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4	EXPERT PANEL ON EFFECTIVE WAYS OF INVESTING IN HEALTH
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6 7 8	(EXPH)
9 10 11 12	Opinion on Benchmarking Access to Healthcare in the EU
13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 29 30 31 32	The EXPH adopted this opinion at the xx ^h plenary of xx

33	About the EXpert Panel on effective ways of investing in Health (EXPH)
34 35 36 37 38	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)
39 40 41 42 43 44	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.
45 46 47 48 49	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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68 Members of the Working Group are acknowledged for their valuable contribution to this 69 opinion.

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90 The declarations of the Working Group members are available at:

- 91 https://ec.europa.eu/health/expert_panel/experts/members_en
- 9293 We are grateful to Marina Karanikolos for assistance with data analysis.
- 94

95 Summary

96 97 Faced with growing evidence that some groups within European Union Member States 98 have been unable to achieve access to necessary healthcare, the European Union has 99 committed to action to reduce levels of unmet need, most recently as an element of the 100 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 101 102 qualitative benchmarks for assessing progress in reducing unmet need for healthcare 103 and to discuss means by which EU funds or other mechanisms might be used to improve 104 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.
- 112 In practice, however, there are many challenges involved in measuring unmet need for particular interventions, precluding its routine use. Consequently, a pragmatic solution 113 involves the use of survey data in which individuals are asked whether they have 114 115 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 116 Conditions (EU-SILC), with subsidiary questions that ask about the reasons for unmet 117 need. The report of the Panel recognises that this approach has a number of limitations, 118 119 and also that there are other sources of data that provide insights into the extent to 120 which you need for healthcare is being met, including comparative data on outcomes 121 related to healthcare, but for the present, the EU-SILC data are the only timely and 122 comparable source of information available across all Member States.
- 123 Using this measure, the Panel draws attention to persisting evidence of relatively high124 rates of unmet need in some Member States, and some groups within them.
- 125 The Panel notes that, consistent with the political objective of achieving convergence 126 within the European Union, there is a strong argument for setting a target for unmet 127 need that is close to that already achieved by the most privileged group within the best 128 performing Member State. However, given the very differing starting positions, the Panel 129 considers that this is, for the present time, unrealistic. It is beyond the scope of the 130 Panel to propose a precise target for reduction in unmet need, given that this will require 131 the commitment of financial and other resources. Instead, the Panel has proposed a 132 mechanism for setting such a target. This involves setting a benchmark of the median 133 value achieved by the best performing Member States, with the expectation that those 134 Member States not yet achieving it should narrow the gap by a given percentage, which 135 might be around 50%, over a defined period of time, which might be three years. Such a 136 target would be ambitious, requiring a significantly faster rate of reduction and has been 137 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.
- 145 The Panel was requested to identify qualitative measures of unmet need. This is 146 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 147 148 standard reporting system was appropriate. Rather, it was recommended that each Member State identify those groups that are most likely to be disadvantaged, according 149 to factors such as age, gender, education, ethnicity, or employment status, analyse the 150 151 appropriate data, and prepare a report on the level and pattern of unmet need among 152 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 153 154 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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167 The opinions of the Expert Panel present the views of the independent scientists who are

168 members of the Expert Panel. They do not necessarily reflect the views of the European

169 Commission. The opinions are published by the European Union in their original language 170 only.

171 <u>http://ec.europa.eu/health/expert_panel/index_en.htm</u>

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242 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 three 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 organizations 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 in its Communication and
 Recommendation 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.

275 The principles and rights enshrined in the Pillar are structured around three categories: equal opportunities and access to the labour market, fair working 276 277 conditions and 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 278 promise of the Treaties of a highly competitive social market economy, aiming at full 279 280 employment and social progress. One of 20 principles of the Pillar is that everyone 281 has the right to timely access affordable, preventative and curative care of good 282 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.

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291 **2. TERMS OF REFERENCE**

- 292 The Expert Panel on effective ways of investing in Health is requested to provide its 293 views on Benchmarking Access to Healthcare by:
- 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.
- 2972. Proposing a qualitative benchmark, based on principles and policy levers that can298 be operationalised, to improve access to healthcare in the EU Member States.
- 299 3. Discussing the possible utilization of EU funds and/or other mechanisms to support
- 300 the improvement of access to healthcare according to the benchmarks proposed.

302 **3. OPINION**

303 **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".

317 In 2017, the European Commission set out proposals for a European Pillar of Social 318 Rights (European Commission 2017). Containing 20 principles, this is intended to build 319 on, and complement, the EU social "acquis", guiding policies in a number of fields 320 essential for well-functioning and fair labour markets and welfare systems within the 321 participating Member States. The principles proposed do not replace existing rights, but 322 offer a way to assess and, in future, more closely align the performance of national 323 employment and social policies. These proposals will be discussed at a European Social 324 Summit, to be held in Stockholm in November 2017. Once established, the Pillar should 325 become the reference framework to screen the employment and social performance of 326 participating Member States, to drive the process of reforms at national level and, more 327 specifically, to serve as a compass for renewed convergence within the euro area. 328 Principle 16 states that "Everyone has the right to timely access to affordable, preventive 329 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 topoverty 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:

343 All states, no matter how poor, should offer a minimum core level of provision, which344 should include at least the following obligations:

• To ensure the right of access to health facilities, goods and services on a nondiscriminatory basis, especially for vulnerable or marginalised groups

- To provide essential drugs, as from time to time defined under the [Word 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).

359 A second set of reasons are instrumental, related to the pursuit of the EU's fundamental 360 goals. Thus, it is now recognised that modern healthcare can do much to prolong life and 361 to prevent disability and suffering, an objective that is implicit in the Treaty obligation to 362 ensure that a high level of human health protection shall be ensured in all of the Union's 363 policies and activities. It is also accepted that health contributes to economic growth, 364 through enhanced productivity and reduced losses from the workforce, and by avoiding 365 the adverse economic consequences of catastrophic expenditure on healthcare (Suhrcke, McKee et al. 2005). Third, inequalities in health undermine progress in reducing social 366 367 exclusion (Marmot, Friel et al. 2008).

368 There are also many reasons why it is in the interests of national governments to 369 minimise unmet need. Thus, at least for now, European citizens, in opinion polls and 370 through their choices at the ballot box, have expressed their support for the welfare 371 state, including the provision of universal health care either by government, social 372 partners or others, within a statutory framework (Missinne, Meuleman et al. 2013). It is 373 also in the interests of those providing health care to minimise unmet need, as a failure 374 to do so will often be more expensive in the long run, as illustrated by studies that have 375 looked at what are called ambulatory care sensitive conditions, whereby failure to 376 identify and treat conditions at an early stage allows them to progress and develop 377 complications that require much more complex and costly treatment (Purdy, Griffin et al. 378 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 ata 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).

