

PATIENT INVOLVEMENT IN HEALTH TECHNOLOGY ASSESSMENT

An interim report on EPF's survey with decision makers in Europe

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The European Patients' Forum (EPF) would like to express its gratitude to all those people and organisations that made this study possible. First of all we thank all the HTA agencies that participated in our previous survey and those that helped us identify some of the decision makers.

We thank the decision makers from the European countries for devoting their time and patience to complete our survey (please see the annex-B for the list of institutions from where the decision makers responded to the survey). Last but not least, we thank all patient organisations that participated in EPF 2010 seminar on HTA and raised strongly the issue of patient involvement in HTA that led to this work.



EXECUTIVE SUMMARY

The research on patient involvement in HTA and decision-making for health technologies was initiated by EPF due to the discussions that evolved from the EPF HTA Seminar in 2010 where many patients' organisations called for support to be meaningfully involved in HTA processes.

In the first stage of this research we conducted a survey with the European HTA agencies to know their perspective on patient involvement. The report on this first stage is available on EPF website. The current report describes the results obtained from the survey with decision makers in European countries who are in charge of making decisions on health technologies. EPF conducted this survey between June 2011 and August 2011 as the second stage of its wider research to address some of the issues in patient involvement in HTA. 18 out of 45 decision makers completed the survey from 13 European countries. While 28 decision makers were identified by HTA agencies the remaining number were identified by contacting the HTA relevant authority or institution. It was a real challenge to identify in each country the decision making bodies and representatives making use of HTA and responsible for health technologies related decisions.

Before exploring the patient involvement dimension, we asked a few questions about the decision-making actors and mechanisms as we expected these to vary across countries. Not surprisingly, also the type and level of patient involvement in decision-making for health technologies is diverse across European countries.

The findings clearly support the need for EPF to continue advocating for patient involvement in HTA. Despite the fact that involving patients is in general considered beneficial there are not many bodies/institutions in charge of decision making on health technologies that do that. And often when there is some form of patient involvement this is not done in a systematic, comprehensive and meaningful way. There are clearly a number of reasons for that and the lack of a methodology and of capacity emerge as important factors in that respect.



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1. INTRODUCTION

Health Technology Assessment is a multidisciplinary tool that ideally should involve patients' perspectives; however, in reality there is still a long way to go in achieving meaningful patient involvement in HTA. The existing material on patient involvement in HTA, though not extensive includes literature, surveys and tools (e.g. literature in IJTAHC, INAHTA surveys and HTAi Glossary for Consumers and Patients). It has been produced to either directly support or to inform and initiate discussion on involving patients, patient organisations, citizens, informal carers and/or consumers in HTA. Despite doing some good groundwork, patient organisations are still struggling to gain a foothold in the HTA process, as was highlighted in EPF's HTA Seminar¹ held in May 2010. The need to follow up on the seminar, during which the patient organisations clearly called for support to be meaningfully involved in HTA processes, led EPF to conduct this research to further explore and address some of the issues around patient involvement in HTA.

The research is divided into three stages. It involves collecting primary data, mainly through surveys and discussions with three main stakeholder groups: HTA agencies (first stage), HTA appraisal committees/policy makers (second stage) and patient organisations (third stage). The report of the first stage was finalised in February 2011.

This report describes the main findings obtained from the second survey. On completion of all the stages (expected in late 2011) a comprehensive report with recommendations will be produced together with a good practice toolkit. In this way, we intend to get a comprehensive overview from the three stakeholder groups' perspectives in order to inform and shape patient involvement in HTA in Europe.

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¹ The seminar report is available at: http://www.eu-patient.eu/Documents/Publications/ConferenceSeminarReports/hta-seminar-2010-brussels-report.pdf).



1.1. Aim of the Research

The aim of the research is twofold:

- I. To identify the current situation, good practices in place and the challenges of patient involvement in HTA in European countries.
- II. To contribute this knowledge to the process of informing and building the capacity of patient organisations, HTA agencies and HTA appraisal committees and decision-makers in Europe, by producing a toolkit (manual, guide or other format).

1.2. Methodology

The scope of patient involvement in the survey is intended to comprise two levels and three types of involvement:

Involvement at organisational level:

1. Patients' organisations through their representatives

Involvement at individual level:

- 1. Lay patients
- 2. Informal carers (relatives and friends).

