An introduction to optimising patient involvement to improve migraine patient outcomes

Spotlight on migraine services and access to appropriate medicines

SUMMARY RESOURCE

Organisations from which information was sourced in support of the Toolkit include:

European Medicines Agency (EMA) | European Patients Forum (EPF) | Health Equality Europe | Health Technology International (HTAi) Patient and Citizen Involvement in HTA Interest Group (PCIG) | HTA agencies in England and Germany | World Health Organisation (WHO)

*This resource was created by KYNE in partnership with European Migraine and Headache Alliance (EMHA), the European Federation of Neurological Associations (EFNA) and Migraine Action.**

The development of the Toolkit was funded by Novartis.

**As of June 2018, Migraine Action has closed.*

Welcome to your Summary Resource

Dear Colleagues

Over the last five years a lot has been achieved in better meeting the needs of those living with migraine, even in the absence of new treatment innovations. Yet, more still needs to be done to address the considerable burden of migraine.

This Summary Resource has been developed to introduce migraine and associated patient organisations throughout the world to the topic of how patient involvement can be optimised to improve migraine outcomes, with a spotlight on the role of patient involvement in improving migraine services and access to appropriate medicines.

This resource is a summary of a more comprehensive Toolkit that has been developed on the same subject. Following review of this document, it is hoped that you might consider using the comprehensive Toolkit, or that you will consider partnering with other organisations to help ensure that your voice is heard.

This document and the accompanying comprehensive Toolkit are just the start. Over the coming months and years, we hope to build on these resources with a range of initiatives and programmes that further advance organisations' capacity and capability in this important area.

We hope that you find your Summary Resource of value and we would welcome any feedback you might have.

Regards

Elena Ruiz de la Torre
Executive Director, Past President
European Migraine and Headache Alliance (EMHA)

Donna Walsh
Executive Director
European Federation of Neurological Alliances [EFNA]

Simon Evans
Chief Executive
*Migraine Action**

The Toolkit comprises original co-created copy and tried and tested educational materials from leading organisations such as WHO, European Patients Academy on Therapeutic Innovation (EUPATI), and Health Technology Assessment International's (HTAi) Patient and Citizen Involvement in HTA Interest Group (PCIG). The Toolkit partners thank these organisations.

**As of June 2018, Migraine Action has closed.*

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EVALUATION OF YOUR SUMMARY RESOURCE

Module one - AN INTRODUCTION TO YOUR SUMMARY RESOURCE

Summary Resource purpose

Your Summary Resource is an introductory educational resource for patient organisations that support those living with and affected by migraine. It is anticipated that it will be used as an introductory resource to patient involvement in migraine service improvement and access to appropriate medicines by smaller patient organisations and those that have limited experience in the area.

Your Summary Resource is an abridged version of a comprehensive Toolkit on the same subject. The full Toolkit provides a lot more information, insight, resources and guidance for patient organisations who currently have the capacity and capability to take a more active role in advancing patient involvement.

A copy of the comprehensive Toolkit resource can be downloaded **here**

Who this Summary Resource is for

This resource has been developed to support those patient organisations with an interest in improving patient outcomes in migraine, but, who may not have the capacity, or a current focus on advancing patient involvement in improving migraine services and access to appropriate medicines.

How to Use Your Summary Resource*

In addition to this section, your Summary Resource comprises five additional modules:

1. The burden of migraine
2. The value of medicines
3. An introduction to patient involvement in Health Technology Assessment (HTA)
4. An introduction to patient involvement in improving migraine services
5. Stakeholder engagement and communication

Hyperlinks: Each section can be accessed by using the hyperlinks within the contents table. While the hyperlinks at the end of each section will return you to the contents table.

Explanations: Within your Summary Resource, where words are underlined, hover your cursor over the word and an explanation will drop down.

Downloads: At the end of each section there are downloadable resources that you can use to further support your understanding of patient involvement.

Evaluation: There is an evaluation form at the end of the document. Please use this to give us your feedback. This will help us to improve any future editions of this resource.

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*In developing your Summary Resource, consideration has been given to the needs of smaller patient organisations, variations in country healthcare systems and within these, the opportunities for patient involvement.

The use of the term ‘patient’

Within your Toolkit, the term ‘patient’ is used to describe those that can inform decision-makers about the needs, experiences and preferences of those affected by migraine. Patients therefore include:

- **Individual patients.** People who have experience of migraine – sometimes termed “lived-experience”
- **Expert patients.** Patients who have experience of migraine and have been trained in areas such as medicines development or service delivery
- **Carers.** Those who provide care and support for people living with migraine, such as family members, friends or volunteers
- **Patient organisation representatives.** Individuals from a patient organisation that have accountability for representing the views of the organisation
- **Patient advocates.** Those who advocate for migraine patients and carers, but are not accountable for representing the views of a patient organisation

Toolkit Development Partners

Your Toolkit was initiated and funded by Novartis. KYNE, a communications consultancy, was engaged by Novartis to work with the European Headache Alliance (EHA), the European Federation of Neurological Associations (EFNA) and Migraine Action (MA) to develop the Toolkit.

EMHA European Migraine & Headache Alliance

The European Migraine and Headache Alliance (EMHA) is a non-profit, patient umbrella group that was launched in 2006. Since then, the Alliance has grown to represent 25 patient groups from across the continent.

www.europeanheadachealliance.org

EFNA EUROPEAN FEDERATION OF NEUROLOGICAL ASSOCIATIONS

The European Federation of Neurological Associations (EFNA) brings together European umbrella organisations of neurological patient advocacy groups, to work with other associations in the field of neurology.

www.efna.net

MIGRAINE ACTION

Migraine Action* is the UK’s leading charity offering support and advisory information to those affected by migraine, whether individuals, families, employers or employees or medical professionals.

www.migraine.org.uk

**As of June 2018, Migraine Action has closed.*

Module two - THE BURDEN OF MIGRAINE

Introduction

Migraine is a distinct neurological disease that is associated with recurrent and often debilitating headaches.

The 'burden of migraine' is a term that is used to describe the impact of migraine on individuals, their families, communities and society. It can also refer to the healthcare system costs of managing migraine, and to the economic impact of migraine on individuals, their employers and on local and national economies.