394 The challenge of operationalising the concept of unmet need, which is in itself 395 considerable given the many methodological issues involved, and which will be discussed 396 later, is complicated further by the qualification in the Charter. Thus, reflecting the 397 Treaty requirement that "Union action shall respect the responsibilities of the Member 398 States for the definition of their health policy and for the organisation and delivery of 399 health services and medical care, the right is to be interpreted "under the conditions 400 established by national laws and practices". In practice, this raises issues of entitlements 401 to care and, specifically, who is considered to make up the population to whom the right 402 applies. For some groups, this is uncontroversial, such as citizens resident in the Member 403 State. For others, such as undocumented migrants, it is often highly contested (Legido-404 Quigley, Urdaneta et al. 2013, Hiam and Mckee 2016).

405 **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 organizational 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).

423 Benchmarking is a continuous process, which enables organizations to strive for and even surpass previously determined standard. In this context, it should not be 424 425 considered as a means of ranking the performance of health systems, although 426 comparative data on performance can be useful for many purposes. Rather it should be 427 viewed as a systematic process of searching for best practices, innovative ideas, and 428 effective operating procedures that lead to improved performance. This requires 429 information, but also the motivation to change, encouraged by a supportive culture and 430 knowledge of what works.

431 3.3. Defining need

432 A useful starting point is to define the need for health care. One of the most widely used 433 definition is views need as "the ability to benefit from health care" (Stevens and Gillam 1998). This has several obvious implications. First, an individual must have a condition 434 435 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 436 437 necessarily mean that there is the means to cure their condition; it may instead be 438 sufficient for there to be the means to alleviate their suffering. However, it also implies 439 that there are no other reasons why they might not benefit from care. For example, a

440 treatment may be available that could extend life from 5 years to 10 years. However, if 441 the individual concerned has a separate life-threatening illness, with a life expectancy 442 measured in months, then they clearly do not have the ability to benefit from treatment. 443 This does, however, raise more complicated issues. Thus, interventions requiring strict 444 adherence to treatment or lifestyle modification may be questioned when, for whatever 445 reason, the individual concerned is unable to adhere to the recommended treatment. 446 The challenges lie in deciding where to set the boundaries. Thus, in some countries, 447 nonurgent treatment is being denied to those who are smokers or who are obese. The 448 issues raised are beyond the scope of this report, but do demand a wide-ranging public 449 discussion. It is, however, the view of the Expert Panel that, while such decisions may be 450 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 451 452 case whatsoever for making them on moral grounds.

453 There is now extensive literature on how need for health care can be measured but, in 454 brief, the task is often quite challenging. First, in many cases, the individual concerned 455 may not realise that they need health care, as is the case with someone who has 456 undiagnosed high blood pressure. Second, even when their condition is symptomatic, it 457 may be necessary to undertake complex, and in some cases, painful or uncomfortable 458 investigations to make a precise diagnosis, and therefore determine whether there is an 459 effective treatment for the condition, and which, by extension, they have a need for. 460 Third, there is the potential for supplier-induced demand, in which an individual may not 461 actually need care, but is advised by a health worker that they do. This situation may 462 arise where that health worker can profit from the administration of unnecessary 463 treatment. The Scottish general practitioner Margaret McCartney has coined the term 464 "patient paradox" when she realised that, at a time when she was struggling to obtain 465 access to essential care for many of her patients from a National Health Service under 466 severe financial pressure, she was being deluged with advertisements from private 467 companies offering screening and treatments that had no evidence of effectiveness

468 (McCartney 2013). Another example comes from Italy. While patients in many Italian 469 regions complain about unacceptable waiting times for diagnostic imaging services, in 470 particular computerised tomography and magnetic resonance imaging (MRI) 471 examinations, the use of these examinations is among the highest in the world, although there is substantial inter-regional variation (Figure 3-1). 472

473 Figure 3-1 Variation in rates of musculoskeletal MRIs among those aged 65 or above in 474 regions in the Italian Regional Collaborative, 2015



475

476 Source: Indicator calculated for a network of Italian Regions by the MeS-Lab (Sant'Anna

School of Avanced Studies) - year 2015. These data are public available at the 477

478 link http://performance.sssup.it/netval/

479 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 480 481 equates to unmet need; there is clear evidence from many countries that some care is 482 inappropriate. Well-known examples include the use of diagnostic tests (Kachalia, Berg 483 et al. 2015) and elective procedures that yield little or no health gain (McKee, Whatling 484 et al. 2005). Thus, it is important to undertake a comprehensive assessment of the 485 situation to put in place the most efficient strategies (Nuti and Vainieri 2012). What is

486 necessary is to ensure that people who might benefit most from a service are those who 487 are actually receiving it (Gray, Airoldi et al. 2017). It is important to recognize that what 488 is portrayed as unmet need may, in some cases, reflect inappropriate expectations or 489 supplier-induced demand, especially where those providing the service have financial 490 incentives for over use. In this context, it is important to take account of the 491 questionable ethics of the extensive marketing of many products of unproven 492 effectiveness, including many alternative treatments, such as homeopathy (Shahvisi 493 2016).

494 Given these challenges, research on need for specific types of health care has, in 495 general, been limited to a few conditions with certain characteristics. These 496 characteristics are that the condition can be recognised accurately by the individual 497 affected, that an effective treatment exists, and there are clear objective criteria for 498 determining whether the individual concerned will benefit from treatment. Typically, 499 research has looked at need for certain forms of non-urgent surgery. Studies of 500 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 501 502 patient can be placed. Clinical judgement, typically based on formal consensus 503 development methods (Black, Murphy et al. 1999), identifies a point on the scale above 504 which the individual is deemed to have an objective clinical need for treatment. The 505 point selected on the scale reflects that at which the net benefits of treatment outweigh 506 the risks. The scale can then be used in a population-based survey to identify the 507 number of individuals in the population who meet this clinically defined criterion for 508 treatment. However, certain challenges arise. First, the individual may have other 509 coexisting conditions that increase the risk of treatment. Second, some individuals who 510 meet the criteria may, as result of personal preference, decline an invitation to be 511 treated. Such individuals, while meeting the objective criteria, would be deemed not to 512 be in need of treatment. However, this approach is only practical in the context of 513 epidemiological research studies.

514 While epidemiological needs assessment, as described in the previous paragraph, can 515 provide valuable information in a defined population, international comparisons confront 516 another problem in that the reference population may differ among countries. Thus, as 517 the Charter of Fundamental Rights notes, the right to health care is granted under the 518 conditions established by national laws and practice, and Member States with different 519 resources can provide different standards for the acceptable level of care as long as this 520 is done in a way that is non-discriminatory. What this means is that, in each Member 521 State, entitlement to health care varies. In some, it is based on residence, for example 522 in the National Health Service in the United Kingdom. In others, it is related to affiliation 523 to an insurer. This insurer may be a private company or a sickness fund, and enrolment 524 may be optional or compulsory. Entitlement to care is also often related to citizenship, 525 and in particular to migration status. Thus, in many countries, undocumented migrants 526 will be excluded. This problem extends to those who are entitled to care in some 527 countries but who are unable to realise this entitlement because of problems in proving 528 it. One of the best-known examples is the situation faced by Roma in several countries, 529 who face major obstacles to obtaining the appropriate documentation to demonstrate 530 their citizenship and entitlement to services (Kuhlbrandt, Footman et al. 2014, Arora, 531 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 532 533 who face similar challenges. This issue was discussed in detail in the Expert Panel's 534 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 needs justify its use. The source of such data is discussed in the following section.