Note that the term "patients" used throughout the text is meant to cover all three above-mentioned categories.

The first step in preparation for the survey was to identify the relevant decision-makers across Europe. It took a month to identify possible participants, establish communication with them and get their consent to take part in the survey. For this, we conducted a survey with HTA agencies across Europe and asked for their support to identify key decision-makers in Europe. 28 decision-makers were identified as a result of this approach. We obtained the contact details of 17 more decision-makers by contacting the relevant national institution(s). 18 out of 45 decision makers from 13 European countries completed the survey. Another five started the survey but did not complete it.

Incomplete surveys were excluded from analysis of the results. During the follow up with decision makers who did not respond to the survey it was found that the reason for the low response rate was primarily due to lack of time. However some of the non-respondents did understand the relevance of this research.

1.3. Profile of Respondents

The distribution of respondents from the European countries is presented below (



Table 1). Out of the 18 decision-makers who responded, the great majority are public officials (16) and half of them (nine) are national health insurance board members. There are also five doctors, two health managers and only one HTA scientist. Note that respondents were able to choose more than one category. Moreover, two-thirds of the respondents are from national institutes and the remaining ones operate at regional level.

Country	Number of respondents
Austria	2
Belgium	1
Croatia	1
Denmark	1
Estonia	2
Hungary	1
Italy	1
Latvia	1
Netherlands	1
Slovenia	1
Spain	4
Sweden	1
United Kingdom	1
TOTAL	18

Table 1: Distribution of respondents among EU countries



2. DECISION MAKING PROCESSES ON HEALTH TECHNOLOGIES AND HTA

Before looking at patient involvement in decision-making related to health technologies we esteemed useful getting some information on the decision-maing process itself.

2.1 Use of HTA in areas of decision-making related to health technologies

The survey results indicate that HTA reports are mainly used for decisions on specific product reimbursement (

Table 2). This is followed by HTA being used in decisions on what treatments should be included and excluded from the national health insurance coverage and for public health services' planning and programming. The use of HTA reports for generating evidence on new and emerging health technologies and for introducing scientifically proven technologies did not score as high.

Use of HTA reports in decision-making	Number of responses
Specific product reimbursement decisions	15
National health insurance coverage decisions	13
Public health services planning and programming	11
Introduction of scientifically proven health technologies	9
Collecting evidence on emerging technologies with limited coverage	8
Other: For measuring added value and defining recommendations of use of new	1
pharmaceutical treatments	

Table 2: Use of HTA reports in decision-making

2.2 Decision-making based on types and areas of application of health technologies

We proposed various health technologies (e.g. drugs, biologics, devices, etc.) and possible areas of application – prevention, screening, diagnosis, treatment, and rehabilitation – for which HTA can be used in relation to decision-making (

Fig. 1).

The use of HTA for decision-making on screening scored the lowest and rehabilitation had the second lowest score. Prevention scored relatively low in all areas with the exception of biologics and, to some extent, drugs. The use of HTA reports for making decisions on equipment and, to some extent, support systems such as EHR or telemedicine systems for diagnosis is higher than average. HTA reports are mainly used for decisions on treatment and we see that it is highest for drugs, and particularly high for devices, medical and surgical procedures, and biologics.



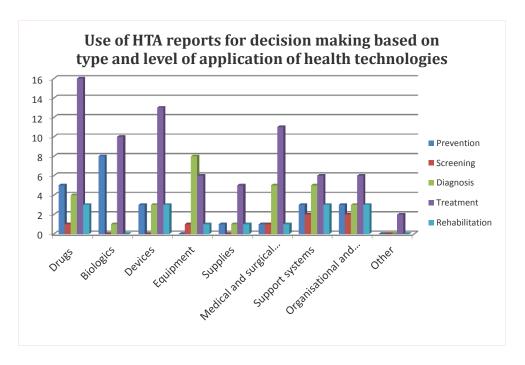


Fig. 1: Use of HTA for decision-making based on type and level of application of health technologies

2.3 Funders/Commissioners of HTA

Respondents reported that the majority of health technology assessments were funded by national governments' institutions (Fig. 2). This involves the Ministry of Health and the National Health Insurance Board. Manufacturers of health technologies also contribute funding towards HTA but on a smaller scale than governments. In some member states there are a few academic institutions that fund and conduct HTA as part of their research activities. Some hospitals commission assessments as well. In general, patients' and citizens' organisations and private health insurance companies do not usually fund HTA research. Regional health authorities were mentioned as 'others'.

