informal payments, as noted above. These are widespread in some of the new Member States. They have been understood as a means of informal exit from the health system, or “inexit” (Gaal and McKee 2004). This follows from the work of Hirschman, who argued that discontented users normally have two options, exit and voice (Hirschman 1970). However, under communism these systems offered neither, requiring a third option. The report noted that the most promising means of eliminating them was to take a comprehensive approach, involving adequate funding for the health system and greatly strengthen governance.

### **3.12.2. Availability & Accessibility**

While noting the complexity involved in measuring access to health facilities, set out above, policies to improve it are likely to involve ensuring that the distribution of facilities matches that population. However, this poses a problem, because of the existence of economies of scale and scope. Thus, all health facilities require a critical mass and baseline level of activity to be viable, both in financial terms and in maintaining the expertise of those who work in them. The size of the critical mass will increase with the degree of complexity treatment being provided. In other words, there is often a trade-off in places where the population density is low. There are a number of imaginative solutions that can overcome this, many in use within the EU. They include the use of remote technologies, such as telemedicine (Saliba, Legido-Quigley et al. 2012), and of shared use of facilities across national borders (Legido-Quigley, Glinos et al. 2012). Thus, it is important to ensure that any surveys recognise that the nearest facility may be in a neighbouring country, although clearly this is only of relevance if

patients are able to cross the border to use it. There may, in some cases, be specific factors to consider, such as cross-border sharing of obstetric facilities, which can work well in some settings (Kiasuwa Mbengi, Baeten et al. 2014), but may create problems where the Member State in which a child is born may have implications for his or her nationality.

### **3.12.3. User experience**

Although discussion of the measurement of user experience focused on waiting times/lists, as noted above, responsiveness involves many other dimensions. Thus, for a service to use, it will be necessary to pay attention to all of them.

### **3.13. Scope for action**

In the report of the Expert Panel on Effective Ways of Investing in Health on "Access to Health Services in the European Union", actions to ensure equitable access were reviewed, summarizing national and EU-policy responses (Expert Panel on effective ways of investing in Health 2016).

The report dealt with 8 dimensions, summarised below. The bullet points, which are based on the evidence in the earlier report and that reviewed previously in this one, are addressed to national and sub-national authorities, the precise nature of which will vary according to the institutional architecture of the health system in question. In each case we also make tentative suggestions about where there may be scope for European Union action to contribute added value, while stressing that each of these suggestions required much more detailed discussion than is possible here. In most cases, the rationale for including them was set out in the previous report.

#### **Financial resources are linked to health need.**

- countries with low levels of public spending on health should allocate a higher share of the government budget to the health sector;

- the availability of public funding for health should be linked to population health needs, especially during economic down-turns;
- public funding should be used for services that are evidence-based;
- sub-national resource allocation formulas should be reviewed regularly to ensure that they keep pace with changing situations;
- provider payment that links payment solely to inputs is undesirable.

The European Union already supports exchange of best practice in many areas, including data collection, helping countries to develop secure and confidential systems of record linkage and development of the expertise to make maximum use of the information so provided. These existing activities offer potential for further development.

### **Services are affordable for everyone.**

- ensure most health system funding comes from public rather than private sources, identifying gaps in publicly financed coverage of cost-effective services;
- keep out-of-pocket payments as low as possible;
- encourage broadening of the basis for entitlement, where there are obvious gaps;
- move away from discriminatory approaches such as entitlement linked to employment status or payment of contribution or situations in which people with different diagnoses are entitled to different benefits (inequity by disease);
- review user charges to ensure that they do not create financial barriers to cost-effective services or undermine financial protection;
- as fiscal and social protection policies are critical to address poverty and income inequality, encourage intersectoral cooperation and integrated health, social, education and employment services.

The European Union could expand the scope of the EU-SILC data to include proxy measures of financial protection and could provide methodological support, in particular to develop comparable standards, for health-related aspects of household budget

surveys. Ideally, these would be extended to look specifically at protection against the risk of catastrophic expenditure.