549 **3.4.** How is unmet need measured at a European level?

550 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 551 undertaken annually, since 2005, in all Member States and the results formed the basis 552 of many indicators in widely used databases (Arora, Karanikolos et al. 2015). The 553 surveys ask respondents whether they have had a need for individual health services, 554 defined as examination or treatment by a physician or equivalent professional, but has 555 556 not been met because of cost, distance, or waiting lists, with the same question asked 557 about dental care (Box 3-1).

559	Box 3-1	Questions on unmet need in EU-SILC (UK questionnaire)	
560	Was there any	y time in the last 12 months when, in your opinion, you personally needed	
561	a medical exa	mination or treatment for a health problem but you did not receive it?	
562	1. Yes		
563	2. No		
564	What was the	main reason for not receiving the examination or treatment (the most	
565	recent time)?		
566	1. Could not afford to (too expensive)		
567	2. Waiting tim	ie	
568	3. Could not t	ake time because of work, care for children or for others	
569	4. Too far to t	ravel/no means of transportation	
570	5. Fear of doc	tor/hospitals/examination/ treatment	
571	6. Wanted to	wait and see if problem got better on its own	
572	7. Didn't know	v any good doctor or specialist	
573	8. Other reaso	ons	

574

575 Like all surveys, however, the data are subject to certain limitations. Thus, the sample 576 size is relatively small, limiting scope for sub-group analysis, especially when the sample 577 is already reduced by limiting it to those who report need for health care. Second, EU-578 SILC data are not fully representative of the population. Specifically, they exclude the 579 institutionalised population, such as those living in health and social care institutions. 580 They also tend to exclude those who are homeless. Both groups are likely to have worse 581 health (and worse access) than the general population. Moreover, while it is intuitive 582 that those who are homeless also have high levels of unmet need, there is also cause for 583 concern that, in some countries, those who are in long-term care may also lack 584 appropriate treatment and, as a result, experience unmet need. Further problems relate 585 to other institutionalised populations, such as prisoners, who often have particular health 586 needs and are also excluded from surveys. Importantly, the surveys do not provide 587 specific information on unmet need for mental health services or for social care, with the

1 latter a particular problem in countries where much of the care provided for people with dementia is in the social care sector. 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).

593 **B**

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

594 We begin with two different people:

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

598 Person B: the need to obtain health services on one occasion but did not access them, so599 again the answer is "yes".

600 If calculated in terms of episodes of need, these two people have 4 of which 2 are601 unmet, so unmet need should be 50%.

If calculated in terms of people having at least one episode of not having access, there is100% 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%.

607

One solution would be to ask respondents what happened the last time they felt sick and not whether they had at least one episode of missing care (for whatever reason). However, this does not address the next point as the EU-SILC data do not 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 selfreported 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.

625 Another approach is to infer the extent of health need by looking at health outcomes. 626 There are several approaches to assessing population health outcomes. The one used 627 most often in assessing the contribution of health care involves variants on the theme of 628 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 629 630 Commonwealth Fund in the USA, and the NHS in England. The most recent iteration has 631 been developed by the Institute of Health Metrics at the University of Washington (GBD 632 2015 Healthcare Access and Quality Collaborators 2017). This goes beyond previous 633 approaches by standardising for risk factors in a population and by creating a frontier 634 quantifying what a country might expect to achieve given its level of development. 635 Summary results of the most recent analysis are shown in Table 3-1. The HAQI scores 636 are on a scale from 0 to 100, with higher scores indicating better performance. The 637 frontier is calculated as what could be expected based on a combination of national 638 income, level of education, and fertility. As can be seen, most Member States achieve or 639 exceed what would be predicted but not all do.

• • -				
	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
	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

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

642

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

644

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.

652 **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, 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 659



661 Source: Calculated from EU-SILC data

662

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



672

673 Source: Calculated from EU-SILC data

674 Thus, in 2015, the percentage of those in the richest quintile reporting unmet need was 675 below 2% while in the poorest quintile it was over 5%. Rates of unmet need are about 676 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 677 678 education or who are unemployed. The changes over time have had a substantial impact 679 on European citizens. One study estimated that, in 2013, an extra 1.5 million people 680 experienced unmet need compared to 2008, although with the earlier rate of decline had 681 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 timeslarger 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 were 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



695



697

698



701

702 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).

710



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





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

718 **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."

731 Thus, the extent to which a condition is regarded as 'abnormal' and requiring treatment 732 varies, reflecting cultural norms and expectations. The decision to seek treatment may 733 be influenced by the opportunity cost of doing so, for example where someone must 734 travel long distances or will lose income if they take time off work. Some individuals may 735 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 736 737 family, friends, and informal carers, access to transport, and information about how to 738 navigate the system. Other barriers exist in health facilities and in interactions with 739 health workers. These include lack of knowledge by health workers, inaccessibility of the 740 facilities, and lack of equipment or supplies. A final set of barriers act at the level of the 741 health system, including the overall level of funding, availability of prepayment 742 mechanisms, such as insurance coverage, the services covered, and mechanisms to 743 ensure that appropriate services are available in each community.

744 **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.

749 Given that Member States have already subscribed to the right to health care, the 750 implication should be that the adequate level of unmet need should be zero, or close to 751 it. It does not mean that all needs should be met whatever the cost of providing that 752 health care. There is clearly an opportunity cost to providing any care. In a system with 753 constrained resources, it is necessary to set priorities that take account of both the cost 754 and the benefit of intervening, although this should be done in a way that is transparent, 755 using processes that ensure that the bodies involved are accountable to those whose 756 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 757 758 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.

765 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.

781 Given the long-established principle of adopting policies that move towards convergence 782 within the EU, there is a strong argument for setting a target that is in the vicinity of 783 that already achieved by the most privileged group in the best performing Member State 784 (i.e. below 1% in 2013). However, recognising the different starting positions of each 785 Member State, it seems reasonable to argue that individual national targets should be 786 set that are challenging but achievable improvements on what has already been attained 787 (Vainieri et all 2016). If a 1% target is agreed, then the timing by which it should be 788 achieved will need to be considered. However, this will clearly need appropriate 789 resources, the allocation of which is a fundamentally political issue at the national level. 790 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 in 791 792 the on the weighted EU average between 2005 and 2015 suggest that, without further 793 actions, this will only be achieved in 2052. It seems reasonable to suggest that a 794 reasonable target might be within about 10 years. This would be challenging but 795 achievable. To bring the unweighted EU average rate below 1% by 2025 would require 796 the rate of decline to be 2.3 times faster than it has been between 2005 and 2015.