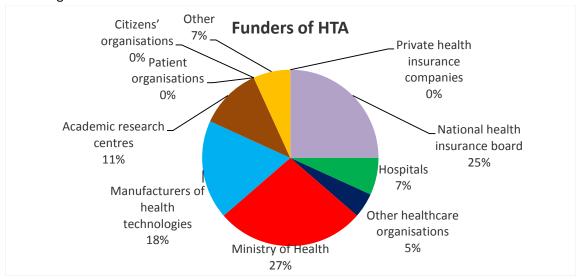


Fig. 2: Funders/Commissioners of HTA



2.4 Producers of HTA

While the main producers of health technology assessments are HTA agencies, some academic institutions in Europe also conduct assessments as part of their research activities (Fig. 3). Hospitals in a few European countries also produce hospital-based HTA. In countries where a formal HTA agency has not been established, the Ministry of Health is the main body running the assessments and other HTA-related activities. This may take place within a specific unit of the Ministry or may occur in general as part of the decision-making process itself. This trend has been usually observed in some Eastern European countries e.g. Estonia, Latvia and Hungary. Manufacturers of health technologies have also been producing HTA but mostly for early stage new and emerging technologies. Health insurance funds and regional health authorities were mentioned as 'others'.

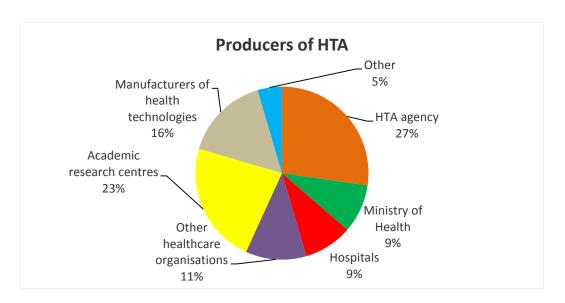


Fig. 3: Producers of HTA

2.5 Users of HTA

The users of HTA in Europe are quite different when compared with the funders and producers of HTA (Fig. 4). In previous sections we saw that academic institutions and manufacturers of technologies also fund and produce HTA but we also see that they are not prominent users of HTA and constitute less than 10% of total users. The majority of users of HTA reports (around 45% of the total users) are the Ministry of Health and the National Health Insurance Boards of the member states. Hospitals and other healthcare organisations that often produce their own HTA make up a total of 20% of the total users. We can also see that 15% of the HTA users comprise healthcare professionals that use HTA reports to guide their work. The groups that use HTA reports the least are lay patients, citizens, informal carers, patient organisations and regional health authorities (mentioned under others). These account for 12% of the total users.



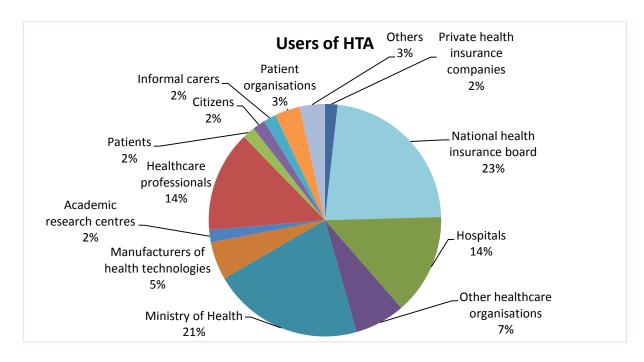


Fig. 4: Users of HTA

2.6 Benefits of HTA in decision-making on health technologies

When decision makers were asked to rate a range of benefits we proposed in relation to using HTA reports for making decisions on health technologies, they mostly scored them between highly and moderately important (

Table 3). There were very few responses that ranged from less to not important. This suggests that the respondents see important benefits of HTA to inform and/or support their decisions.

