



Patient Engagement in Health Technology Assessment (HTA)

2nd Workshop

17 November 2010

Thon Hotel City Centre, Brussels, Belgium

Co-chairs of the Workshop

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The event was kindly sponsored by CSL Behring, European Federation of Pharmaceutical Industries and Associations (EFPIA), GSK – GlaxoSmithKline, Lilly, Pfizer and Shire.

We are also grateful for the support of European AIDS Treatment Group (EATG), EuropaBio – European Association for BioIndustries, European Genetic Alliances' Network (EGAN), European Patients' Forum (EPF), EURORDIS – Rare Diseases Europe, Genetic Alliance UK and the University of Glasgow.

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December 2010

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EXECUTIVE SUMMARY

Health technology assessment (HTA) – a multidisciplinary field of policy analysis that studies the medical, social, ethical, and economic implications of development, diffusion and use of health technology – is increasingly playing a central role in how national healthcare priorities are set and service provision is delivered in most EU member states.

It should benefit both patients and healthcare payers by allowing faster, evidence-based access to innovative technologies that are clinically sound and cost-effective, while helping to eliminate treatments and practices that are shown to deliver limited health benefits or financial value. However, the role of the patient in the HTA process is often ill defined, with widely varying criteria on which HTA decisions are based being applied in EU Member States, which can lead to inequality of access to treatment.

The role of patients in HTA

In order to increase the understanding of the contribution that patients and patient organisations can make to HTA, EPPOSI (European Platform for Patients' Organisations, Science and Industry) organised a two-stage workshop. The first part took place in Brussels on 29 June 2010 and brought together an invited group of experts representing all stakeholder groups to explore the context in which HTA is currently undertaken and how "patient engagement" can play a greater role within it.

The participants concluded that patients' participation in HTA is invaluable as they provide unique perspectives and real-life experience which can:

- inform the translation of evidence of efficacy (such as clinical trial results) towards the concept of effectiveness (actual experience)
- inform economic models based on delineating disease pathways, treatment preferences and the burden of disease
- provide invaluable insights into living with the disease and unmet needs that inform value judgments in the deliberative process.

To encourage the effective participation of patients in HTA, it was agreed that a follow-up workshop would be needed to draw up the key elements of consensus guidelines which could be developed into concrete recommendations and promoted to national agencies, the European Commission/EUnetHTA and international organisations such as HTAi.

The follow-up workshop was held on 17 November 2010 in Brussels and was open to all stakeholders and interested parties. It attracted nearly 80 attendees representing patients' associations, payers, EU and national policy-makers in public health, HTA and ICT, healthcare professions, pharmaceutical and medical diagnostics industries, scientists and researchers (see full list on page 14).

Through a mixture of panel debates, plenary and breakout sessions, the participants focused their discussions on four main questions from which they set out to elicit recommendations to improve patient engagement in HTA:

1. How should we engage with patients to ensure that HTA is truly patient-centred and when and how should patients engage in the HTA process?

2. What questions can patients ask of the “hard” evidence to be sure that it reflects their concerns?
3. How can patient organisations collect evidence that will be useful for HTAs?
4. What can HTA agencies do to improve engagement with patients?

Recommendations from the workshop

Concluding the workshop, co-chairs Dr Karen Facey, Alastair Kent and Andrea Rappagliosi summarised the main focus of the recommendations:

- 1 **Policies for patient engagement:** every HTA Agency should create a clear policy outlining how they will involve patients in the HTA process and how that process will take account of patients’ perspectives. Examples of best practice in Europe and internationally (eg including Canada and Australia) should be used to generate minimum standards for involvement that can be adapted and replicated nationally and locally. This should include examples from other related fields, such as the European regulatory processes where patients and patients’ organisations are involved in the risk/benefit assessment and actively participate in the definition of what constitutes value.
- 2 **Education:** patients must be educated to better understand the concepts underpinning HTA so they understand how to contribute evidence that provides added value to the process. Similarly, HTA decision-makers and clinicians need to be better educated about patients’ real-life experiences in order to move beyond clinical and cost-effectiveness issues when making decisions to take into account the full range of psychosocial aspects affecting patients’ treatment and care: family and carer support, quality of life and wellbeing, employment etc.
- 3 **Resources:** increasing patient engagement will take manpower and resources and should be transparent (educational and financial support to patients’ groups in order for them to participate, extra manpower at HTA agencies to help patients participate).
- 4 **Collaboration:** the only way to achieve real patient engagement in HTA is through greater collaboration between patients, HTA agencies, clinicians, academia and industry and to be clear about where and how collaboration can take place.