797 Clearly, progress against the required performance would be monitored regularly in the798 intervening period.

799 As to the national targets, again, it is ultimately a political decision as to where the 800 target should be set. After detailed discussion, we believe that the following approach 801 could be appropriate, on the basis of considerations of feasibility, simplicity, and data 802 availability. This envisages that the initial target would be defined as the median value 803 achieved by the best performing tercile of Member States (this could also be the best 804 performing quartile or quintile – the choice will make little difference). Given the intrinsic 805 variability associated with the small numbers in the surveys, we propose that this should 806 be averaged over several years (between 3 and 5). This means that some Member 807 States will already have achieved this target, but most would not have. Recognising that 808 it may be more difficult for those further from the target to make progress, we propose 809 that each would be expected to close the gap between its current performance, averaged 810 over 3 years, and the target by certain percentage over a defined period of time. We 811 propose that this percentage might reasonably be 50% and the time period three years, 812 while recognising that the precise figures will be subject to political agreement.

813 This approach is set out mathematically in Box 3-3. The benchmark figure is defined as 814 the median value obtained in countries in the lowest tercile of unmet need. To allow for 815 fluctuations related to sampling, this is averaged across the three most recent years for 816 which data are available for all countries (2013-15). Each country's level of unmet need 817 in 2015 is then calculated. In some cases, this causes a country in the best performing 818 tercile over the past three years to be above the benchmark if its reported performance 819 has deteriorated. Those countries exceeding the benchmark are then given a target of 820 reducing the gap between the score in 2015 and the benchmark by 50%. This would 821 allow every Member State to have a specific target that is both challenging and fair. The 822 implications for each Member State are shown in Figure 3-8.

824	Box 3-3 Possible formula for generating target for unmet need		
825	We denote TG_t as the overall target (across all EU member states) in period t, and UN_{it}		
826	as unmet need of country i in period t.		
827	Then, we can write the target for country i in period t, $\ TG_{it}$, as a function of the same		
828	country unmet need and the overall target:		
829	$TG_{it} = max(TG_t, TG_t + (x\%) * (UN_{it} - TG_t))$		
830	where $x\%$ is the adjustment parameter required to close the gap between unmet need in		
831	country i in period t in k years (e.g. 50% of the gap in 5 years, 40% of the gap in 4		
832	years etc.).		
833	The overall target could be computed as a function of the unmet need across all		
834	countries in the previous years. Suppose for example that we use the median unmet		
835	need averaged across the three previous years. Then,		
836	$TG_{t} = \frac{1}{3} \sum_{t=3}^{t-1} (median \ UN_{it} \ i \ in \ I)$		
837	where I is the reference set of EU countries.		

840Figure 3-8Gap between level of unmet need in 2015 and benchmark based on best841performance in past three years

842



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 are no differences in countries that justify a principle of target differentiation.

851 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.

858 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 859 860 inequities in access on which attention is focussed should take account of national 861 context, with reporting of a range of quantitative and qualitative assessments as 862 appropriate. Thus, while gender is likely to be of interest everywhere, it may be 863 important to consider issues such as age, rural habitation, or specific ethnicities only in 864 some settings. This has certain implications. A comprehensive strategy to reduce unmet 865 need must understand the nature of disadvantage in each country and devise strategies 866 that explicitly seek to address it. This will often require bespoke systems of data 867 collection, coupled with a detailed understanding of the cultural issues involved in 868 health-seeking behaviour. This national approach is consistent with the accumulated 869 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 870 871 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 872 873 data. Even for countries currently meeting the eventual target set, its monitoring is 874 relevant to detect and act early on future deviations. It may also help to fine tune 875 policies.

876 3.10. Second level indicators

877 As noted above, there are many reasons why some individuals, and some groups within 878 populations experience greater levels of unmet need than others. These issues were 879 explored in considerable detail in the Expert Panel's previous report on access to care 880 (Expert Panel on effective ways of investing in Health 2016). They followed three broad 881 categories, affordability, availability (and accessibility) and acceptability (user 882 experience). Each, in turn, is separated into three further headings. Thus, affordability 883 can be ensured by having financial resources that are linked to health need, services 884 that are affordable for everyone, and ensuring those services are relevant, appropriate, 885 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.

889 These categories suggest several second level indicators, each of which can help to 890 explain overall levels of unmet need in a country. However, for these purposes, it is 891 necessary to make a decision about how parsimonious such a set of indicators should be. 892 Thus, it could be argued that a very large number of existing measures have some 893 relationship to need for health care and the extent to which it is met, such as the share 894 of national income being spent on health or the numbers of health workers per head of 895 population. However, in all of these cases, the relationship is somewhat indirect, and in 896 many cases, the key issue is the distribution rather than the absolute level in a country. 897 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 898 899 is, however, an argument for seeking to make them congruent with existing data, to the 900 extent possible. In this context, the key consideration is the categorisation of reasons for 901 unmet need in the EU SILC data. Respondents are given three options, with unmet need 902 being attributed to cost, travel distance, or waiting lists. These map nicely onto the three 903 broad categories identified in the Expert Panel's earlier report. Thus, cost equates to 904 affordability, travel distance captures aspects of availability, and waiting time is a key 905 dimension of user experience. The Expert Panel believes that all of these are important 906 and should be monitored at a European level, although the importance on individual 907 measures will vary among Member States depending on the progress they have made 908 previously and what still needs to be done. We will now consider each of these in turn.

909 Before doing so, it is however, necessary to reflect upon the point at which need is 910 considered to have been met. For the patient, this is relatively straightforward, as it is 911 the point at which the condition is cured or symptoms alleviated, even if the ultimate 912 outcome is death. However, there are enormous practical difficulties in operationalising 913 this for routine measurement. Instead, it is more usual to define needed as having been

914 met when the patient has made first contact with the health system. It is, however, fully 915 recognised that this is a very incomplete, and arguably irrelevant measure of met need, 916 even more so at a time when interactions with health system are assuming many non-917 traditional forms, including via the Internet.

918 This is an issue that will require further consideration. Thus, the growth of chronic 919 disease and multi-morbidity means that many patients will be on a prolonged journey 920 through the health system, and for them, the crucial question will be the extent to which 921 their needs are met at each point on that journey. The challenges are often exacerbated 922 for those with mental health or social care needs. It is not, however, clear, how this can 923 easily be addressed in a consistent way using survey data. There is potential to use 924 administrative data on regular contacts with patients at all levels of care for the purpose 925 of following the patients' journey within the health care system, at least in systems 926 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.

933 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

941 some extent, measurable and, in some cases, are already incorporated in routine942 statistics.

943 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 944 945 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 946 947 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 948 949 through the welfare system. However, for the present purposes, the very existence of a 950 prepayment system will increase the probability that need will be met. Consequently, it 951 is reasonable to focus attention on the other elements of expenditure on healthcare.

952 Co-payments are similarly complex. Often, they vary, according to the type of service 953 provided or the medicines received. There are very frequent exemptions. Thus, in 954 Portugal, where there have been considerable changes in the co-payment regime in 955 recent years, the net result is quite complex because of the extent to which exemptions 956 for some have compensated for higher payments by others (Legido-Quigley, Karanikolos 957 et al. 2016).

958 The OECD define household out-of-pocket expenditure on health as comprising 959 expenditures borne directly by a patient where insurance does not cover the full cost of 960 the health good or service. They include cost-sharing, self-medication and other

961 expenditure paid directly by private households. In some countries, estimations of 962 informal payments to health care providers are also included. Using this definition, the 963 figures for 2015 range from 6.8% of total household expenditure in France to 41.6% in 964 Latvia (Figure 3.9).