The respondents unanimously agree that the most important benefit of HTA is to support decision-making to promote sustainability of the health system, to help making informed decisions about investments/disinvestment of health technologies and to reduce costs and create additional spending possibilities. Other important benefits of HTA indicated are "improving transparency and accountability of the decision-making process", "improving the quality of health systems", "making treatments more relevant to patients' needs and preferences" and "helping to address unmet medical needs".

Benefits of HTA	Highly to moderately important	Less to not important	Don't know
Supports decision-making to promote sustainability of the health system	18	0	0
Helps to take informed decisions about investment/disinvestment of health technologies	18	0	0
Reduces costs and creates additional spending possibilities	18	0	0
Improves transparency and accountability of the decision-making process	17	1	0
Improves the quality of health services	16	0	1
Makes treatments more relevant to patients' needs and preferences	15	0	2
Helps to address unmet medical needs	15	1	2

Table 3: Benefits of HTA in decision-making on health technologies



2.7 Elements of HTA and their influence in decision-making

We asked decision makers to rate the level of influence that different elements that are included in a HTA report have on their decisions (

Table 4). Clinical efficacy and effectiveness, economic evaluation, safety, health problem and use of technology, unmet medical needs and organisational issues have equally very high influence on decision-making. Other elements such as legal issues, technical properties, ethical and social issues, and evidence on patient perspectives were seen as relatively less influential in decision-making.

Elements of HTA	Highly to moderately influential	Less to not influential	Don't know
Clinical efficacy and/or effectiveness	17	0	1
Economic evaluation	17	0	1
Safety	17	0	1
Health problem and use of the	17	0	1
technology			
Unmet medical needs	17	0	1
Organisational issues	17	0	1
Legal issues	16	1	1
Technical properties	16	0	2
Ethical issues	15	2	1
Social issues	14	2	2
Evidence on patient perspectives	14	3	1

Table 4: Elements of HTA

2.8 Regulatory frameworks related to HTA

The majority of respondents (14) declared that in their country there are official guidelines and laws for decision-making processes on the introduction and reimbursement of health technologies (Table 5). However, according to half of the respondents (nine) clear guidelines regarding the assessment of health technologies are still lacking in some European countries that have not yet institutionalised HTA. A couple of decision makers were not sure if such guidelines exist, but most of them (11) were able to specify the different laws and regulations used to support decision-making on health technologies such as national health care planning, laws related to medical treatment and pharmaceuticals, and other types of regulations approved by relevant bodies — i.e. reimbursement procedures and ad-hoc regulations on the approval and implementation of new health technologies.



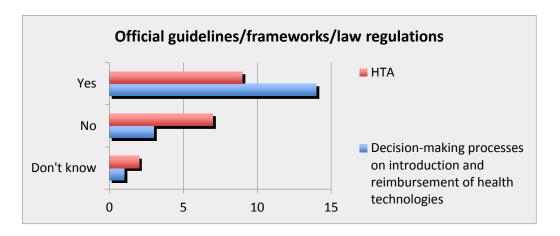


Table 5: Official guidelines, frameworks or law regulations in respondents' countries/regions

2.9 Challenges to the implementation of decisions taken based on HTA

One of the controversial aspects around HTA is that often clear decision paths emerging from the assessments do not translate into decisions that are consistent with the evidence provided by HTA. We were interested in knowing more about the challenges in this respect and the respondents provided useful insights. Out of 15 respondents, four people indicated economic factors as a challenge while three of them also pointed out to the lack of human resources as well. Three respondents mentioned that key decision-makers had inadequate knowledge about HTA or that HTA is not given due consideration. One of the respondents stressed the difficulty in ensuring equity of access and at the same time cost-effectiveness. Conflict of interest between stakeholders was mentioned as another barrier as well by two respondents. Patient organisations and industry were indicated by one respondent as a source of challenge without further elaboration on the reasons. Finally, lack of legislation with regard to the role of HTA and reluctance from the part of providers were also mentioned.

2.10 Elements that support implementation of decisions based on HTA

We were also interested in knowing which elements support the implementation of decisions informed by HTA. We need to say that the respondents' answers sometimes pointed out to challenges rather than supporting elements. We have therefore included those answers under the previous paragraph.