Next steps

These recommendations will form the basis of EPPOSI’s new HTA thematic programme, to be launched in Spring 2011, and developed into concrete guidelines which can be promoted to national agencies, the European Commission/EUnetHTA and international organisations such as HTAi.

As EPPOSI’s Executive Director Jacqueline Bowman explained, “The Programme of work will be based on EPPOSI’s unique patient-science-industry partnership approach to research, peer review, concrete recommendations and dissemination. It will seek to build multi-stakeholder innovative models for rational decision-making processes in the context of very diverse EU health systems with scarce health resources. The key will be to build a sustainable model which carries patients’ as well as public confidence.”

INTRODUCTION

The role of the patient in health technology assessment (HTA) – a multidisciplinary field of policy analysis that studies the medical, social, ethical, and economic implications of the development, diffusion and use of health technology – is often ill-defined, with wide variations in criteria on which HTA decisions are based being applied in EU Member States, which can lead to inequality of access to treatment.

The European Commission and EU Member States have attempted to address this by setting up EUnetHTA, a Joint Action network of 34 government-appointed organisations from the EU Member States, accession countries and EEA (European Economic Area), which runs from January 2010 to 2012.

Its aims are to:

- help clarify what can be better achieved on HTA at EU level
- reduce duplication of work between national agencies
- spread expertise for the benefit of all participating countries
- strengthen evaluations carried out by EU countries
- develop transparent governance tools for all stakeholders
- policy and process for stakeholder involvement in European collaboration on HTA
- develop joint processes of sharing workload in producing scientific assessments on interventions, medical devices and pharmaceuticals
- implement the Pharmaceutical Forum's recommendations on relative effectiveness of pharmaceuticals.

Finn Børllum Kristensen, Chairman of the Executive Committee of the EUnetHTA and a speaker at EPPOSI's November workshop, endorsed the need for HTA agencies to do more to support patient engagement, "It's my view that all agencies should have policies for patient involvement. There is a clear need for more transparency on the work of agencies and clear indications on where patient engagement should take place."

EPPOSI'S TWO-STAGE APPROACH TO IMPROVING PATIENT ENGAGEMENT

1st Workshop

In order to increase the understanding of the contribution that patients and patient organisations can make to HTA, EPPOSI (European Platform for Patients' Organisations, Science and Industry) organised a two-stage workshop. The first part took place in Brussels on 29 June 2010 and brought together an invited group of experts representing all stakeholder groups to explore the context in which HTA is currently undertaken and how "patient engagement" can play a greater role within it.

The participants concluded that patients' participation in HTA is invaluable as they provide unique perspectives and real-life experience which can:

- inform the translation of evidence of efficacy (such as clinical trial results) towards the concept of effectiveness (actual experience)
- inform economic models based on delineating disease pathways, treatment preferences and the burden of disease
- provide invaluable insights into living with the disease and unmet needs that inform value judgments in the deliberative process.

To encourage the effective participation of patients in HTA, it was agreed that a follow-up workshop was needed to draw up key elements of consensus guidelines which could be developed into concrete recommendations and promoted to national agencies, the European Commission/EUnetHTA and international organisations such as HTAi.

2nd Workshop

The follow-up workshop was held on 17 November 2010 in Brussels and was open to all stakeholders and interested parties. It attracted 75 attendees representing patients' associations, payers, EU and national policy-makers in public health, HTA and ICT, pharmaceutical and medical diagnostics industries, scientists and researchers (see full list on page 14). Through a mixture of panel debates, plenary and breakout sessions, the participants focused their discussions on four main questions from which they set out to elicit concrete recommendations to improve patient engagement in HTA:

1. How should we engage with patients to ensure that HTA is truly patient-centred and when and how should patients engage in the HTA process?
2. What questions can patients ask of the "hard" evidence to be sure that it reflects their concerns?
3. How can patient organisations collect evidence that will be useful for HTAs?
4. What can HTA agencies do to improve engagement with patients?