965



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



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

975 Source: OECD

The interpretation of out-of-pocket payments can be problematic. For example, an 976 977 individual with private health insurance who visits a specialist several times will have 978 their needs met but may incur high out-of-pocket payments (as will also be the case 979 when significant user charges exist in a publicly funded National Health Service). In 980 contrast, an individual who never visits a doctor will have zero out-of-pocket payments 981 but, if ill, may have a high level of unmet need. Out-of-pocket payments are the result of 982 very different institutional arrangements in terms of public-private mix on both funding 983 and provision. There is also the issue of informal payments, some of which may take the 984 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 985 986 example, data from 2014 show that the share contributed by spending on 987 pharmaceuticals ranges from 16% in Luxembourg to 75% in Romania (OECD 2016).

988 Thus, they represent a useful indicator but only if combined with a good understanding989 of the diverse institutional settings in which they originate.

990 The third element is catastrophic expenditure. Yet, although this measure is often used 991 in international comparisons, it is more problematic than is sometimes recognised (Xu 992 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 993 994 others up to one year. Second, surveys typically miss those households that forgo treatment because it is unaffordable, thereby avoiding what would otherwise be 995 996 catastrophic expenditure. Third, although less directly relevant here, illness incurs costs 997 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 998 999 considered as a means to reveal limitations in access to healthcare due the financial 1000 hardship resulting from out of pocket payments.

1001 In practice, data on catastrophic expenditure are not routinely available in all Member 1002 States. They are usually derived from family budget surveys, typically collected every 1003 five years, although with inconsistencies across countries. If used, a number of 1004 alternative definitions would need to be explored (e.g. payment as ratio of non-food 1005 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.

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1018

1019 Source: calculated from EU-SILC data

1020 3.10.2.Availability & Accessibility

Availability relates to the existence of facilities that provide services that can meet the 1021 1022 needs of potential patients. Again, this is potentially extremely complicated, as patients 1023 with complex needs will require highly specialised facilities. Consequently, pragmatically, 1024 it seems reasonable to consider availability as the existence of facilities meeting some 1025 basic level of provision, such as primary care clinics. Availability has several dimensions, 1026 spatial, temporal, and formal. Thus, there is a well-known gravity effect, whereby rates 1027 of attendance at health facilities fall off markedly with increasing distance. This is a non-1028 linear relationship, approximating to the well-known adverse square law, although there 1029 is some variation according to the nature of the needs being met (McKee, Gleadhill et al. 1030 1990, Jordan, Roderick et al. 2004). However, to complicate matters, distance can be 1031 measured in several ways. These measures range from the simple straight line between 1032 the patient's home and a facility, the so-called crow fly distance, to travel time, which 1033 varies according to the means of transport available to the individual. Thus, a facility 1034 that may appear close for someone with their own car may be relatively inaccessible for

1035 someone dependent on public transport, while in some remote areas, as in Finnish 1036 Lapland, it may be quicker to fly to the capital than to drive to the nearest tertiary 1037 hospital. It should also be noted that, in some cases, people may be willing to trade 1038 what they perceived to be the advantages of living in a remote rural area for access to 1039 healthcare. However, this highlights the need for information on unmet need to be 1040 interpreted in the light of evidence on the travel distances of the population from major 1041 settlements in some countries. A further complication relates to the starting point for the 1042 potential patient. Individuals live their life in complex spaces, encompassing home, work, 1043 and leisure locations. A facility that is close to them at one point in the day may be 1044 distant at another (e.g. while the individual is at work). Conversely, a facility close to 1045 where they live may yet be inaccessible at night if it is only open during working hours. 1046 This leads onto the next point.

1047 The temporal dimension relates to when the facility is open. Thus, in Greece, reductions 1048 in opening hours of clinics were associated with a significant increase in unmet need for 1049 care (Kentikelenis, Karanikolos et al. 2014).

1050 Opening hours should ideally relate to when services are needed, so while emergency 1051 care facilities should be open twenty-four hours a day, routine clinics need not be.

1052 The formal dimension relates to the extent to which services are open only to those with 1053 particular characteristics. This may be insurance status, occupation, or some other 1054 parameter. This may be relevant for groups such as population groups, such as the 1055 homeless, long-term unemployed, undocumented migrants, people with severe and 1056 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

1063 take account of appropriateness, as not all facilities will be able to offer care for every1064 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 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).

1075 **3.10.3.User experience**

1076 User experience is also a multidimensional construct. It is subject to numerous biases 1077 and is time dependent. Thus, a service perceived as unacceptable immediately after it 1078 was received may be reassessed more favourably later, and vice versa. It covers all 1079 aspects of the care provided, including both clinical interventions and what might be 1080 described as customer experience, such as the extent to which the patient is welcomed 1081 to the facility, the quality of the facility, encompassing such issues as ease of navigation 1082 around it, comfort, choice and quality of food, and facilities for friends and relatives. It 1083 also includes the extent to which patients' preferences are taken into account. This is 1084 especially challenging. While there is a growing consensus that the decision to intervene 1085 should be taken jointly by the patient and their health provider, or increasingly, 1086 multidisciplinary team of providers, based on the provision of appropriate information, 1087 there are also some patients that would prefer that the choice be taken for them. 1088 Clearly, it is important that all those involved in such decisions find the right balance.

1089 Methods to evaluate user experience have been developed and implemented, such as 1090 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).

1097 These considerations make it challenging to operationalise the concept of user 1098 experience. However, it can be considered as equating to the measure of responsiveness 1099 used in the 2000 World Health Report (World Health Organization 2000). This had 1100 several elements, falling into two broad categories. The first category related to respect 1101 for persons, including respect for the dignity of the person, confidentiality, and autonomy 1102 to participate in choices about one's health. The second was client orientation, which 1103 included prompt attention, communities of adequate quality, including cleanliness, 1104 access to social support networks, and choice of provider. All of these factors could, in 1105 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 1106 unmet. The previous report of the Expert Panel on access to health services noted that: 1107

1108"People need to be willing to use available services, and when they use health1109services, their experience should be as positive as possible because user1110experience shapes expectations and can influence health care-seeking behaviour in1111the future. Services that fail to be acceptable to people are likely to be under used,1112with negative implications for health, efficiency in the use of health system1113resources and equity in use." (Expert Panel on effective ways of investing in Health11142016)

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.

1119 We, therefore, suggest that user experience as a potential cause of unmet need should 1120 be addressed through the EU-SILC data which ask about whether unmet need was due 1121 waiting time, which could be further complemented or validated from OECD data 1122 collection on waiting times from administrative data (Siciliani, Moran et al. 2014). Care is 1123 required in defining the indicator. In a health system, there may be several waiting 1124 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 1125 1126 care helps waiting times for surgery as less people reach that stage), etc.

1127

7 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).

1136 The data are from administrative sources and are representative of large populations of 1137 patients receiving a specific non-emergency treatment. Countries differ in key reported 1138 indicators. For example, some countries report the mean waiting times, while others only 1139 the median. Moreover, some countries report the waiting time of patients "on the list" at 1140 a point in time (e.g. every quarter), while others report the waiting time of patients who 1141 have been "treated" in a given year (as in the figure below); these will give different 1142 representations of the waiting time phenomenon (Dixon and Siciliani 2009).

