

PATIENT INVOLVEMENT IN HEALTH TECHNOLOGY ASSESSMENT

An interim report on EPF's survey with HTA Agencies in Europe

ACKNOWLEDGEMENTS

The European Patients' Forum (EPF) would like to express its gratitude to all those people and organisations that made this research possible. First of all, we thank all the HTA agencies that participated in our survey, especially the respondent from each agency for devoting their time and patience to completing the questionnaire (*please see the annex for the list of agencies*). We must also acknowledge the generous help that we received from Dr. Finn Borlum Kristensen (EUnetHTA Secretariat) and Dr. Inaki Guitierrez Ibarluzea (Vice Chair of EuroScan) in promoting our research and guiding us in the right direction. Without their support, we would not have had such a good response rate. We thank OSTEBA, the Basque Office for HTA in Spain and VASPVT, the state healthcare accreditation agency under the MoH in Lithuania, for participating in our pilot study and giving us valuable input to improve the questionnaire. 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, which led to this research.

EXECUTIVE SUMMARY

Patient involvement in Health Technology Assessment (HTA) is still in its infancy, although several efforts have been initiated in recent years. In the course of EPF's HTA Seminar in 2010, many patient organisations called for support for them to be meaningfully involved in HTA processes. This is an interim report of the main results obtained from the survey with HTA agencies in Europe which EPF conducted between November 2010 and February 2011, as a part of its wider research to address some of the issues regarding patient involvement in HTA. 40 out of 50 HTA agencies completed the survey from as many as 23 European countries. The type and level of patient involvement varies widely, which is a reflection of the different rationale, motivation and approach applied in each country.

Very few HTA agencies currently involve and integrate patients' perspectives in their reports and conduct formal evaluation of the impact of patient involvement in HTA. Apart from financial resource constraints, the main challenges are perceived to be the lack of capacity, time and good methodologies to involve patients. Above all, the question of the exact stage of HTA where patient engagement is needed or is most useful is still being debated. The last phases of HTA (external review, and diffusion and dissemination) accommodate some patient involvement, but there is none or low involvement in the first few phases of HTA (identification, filtration, prioritization). The respondents have said that ideally they would like to improve patient involvement in the first phases of HTA.

The agencies mainly use easy-to-read HTA summaries to facilitate patient involvement, but they need to improve other means of facilitation, such as education and training programmes and holding public conferences, seminars and workshops. They have provided some recommendations to patient organisations on how to get involved in HTA, and they suggest that the latter would need to start by first understanding the principles of HTA and then being pro-active to identify ways and means to get involved. Above all patient organisations have to be vigilant and flexible to emerging opportunities. They must demand transparency in decision-making and a legal framework for patient involvement in HTA. The perspective of patient organisations themselves will be collected in the next phase of EPF's research on patient involvement in HTA, planned for the period March-April 2011.

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1. EUROPEAN SURVEY WITH HTA AGENCIES ON PATIENT INVOLVEMENT IN HTA

1.1 . 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), patient organisations (second stage) and HTA appraisal committees/policy makers (third stage). In the first stage of the research, EPF completed a survey with the HTA agencies in European countries. This is an interim report of the main findings obtained from that survey. The report intends to provide a clearer picture of patient involvement in HTA agencies in Europe and to inform EPF's next stages of the research. On completion of the whole research project (expected by July), a comprehensive report with recommendations and a good practice toolkit will be produced. In this way, we intend to get a comprehensive

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

overview from the three stakeholder groups' perspectives in order to inform and shape HTA patient involvement in the EU.

1.2. RESEARCH AIM

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).

1.3 . METHODOLOGY

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

Involvement at organisational level:

1. Patient organisations through their representatives

Involvement at individual level:

2. Lay patients
3. Informal carers (relatives and friends).

Note: Sometimes the term “patients” is used in the text; however, it is used in general terms and is meant to cover all of the three categories described above.