### **Services are relevant, appropriate and cost-effective.**

- ensure the publicly financed benefits package covers the full spectrum of services, and is correlated with population health needs and does not result in inequity by disease;
- take steps to avoid over-medicalisation;
- support the development of evidence-informed public health policies, including health promotion and disease prevention approaches, interventions and monitoring;
- put in place systematic priority-setting processes to enable HTA-informed, cost-effective coverage decisions for both new and existing technologies;
- develop clinical guidelines and referral systems, adapt guidelines to meet the needs of people with multiple morbidities and monitor adherence to guidelines;
- establish information systems to identify (and publicly report on) practice variations and patient outcomes and to support effective decision making by health professionals and patients;
- develop and implement innovative payment systems that optimise the effectiveness and efficiency of health systems.

The European Union has already done much to promote these actions, especially through the Horizon 2020 research programme and its predecessors, but also through initiatives in areas such as information technology and those carried out by projects such as EUnetHTA. All of these offer scope for further development.

### **Facilities are within easy reach.**

- create administrative structures that can take a population-wide perspective and that have the managerial tools required for capacity planning;
- engage in area-level planning to create networks of dispersed facilities feeding into central ones, based on agreed clinical pathways;
- develop mechanisms to facilitate the transport of patients to health facilities or health professionals to patients.

The European Union has already done much to improve access, through its structural funds, arrangements for cross-border care (especially as border areas often have low population densities) and European Reference Networks. All of these initiatives offer further potential.

### **There are enough health workers, with the right skills, in the right place.**

- put in place processes to train adequate numbers of health workers with the necessary skills to meet population needs;
- ensure an appropriate mix of skills is in place, taking account of the national context. this may require investment in additional administrative or care staff to relieve pressure on specialised health professionals, the development of specialist nurses, or task shifting, and competency-sharing with delegation of certain roles to less specialised staff where this can be clearly shown to be beneficial to patients;
- establish working conditions designed to retain staff in underserved countries and areas: remuneration commensurate with skills and attention to broader working conditions, including access to peer support and continuing professional development.

The European Union could support improvements on the collection of data on health worker functions, remuneration and working conditions. It could promote ethical

practices in international recruitment in line with the WHO Global Code of Practice on the International Recruitment of Health Personnel.

### **Quality medicines and devices are readily available.**

- Member States can benefit from common strategies to enhance access to medicine and devices;
- instruments are available, or should be made available, to improve negotiations between public payers and innovators for new medicines;
- dialogue between member states and stakeholders should explore ways to reward R&D investment fairly but efficiently;
- creating greater transparency about the costs of pharmaceutical products and the price of medicines would provide better grounds for assessing affordability, equitable access, fairness in pricing and incentives to develop new medicines;
- strengthening access to off-patent and new medicines requires a comprehensive approach;
- improve information systems and data collection at regional, national and EU level.

The European Union could support existing initiatives to support improved approaches to procurement of medicines, based on transparency of prices. This will be a priority of the forthcoming Austrian Presidency. It could also encourage cooperation between Member States in the development of e-health solutions and information exchange between authorities and agencies across Member States.

### **People can use services when they need them.**

- there is a need to enhance the evidence base for strategies to improve health literacy and empower service users;

- it should be ensured that people have access good information about health services in their own language and have access to translation or interpretation services when required;
- culturally sensitive and appropriate services should be strengthened (cultural competence);
- specify and adhere to maximum waiting times; differentiate waiting times by severity of illness;
- individual health facilities can and should take a wide range of relatively straightforward steps to make existing services more easily accessible to the general population and to meet the needs of people with physical and intellectual disabilities.

The European Union could support efforts to harmonise definition and data collection for waiting list/time indicators. It could also contribute to set and enforce standards for disabled access in all facilities, including those delivering healthcare.

### **Services are acceptable to everyone.**

- improve the communications skills of health workers, including transcultural aspects;
- conduct regular national surveys of user experience of the health system, following good practices in countries such as Denmark, Spain, Sweden and the United Kingdom.