1143



1149 **3.10.4.Inequalities & Inequities**

As will be clear from the preceding discussion, to be relevant, measures of unmet need 1150 1151 should capture both the absolute level and distribution within a population. There are 1152 different approaches to measuring inequalities. The first is a simple mathematical 1153 approach, looking at the degree of dispersion of a measure without any presupposition 1154 as to the underlying reasons. There are a number of statistical approaches, such as the 1155 sum of differences between all pairs of variables or the sum of absolute differences from 1156 the mean value (z-score). This approach has the advantage of being applicable in all 1157 settings but the limitation that it says little about the reason for the degree of dispersion. 1158 The second involves pre-specifying those characteristics of subgroups within the 1159 population associated with differences in unmet need. Reflecting the findings presented 1160 above, these are likely to include age, gender, income, and education, as well as, almost 1161 certainly, ethnicity. The difficulty arises when conducting international comparisons.

1162 Other than age, gender, and education, few are consistently collected across countries. 1163 Moreover, the characteristics of interest may vary from one country to another. Thus, 1164 language or ethnicity may be of particular interest in one country but much less so in 1165 another. A further problem arises as some of the categories may be quite 1166 heterogeneous. Thus, some standard employment groupings may include people with 1167 quite different experiences. Ethnicity is particularly problematic. Thus, there may be 1168 considerable differences in the experiences of individuals from groups of neighbouring 1169 countries, as is the case with Indians, Pakistanis and Bangladeshis in the United 1170 Kingdom. Certain statistical problems may arise if the relative size of the categories 1171 varies greatly. Thus, where two categories of people form the top and bottom 2% of the 1172 distribution in a population, the distance between them will inevitably be much wider 1173 than in a country where they form the top and bottom 20%. A further problem relates to 1174 the issue of intersectionality, or the interaction between variables such as gender and 1175 ethnicity or religion (Bauer 2014).

1176 There are number of approaches in the literature measuring inequalities in health and 1177 healthcare utilisation (Wagstaff and Van Doorslaer 2000) that can be usefully adapted to 1178 the context of unmet need. To measure absolute inequalities within each country and 1179 compare across countries an approach based on the Lorenz curve could be used, plotting 1180 unmet need (ranked in increasing order) against the cumulative proportion of unmet 1181 need. This approach has been used for example to measure health inequalities (as 1182 measured by mortality or self-reported health). A regression-based approach could be 1183 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-

1190 economic inequalities in unmet need. In its simplest formulation, this would involve 1191 regressing unmet need against socioeconomic status either for each country or for all 1192 countries (interacting socioeconomic status with country dummies). This regression 1193 approach would also give the option of taking account of certain variables (e.g., age and 1194 gender), providing a measure of socio-economic inequalities in unmet need which 1195 controls for populations characteristics. In contrast to the evidence on socio-economic 1196 inequalities in utilisation, it is not necessary to control for need (most often proxied by 1197 self-reported health) since this is already encompassed in the concept of unmet need 1198 (though the approach only holds if different individuals within and across countries 1199 perceive unmet need in the same way, which may not necessarily be the case). If unmet 1200 need is perceived differently, the inclusion of objective measure of need, e.g. morbidity 1201 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 1202 1203 sophisticated analysis than is required if only collecting statistics and making them 1204 available. An unresolved issue is who will be responsible for producing such regression 1205 analysis.

1206 The evidence has generally focussed on inequalities (differences) or inequities 1207 (differences that are unfair) in either health or utilisation (health care). The focus on 1208 unmet need is different since it blends both aspects of health, with poorer health 1209 increasing unmet need, and utilisation, with better access to healthcare reducing unmet 1210 need. The distinction between fair and unfair inequalities however remains. For example, 1211 countries differ in the public-private insurance mix, with some countries having 1212 duplicative private health insurance (e.g. in Italy, Spain and the UK) with patients with 1213 private health insurance being able to get treatment after shorter waits and able to 1214 choose their doctor. Some might argue that differences in unmet need by socioeconomic 1215 status due to richer individuals holding voluntary private health insurance is not 1216 considered unfair, even while agreeing that differences in unmet need by socioeconomic 1217 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.

1224Figure 3-13Percentage of respondents reporting unmet need due to care being too1225expensive, too far to travel, or long waiting list, by income quintile (2015)1226

- 20 18 16 14 Percentage 12 10 8 6 4 2 T Ι Т 0 Hungary Latvia .uxembourg Malta Netherlands Germany Ireland Greece Croatia Cyprus Poland Bulgaria Czech Republic Estonia Spain rance Italy Lithuania Au stria Romania Belgium Denmark ortugal Slovenia Slovakia Finland Sweden United Kingdom
- 1227
- 1228 Note: In each case the poorest income quintile is the highest value and the richest is the1229 lowest
- 1230 Source: calculated from EU-SILC data

1231 It should also be noted that inequalities may be higher in countries where unmet need is 1232 higher, and may reduce when the overall level of unmet need is reduced. An alternative 1233 indicator is to produce simple inequality indices which standardise for the level of unmet 1234 need (e.g. the coefficient of variation).

1235 **3.11. Proposals for additional data collection**

1236 The EU-SILC data have many strengths, especially that they already exist and have done 1237 for over a decade, providing a meaningful baseline against which to assess future 1238 developments. However, as described previously, they also have many weaknesses, 1239 including their restricted coverage, especially of some groups who are most vulnerable to 1240 unmet need, and their relatively few variables that can shed light on the nature and 1241 reasons for unmet need. Consequently, we consider it necessary to make proposals for 1242 investment in additional data sources that can inform policy and practice in the future. 1243 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. 1244 Among them is the Survey of Health, Ageing and Retirement in Europe (SHARE). This 1245 1246 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 1247 1248 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 1249 1250 other (Gannon and Davin 2010).

1251 The second include those that are already in place in all Member States but which could 1252 be strengthened. The most obvious example is the EU-SILC, which contains few 1253 questions related to health need. While recognising the constraints imposed by 1254 participant fatigue, we propose a review of the variables currently collected to identify a 1255 small number of additional variables that could inform the quest to reduce unmet need. 1256 In particular, it will be important to improve the availability of data on mental health, 1257 and on unmet need for care of those with mental disorders. Another priority is to 1258 enhance mechanisms for collecting data on the most marginalised populations, groups 1259 whose characteristics will differ among countries, but who are often excluded from surveys, including, as already noted, the EU-SILC. 1260

1261 The third category includes resources that do not currently exist or do so only in an *ad* 1262 *hoc* form. These might include the regular use of studies of so-called tracer conditions, 1263 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.

1268 **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.

1272 3.12.1.Affordability

1273 The Expert Panel's previous report noted the existence of variation in the benefits 1274 package in different Member States. It seems likely that these differences could 1275 contribute to differences in unmet need, for example where a particular service is 1276 excluded from the benefit package.