HTA agencies were identified from both European and international HTA networks (EUnetHTA, INAHTA, EuroScan and ISPOR member lists), but the survey focuses on Europe. The survey used purposive and snowball sampling to identify and invite participants from HTA agencies (a total of 50). The sampling was done independently of the agencies' current status regarding patient involvement in HTA. Both formally established HTA agencies and, in their absence, national/regional bodies that are responsible for HTA were included in the research. The survey was piloted with two HTA agencies (in Spain and Lithuania) and the questions were modified based on their input. The questionnaire comprised multiple-choice questions and open and closed ended questions. It also ensured flexibility in order to collect

qualitative perspectives of HTA agencies. The Survey Monkey online tool was used to conduct the survey and it was sent electronically to participants' official email addresses. The actual survey was conducted between 23 December 2010 and 4 February 2011. The deadline was extended to 11 February 2011 to allow a few respondents to complete it with flexible timing. A formal request was sent to EUnetHTA Secretariat and EuroScan Vice-Chair to encourage participation of their members in the survey. Confidentiality of information was ensured through prior consent from respondents.

2. RESULTS OF THE SURVEY

40 out of 50 HTA agencies completed the survey, although 43 had originally started answering it. Incomplete answers were excluded from analysis of the results. The distribution of respondents can be seen below (See Fig.1).

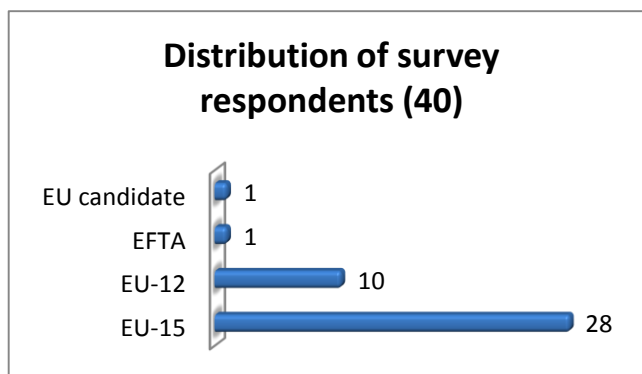


Fig.1

The respondents came from one or more HTA agencies of the following countries:

EU-15: Austria, Belgium, Denmark, Finland, France, Germany, Greece, Ireland, Italy, Netherlands, Spain, Sweden and United Kingdom; *EU-12*: Czech Republic, Estonia, Hungary, Latvia, Lithuania, Malta, Poland and Slovenia; *EU candidate countries*: Croatia; *EFTA countries*: Norway (see the annex for the list of Agencies that participated in the survey).

2.1 BACKGROUND

Out of the 40 HTA agencies that responded, just over half of them (22) do not involve patients in HTA and nearly half of them (18) do involve patients in HTA (See Fig.2). We also asked the agencies about patient involvement in Clinical Practice Guidelines (CPG), to see whether they had any experience with patient involvement even if not specifically on HTA. 13 out of 40 agencies produce CPG, and nearly 50 percent of them had patient involvement. This shows that the proportion of patient involvement in HTA and CPG is nearly the same.

The situation regarding HTA patient involvement is quite different in EU-15, EU-12, EU candidate and EFTA countries (See Fig.2), with only EU-15 member states having an equal

number of agencies that involve and do not involve patients in HTA. EU-12, EU-candidate and EFTA countries have a higher proportion of agencies with no patient involvement.