When building an argument for improving services and access to appropriate medicines, evidence regarding the burden of migraine is a critical component of patient involvement. This could include the information included within your Summary Resource, as well as additional information you may have on file.

Some patient organisations also generate their own insight into the burden of migraine, for example by undertaking a survey of patients. The benefits of this are considered further in module four and module five.

> "Headache disorders, including migraine and tension-type headache, are among the most prevalent disorders of mankind. They are under-recognised, under-diagnosed and under-treated. Financial costs to society through lost productivity are enormous – far greater than the health-care expenditure on headache in any country.[1]"
>
> *World Health Organisation (WHO), Atlas of Headache Disorders*

Key Points

- Migraine is a distinct neurological disease that is associated with recurrent and often debilitating headaches[2]
- Migraine is the third highest cause of disabilities in the under 50s[2]
- Migraine has a profound and limiting impact on an individual's abilities to carry out everyday tasks[3]
- Migraine is associated with significant financial cost to society[3]

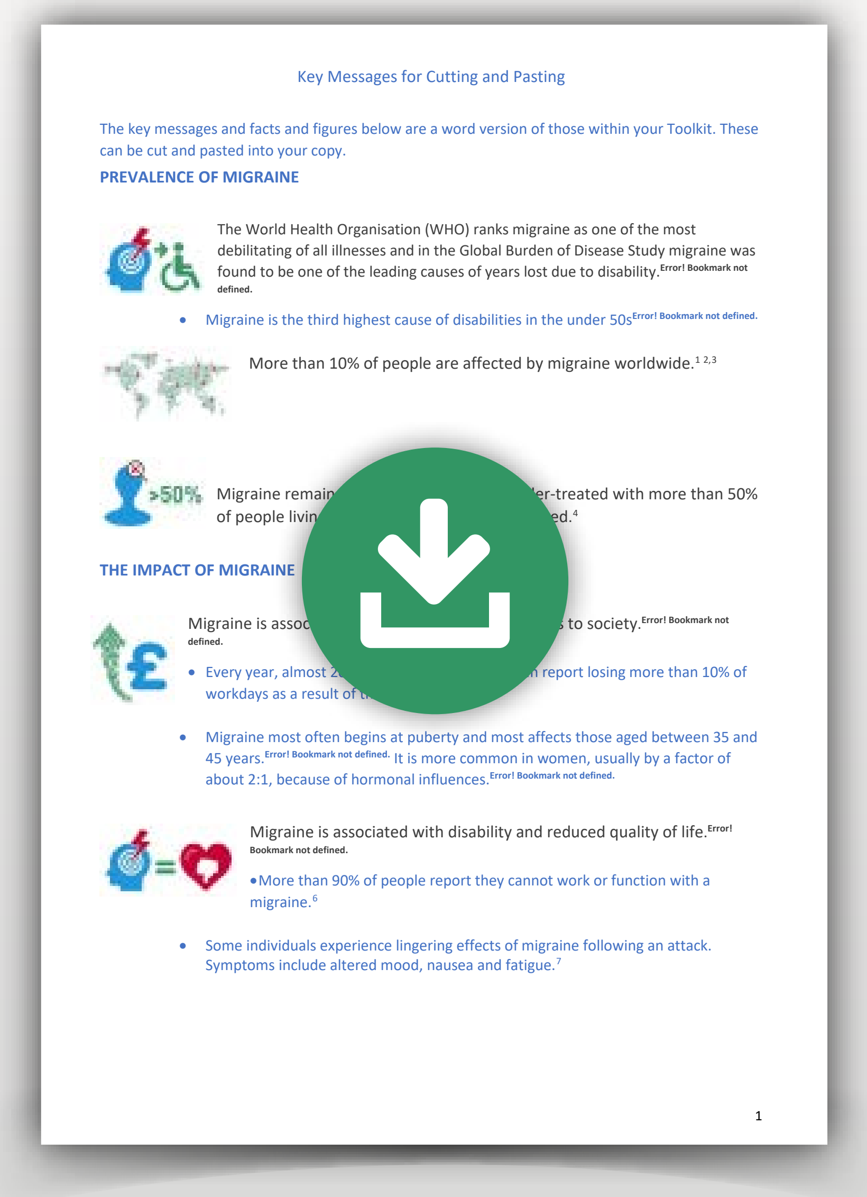
Using infographics

Infographics are graphic visual representations of information, data or knowledge intended to present complex information quickly and clearly. They can add value to any content you are generating as they can help the reader better understand the important points you are putting across.

Referencing

Whenever possible, messages that state something as fact should be referenced to a respected source. Doing this will help to demonstrate that the data has undergone independent scientific scrutiny, while adding both credibility and validity to the message.

Resource



Key Messages for Cutting and Pasting

The key messages and facts and figures below are a word version of those within your Toolkit. These can be cut and pasted into your copy.

PREVALENCE OF MIGRAINE

The World Health Organisation (WHO) ranks migraine as one of the most debilitating of all illnesses and in the Global Burden of Disease Study migraine was found to be one of the leading causes of years lost due to disability.[Error! Bookmark not defined.]

- Migraine is the third highest cause of disabilities in the under 50s[Error! Bookmark not defined.]

More than 10% of people are affected by migraine worldwide.[1] [2,3]

Migraine remain
er-treated with more than 50%
of people livin
ed.[4]

THE IMPACT OF MIGRAINE

Migraine is assoc
to society.[Error! Bookmark not defined.]

- Every year, almost 2
report losing more than 10% of
workdays as a result of t
- Migraine most often begins at puberty and most affects those aged between 35 and 45 years.[Error! Bookmark not defined.] It is more common in women, usually by a factor of about 2:1, because of hormonal influences.[Error! Bookmark not defined.]

Migraine is associated with disability and reduced quality of life.[Error! Bookmark not defined.]

- More than 90% of people report they cannot work or function with a migraine.[6]
- Some individuals experience lingering effects of migraine following an attack. Symptoms include altered mood, nausea and fatigue.[7]

1

Source and format

Comprehensive Toolkit
Two-page word document

Resource title

Burden of migraine key messages and facts and figures with infographics

Direction for use

This is a Word document of the key messages and facts and figures from the comprehensive Toolkit.