### **3.14. Proposals for qualitative measures**

Given the complexity of unmet need for health care and its many causes, the indicators discussed above can never be more than that, simply indicators. Even the secondary indicators will only go so far in explaining differences in unmet need. It will be necessary to supplement these measures with additional information, in order to be able to assess the indicators appropriately and, potentially, to move from indicators to policy action.

Such information must take account of the particular national context. Thus, unmet need due to distance from facilities should be understood differently, and reacted to differently, in, for example, Luxembourg, than in Northern Sweden.

We propose development of a self-assessment tool, based on the concepts of affordability, availability, accessibility, and user experience as used above. Such a tool would need to be designed in a way that captured policy relevant inequalities within each country, the structure and operation of health systems, and other national specificities. These may influence the operationalisation of items like 'user experience', affordability, inequality and the population included. An example is the definition of 'necessity of treatment' in the Netherlands, which is used in prioritisation of interventions for funding (Rappange and Brouwer 2012).

Importantly, we do not advocate the adoption of a standard approach for use everywhere, because the issues to be addressed vary. Thus, while research by Eurostat using EU-SILC data has demonstrated some general patterns in the correlates of unmet need across Europe, such as greater unmet need by those with lower incomes, who are older, or who have less education, there are also quite a number of exceptions (Eurostat 2017). For example, reported unmet need is actually lower among older people in France and Sweden.

Importantly, there are many groups who are not identified separately in EU-SILC data who are known, from other research, to be especially disadvantaged in obtaining access to care. These include certain ethnic or religious minorities, or those living in certain remote areas. It is, however, essential to recognise the complexity of the situation. Thus, while some ethnic minorities may be disadvantaged, others may not be, depending on factors arising from the characteristics of the minority concerned, including their degree of assimilation, their pattern of educational and employment status, their language ability, and the presence or absence of cultural barriers, as well as factors related to the provision of health services, including the scale and nature of



discrimination and the availability of culturally appropriate services (Rechel, Mladovsky et al. 2013).

The development of such a tool would involve: (i) defining access and its constituent elements, (ii) setting standards for its measurement, setting objectives for achievement in access to health care, (iii) interpreting data on access, (iv) qualitative research on access and (v) developing policy recommendations to improve access in general or for specific groups. We envisage that the approach would be iterative, starting from data on levels and determinants of unmet need from EU-SILC data, but also from research undertaken in the Member State concerned. Member States must thus determine whether the dominant concerns relate to access in general or for particular groups or to certain services. These will vary, geographically and over time.

Monitoring access to health care in itself is of limited value if not accompanied by the development of responses that are evaluated, and a willingness to act upon the findings.

Hence, for the qualitative framework, we urge national governments to perform a self-assessment. A possible outline is as follows:

- a) a preamble with a statement on general policy goals in relation to (access to) health care;
- b) a summary of those groups that are likely to be disadvantaged. This should be based on a systematic analysis of characteristics that may give rise to disadvantage. A possible list, although not exhaustive, would include age, gender, education, income, disability, health status (especially the presence of mental illness), geographic location, homelessness, ethnicity, and religion. It should also consider intersectional issues, such as where being female of a particular religion may be especially disadvantageous;
- c) overview of the rights (both in terms of entitlements and effective execution of rights) of access to healthcare according to occupation/employment status. This analysis should include groups that are stigmatised, such as sex workers, and

those in informal employment who are especially vulnerable. A particular emphasis should be placed on self-employed people and those in non-standard forms of work, taking account of the multiplicity of new types of contracts (in particular: casual work, involuntary part-time work, platform work, domestic workers, temporary agency workers). The analysis could integrate EU SILC data on unmet needs for self-employed people (in 2015, of those self-employed 55% were more likely to experience unmet needs than employees) as far as non-standard forms of work are concerned, it should look at legislative solutions in place and conditions for effective execution of rights to healthcare (identifying possible barriers resulting from contractual conditions, non-compulsory insurance schemes, non-adherence to insurance due to affordability or financial hardship, etc);