Laws, regulations and guidelines together with the role played by the competent authorities were indicated by the majority of respondents as supporting elements for the implementation of decisions based on HTA. It seems therefore that a regulatory framework – in whatever form is present in a certain country – does support decision making and implementation of decisions shaped by HTA evidence.

Other replies describe rather desired elements that would play a facilitating role. For instance, alternative health delivery configurations and sustainable financing to ensure that the budgetary impacts of the technologies' inclusion in reimbursement plans should be predicted and financed on the long term.

A couple of respondents suggested that clear evidence-based information on the added value of the technologies (safety, efficacy, efficiency) would faciliatate the taking and implementation of decisions.



3. PATIENT INVOLVEMENT IN DECISION-MAKING RELATED TO HEALTH TECHNOLOGIES

3.1 Current patient involvement in decision-making related to health technologies

When we asked the respondents about the ways patients get involved in decision-making in relation to health technologies, the majority indicated moderate or no involvement at all for the different items we proposed (

Table 6). This means that overall there is not much patient involvement in decision-making related to health technologies.

Patients and patient representatives are mostly involved through the possibility of appeal for patients/patient organisations against the final recommendations of the decision-makers, through public consultations, and through presence in appraisal committees.

Another way patients can contribute to decision-making is by providing through HTA reports patient evidence that is then weighted in the decisions. Finally, there is very little patient involvement in prioritising the research topics or scoping.

Types of patient involvement in HTA	Highly to moderately involved	Less to not involved	Don't know
Possibility of appeal for patients/patient organisations against	10	7	1
the final recommendations of the decision makers			
Involvement through public consultations	9	9	0
Involvement in appraisal committees	8	10	0
Patient evidence provided through HTA has been weighted in	8	8	2
the decision and is clearly included in public reports and			
communications			
Involvement in prioritising the research topics/topic	4	11	3
selection/scoping			

Table 6: Forms of patient involvement in decision-making related to HTA

3.2 Main interlocutors from the patient community who contribute patient perspective to decision-making on health technologies

The main interlocutor from the patient community giving views to decision-making on health technologies are the representatives of formally established patients' organisations (Table 7). Involvement of lay patients and representatives of informal patient groups is negligable. Moreover, according to the respondents, informal carers are not involved at all. Other interlocutors include representatives of consumers and representatives from health insurance organisations.



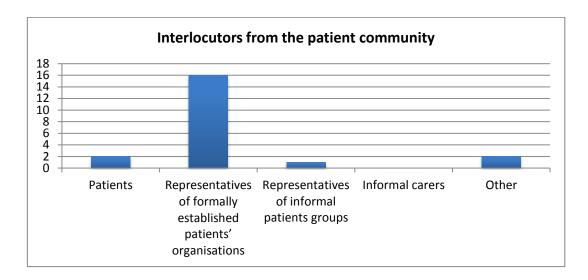


Table 7: Main interlocutors from the patient community

3.3 Appraisal committees for health technologies

Two thirds of the respondents said that there is an appraisal committee at national level that makes decisions on health technologies. The remaining one third said that there is no appriasal committee in their country or that they did not know about one.

3.4 Stakeholder groups contributing a patient perspective in appraisal committees for health technologies

The majority of stakeholders that contribute a patient perspective in appraisal committees were indicated to be doctors (nine) followed by patient organisations (eight). The third highest scoring group is healthcare managers (six). Lay patient (four) and nurse (four) representation is moderately low. Ethicists (two) and citizens (one) are the least represented stakeholder groups on appraisal committees, while informal carers are not represented at all (8).

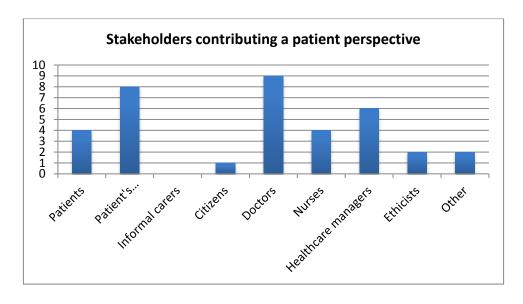


Table 8: Stakeholders contributing a patient perspective



3.5 Selection of stakeholder groups in appraisal committee for health technologies

After clarifying with decision makers the different stakeholder groups that represent patient perspectives in appraisal committees we enquired about the selection process of the committee members. While in some countries the selection criteria are included in national regulations, in others there is no established method.