Download and use the contents of this document by clipping the key messages and infographics into materials you may be generating.

This will also transfer the reference to the end of your document.

Next steps:

- Download the document above to review the key messages and facts and figures
- Add additional information you might have to the document to generate an information source that is right for you

Module three - THE VALUE OF MEDICINES

Introduction

Medicines have been around for thousands of years, and today medicines and vaccines are some of the most powerful tools we have in helping people live longer, healthier and more productive lives.

But the benefits of medicines go far beyond the individual alone. Treating and preventing disease benefits families, communities and societies, and both contribute to the economic success of countries and regions throughout the world.

With about 7,000 medicines in development[5], a new wave of medical innovation will continue to play a key role in addressing the challenges faced by patients and healthcare systems. Yet it won't stop at 7,000. An aging population, advances in technology and the many conditions for which there is still a high unmet medical need, mean that even more medicines will be developed.

> “Pharmaceutical innovations (including medicines and vaccines) accounted for 73% of the total increase in life expectancy between 2000 and 2009.[4]”
>
> *National Bureau of Economic Research*

Key Points

- The positive impact of medicine includes reduced death rates from disease and improved cure rates. Examples include:
  - The decline in death rates from cancer by 20% over the past 20 years[6]
  - Hepatitis C cure rates of over 90% within as little as eight weeks with new therapies, compared to 41% in those being treated for 48 weeks just over a decade ago[7]
- Innovative medicines can put healthcare systems on a more sustainable path by reducing costs in other parts of the healthcare system such as hospitalisations and clinicians' time. For example:
  - Per capita expenditure on cardiovascular hospitalisations in 20 OECD Countries would have been $89 (70%) higher in 2004 had new cardiovascular medicines not been introduced in the period 1995–2004[8]
- Innovation can deliver significant societal value as development is strongly targeted at societal disease priorities, while innovative new therapies have enabled patients to continue contributing to society. For example:
  - In France, 82.1% of working women diagnosed with breast cancer returned to full-time and part-time work after a median sick leave of 10.8 months[9]
- Patients living with migraine and their carers have a critical role in supporting decision- makers in their consideration of the value of a medicine

Investment in Medicines

Effective medicines are complex and take a long time to develop, and pharmaceutical companies invest significant resources into developing new medicines for areas of high unmet need.

The pharmaceutical industry also works closely with governments, health technology assessment (HTA) agencies and other similar organisations to agree an affordable price for medicines that reflects the value they bring to patients and the healthcare system. This enables them to recoup their costs and invest in developing new medicines.

If you would like to know more about the value of medicines, you may find the European Federation of Pharmaceutical Industries and Associations (epfia) webpages useful:

https://www.efpia.eu/about-medicines/use-of-medicines/value-of-medicines/

Next steps:

- Use the downloads above to access further information on the value and development of medicines
- Use the website link to find out more about the value of medicines. This includes a presentation developed by the European trade body for the pharmaceutical industry that can be reviewed and used

Resources


THE VAL EDICINES

Source and format

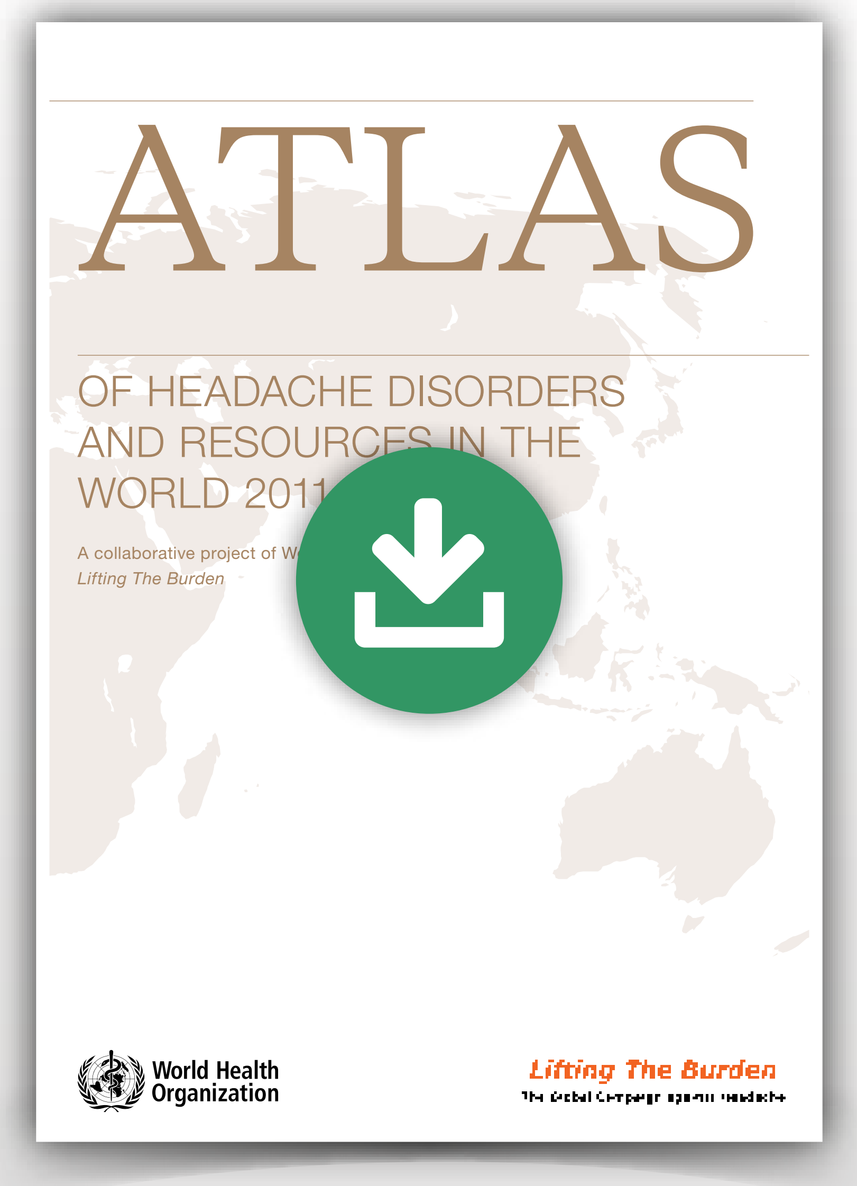
Comprehensive Toolkit
5-page PDF document

Resource title

Value of medicines facts and figures

Direction for use

This document contains more detailed information on the value of medicines taken from the from the comprehensive Toolkit.