- d) a review of data, from EU-SILC and national surveys, including those targeted at particular groups, of published literature on access to care, and from other sources, including reports by civil society groups. We encourage the use of ad hoc studies to understand the barriers experienced by particular groups. These could draw on More detailed analyses could draw on previous research using tracer conditions, as mentioned above, that seek to capture the barriers facing patients as they seek to access and achieve continuity of care (Balabanova, McKee et al. 2009, Kuhlbrandt, Balabanova et al. 2014, Risso-Gill, Balabanova et al. 2015);
- e) an analysis of gaps in the available knowledge and an agenda for research;
- f) proposals for actions to address the problems identified. These could usefully be formulated according to a standard set of headings (Box 3-5).

### **3.15. Migrants**

As has been noted in several places in this opinion, there are particular challenges in obtaining data on migrants, and especially those who are undocumented. One important source of information on policies related to these groups is the MIPEX project. While it

does not include measures of met and unmet need *per se*, it does provide valuable information on the policies adopted by Member States that will impact on the extent to which the needs of these especially vulnerable people is being met. Thus, the MIPEX Health strand uses standardised, carefully defined indicators of policies regulating health care for migrants in Europe and several non-European countries. Data are provided by independent national experts and cross-checked by peers. The selection of items is based on the Council of Europe's Recommendations on mobility, migration and access to healthcare (2011), which in turn were based on extensive scientific reviews and consultations. Items focus on issues on which inequities between migrants and non-migrants have been found to arise.

MIPEX contains 4 scales, each containing 6 questions, which may have one or more indicators. (One question had to be eliminated for methodological reasons, so the scale has 23 questions.) Questions are scored on a three-point scale in terms of the equitability of policies towards migrants, using a three-point scale: (1) no effort to avoid inequities; (2) a defined intermediate position; (3) equitable or nearly equitable policies.

- **Legal entitlement to health care** (conditions imposed, extent of coverage) and administrative obstacles to exercising them (documents that are hard for migrants to obtain, discretionary judgements).
- **Accessibility** (information for migrants *and service providers* on entitlements and use of health services; health promotion for migrants; use of mediators to facilitate access; threat of reporting to authorities).
- **Appropriateness and acceptability of care** (interpretation facilities, standards for cultural competence or diversity and training in these, migrant involvement, diversity in the health workforce, adaptation of diagnostic and treatment methods).
- **'Flanking measures' to improve A-C** (data collection and research, 'health in all policies' approach, 'whole organisation' approach, leadership by government, involvement of stakeholders and inclusion of migrant organisations).

Scores are calculated for each scale separately and for the whole questionnaire. Full details of the scale's statistical properties are provided in the Summary Report (International Organisation for Migration 2016). The Expert Panel commends this work and wishes to draw the attention of those involved in preparing and using the reports proposed here to this work.

### **Box 3-5 Checklist for measures to address unmet need**

1. Specify the main reasons for and expectations from the policy intervention. (Explain the reason for particular design and potential evidence for its effectiveness)
2. Which element(s) of access is the policy aiming to improve and how? (Explain the mechanism)
3. For which group(s) in society will the policy improve access? Will these decrease inequalities in access and/or health?
4. What is the expected (health) benefit of the particular intervention?
5. What are the expected costs of the intervention and who will pay these? (Note that besides financial costs this may also include reduced access or health in other areas or groups)
6. What are the main risks of the proposed policy?
7. Are the relevant (patient) groups involved in design of the policy?
8. How and by whom will the results of the policy be evaluated?

While we recommend that this self-assessment be undertaken by governments, we also encourage separate the shadow reports, such as those on the United Nations Convention on the Rights of the Child undertaken by non-governmental organisations (Hamm 2001). Finally, although we envisage that the self-assessment reports will be of most value to the countries themselves, we believe that there is considerable scope for shared learning, in particular from those countries that have been most successful in reducing levels of unmet need over time, with a particular focus on policy responses that have managed to improve access and reduce unmet need for systematically underserved population groups. For this reason, it is desirable that the reports be published and easily

available. To the extent possible, they should be reported in a standardised format that would make it easy to undertake comparative analysis.