SETTING THE FRAMEWORK

The opening panel debate, chaired by Hilda Bastian, Head of the Health Information Department of IQWiG (Germany's HTA agency - Institute for Quality and Efficiency in Health Care), outlined the key challenges to ensuring greater patient participation in HTA from the perspectives of patients - represented by Yann Le Cam, CEO of EURORDIS (European Organisation for Rare Diseases) - science and academia, by Prof Helle Ploug-Hansen of the Institute of Public Health Research Unit: Health, Environment & Society, University of Southern Denmark - and industry, by Maria Fagerquist of EFPIA (European Federation of Pharmaceutical Industries and Associations).

Science

Prof Ploug-Hansen emphasised the importance of using multiple research methodologies to ensure that patients' wider perspectives are taken into account - qualitative studies, quantitative studies, syntheses of qualitative studies and literature reviews (even unpublished studies where relevant) - to deepen knowledge and produce more rounded and robust evidence. She also made the point that in HTA contexts, the term 'patient' can also refer to 'citizen', 'customer', 'user' and 'individual'.

She also advocated a more anthropological approach to the collection of evidence to include the wider psycho-social aspects of patients' daily lives which impact on how they deal with their disease or condition and which help strengthen best practice. Depending on the context, the answers elicited can be very different: for example, whether the patient is in hospital or at home, the kinds of care and support networks in place and so on. However, she emphasised that it is the researchers who must interpret the data but the processes must be transparent so that both the patients and researchers' perspectives and roles are clear.

Industry

Drawing on her former experience at the Swedish Pricing and Reimbursement Authority (TLV) - an agency that applies HTA in its decision-making - Maria Fagerquist asserted the right of patients to be involved in HTA as not only democratic but irrefutable, commenting that “you cannot possibly exclude arguably the most central stakeholder from the process.” Not only are they the only ones to know the full implications of a disease and its treatment but a greater sense of engagement leads to greater commitment to treatment. Effectiveness – a key determinant of HTA - is based on the actual use of medicines so patients’ preferences should therefore be an integral part of assessments, she argued.

She cited three examples of good practice:

- **Sweden** – patient representatives participate as members of expert groups of the Swedish Council on Health Technology Assessment (SBU) on equal terms as other clinical and pharmaceutical experts. The patient representative provides a patient perspective on ethical considerations, as well as interpreting and assessing the reasonableness of study outcomes.
- **Scotland** - Scottish Medicines Consortium (SMC) has an online web-based patient submission system which is prepared by Patient Interest Groups which collect comments from patients and carers. A user-friendly patient submission template has been created to make it easier for patients to share their experiences and give their perspective on a range of issues, including how medicine meets patients’ needs; the advantages/disadvantages over other available medicines; and how the medicine impacts on patients/carers’ lives
- **Australia** – consumer impact statements are sought to find out what impact a disease has on the daily life of patients and there is a consumer representative on the PBAC (Pharmaceutical Benefits Advisory Committee) who has advance notice of and input in the agenda.

However, overall, she concluded, progress was patchy with too few examples of successful patient involvement at the level of “setting the process” and stressed that patients need training and support to be fully involved.

Patients

Yann Le Cam argued that only patients can offer a truly all-encompassing perspective on all aspects essential to good HTA decisions. Patients are the only people with direct, real-life experience of living with a particular disease and able to closely monitor the true effects of drug therapies and dosages. They also know the daily practicalities of navigating health systems and administrations, medical practices and care networks, so it is essential that they are involved. He also noted that patients have already gained a lot of experience in participating in other European health regulatory areas, such as in EMA (European Medicines Agency) and on pharmaco-vigilance issues, which is leading to better outcomes.

This unique perspective offered crucial added value across HTA processes, he believed, from helping to improve the design of trials, recruitment and end points to the interpretation of data.

As further evidence, he offered two additional benefits of patient involvement:

1. self-reported outcomes on risks, benefits and effectiveness, which are very important before and after marketing authorisation, and working with regulatory agencies
2. studies of patients’ treatment preferences which can provide a bridge between EMA and HTA at national levels.