ATLAS
OF HEADACHE DISORDERS AND RESOURCES IN THE WORLD 2011
A collaborative project of W
Lifting The Burden
World Health Organization
Lifting The Burden
The Global Campaign against Headache

Source and format

WHO in partnership with Lifting The Burden
35-page PDF

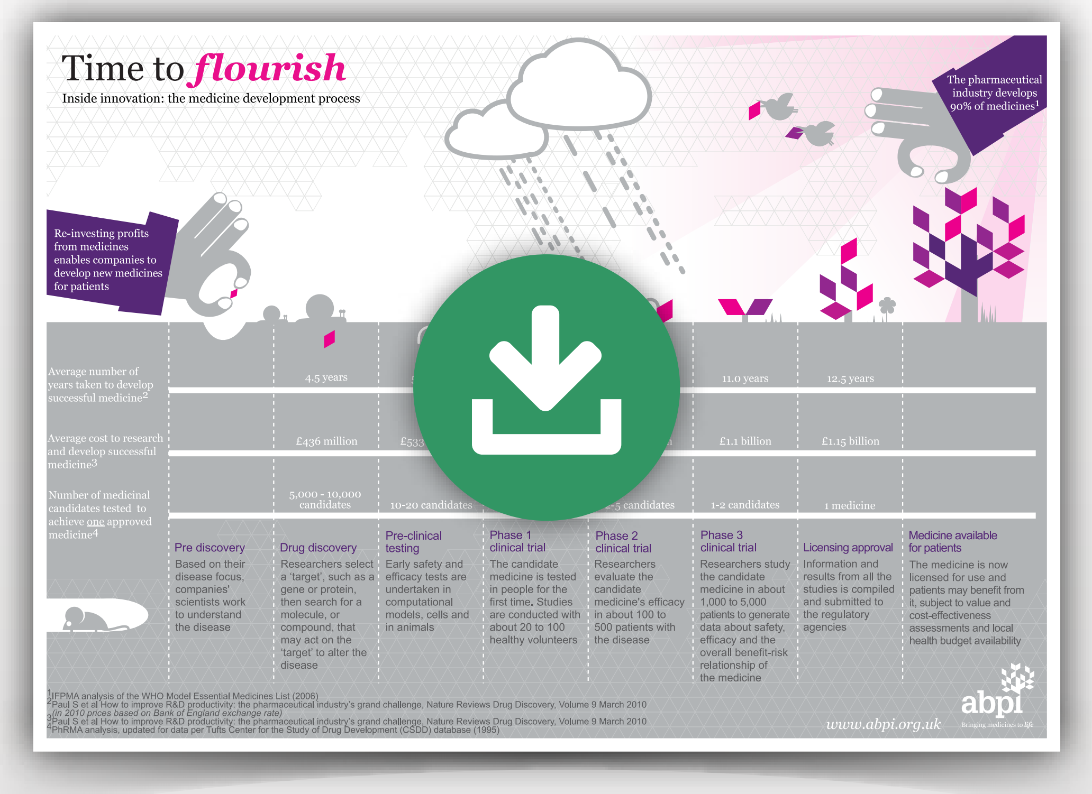
Resource title

Atlas of Headache Disorders

Direction for use

Download and use this document to further your understanding of the burden of headache disorders and the resources available to reduce the burden.

Its content can also be used to highlight the worldwide neglect of this major cause of public ill-health and the inadequacies of responses to it in countries throughout the world.


Time to *flourish*
Inside innovation: the medicine development process
abpi

Source and format

Association of British Pharmaceutical Industries (ABPI)
One-page PDF infographic

Resource title

Time to Flourish. Inside innovation: the medicine development process

Direction for use

Download and use this to help you understand the timelines for development of a medicine and the costs associated with this.

Module four - AN INTRODUCTION TO PATIENT INVOLVEMENT IN ACCESS TO APPROPRIATE MEDICINES

This section of your Summary Resource considers the complex subject of patient involvement in access to appropriate medicines through health technology assessment (HTA).

This section is intended to provide you with an introduction to the topic only. If you wish to learn more about this important topic, it is recommended that you speak to other organisations who have experience of HTA, those agencies that manage HTA, or that you consider using the comprehensive Toolkit.

Acknowledgement: This section has been adapted from Understanding Health Technology Assessment, Health Equality Europe.[10]

> "If you're not involving patients, you're not doing health technology assessment!
>
> It's that simple. Patient involvement improves the quality, relevance, and value of HTA. It is difficult to conceive of health technology assessment being conducted in a meaningful way in the twenty-first century without the involvement of patients."
>
> *Brian O'Rourke Canadian Agency for Drugs and Technologies in Health (CADTH), Ottawa, ON, Canada*
>
> *Chair of the International Network of Agencies for Health Technology Assessment (INAHTA), Edmonton, AB, Canada*

Key Points

- Patients have a critical role in HTA as what patients know about the impact of living with migraine, and its treatment, can inform assessments of medicines developed to treat migraine and its symptoms
- Meaningful involvement in HTA can take a lot of time, require considerable resource and it necessitates knowing the what, why, when and how of HTA. Partnering with other organisations is a good way to overcome these challenges
- A joint contribution to HTA from several patient organisations, who between them represent the views of a large number of patients, may be very powerful. By presenting a united voice, there may be a greater chance that this voice will be heard
- The sort of experience-based information that patients would otherwise contribute to HTA processes can be useful in raising public awareness about the impact of migraine and the need for effective management

Introduction

The call to focus healthcare decisions on the needs of patients often seems overshadowed by the requirement to overcome financial pressures and ensure efficiency. The question is whether we can achieve value for money in a health service system, while taking account of the needs, experiences and preferences of patients.