**3.16. Scope for utilization of EU funds and/or other mechanisms to support the improvement of access to healthcare according to the benchmarks proposed.**

First, as the problems facing each Member State will differ, as will the solutions, it will be necessary for policies to be designed, developed and implemented at the level of the Member State, ideally based on the self-assessment set out above. In some cases, the responses might be able to exploit existing EU funding mechanisms, such as structural funds or low cost loans from the European Investment Bank, where, in addition, supporting investment environment under the Investment Plan for Europe is available through the European Investment Advisory Hub (European Investment Bank 2017) and the EU Investment Project Portal (European Commission 2017).

European Structural and Investment Funds (ESIF) are the main mechanism for obtaining funds to invest in healthcare, offering support for the EU Cohesion Policy seeking to reduce economic and social disparities between regions in Europe. Health, as an important contributor to regional development and competitiveness, is supported by the European Regional Development Fund (ERDF) and European Social Fund. Health investments by the ESIF must form part of a coherent policy strategy, based on a needs assessment, and should demonstrate cost-effectiveness (European Commission 2014). Thus, ongoing investments in infrastructure are included within larger health investment policies including: (i) deinstitutionalization and development of community-based care, (ii) promotion of active and healthy ageing, (iii) improving access to and quality of health care services, (iv) health promotion and disease prevention, (v) continued education of medical staff and (vi) increased efforts in the field of e-health (European Commission 2016). Nevertheless, there is much scope to improve access to high quality health care through upgrading existing healthcare infrastructure, although this should take an integrated investment approach: infrastructure, technology and service models should

be considered together – an “investment triangle in health” (European Commission 2017).

Technical assistance available through the Structural Reform Support Service provides assistance for EU countries to design and carry out structural reforms as part of their efforts to support job creation and sustainable growth. At their individual request, Member States can receive funding to design reforms to increase access to healthcare, with self-assessment of needs and challenges being an integral part of such projects.

There are also some Europe wide initiatives that offer potential to reduce unmet need for healthcare. The following list is not exhaustive, but does give some idea of the scope of activities underway and their future potential.

### **Support for better information**

The European Research Infrastructure Consortium on Health Information for Research and Evidence-based Policy has identified significant weaknesses in health information (infra)structures in Europe (HIREP-ERIC 2017). This is something that could be addressed using structural funds. A proposed area that could be developed would be to support evaluation of methods to use administrative data already routinely collected for central purposes according to unified national methodologies (i.e. for national statistics, health insurance) to produce benchmarks for access to healthcare. Administrative data are relatively inexpensive, readily available, and already used for hospital quality improvement / quality benchmarks. In the USA the Agency for Healthcare Research and Quality has shown what can be done with investment in development and refinement of administrative data to generate indicators for use in quality improvement and national tracking (Agency for Healthcare Research and Quality 2017). There are other examples of how such data can be used to produce quality measures (Iezzoni 1997, Weingart, Iezzoni et al. 2000, Department of Health 2002).

Throughout this report, the limitations of available data have been noted. There are, however, a number of data sources that could, with limited investment, make a greater

contribution. One is the Survey of Health, Ageing, and Retirement in Europe, which collects extensive data on those aged 50 and over in 27 European countries and Israel. There is a strong case for reviewing how it might be used and, if necessary, augmented to yield more detailed information on unmet need for health care, and its determinants, in Europe.

### **Support for exchange of best practice**

The Research Area network (ERA-NET), funded by Horizon 2020, offers a tool to support exchange of good practices among Member States. The European Innovation Partnership on Active and Healthy Ageing has established a repository of innovative practices, many of which can contribute to reducing barriers faced by older people. The Patient Access Partnership (PACT) has developed a framework for improving access to health care within and between European countries. This framework includes: (a) the '5As' definition of access, which details the five critical elements (adequacy, accessibility, affordability, appropriateness, and availability) of access to health care, (b) a multi-stakeholder approach to mapping access, and (c) a 13-item questionnaire based on the 5As definition (Souliotis, Hasardzhiev et al. 2016). More generally, the European Patient Forum suggests that more research is needed to define indicators of access and health system performance, using EU funds from sources such as the public health programme and Horizon 2020. They argue that patient organisations should be involved meaningfully in these projects, according to existing good practices/recommendations (European Patient Forum 2016).