1277 That report also looked at user charges, noting how these also varied among Member 1278 States. There were three reasons for applying user charges. The first is to limit access to 1279 health care as a means to contain public spending on health, even though this may transfer costs to the individual. Second, to direct patients towards more cost-effective 1280 services. And third, to raise revenue for the health system. As was noted, there was little 1281 evidence to support any of these and the lack of a strong evidence base for user charges 1282 1283 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 1284 1285 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 1286 1287 complications in operating the system. Third, they do not differentiate between 1288 necessary and unnecessary care in deterrent effect. There is, however, one possible 1289 exception. This is that they could be used to influence behaviour where the patient is 1290 faced with a choice as to how or where to obtain care. Thus, a charge may sometimes be 1291 appropriate to deter patients from buying unnecessary drugs or encourage patients to

1292 attend primary care facilities rather than direct attendance at specialist facilities. 1293 However, even here, it is important to look at the reasons why patients go to a less 1294 appropriate setting, which may reflect geographical, temporal, or other barriers to 1295 accessing primary care. A related, but more difficult issue is that of informal payments, 1296 as noted above. These are widespread in some of the new Member States. They have 1297 been understood as a means of informal exit from the health system, or "inxit" (Gaal and McKee 2004). This follows from the work of Hirschman, who argued that 1298 1299 discontented users normally have two options, except and voice (Hirschman 1970). 1300 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 1301 1302 comprehensive approach, involving adequate funding for the health system and greatly 1303 strengthen governance.

1304 3.12.2.Availability & Accessibility

1305 While noting the complexity involved in measuring access to health facilities, set out 1306 above, policies to improve it are likely to involve ensuring that the distribution of 1307 facilities matches that population. However, this poses a problem, because of the 1308 existence of economies of scale and scope. Thus, all health facilities require a critical 1309 mass and baseline level of activity to be viable, both in financial terms and in 1310 maintaining the expertise of those who work in them. The size of the critical mass will 1311 increase with the degree of complexity treatment being provided. In other words, there 1312 is often a trade-off in places where the population density is low. There are a number of 1313 imaginative solutions that can overcome this, many in use within the EU. They include 1314 the use of remote technologies, such as telemedicine (Saliba, Legido-Quigley et al. 1315 2012), and of shared use of facilities across national borders (Legido-Quigley, Glinos et 1316 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 1317 1318 patients are able to cross the border to use it. There may, in some cases, be specific 1319 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.

1323 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.

1327 **3.13. Scope for action**

1328 In the report of the Expert Panel on Effective Ways of Investing in Health on "Access to 1329 Health Services in the European Union", actions to ensure equitable access were 1330 reviewed, summarizing national and EU-policy responses (Expert Panel on effective ways 1331 of investing in Health 2016).

The report dealt with 8 dimensions, summarised below. The bullet points, which are 1332 1333 based on the evidence in the earlier report and that reviewed previously in this one, are 1334 addressed to national and sub-national authorities, the precise nature of which will vary 1335 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 1336 1337 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 1338 1339 including them was set out in the previous report.

- 1340 **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.

1349 The European Union already supports exchange of best practice in many areas, including 1350 data collection, helping countries to develop secure and confidential systems of record 1351 linkage and development of the expertise to make maximum use of the information so 1352 provided. These existing activities offer potential for further development.

- 1353 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.

1371 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.

1388 The European Union has already done much to promote these actions, especially through 1389 the Horizon 2020 research programme and its predecessors, but also through initiatives 1390 in areas such as information technology and those carried out by projects such as 1391 EUnetHTA. All of these offer scope for further development.

- 1392 **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.

1399 The European Union has already done much to improve access, through its structural 1400 funds, arrangements for cross-border care (especially as border areas often have low 1401 population densities) and European Reference Networks. All of these initiatives offer 1402 further potential.

1403 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.

1420 **Quality drugs and devices are readily available.**

Member States can benefit from common strategies to enhance access to
 medicine and devices;

1423	•	instruments are available, or should be made available, to improve negotiations
1424		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.

1439 **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.

1456 **Se**

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.

1462 **3.14. Proposals for qualitative measures**

1463 Given the complexity of unmet need for health care and its many causes, the indicators 1464 discussed above can never be more than that, simply indicators. Even the secondary 1465 indicators will only go so far in explaining differences in unmet need. It will be necessary 1466 to supplement these measures with additional information, in order to be able to assess 1467 the indicators appropriately and, potentially, to move from indicators to policy action. 1468 Such information must take account of the particular national context. Thus, unmet need 1469 due to distance from facilities should be understood differently, and reacted to 1470 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).

1479 Importantly, we do not advocate the adoption of a standard approach for use 1480 everywhere, because the issues to be addressed vary. Thus, while research by Eurostat 1481 using EU-SILC data, has demonstrated some general patterns in the correlates of unmet 1482 need across Europe, such as greater unmet need by those with lower incomes, who are 1483 older, or who have less education, there are also quite a number of exceptions (Eurostat 1484 2017). For example, reported unmet need is actually lower among older people in France 1485 and Sweden.

1486 Importantly, there are many groups who are not identified separately in EU-SILC data 1487 who are known, from other research, to be especially disadvantaged in obtaining access 1488 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. 1489 1490 Thus, while some ethnic minorities may be disadvantaged, others may not be, depending 1491 on factors arising from the characteristics of the minority concerned, including their 1492 degree of assimilation, their pattern of educational and employment status, their 1493 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 1494 1495 discrimination and the availability of culturally appropriate services (Rechel, Mladovsky 1496 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 tocertain services. These will vary, geographically and over time.

1506 Monitoring access to health care in itself is of limited value if not accompanied by the 1507 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 lilness), geographic location, homelessness, ethnicity, and religion. It should also consider intersectional issues, such as where being female and of a particular religion may be especially disadvantageous.
- 1519 c) Overview of the rights (both in terms of entitlements and effective execution of 1520 rights) of access to healthcare according to occupation/employment status. This 1521 analysis should include groups that are stigmatised, such as sex workers, and 1522 those in informal employment who are especially vulnerable. A particular 1523 emphasis should be placed on self-employed people and those in non-standard 1524 forms of work, taking account of the multiplicity of new types of contracts (in 1525 particular: casual work, involuntary part-time work, platform work, domestic 1526 workers, temporary agency workers). The analysis could integrate EU SILC data 1527 on unmet needs for self-employed people (in 2015, of those self-employed 55% 1528 were more likely to experience unmet needs than employees) as far as non-1529 standard forms of work are concerned, it should look at legislative solutions in place and conditions for effective execution of rights to healthcare (identifying 1530

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.
- 1541 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.
- 1543 f) Proposals for actions to address the problems identified. These could usefully be 1544 formulated according to a standard set of headings (Box 3-5).

1546 **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 this 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?

1547

1548 While we recommend that this self-assessment be undertaken by governments, we also 1549 encourage separate the shadow reports, such as those on the United Nations Convention

1550 on the Rights of the Child undertaken by non-governmental organisations (Hamm 2001).