The answer is yes. But, only through transparent, systematic processes to which all stakeholders can contribute and in which all evidence is judged fairly and rigorously. Health Technology Assessment is one such process.

About Health Technology Assessment

Health technology assessment is a multidisciplinary process that summarises information about the medical, social, economic and ethical issues related to the use of a health technology in a systematic, transparent, unbiased and robust manner. Its aim is to inform the development of safe, effective health policies that are patient-focused and seek to achieve best value as defined by decision makers. Health technology assessment underpins decisions such as:

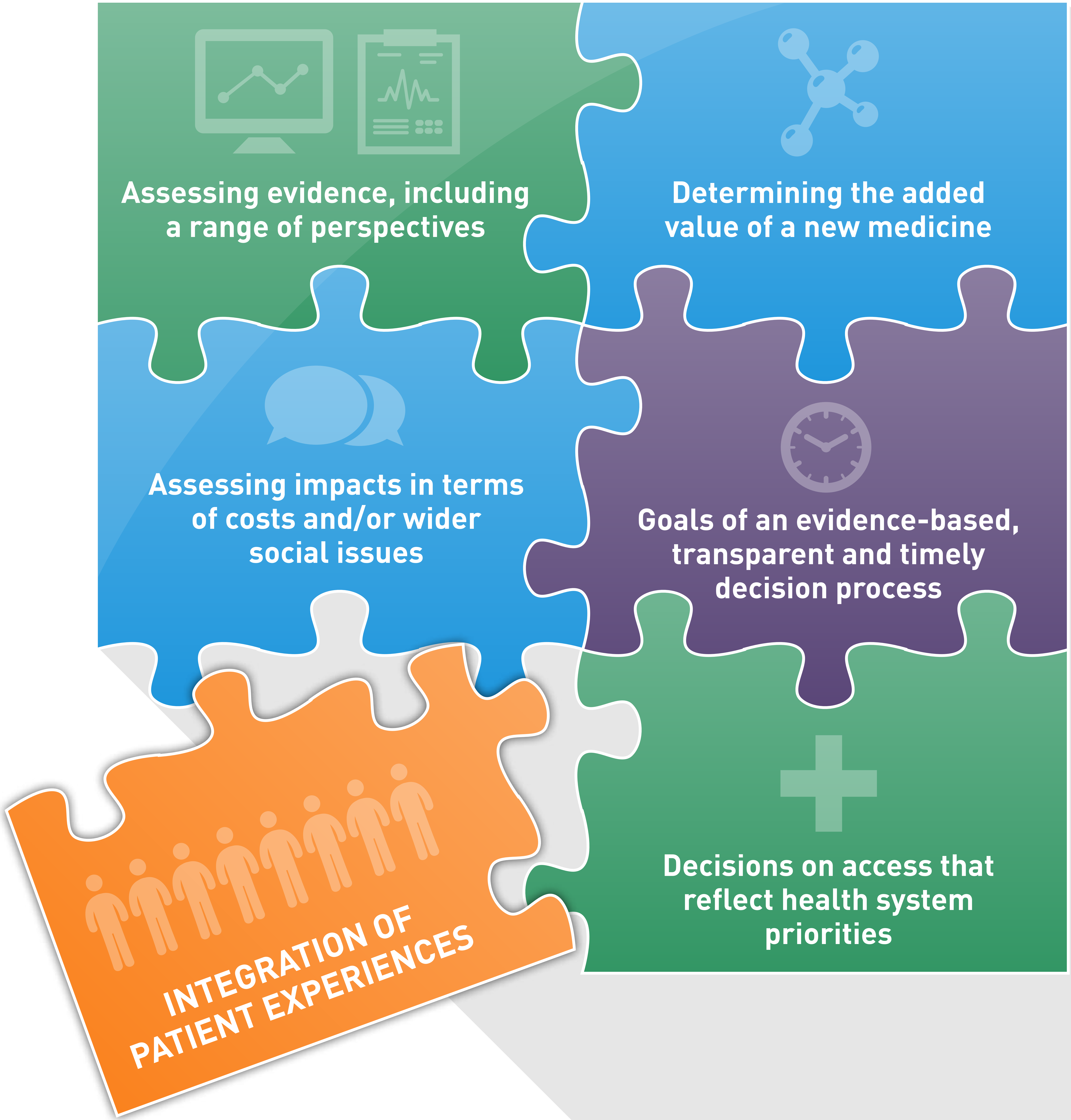
- Should treatment A be reimbursed in a national healthcare system?
- For which patients should it be provided?
- For how long should patients receive the treatment?

Health technology assessment processes may vary between HTA agencies and so may the evidence they consider and the questions they ask about the medicine.

Figure one provides an overview of the functions of HTA and how patient experiences can integrate into this.

Health technology

Figure one: Functions of HTA



Why is HTA needed?

People facing the challenge of illness need to receive effective treatment and care to give them the best possible chance of health. At the same time, there is a public health need to prevent disease wherever possible. However, available resources need to be allocated appropriately based on their value for money. Health technology assessment provides information to inform these decisions.

How is HTA used?

Health technology assessment is used differently across countries. In some countries, it is used to guide decisions about if and how medicines and other technologies should be used in a health service, based on an assessment of whether they provide value for money. In other countries, it guides decisions about reimbursing the costs of medicines.

How is HTA carried out?

The assessment process varies from organisation to organisation and visiting their websites can provide you with additional information.

Should you get involved in an HTA?

You might consider contributing information to an assessment about migraine or its treatment if the HTA will impact on you or someone close to you, or the people who use the services of your organisation.

However, as involvement can be a very time-consuming process, experience has shown that organisations that want to get involved need to ensure that they fully understand the HTA what, why, how and when in their country. They also need to have the time and resources to get involved. This helps to ensure that any contribution is meaningful and adds the most value to HTA.

Many patient organisations therefore take the decision to partner with other organisations. This could involve partnering with relevant patients organisations who have experience in HTA, pooling resources with those that don't, or a mixture of both.