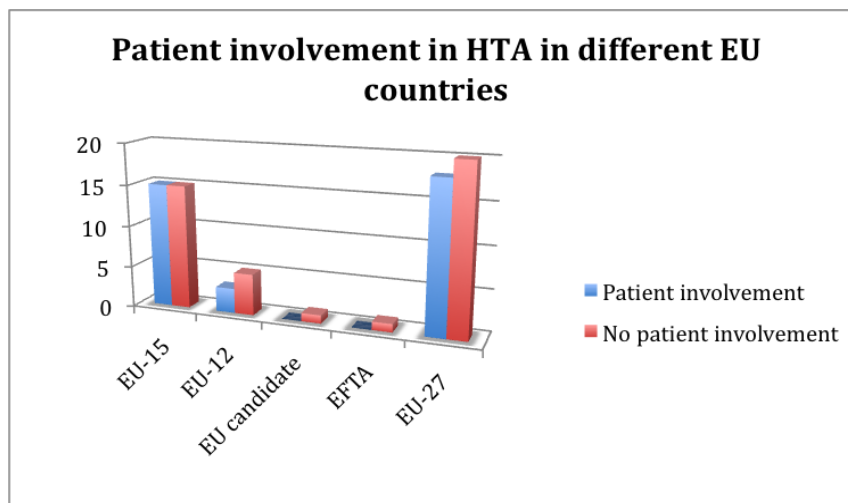


Fig.2

2.1.1 Span of patient involvement

The beginning of patient involvement in HTA differs across the EU member states. Those that have established it in the past 5-10 years or so come from the EU-15 (e.g. Denmark, Sweden, UK, Spain and Netherlands) whereas those that established it in the past 1-5 years comprise a mixture of EU-12 and EU-15 member states, though consisting more of the former (e.g. Hungary, Latvia, Austria, Ireland, Italy, Lithuania and Malta).

2.1.2 Providers of patients' perspectives

Among those HTA agencies that have patient involvement, the interlocutors bringing patients' perspectives are mainly patient representatives of patient organisations (17) followed by lay patients (10) and informal carers (6). The latter two sources are currently being included in countries like Denmark, Hungary, and the UK, and some countries (e.g. Italy, Malta, Spain and Sweden) are involving lay patients but not informal carers. While 18 HTA agencies assess patients' perspectives through that cooperation, 14 of them actually integrate those perspectives (needs, preferences, patient evidence) in their HTA reports.

2.1.3 Cooperation with patient organisations

Each HTA agency that has patient involvement has cooperated with between one and 10 patient organisations, with the majority of the agencies having links with at least three patient organisations. There was an exception only in the case of one agency (the UK's NICE), where the figure was significantly higher than 10. Most of the patient organisations operate at a national level, with very few operating at regional or European levels.

2.1.4 Reasons behind patient involvement

The main reasons for initiating patient involvement in HTA (See Fig.3) are own agency initiative (14 agencies) and observation of other agencies' experiences (six agencies). Other reasons such as demand from patient organisations and suggestion by HTA networks were found to be lower. The least indicated reasons were political and academic interests.

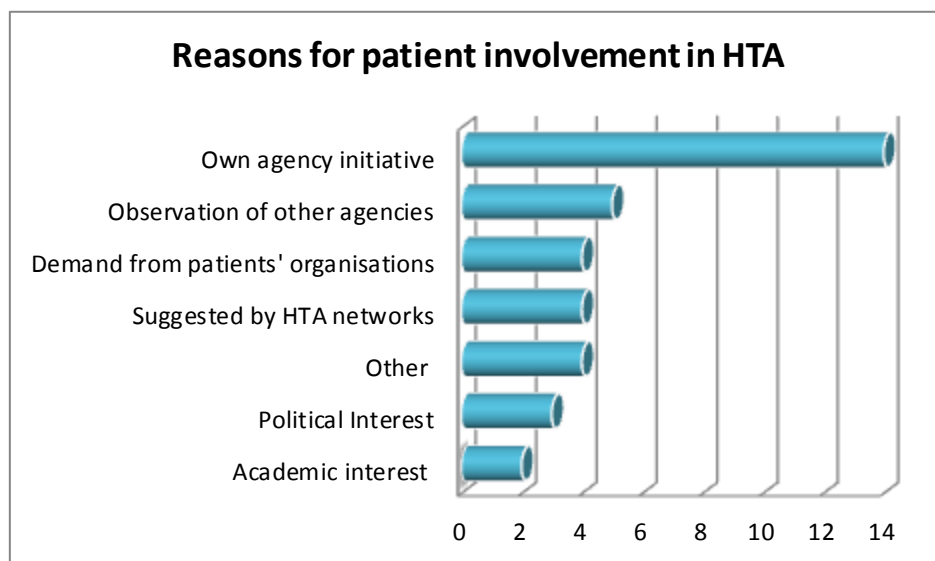


Fig.3

2.1.5 Current type and level of patient involvement

The current type and level of patient involvement ranges from absolutely no involvement to strong involvement depending on the different phases of HTA (See Table 1). Moderate to strong involvement is mainly seen in the phases of assessment, production of information, external review, and diffusion and dissemination, with the most involvement in the latter two aspects. Low or no involvement is seen in the phases of identification, filtration, and prioritisation.