In some countries there is an established recruitment process that occurs in consultation with patient organisations. In other countries the national health insurance board or another institution is responsible for recruiting the representatives. Six respondents stated that patient organisations are contacted and asked to send representatives to appraisal committees as it is done with other stakeholder groups.

3.6 Challenges for patient involvement in decision-making for health technologies

According to the respondents, the major challenges for patient involvement in the decision-making process for health technologies is the "lack of an agreed good method for patient involvement" and "lack of human resources to involve patients" (

Table 9). The second major challenge is the "credibility of patient perspective". "Knowing the right stage to get involved", "lack of commitment from patients" and "time intensive" scored moderately challenging. "Conflict of interest", "lack of commitment from their entity/institution", and "lack of financial affordability" are seen less challenging, while "technical and language difficulties" is perceived as the least challenging item.

Challenges for patient involvement	Highly to moderately	Less to not	Don't know
	challenging	challenging	KIIOW
Lack of agreed and good method for patient involvement	14	2	2
Lack of human resources capacity to involve patients	14	2	2
Credibility of patient perspective	13	2	3
Knowing the right stage to get involved	12	3	3
Lack of commitment from patient/patient organisations	11	3	4
Time intensive	11	3	4
Conflict of interest	10	5	3
Lack of financial affordability	8	3	7
Lack of commitment from my entity/institution	8	7	3
Technical and language difficulties	6	10	2

Table 9: Challenges for patient involvement in decision-making for health technologies

3.7 Impact of patient involvement in decision-making for health technologies

The highest impact of patient involevement is seen in "increased transparency and accountability of decision-making" (

Table 1010). This is followed by "decisions that meet patients needs in terms of quality of life and patient expected outcomes", "addressing unmet medical needs of patient groups", and "higher reliability and relevance of decisions. Moderate impact is observed for "decisions will be more consensus driven" and "patient centeredness of health expenditures", while the least was observed for the "increased timeliness in making decisions".



Impact for patient involvement	High to moderate impact	Less to no impact	Don't know
Increased transparency and accountability of decision-making	15	2	1
Decisions that meet patients' needs in terms of quality of life and patient expected outcomes	14	3	1
Addressing unmet medical needs of patient groups	14	3	1
Higher reliability and relevance of decisions (e.g. which treatment and care should be available)	14	2	2
Decisions will be more consensus-driven	13	2	2
Patient centred health expenditures	11	4	3
Increased timeliness in making decisions	7	7	3

Table 10: Impact of patient involvement in decision-making for health technologies

3.8 Facilitators of patient involvement in decision-making for health technologies

From the survey it is clear that there are no common methods to facilitate patient involvement in decision-making for health technologies. When asked about how the decision-making entity/institution facilitate patient involvement in HTA-based decision-making, most respondents indicated that "easy access to key reports/guides/protocols on HTA" is used the most (

Table 1). On the other hand, according to the respondents, "education and training courses to patients/informal carers/patient organisations involved in the decision-making" is used the least by the decision-making bodies. Responses for the remaining three items – namely, "easy, understandable and timely accessibility of information on how to contribute to HTA based decision making for health technologies", "easy to read summaries in HTA reports that can be understood by patients/patients' organisations/ informal carers", and "public documents that describe transparent mechanism in how patient views influence decision-making" are moderately used by the decision-making bodies.

Facilitators of patient involvement	Always to	Rarely or	Don't
	sometimes used	never used	know
Easy access to key reports/guides/protocols on HTA	12	3	2
Easy, understandable and timely accessibility of information on	10	5	2
how to contribute to HTA based decision making for health			
technologies			
Easy to read summaries in HTA reports that can be understood by	8	6	3
patients/patients' organisations/informal carer			
Public documents that describe transparent mechanism in how	7	7	3
patient views influence decision-making			
Education and training courses to patients/ informal	6	7	4
carers/patient organisations involved in the decision-making			

Table 1: Facilitators by the decision-making entity/institution for patient involvement



3.9 Good practice of patient involvement in decision-making for health technologies

When decision makers of health technologies were asked to give feedback on existing good practices of patient involvement in decision-making for health technologies, very little evidence of good practice was indicated. Receiving only three responses points out to the possible conclusion that there are only a few good practices known by decision-makers themselves.