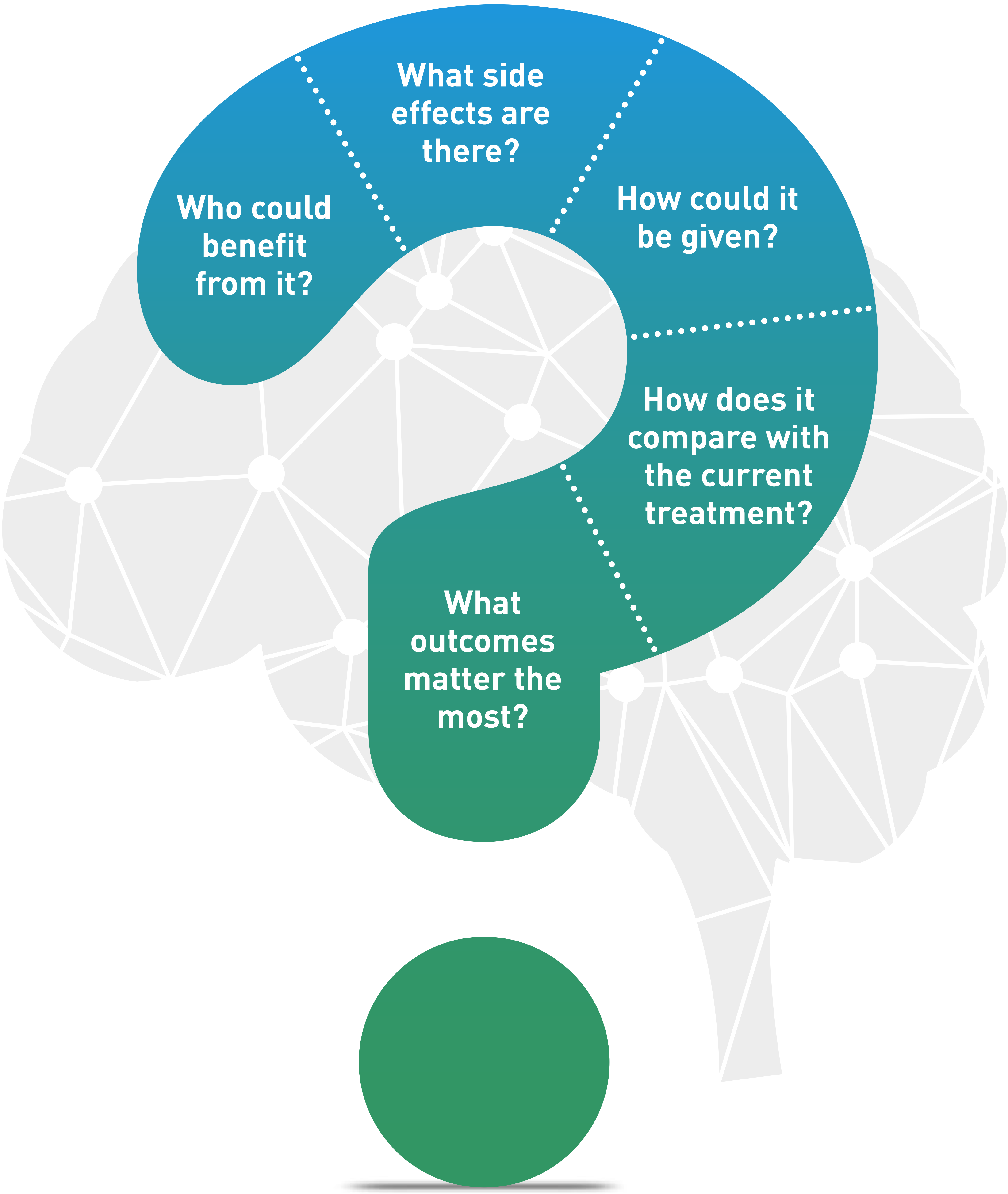
Benefits of partnerships

A joint contribution from several patient organisations, who between you represent the views of a larger number of patients, may be very powerful. By presenting a united voice, there may be a greater chance that your voice will be heard.

In addition to other patient organisations, you may benefit from working with your colleagues in a range of settings, including scientific societies and universities. Many of these groups will be involved in the HTA process; for example, they may contribute evidence that is considered in the process, or they may clarify how the technology would be used.

More about patient involvement in HTA

Health Technology Assessment addresses important questions about a medicine such as:



Often, it is an expert panel or committee that asks these questions and who interprets the evidence in the context of how healthcare is provided locally, while highlighting gaps and uncertainties in the information they have to answer the questions.

Traditionally, these panels or committees have been made up of researchers and health professionals who specialise in the area. However, increasingly HTA agencies are involving patients and their representatives to support their thinking.

The reasons for this are clear. No one else can explain the impact of a disease or a medicine better than a patient. Patients are therefore experience-based experts.

What patients know about the impact of living with migraine means that evidence from patients can inform the assessment of medicines being developed to treat migraine and its symptoms.

Types of patient involvement in HTA

Figure two below summarises the two approaches to patient involvement in HTA, while figure three considers the type of valuable input that patients can provide as part of their HTA participation.

Figure two. Patient involvement in HTA

Patient involvement encompasses two distinct but complementary approaches, both of which can add value to decision making:

Patient participation	Research into patient aspects
Patients interacting in the HTA process e.g. presenting to a committee, inputting into the process by submitting a written response to a public consultation	Patient-based evidence from qualitative research and quantitative research into patients' needs, preferences and experiences such as peer-reviewed research into the unmet needs in migraine management

Figure three. Patient input that can be of value to HTA

Burden of illness	Experience of current treatment	Impact on caregivers	Medicine being assessed
• Migraine symptoms that are difficult to live with • Limitations migraine imposes on daily life, social life and ability to work • Impact of migraine on mental wellbeing • Approaches to managing migraine pain	• The benefits of the medicines on daily life, social life and ability to work • Side effects that are troublesome • Whether it works well and any problems taking the treatment • Any challenges patients have faced with the delivery of care that supports effective treatment	• Costs associated with supporting a person living with migraine • Limitations migraine imposes on relationship, daily life and social life • Paying for childcare because the patient cannot look after the child/children • Taking time off work to deal with things a person having a migraine attack cannot do	• Expectation from the medicine • How important the medicine's benefits are and how they compare to other treatments • How potentially unwanted effects compare to current treatment • The benefits of the medicines on daily life, social life and ability to work

Generating patient experience-based evidence

Whether inputting into HTA directly, or whether you are partnering with other patient organisations, the information you share will depend on the HTA agency's requirement. For this reason, it is a good idea to ask the agency for advice, or ensure that those you are partnering with have done this.