	No involvement	Low involvement	Moderate involvement	Strong involvement	Don't know	Not relevant
Identification	4	8	3	1	1	1
Filtration	12	1	1	1	2	1
Prioritisation	11	2	3	2		
Assessment	5	4	4	4	1	
Produce information	4	3	5	3	2	1
Internal review	7	2	3	2	1	3
External review	3	4	3	5	2	1
Diffusion and dissemination	4	3	6	3		2

Table 1: Types and levels of patient involvement

2.1.6 Competencies required to participate in HTA

The knowledge and skills required by patients/patient organisations/informal carers to be involved in HTA are quite clear from the agencies' responses (*See Table 2*). Competencies up to a minimum level are required in basic concepts of HTA and Evidence Based Medicine (EBM), understanding of HTA methodology, knowledge of the disease, and practical knowledge of how and when to contribute to. Knowledge to interpret clinical research was considered to be one of the least important requirements for contributing to HTA.

	No importance	Little importance	Moderate importance	High importance	Don't know	Not relevant
Introduction to EBM and HTA and basic concepts	5	4	4	3		2
Understanding of HTA methodology	6	2	5	3	1	1
In depth knowledge of how and when to contribute evidence	3	5	6	3	1	
Practical knowledge of how and when to contribute evidence	2	5	6	2	2	1
Knowledge to interpret standard clinical research	7	5	3		1	2

Table 2: Competencies required to participate in HTA

2.2 IMPACT OF PATIENT INVOLVEMENT IN HTA

When we asked the HTA agencies what the impact of patient involvement on their work was, the majority of them responded that it had a high impact on increasing the accuracy in measuring the needs and preferences of patients, and led to a better understanding of the impact of technologies in a real-life context (e.g. barriers to complying with current therapy, side-effects, the patient's ability to pay, etc.) (See Table 3). This was followed by a better understanding of the quality of life aspects, where most of the respondents indicated a moderate to high impact. The involvement of patients to improve the quality of assessments, reliability and relevance of reports to the local context were seen to have only moderate impact, with some disagreement. The least impact of patient involvement was observed in improving the timeliness and reducing the costs of HTA reports.

Although the positive impact of patient involvement in HTA was conveyed clearly by the HTA agencies, very few agencies (only 2 out of 18) have carried out a formal evaluation of this impact.

	No impact	Little impact	Moderate impact	High impact	Don't know	Not relevant
Better quality of assessment and comprehensive information	1	3	5	5	4	
Better understanding of technology impact in real life context (e.g. barriers to comply to current therapy, side effects, patient capacity to pay, etc.)	1		9	7	1	
Better understanding of the quality of life aspects	1	3	8	5	1	
Higher accuracy in measuring needs and preferences of patients	2		9	6		1
Higher reliability and relevance of reports to the local context	3	3	6	4	2	
Increased timeliness in producing information	5	2	2	2	3	4
Lower costs for producing reports	6	2			6	4

Table 3: Impact of patient involvement in HTA

2.3 GOOD PRACTICES OF PATIENT INVOLVEMENT IN HTA

When we asked the HTA agencies how they facilitate patient involvement in HTA, the majority of them stated that they often employ easy-to-read HTA summaries and access to key reports, guides and protocols (*See Table 4*). These are followed by the organisation of workshops, seminars and conferences. Specific information on how to contribute to HTA was employed only by a few respondents, with nearly half of them never or rarely using this. Education and training programmes, special websites and forums dedicated to patient involvement in HTA, transparency in how patient views influence decision-making, and regular distribution of newsletters are only sometimes used by the agencies.