3.10 Future plans for patient involvement in decision-making for health technologies

Until this point, decision makers had been asked about the current situation of patient involvement in decision-making for health technologies. When we asked them about their future plans to involve patients a mix of statements were received. Out of 18 respondents, four stated that they are planning to involve patients in decision-making for health technologies and three said that they already involve patients. On the other hand, five respondents stated that they do not intend to involve patients in the future and the remaining six either stated that they did not know or did not respond to the question.



4. CONCLUSIONS

Finding the right interlocutors: We esteem important to mention that it was very challenging to identify the relevant decision makers across Europe; we consider this element not very encouraging for patient involvement in decision-making on health technologies. A first step in strengthening patient involvement in decision-making is to be able to better identify relevant decision makers across Europe and to establish clearer communication paths with them regarding this subject.

Transparency: In most countries there are laws, regulations, guidelines that support decision-making on health technologies and HTA was indicated by respondents as highly impacting the transparency of decisions in a positive way. However, transparency of decisions remains one of the key concerns for patient organisations and therefore this aspect requires significant further investigation.

Level of involvement: The overall impression we get from the survey is that patient involvement in decision making is not very high. In terms of forms of involvement, the possibility to appeal against decisions scored highest and patient organisations would certainly argue about this being a real form of involving them. Public consultations are also quite used; this study did not explore however the extent these consultations influence the decisions made.

The participation in **appraisals committees** in charge of decisions on health technologies – which in principle is a more structured and institutionalised way of involvement – is moderately used as an approach. However, looking at appraisals committees from another angle, it is quite surprising to see that doctors are those mainly providing a patient perspective in appraisal committees, whereas we would argue patient organisations and/or lay patients are those best placed to express patients' views. It is also not reassuring that in many countries there is not a transparent selection process for members of these committees.

Challenges: Like for HTA agencies, they main challenges decision makers have to involve patients are the lack of an agreed good method for patient involvement and capacity issues. This recurrent theme gives an indication of one of the clear next steps to advance patient involvement. Another challenge considered important by decision-makers was the credibility of the patient perspective. This needs further exploring.

A real commitment is needed: We see the same approach as HTA agencies also in terms of facilitating patient involvement; decision-makers preferred method is to provide easy access to key reports, guides, protocols. The one less used on the other hand is education and training for patient representatives. By just providing access to information without a real skills-building it is hard to imagine that a meaningflu patient involvement can take place. Moreover, very few examples of good practice were indicated by respondents, which points to a need to improve shering of those good practices that are available.

Patient involvement in the future? It is not very encouraging to see that out of the 18 respondents five do not intend to involve patients in the future and six did not reply or did not know. Addressing some of the challenges described would possibly contribute to a better future scenario. Moreover, where



respondents said that patient involvement has reached a proper level there is the need to clarify what this means in concrete.



Annex 1 - List of institutions that responded to the survey

- 1. Viborg, Silkeborg, Hammel & Skive Hospital, Central Denmark Region
- 2. National Institute of Health and Clinical Excellence, United Kingdom
- 3. Ministry of Health, Slovenia
- 4. National Health Insurance Fund, Hungary
- 5. National Health Insurance Board, The Netherlands
- 6. Emilia Romagna Region Primary Care Department, Italy
- 7. Ministry of Social Affairs, Estonia
- 8. National Health Advisory Board, Spain
- 9. Ministry of Health, Spain
- 10. Croatian Institute for Health Insurance
- 11. Health and Consumer Affairs, Basque Government, Spain
- 12. County Council of Jamtland, Sweden
- 13. Hauptverband der Österreichischen Sozialversicherungsträger, Austria
- 14. The Centre of Health Economics Ministry of Health, Latvia
- 15. Catalan Health Service, Catalunya, Spain
- 16. National Institute for Health and Disablement Insurance, Belgium
- 17. Estonian Health Insurance Fund
- 18. Federal Ministry of Health, Austria