The experience-based information that patients could contribute to HTA processes can be useful in raising public awareness about the impact of migraine and the need for better management. It can help make the case for better treatment in a variety of settings such as media campaigns and lobbying, or in individual consultations with doctors.

In generating evidence, patient organisations can collect information on the needs, preferences and experience of migraine patients from a range of sources. These may include:

- Data from enquiries to a helpline that uncover relevant information
- A survey of patients' experiences. For example, by using an on-line survey tool
- Focus groups or one-on-one discussions with patients
- Issues that have been discussed on websites or at official meetings

Personal quotes or experiences

Conclusion

Health technology assessment is likely to become an increasingly important influence in decisions about what is provided in healthcare, including patient access to new migraine medicines.

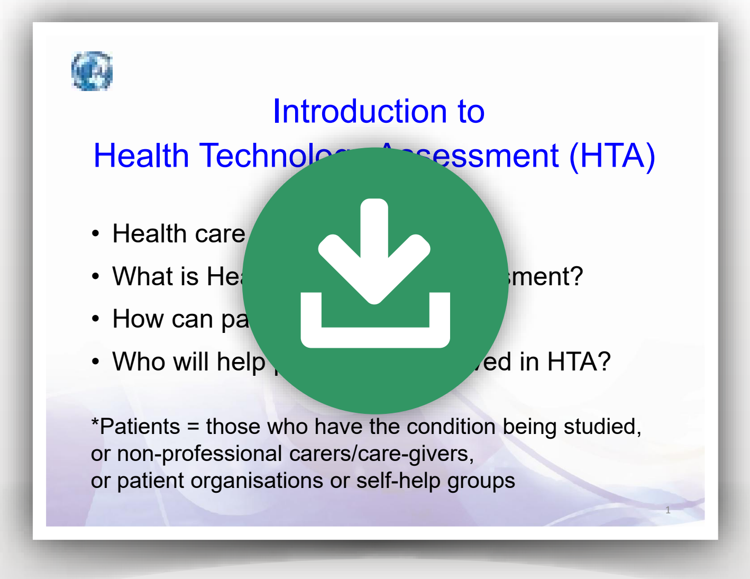
It is important that HTA takes account of the needs, experiences and preferences of the people who will be most affected by its recommendations: patients and their caregivers.

Participating in a HTA can be time consuming and challenging. However, it is a real opportunity to influence the delivery of healthcare.

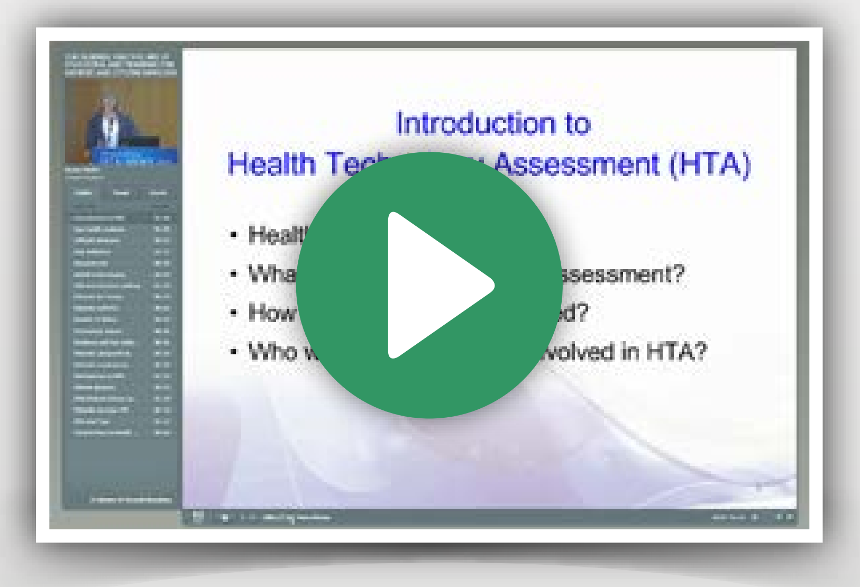
Patient organisations that do not have the capacity or expertise to input directly into HTA should therefore consider partnering with other patient organisations to help ensure that their voice is heard.

Resources

If you would like to know more about HTA, the resources on the next page can be downloaded. Alternatively, you could consider reviewing the comprehensive Toolkit.


Introduction to
Health Technol essment (HTA)
- Health care
- What is He ment?
- How can pa
- Who will help ed in HTA?

*Patients = those who have the condition being studied, or non-professional carers/care-givers, or patient organisations or self-help groups


Introduction to
Health Tec Assessment (HTA)

Source and format

Karen Facey, HTAi Patient and Citizen Involvement in HTAi Interest Group
19-page presentation on PDF format
22-minute webinar

Resource title

An introduction to HTA

Direction for use

Download the presentation, or view the webinar for an overview of HTA. This will help reinforce the key learnings from your Toolkit and provide additional insight into the topic.


EUPATI Netw
September 2

Strengthening patient involvement in Health Technology Assessment (HTA)

Source and format

European Patient Academy on Therapeutic Innovation (EUPATI)
80-minute webinar

Resource title

Strengthening Patient Involvement in Health Technology Assessment

Direction for use

View the webinar for an introduction to patient involvement in a video format. This will help reinforce the learnings from your Toolkit and provide additional insight into the topic.


HTAi: An International Society for the Promotion of Health Technology Assessment

Good practices in volvement in HTA
Are the used?