	Never used	Rarely used	Sometimes used	Often used	Don't know	Not relevant
Easy, understandable and timely accessibility of information on HTA and how to contribute to its development	3	4	3	5	1	2
Easy to read HTA summaries			3	10	3	2
Education and training courses to patients/informal carers/patient organisations	4	2	7	2	1	2
Transparency in how patient views influence decision-making	4	1	5	4	3	1
Regular distribution of newsletters	6		4	4	1	3
Easy accessibility to journals	6	1	2	3	3	3
Organising workshops, seminars, conferences	1	4	8	3		2
Easy access to key reports/guides/protocols	1	1	3	10	1	2
Dedicated websites and forums	4	3	7	2		2

Table 4: Good practices of patient involvement in HTA

Next, we asked for specific examples of good practice in HTA patient involvement. The agencies either answered from their own experience or from other agencies' experiences. The main good practices indicated were:

1. **Involving public contributors** to review research articles and full grant applications, and in prioritisation panels and commissioning boards;
2. A **public involvement unit** within the agency which gives advice on appropriate patient groups/organisations to involve in HTAs, and convenes a public involvement network involving representatives from a range of patient organisations as a conduit for sharing good practice;

3. A dedicated team of permanent **staff** in the agency who are completely focussed on and responsible for patient, carer and public involvement across all of the agency's work on patient and public involvement programmes. Availability of formal and informal support and contact details - email, phone, face to face meetings etc;
4. A formal patient, carer and public involvement **policy** made available on the website of the agency, which sets out the mission, values and commitment to this work and the principles that are followed;
5. Offer **payment** for lay involvement - attendance fees for lay committee members, one-off payments to patient organisations per topic they participate in. Travel and food expenses covered - also carers and childcare costs if needed - to attend meetings, workshops and training;
6. Set up an **advisory committee** of lay people including patients;
7. Use a **reviewer form** specially designed for patients to review the HTA grant applications;
8. Write a **handbook** with all the different roles patient representatives may take;
9. Organise **HTA events** specially related to patient participation, where patient representatives are asked to think about relevant issues regarding research.

2.3. CHALLENGES FOR PATIENT INVOLVEMENT IN HTA

The barriers to patient involvement in HTA came through quite clearly from the responses received (See Table 5). The two major challenges for most HTA agencies are the lack of capacity to involve patients and the fact that it is time-consuming. This was followed by four other reasons: there is no agreed method to involve patients in HTA; knowing the exact stage of HTA where patient engagement is needed or is most useful is still unclear, lack of financial resources, and scientific credibility of patient evidence. Disagreement was seen equally in two areas: commitment from patients, and technical and language difficulties. Most of the agencies esteem that lack of interest on the part of the HTA agency, conflict of interest, or the lack of commitment from HTA staff are not major challenges.

	Strongly disagree	Disagree	Agree	Strongly agree	Don't know	Not relevant
Lack of agreed and good method to obtain patient evidence	3	10	11	8	5	3
Knowing the stage at which the engagement is needed or most useful	2	9	15	5	7	2
Credibility of patient evidence	4	13	12	2	5	4
Lack of capacity to involve patients	3	4	17	9	3	4
Commitment from patients/informal carers/patient organisations	4	12	8	1	10	5
Commitment from HTA staff	6	13	5	1	8	7
Technical difficulties to understand the technical language from the patient side	4	12	8	3	8	5
Time intensive	1	5	13	12	3	6
Lack of affordability	1	10	10	5	7	7
Lack of interest of agency	7	19	1		5	8
Conflict of interest	7	13	4	1	6	9