1551 Finally, although we envisage that the self-assessment reports will be of most value to 1552 the countries themselves, we believe that there is considerable scope for shared 1553 learning, in particular from those countries that have been most successful in reducing 1554 levels of unmet need over time, with a particular focus on policy responses that have 1555 managed to improve access and reduce unmet ned for systematically underserved 1556 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 1557 1558 would make it easy to undertake comparative analysis.

3.15. 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 1562 1563 necessary for policies to be designed, developed and implemented at the level of the 1564 Member State, ideally based on the self-assessment set out above. In some cases, the 1565 responses might be able to exploit existing EU funding mechanisms, such as structural 1566 funds or low cost loans from the European Investment Bank, where, in addition, supporting investment environment under the Investment Plan for Europe is available 1567 1568 through the European Investment Advisory Hub (European Investment Bank 2017) and the EU Investment Project Portal (European Commission 2017). 1569

1570 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 1571 reduce economic and social disparities between regions in Europe. Health, as an 1572 important contributor to regional development and competitiveness, is supported by the 1573 European Regional Development Fund (ERDF) and European Social Fund. 1574 Health 1575 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). 1576 Thus, ongoing investments in infrastructure are included within larger health investment 1577 policies including: (i) deinstitutionalization and development of community-based care, 1578 1579 (ii) promotion of active and healthy ageing, (iii) improving access to and quality of health 1580 care services, (iv) health promotion and disease prevention, (v) continued education of 1581 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 1582 1583 through upgrading existing healthcare infrastructure, although this should take an 1584 integrated investment approach: infrastructure, technology and service models should 1585 be considered together - an "investment triangle in health" (European Commission 1586 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.

1592 There are also some Europe wide initiatives that offer potential to reduce unmet need for 1593 healthcare. The following list is not exhaustive, but does give some idea of the scope of 1594 activities underway and their future potential.

1595 Support for better information

1596 The European Research Infrastructure Consortium on Health Information for Research 1597 and Evidence-based Policy has identified significant weaknesses in health information 1598 (infra)structures in Europe (HIREP-ERIC 2017). This is something that could be 1599 addressed using structural funds. A proposed area that could be developed would be to 1600 support evaluation of methods to use administrative data already routinely collected for 1601 central purposes according to unified national methodologies (i.e. for national statistics, 1602 health insurance) to produce benchmarks for access to healthcare. Administrative data 1603 are relatively inexpensive, readily available, and already used for hospital quality 1604 improvement / quality benchmarks. In the USA the Agency for Healthcare Research and 1605 Quality has shown what can be done with investment in development and refinement of 1606 administrative data to generate indicators for use in quality improvement and national 1607 tracking (Agency for Healthcare Reserach and Quality 2017). There are other examples 1608 of how such data can be used to produce quality measures (Iezzoni 1997, Weingart, 1609 Iezzoni et al. 2000, Department of Health 2002).

1610 Throughout this report, the limitations of available data have been noted. There are, 1611 however, a number of data sources that could, with limited investment, make a greater 1612 contribution. One is the Survey of Health, Ageing, and Retirement in Europe, which 1613 collects extensive data on those aged 50 and over in 27 European countries and Israel. 1614 There is a strong case for reviewing how it might be used and, if necessary, augmented

1615 to yield more detailed information on unmet need for health care, and its determinants,1616 in Europe.

1617 Support for exchange of best practice

1618 The Research Area network (ERA-NET), funded by Horizon 2020, offers a tool to support 1619 exchange of good practices among Member States. The European Innovation 1620 Partnership on Active and Healthy Ageing has established a repository of innovative 1621 practices, many of which can contribute to reducing barriers faced by older people. The 1622 Patient Access Partnership (PACT) has developed a framework for improving access to 1623 health care within and between European countries. This framework includes: (a) the 1624 '5As' definition of access, which details the five critical elements (adequacy, accessibility, 1625 affordability, appropriateness, and availability) of access to health care, (b) a multi-1626 stakeholder approach to mapping access, and (c) a 13-item questionnaire based on the 1627 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 1628 1629 system performance, using EU funds from sources such as the public health programme 1630 and Horizon 2020. They argue that patient organisations should be involved meaningfully in these projects, according to existing good practices/recommendations 1631 (European Patient Forum 2016). 1632

1633 European Reference networks

1634 European Reference Networks now link over 300 hospitals in 26 Member States, offering 1635 access to highly specialised care for complex or rare diseases and conditions (European 1636 Commission 2017). While benefiting only small numbers of patients, relatively, they 1637 represent a concrete manifestation of what the European Union can do that is beyond 1638 the capacity of any individual Member State. However, while EU funding supports the 1639 operation of the networks, there are concerns that their benefits may not be available 1640 equally to all Europeans, especially those in poorer Member States. Consequently, there 1641 is a case for examining whether EU funding might be able to address this.

1642 **3.16. Conclusion**

1643 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 1644 1645 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 1646 1647 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 1648 1649 framework to lead the way forward for better understanding, identifying, and addressing 1650 the gaps in access to healthcare.

1651 The extent to which Europe's citizens experience unmet need for health care varies 1652 enormously. While it now appears that increases in several countries, coinciding with 1653 austerity policies, may now be reversing, there can be no grounds for complacency. 1654 There is now high level political commitment to address this issue but, to do so, it is 1655 essential to put in place systems to quantify the scale of the problem and monitor the 1656 impact of policies.

1657 In practical terms, there is only one source of data collected in all Member States in a 1658 reasonably consistent way. This is the EU-SILC which, fortunately, has been collected for 1659 a number of years, making it possible to define a baseline. However, it is in many 1660 respects quite limited. Sample sizes are low, only a few questions on unmet need are 1661 included, and the samples do not capture the entire population, with some important exclusions of vulnerable groups. Nonetheless, pending any future improvements, we 1662 1663 recommend that it be used as a basic means of monitoring unmet need. We also propose 1664 a mechanism to set goals for progress in reducing unmet need that recognise the 1665 different starting points of Member States but which are both challenging and 1666 achievable. However, we note that selection of the precise targets is a political rather 1667 than a technical process. We believe that it should be possible to agree and implement such targets within 1-2 years. 1668

1669 While it is essential to have information on overall levels of unmet need, it is as 1670 important to be able to explain them. The EU-SILC data provide some insights, with 1671 questions on affordability, availability, and acceptability. However, appropriate policy 1672 changes require much more information. Consequently, we recommend that Member 1673 States undertake qualitative assessments of unmet need, taking account the specific 1674 issues they face and the groups and services that are most affected. We do not propose 1675 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. 1676 1677 However, we do recommend that these assessments should be published and should be 1678 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.

1691

1693 **4. LIST OF ABBREVIATIONS**

- 1694 ERA-NET European Research Area Network
- 1695 ERDF European Regional Development Fund
- 1696 HIREP-ERIC European Research Infrastructure Consortium on Health Information for
- 1697 Research and Evidence-based Policy
- 1698 ESIF European Structural and Investment Funds
- 1699 EU European Union
- 1700 EU-SILC European Union Survey of Income and Living Conditions
- 1701 OECD Organisation for Economic Co-operation and Development
- 1702 PACT Patient Access Partnership
- 1703
- 1704

1705 **5. REFERENCES**

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