Much more needs to be done to experiment with and expand on these methodologies, he urged. But there is much that is happening: in the field of orphan drugs, he noted that there is now 10 years of evidence since the EU directive came into effect to endorse reimbursement decisions at national level; DG Enterprise & Industry has just launched a two-year process looking at conditional pricing; and EURORDIS is now offering a training programme on HTA to create critical mass and skills so patients can really participate nationally and in EUnetHTA.

ADDRESSING THE CHALLENGES: 4 KEY QUESTIONS

To address the four key questions outlined in the objectives (page 7), the participants divided into four breakout groups, maintaining a strict stakeholder balance in each. The morning sessions were devoted to evaluating the challenges of achieving greater patient participation from the perspectives of patients, agencies, industry and science. The follow-up sessions in the afternoon, comprising a different mix of participants, focused on how to build on the previous breakout session outcomes and come up with more concrete recommendations to lead to best practice in patient engagement in HTA across Europe.

1 HOW SHOULD WE ENGAGE WITH PATIENTS TO ENSURE THAT HTA IS TRULY PATIENT-CENTRED AND WHEN AND HOW SHOULD PATIENTS ENGAGE IN THE HTA PROCESS?

The session was chaired by Dr Karen Facey of Health Technology Assessment International (HTAi) and Yann Le Cam of EURORDIS. The discussions centred on the need for the clear recognition of the value of patients' perspectives and to obtain a clear commitment to include patient involvement at all levels: governance, committees, technology and medicine where HTA processes are involved. It was noted that EUnetHTA has a stakeholder involvement policy (not just for patients) and that it would be helpful if each HTA Agency had a patient involvement policy that clearly outlined how patients' perspectives were sought and how patients and patient organisations could get involved in the HTA process.

How should this be done? Patients should be involved in scoping the HTA and submission of evidence (using social media and networking, self-reported outcomes, patient preferences and patient organisation databases). HTA agencies should support patient organisations to understand the type of information that is valuable.

Proper training is also important but it was agreed that the key point is that this must be organised by patient groups and not by HTA agencies but to have staff from HTA agencies involved. Different training programmes already exist - EFNA-LSE training was cited as one example - but summer schools could also be instituted and patient organisations could also share tools. HTAi has developed a glossary for patients and promotes a patient's Guide to HTA. HTA agencies also need to organise regular sessions to introduce themselves to patient organisations in their countries, explain what they do and how their processes work.

HOW SHOULD WE ENGAGE WITH PATIENTS TO ENSURE THAT HTA IS TRULY PATIENT-CENTRED AND WHEN AND HOW SHOULD PATIENTS ENGAGE IN THE HTA PROCESS?

MAIN FINDINGS

1. All HTA agencies in Europe should have a policy that presents how they involve patients and patient evidence in their HTA process. Ideally this should be based on a minimum set of actions to engage patients in their work and ensure that their views are taken account of in decision-making.
2. To promote education on HTA on how to get involved as a patient representative to add value to the system
3. Good starting points: The International Network of Agencies for HTA has already performed 1 survey of consumer involvement in HTA agencies and is in the process of doing another. The European Patients' Forum is undertaking a survey of agencies and patient organisations in Europe to determine involvement. EFPIA is also conducting research into patient involvement in HTA processes and EUnetHTA is creating a core model for HTA that includes consideration of patient issues. EPPOSI might want to consider activities that promote collaboration among these groups.

2 WHAT QUESTIONS CAN PATIENTS ASK OF THE "HARD" EVIDENCE TO BE SURE THAT IT REFLECTS THEIR CONCERNS?

The session was chaired by Prof Helle Ploug-Hansen of the University of Southern Denmark and Maarten de Wit of the Dutch League of Arthritis Patients' Associations

The group discussed the too narrow focus of most HTA agencies on 'hard' evidence criteria (mainly based on clinical trials) which exclude patients' real-life daily experiences and other important factors such as family life, the work environment and social networks.

In the participants' view, HTA agencies needed stronger and clearer structures to allow the consideration of evidence based on both qualitative and quantitative research methods and to provide patients' representatives with adequate support and training to enable them to participate on an equal footing with other relevant stakeholders. This would also help to mitigate any potential safety issues inherent in 'softer' evidence, as well as allow national and regional differences to be taken into account.