Table 5: Challenges for patient involvement in HTA

2.4. IDEAL TYPE AND LEVEL OF PATIENT INVOLVEMENT IN HTA

After assessing the current type and level of patient involvement in the agencies, we then explored their views on the ideal type and level of patient involvement in HTA in their agencies. The results show a stark difference between real and ideal situations. The stages of HTA indicated as having less patient involvement at present (*See Table 1 page 11*) are considered to be of high relevance for the ideal patient involvement in HTA (*See Table. 6*). It was noted that the current patient involvement in the first few stages of HTA (i.e. identification, filtration and prioritisation) is rather weak. However, ideally the agencies would like to see strong patient involvement in the identification and prioritisation phases, although they were not sure regarding filtration. As we progress to the last stages of HTA (i.e. assessment, internal review, external review and diffusion), where stronger patient involvement was indicated by the agencies in the current situation, the survey shows a desire for further improvement in these areas too. The stages of diffusion and dissemination in this context are those considered most important by the agencies for having patient involvement. On the other hand, only in the internal review stage do HTA agencies prefer to have a low involvement of patients.

	No involvement	Low involvement	Moderate involvement	Strong involvement	Don't know	Not relevant
Identification	1	8	15	9	5	2
Filtration	5	9	12	1		3
Prioritisation	1	7	13	12	5	2
Assessment	6	5	14	6	7	2
Internal review	11	8	6	4	7	4
External review	2	6	12	14	5	1
Diffusion and dissemination	1		11	22	4	2

Table 6: Ideal types and levels of involvement in HTA

2.5. RECOMMENDATIONS BY THE HTA AGENCIES TO PATIENT ORGANISATIONS

We asked the HTA agencies to give any concrete recommendations that they may have to patient organisations to be involved in HTA. The key recommendations formulated are listed below; they are a summary of the main items and do not represent exact quotes formulated by the agencies.

A. Recommendations for getting involved in the work of HTA agencies

1. Educate the organisation's representatives so that they have a basic understanding of Evidence Based Medicine (EBM) and HTA. This covers two things: a broad-based understanding of the nature of HTA and its role in the allocation of healthcare resources and in decision-making should be understood; increasingly, some of the more scientific aspects and cost-effectiveness issues should be understood, and the organisations' representatives should be trained in these aspects.
2. Approach the HTA agency pro-actively to ask for involvement and respond to invitations to participate in HTA activities. Following up on information about health technologies and the work of HTA agency would help organisations stay pro-active.
3. Engage in different HTA forums where the producers meet and suggest how patient involvement can be achieved in HTA through clear proposals and comments on existing HTA. Provide input to the identification of relevant assessment topics.
4. Meet with staff from the Agency (ideally someone whose job it is to support patient organisation involvement) to learn about the processes and how best to get involved (who to send to meetings, what to put on forms, what type of evidence is most useful).

5. Understand the processes of the HTA agency. There are often very clearly defined methods and processes that have to be followed and strict timelines that must be adhered to.
6. If the agency has a glossary, ask for it, and use that to better understand the language/jargon/acronyms the agency uses.
7. Contact other patient organisations that are experienced in engaging with the agency's work and see whether you can learn from them.
8. Demonstrate independence by diversifying the organisation's financial support and having a transparent framework for cooperating with industry. This will help support one of the core principles of HTA, i.e. to remain transparent.

B. Recommendations for getting involved in the decision-making processes on the introduction of health technologies

1. Ensure that there are two lay representative members of the group in the planning and decision-making processes of health service boards.
2. Stay in contact and build links with decision-makers and ask for more accountable and transparent decisions. Cooperate in building the rules for transparency. This can also be achieved by calling for more transparency in decision processes, using the media, and demanding the legal regulation of patient involvement.
3. Lay people or citizens should also represent the views, beliefs and opinions of patients and carers affected by the condition. They should also champion the evidence sent in by the patient organisations, and make sure it is raised in the decision-making discussions.
4. Ask for payment and relevant training that is tailored to needs and backgrounds. Lay members should have equal status on the committee and have full-voting rights, as all other committee members do. There should always be at least two lay members on a group, to ensure the patient and public voice is a real one and it is not just tokenistic, or a box-ticking exercise to have them there.

5. Participate in review processes of HTA reports and ask for a version that is understandable by patients/patients' groups/patient organisations where applicable.
6. Be a member of hearing boards at any local hospital and do lobby work in the national health department.
7. Try to have a representative participate in one of the committees that judge the value of HTA research.
8. Actively initiate and participate in public debates on introduction of technologies.