### **European Reference Networks**

European Reference Networks now link over 300 hospitals in 26 Member States, offering access to highly specialised care for complex or rare diseases and conditions (European Commission 2017). While benefiting only small numbers of patients, relatively, they represent a concrete manifestation of what the European Union can do that is beyond the capacity of any individual Member State. However, while EU funding supports the operation of the networks, there are concerns that their benefits may not be available

equally to all Europeans, especially those in poorer Member States. Consequently, there is a case for examining whether EU funding might be able to address this.

### **3.17. Conclusion**

The principles and rights enshrined in the European Pillar of Social Rights, including access to healthcare, fall under the competence of the EU, the Member States and social partners. Being a joint endeavour, the pillar sets the framework to improve social standards in Europe, but the centre of gravity remains with national and local authorities. This opinion provides guidance and a tool which could be used by Member States to progress on closing their gaps in access to healthcare. It sets a practical framework to lead the way forward for better understanding, identifying, and addressing the gaps in access to healthcare.

The extent to which Europe's citizens experience unmet need for health care varies enormously. While it now appears that increases in several countries, coinciding with austerity policies, may now be reversing, there can be no grounds for complacency. There is now high level political commitment to address this issue but, to do so, it is essential to put in place systems to quantify the scale of the problem and monitor the impact of policies.

In practical terms, there is only one source of data collected in all Member States in a reasonably consistent way. This is the EU-SILC which, fortunately, has been collected for a number of years, making it possible to define a baseline. However, it is in many respects quite limited. Sample sizes are low, only a few questions on unmet need are included, and the samples do not capture the entire population, with some important exclusions of vulnerable groups. Nonetheless, pending any future improvements, we recommend that it be used as a basic means of monitoring unmet need. We also propose a mechanism to set goals for progress in reducing unmet need that recognise the different starting points of Member States but which are both challenging and achievable. However, we note that selection of the precise targets is a political rather



than a technical process. We believe that it should be possible to agree and implement such targets within 1-2 years.

While it is essential to have information on overall levels of unmet need, it is as important to be able to explain them. The EU-SILC data provide some insights, with questions on affordability, availability, and acceptability. However, appropriate policy changes require much more information. Consequently, we recommend that Member States undertake qualitative assessments of unmet need, taking account the specific issues they face and the groups and services that are most affected. We do not propose a blueprint for doing this; rather we argue for responsible authorities to explore, with the research community, the most appropriate design for the questions they are asking. However, we do recommend that these assessments should be published and should be subject to consultation with the public.

We also make a number of suggestions for policies to reduce unmet need. We do not go into detail with them as they were covered in detail in our previous report. However, we do identify a number of European initiatives that can facilitate exchange of good practice and investment in areas that can help reduce unmet need.

Although not addressed in detail here, it is apparent that there is a great need for further research on unmet need and its determinants in Europe. This should include studies that help to understand how need for healthcare is perceived among and within Member States, the practical barriers that different groups face, and the effectiveness of interventions to overcome these barriers.

Finally, if our recommendations are accepted and implemented, it can be expected that the scale and nature of unmet need in Member States will be much better understood. Consequently, we recommend that this issue is revisited in 3-5 years.

#### **4. LIST OF ABBREVIATIONS**

ERA-NET	European Research Area Network
ERDF	European Regional Development Fund
HIREP-ERIC	European Research Infrastructure Consortium on Health Information for Research and Evidence-based Policy
ESIF	European Structural and Investment Funds
EU	European Union
EU-SILC	European Union Survey of Income and Living Conditions
OECD	Organisation for Economic Co-operation and Development
PACT	Patient Access Partnership

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