WHAT QUESTIONS CAN PATIENTS ASK OF THE “HARD” EVIDENCE TO BE SURE THAT IT REFLECTS THEIR CONCERNS?

MAIN FINDINGS

- 1 HTA stakeholders should develop and follow guidance for patient involvement. Good guidance is lacking not just for patients but researchers
- 2 HTA agencies should provide evidence on:
 - societal and cultural aspects
 - Impact on daily life
 - Patient journeys
 - Ethical concerns
 - Quality of life
 - Combining qualitative and quantitative research
- 3 HTA agencies should provide training for patients and researchers on how to collaborate in an HTA Process. Competences to achieve this do not come automatically
- 4 Strong wish from patients’ organisations for EPPOSI to create a European Charter for patients to have fair access

3 HOW CAN PATIENT ORGANISATIONS COLLECT EVIDENCE THAT WILL BE USEFUL FOR HTAs?

The session was chaired by Liuska Sanna of the European Patients’ Forum and Andrea Rappagliosi of GSK. The discussions uncovered a wide range of questions and challenges, including the difficulties for patient organisations to gather the evidence and knowing what HTA agencies are actually looking for; the difficulties for patient organisations to format the information for the purposes of the HTA – how this can be standardised and how ‘soft’, more anecdotal, data on patients’ daily experience can be incorporated; the independence of evidence provided – who pays to help patient organisations collect evidence and transparency issues; knowing which methodologies/approaches patient organisations can use to collect and present evidence; and getting HTA agencies to take into account patients’ preferences and their own value judgments on treatment methods.

HOW CAN PATIENT ORGANISATIONS COLLECT EVIDENCE THAT WILL BE USEFUL FOR HTAS?

MAIN FINDINGS

1. Foster the early engagement of patient organisations in clinical trials to integrate quality of life, social and ethical information into the evidence-collection for HTA agencies.
2. Involve patient organisations in gathering data post-marketing authorisation to inform long-term relative effectiveness assessments.

4 WHAT CAN HTA AGENCIES DO TO IMPROVE ENGAGEMENT WITH PATIENTS?

The session was chaired by Alastair Kent of Genetic Alliance UK and Lizzie Amis of NICE (National Institute for Health and Clinical Excellence, England). The group noted that before HTA agencies can improve engagement with patients they must secure political engagement to ensure trust and effectiveness, as well as high-level policy agreement on the engagement of patients at all levels.

Other key challenges highlighted during the discussions included the need for clear, two-way channels of communication and information between agencies and patients, where patients are consulted (early), treated as experts and given equal status as other decision-makers in HTA processes. Transparency was also key so that all stakeholders – policy-makers, patients, academics and industry - understood the process and knew what was expected of them, when and why.

The participants also raised the importance of quality of life issues which must be taken into account in HTA decisions, not just for the patient but for family members and carers. They highlighted the need for cost issues to be broadened to look at the costs to society as a whole, not just to the health system payer. Finally, they concluded that many patients' organisations lack the capacity, resources and knowledge to interact with HTA processes and need help, training and support to become fully involved.

WHAT CAN HTA AGENCIES DO TO IMPROVE ENGAGEMENT WITH PATIENTS? MAIN FINDINGS

HTA agencies:

1. should have lay members on the board in sufficient numbers to have real input
2. should engage with patient organisations relevant to the particular HTA on all topics
3. need to have staff whose job it is to engage with patients
4. need to understand that engagement = partnership and mutual give-and-take but not all patient organisations are realistically able to sustain that
5. should support systematic access to education or capacity-building to enable patient organisations to be able to move to engagement
6. should make a systematic commitment to share best practice throughout Europe –via EUnetHTA?
7. need to be clearer about what they expect from patients (and realistic – most aren't scientists) so they don't put them off by asking too technical or scientific questions

FINAL RECOMMENDATIONS

In the final wrap-up debate before presenting the final recommendations, there was general agreement that more training and education of both patient organisation leaders and HTA agency staff was urgently needed in order to ensure a better understanding by both sides of what constitutes acceptable evidence and how it should be submitted.