3. CONCLUSIONS

The conclusions formulated in this paragraph are preliminary; more solid conclusions will be formulated after completing the surveys with patient organisations and HTA decision-makers.

Diversity across countries: It is not surprising that HTA patient involvement in EU-15, EU-12, EU candidate and EFTA countries appears to vary considerably. This is likely to depend on several factors, which certainly include the more recent practice of HTA in certain member states and the different traditions and culture regarding patient involvement. This raises the necessity to further explore the needs of HTA agencies that are less experienced in this respect and to envisage building capacity for patient involvement. Capacity building for patient involvement in HTA should not just entail educational or training activities; attention must be given to other factors that can affect patient engagement. In the context of capacity building, these are: organisational development, workforce development, partnership working, leadership and resources allocation.

Broadening the range of perspectives: The main providers of patients' perspectives in HTA are representatives of patient organisations followed by lay patients and informal carers. The latter two are involved by very few agencies across Europe. It would be interesting to explore the implications of involving patient representatives rather than lay patients or informal carers; this research did not have the means to do so. It was also found that on average, HTA agencies cooperate with three patient organisations mostly operating at national level within each country. This implies that HTA agencies could expand their networks with patient organisations based on their areas of focus.

Integrating the patient perspective: Almost all of the agencies with patient involvement integrate patients' perspectives (needs, preferences, patient evidence) into their HTA reports in practice. It is very important for patients who have devoted their time and experience to cooperate with the agencies to see that their input is valued and integrated into the actual results. If this does not happen, it will result in frustration and lack of

motivation to be involved again; the very rationale behind the involvement would then have to be questioned.

Clarity and support to initiate patient involvement: Two interesting features have emerged with regard to elements that could strengthen patient involvement in HTA: the need for a clear methodology for HTA agencies on how to involve patients and for a policy framework to guide this approach. We hope the results of the work EPF has undertaken will help in the first aspect; as for the latter, it will be very instructive to learn what policy- and decision-makers think about it.

HTA competencies required for patient engagement: HTA obviously contains several phases, and as we move to the last phases of HTA (external review, diffusion and dissemination) patient involvement gradually increases, suggesting that there is low or no involvement in the first few phases of HTA (identification, filtration, prioritization). This could be due to a range of reasons, depending on the nature and specific interests of each agency. However, specific competencies are also needed to understand HTA and to meaningfully contribute to it. Practical knowledge of how and when to contribute to HTA comes top of the list. This again reflects on the kind of capacity-building that is needed for patients/informal carers/patient organisations. Comprehensive coaching is necessary to ensure that patients are trained in the required areas, and this could be provided by the HTA agencies themselves or other stakeholders with the relevant expertise. Resources can be pooled from different stakeholders e.g. appraisal committees, national/regional health systems, academic institutions, patient organisations/umbrella organisations that may bring in their expertise, financial and mentoring support. The agencies often use easy-to-read HTA summaries and access to key reports, guides and protocols to facilitate patient involvement in HTA. However clear information on how to participate to relevant education and training programmes are still scarce. This can be overcome by involving other stakeholders who might be better suited to delivering accessible and effective training opportunities.

Need to assess the impact of patient involvement in HTA: HTA agencies have agreed that patient perspectives can have a high impact on improving the accuracy of assessing the needs and preferences of patients, and achieving better understanding of the impact of technologies in a real-life context. However, very few agencies have carried out a formal

evaluation of the impact of patient involvement in HTA. Integrating a structured assessment of the contribution of patients to HTA could help improve both patient involvement as well as the HTA reports, by identifying gaps and success factors.

Identifying, assessing and sharing good practices of patient involvement in HTA: A number of good practices have been identified by some HTA agencies. These mainly include: having dedicated staff or a separate unit to address patient involvement within the agency; developing a special policy to facilitate patient involvement; producing handbooks; financial incentives; and organising HTA events to promote patient involvement. There might be a challenge in transferring available good practice from their specific source to different EU contexts. This can be mitigated by being clear about current circumstances affecting patient involvement in the recipient countries/region; identifying strengths and weaknesses; and from that, identifying and reviewing relevant good practice from accredited sources.

Closing the gap between ideal and real conditions: Ideally, the agencies would like to improve patient involvement in the initial phases as well as the final phases of HTA. The majority of them would like to see strong patient involvement in diffusion and dissemination. To close the gap between what exists and what is considered ideal, the recommendations of HTA agencies to patient organisations must be considered and implemented where feasible. Some of the main recommendations include: staying proactive and initiating communication with different stakeholders; getting trained in at least the basics of HTA; continuous networking with policy-makers and agencies; demanding a legal framework to support patient involvement; and demonstrating the right capacity to be involved. Improvement will much depend on how patient organisations are able to maximize these features and what kind of optimal support can be provided to them in order to achieve this.

Annex- List of HTA agencies participating in the survey

1. Austria GÖG Gesundheit Österreich GMBH
2. Austria HVB Hauptverband der Österreichischen Sozialversicherungsträger
3. Austria LBI/HTA Ludwig Boltzman Institute of Health Technology Assessment
4. Belgium KCE, Belgian Health Care Knowledge Centre
5. Czech Republic HTA consultant
6. Denmark CAST, Center for Applied Research and Technology Assessment
7. Denmark DACEHTA, Danish Centre for Health Technology Assessment
8. Denmark DSI, Danish Institute for Health Services Research
9. Denmark HTA/HSR-DHTA HTA & Health Services Research
10. Estonia UTA, University of Tartu
11. Finland FinOHTA, Finnish Office for HTA
12. France, CEDIT Comité d'Évaluation et de Diffusion des Innovations Technologiques
13. Greece NSPH, National School of Public Health
14. Hungary EMKI, Institute for Healthcare Quality Improvement and Hospital Engineering
15. Hungary ESKI, National Institute for Strategic Health Research
16. Hungary HunHTA, Health Economics and Technology Assessment Research Centre, Corvinus University of Budapest
17. Ireland HIQA, Health Information and Quality Authority
18. Italy AGE.NA.S., Agenzia Nazionale per i Servizi Sanitari Regionali
19. Italy ASSR Regione Emilia Romagna, Agenzia Sanitaria e Sociale Regione Emilia Romagna
20. Italy Regione Veneto, Direzione Piani e Programmi Socio Sanitari
21. Italy UVT, HTA Unit in "A.Gemelli" Teaching Hospital
22. Latvia VEC, Centre of Health Economics
23. Lithuania VASPVT, State Health Care Accreditation Agency, Ministry of Health
24. Malta SSD/MSOC, Minsitry for Social Policy / Strategy and Sustainability Division
25. Netherlands ZonMw, The Medical and Health Research Council of The Netherlands
26. Norway NOKC, Norwegian Knowledge Centre for the Health Services
27. Poland AHTAPol, Agency for HTA
28. Slovenia NIPH-RS, National Institute of Public Health of the Republic of Slovenia
29. Spain AETSA, Andalusian Agency for Health Technology Assessment
30. Spain AVALIA-T, Galician Agency for HTA
31. Spain CAHIAQ, Catalan Agency for Health Information, Assessment and Quality (formerly CAHTA)
32. Spain ISCIII/AETS, Agency for Health Technology Assessment, Instituto de Salud Carlos III
33. Spain OSTEBAS, Basque Office for Health Technology Assessment
34. Spain UETS, Health Technology Assessment Unit, Agencia Laín Entralgo
35. Sweden SBU, Swedish Council on Technology Assessment in Health Care
36. United Kingdom NETSCC, NIHR Health Technology Assessment Programme (former NCCHTA)
37. United Kingdom NHSC, National Horizon Scanning Centre
38. United Kingdom NHS-QIS, Quality Improvement Scotland
39. United Kingdom NICE, National Institute for Health and Clinical Excellence
40. Croatia Agency for Quality and Accreditation in Health