It was also noted that new ways of measuring patient evidence would be needed if HTA were to make rounded decisions. However, there was concern that incorporating 'softer' patient evidence into assessments must not mean 'lower' standards of evidence which could result in patients receiving inadequate, or potentially unsafe treatments and care.

Ultimately, it was agreed that the next step must be a move from talking about patient involvement to formalising it, whether through EUnetHTA or other European HTA networks.

Concluding the workshop, co-chairs Dr Karen Facey, Alastair Kent and Andrea Rappagliosi summarised the main focus of the recommendations:

- 1 **Policies for patient engagement:** every HTA Agency should create a clear policy outlining how they will involve patients in the HTA process and how that process will take account of patients' perspectives. Examples of best practice in Europe and internationally (eg including Canada and Australia) should be used to generate minimum standards for involvement that can be adapted and replicated nationally and locally. This should include examples from other related fields, such as the European regulatory processes where patients and patients' organisations are involved in the risk/benefit assessment and actively participate in the definition of what constitutes value.
- 2 **Education:** patients must be educated to better understand the concepts underpinning HTA so they understand how to contribute evidence that provides added value to the process. Similarly, HTA decision-makers and clinicians need to be better educated about patients' real-life experiences in order to move beyond clinical and cost-effectiveness issues when making decisions to take into account the full range of psychosocial aspects affecting patients' treatment and care: family and carer support, quality of life and wellbeing, employment etc.
- 3 **Resources:** increasing patient engagement will take manpower and resources and should be transparent (educational and financial support to patients' groups in order for them to participate, extra manpower at HTA agencies to help patients participate).
- 4 **Collaboration:** the only way to achieve real patient engagement in HTA is through greater collaboration between patients, HTA agencies, clinicians, academia and industry and to be clear about where and how collaboration can take place.

NEXT STEPS

The recommendations will form the basis of a new HTA thematic programme, to be launched by EPPOSI in Spring 2011, and ultimately developed into concrete guidelines which can be promoted to national agencies, the European Commission/EUnetHTA and international organisations such as HTAi.

As EPPOSI's Executive Director Jacqueline Bowman explained, "The programme of work will be based on EPPOSI's unique patient-science-industry partnership approach to research, peer review, concrete recommendations and dissemination. It will seek to build multi-stakeholder innovative models for rational decision-making processes in the context of very diverse EU health systems with scarce health resources. The key will be to build a sustainable model which carries patients' as well as public confidence."

LIST OF PARTICIPANTS

Lizzie Amis	NICE (National Institute for Health and Clinical Excellence, England)
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Aleidis Lasure	Tibotec
Anne-Grethe Lauridsen	European Gaucher Alliance
Yann Le Cam	EURORDIS (Rare Diseases Europe)
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Cees Smit	European Genetic Alliances' Network (EGAN/VSOP)
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Layla Theiner	Cancer Research UK
Geraint Thomas	GSK Pharma Europe
Vladimir Tomov	Confederation of Health Protection (Bulgaria)
Sheila Tunstall-James	Patient and Public Involvement Group at Scottish Medicines Consortium
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Sonia van Weely	Dutch Steering Committee on Orphan Drugs
Jonathan Ventura	EPPOSI
Jean-Marie Vlassembrouck	Baxter
Maria Zaragoza	Pelvic Pain Support Network

USEFUL LINKS

European Commission

- Public Health

http://ec.europa.eu/health/index_en.htm

- Innovation Union

http://ec.europa.eu/research/innovation-union/index_en.cfm

- Research & Innovation – Health

http://ec.europa.eu/research/health/index_en.html

- ICT for Better Healthcare in Europe

http://ec.europa.eu/information_society/activities/health/index_en.htm

EUnetHTA

www.eunethta.eu

Innovative Medicines Initiative

<http://www.imi.europa.eu/>

ABOUT EPPOSI

Founded in 1994, EPPOSI (European Platform for Patients' Organisations, Science and Industry) is an independent, not-for-profit, partnership-based and multi-stakeholder think tank based in Brussels, Belgium, committed to making the EU-2020 strategic vision work through the health and wellbeing of its citizens.

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