Karen Facey
k.facey@btinternet.com @KMFacey
Coordinator – HTAi Patient Involvement Methods and Impact Working Group
http://www.htai.org/interest-groups/patient-and-citizen-involvement.html

Source and format

European Patient Academy on Therapeutic Innovation (EUPATI)
14-page PDF slide presentation

Resource title

Good practices in patient involvement in HTA

Direction for use

Download and view this presentation to learn more about good practices regarding patient involvement and to reinforce the learnings from your Toolkit.

Next steps:

- Consider reviewing module four within the comprehensive Toolkit. This considers the topic in a lot more detail
- Consider contacting other patient organisations to better understand what experience they have in HTA and whether you could partner with them should there be an opportunity to do so

Module five - PATIENT INVOLVEMENT IN IMPROVING MIGRAINE SERVICES

Patient involvement in improving migraine services is an area that many patient organisations have a lot of experience in. However, while there is a range of guidance and support for healthcare providers on how to engage patients in improving migraine services, there is limited guidance specifically for patients and those that advocate on their behalf. Therefore, this section introduces some of the basics and it adapts some of the learnings from patient involvement in Health Technology Assessment (HTA) where there is evidence-based guidance that supports patient involvement.

> “Headache disorders, including migraine and tension-type headache, are among the most prevalent disorders of mankind. They are under-recognised, under-diagnosed and under-treated. Financial costs to society through lost productivity are enormous – far greater than the health-care expenditure on headache in any country.[1]”
>
> *World Health Organisation and Lifting The Burden*

Key Points

- Better involvement of patients in their migraine services is not a nice-to-have, it is fundamental to the effective delivery of services
- Migraine patients have a critical role to play in improving their services. The insight, experience and expertise of patients can help improve migraine management by making it more tailored and more sustainable, and by helping to ensure that new services and service changes have legitimacy
- The key to effective patient involvement in improving migraine services is to ensure that the important messages you want to get across are clear and that they are supported by evidence from patients
- Where there are limited, or no opportunities for patients to get involved in how their migraine services are delivered, other approaches to informing decision-makers should be considered

Introduction

More needs to be done to address the significant burden of migraine and this includes better migraine healthcare services.

As it is migraine patients and their carers who are using these services, they are the experience-based experts. Therefore, patient needs, perspectives and experience should be considered when those who provide migraine services construct, deliver and evaluate them.

Identifying and Addressing the Unmet Needs in Migraine Services

As a starting point, it is important to understand how migraine services are delivered in your country and how this compares to what would be considered best practice.

The European Headache Foundation and *Lifting The Burden*: the Global Campaign against Headache provides a basic model of healthcare organisation for Europe that can be used as a basis for assessing services. This can be downloaded at the end of this section.

In terms of identifying the unmet needs in migraine services at a national, regional or local level it is widely accepted that seeking the views, opinions and experience of migraine patients and their carers is the most appropriate way to identify gaps in migraine services and/or areas for service improvement.

Figure four summarises the four steps to patient involvement in improving migraine services.

Where there are no opportunities for direct patient involvement, many organisations adopt other approaches to improving migraine services. For example, running a media campaign – based on patient and carer feedback – calling for improved services.

Figure four. Patient involvement in service provision

1. HEADACHE SERVICES

Understand how services are delivered

2. UNMET NEEDS

Survey patients and carers to get their views, opinion and experience

3. PATIENT INVOLVEMENT

Identify opportunities to input into and inform service delivery and improvement

4. BROADER OUTREACH

Use other approaches to raise awareness of the unmet needs for migraine patients

Definitions

Patient Involvement in Improving Migraine Services

Older models of migraine care often treat patients as a passive group who are simply told what to do and are managed accordingly.

However, times are changing. Increasingly it is being recognised that the views and opinions of patients are as significant as those of any other stakeholder in the healthcare process and that patient involvement goes beyond an individual's care. It includes the systems, processes and care pathways that are developed for patients.

The importance of patient involvement

Migraine patients have a critical role to play in improving their services. The insight, experience and expertise of patients can help improve migraine management by making it more tailored and more sustainable, and by helping to ensure that new services and service changes have legitimacy.

Decision-makers responsible for migraine services should engage with, involve and empower patients. Patients are not just experts in their own lives, conditions and care needs, they also hold vital knowledge about local services that can be used to improve their care.

Migraine patients who use services also see the best and the worst that is on offer, and understand the emotional toll of ill-health and caring.

Patient needs, experience and perspectives are therefore critical to driving improvements, making services more responsive to people's actual needs.

Planning for patient involvement

It is widely recognised that for patient organisations, one of the most important aspects of patient involvement in improving migraine services is monitoring and planning. This involves:

- Identifying what services reviews are taking place, and where possible register as a stakeholder
- Clarifying whether there is a role for you directly, or indirectly through supporting migraine patients
    - Where there is a direct role for your organisation: clarifying what information is needed, whether you can generate this and how long it will take
    - Where you are supporting patients: what support needs they have and whether you can provide this support

Indirect support

Finding out what service reviews are taking place

While you are likely to be aware of any national service reviews, patients who use your services or visit your website are a good source of insight into regional and local service reviews. Other neurology patient organisations and medical organisations may also be a good source of information.

Preparing for patient participation

The key to effective patient involvement in improving migraine services is to ensure that the important messages you want to get across are clear and that they are supported by evidence from patients.

Building relationships with patient organisations from other disease areas can also be useful, especially in sharing ideas & approaches that have and haven't worked. Larger groups with paid staff may even offer a mentoring service or offer free advice.

In addition to those approaches to uncovering patient needs, experiences and perspectives considered in figure two, additional sources of evidence could include:

- Relevant information uncovered by enquiries to a help line
- Insights from support groups regarding the problems patients and carers face
- Issues discussed in chat rooms or at an official meeting

Contributing in person

When contributing in person (e.g. by attending a focus group), make sure you prepare for this and have the key messages you want to communicate. Also, be prepared to contribute to any discussion and to answer any questions you may be asked.

Before contributing in person, it is a good idea to contact the person organising this to confirm what they will be asking.

Conclusion

Gathering information about patients' experience of migraine services is not new. However, approaches that gather data and insight only may not be the most effective in the development of services that really matter to patients.

Given that new approaches to seeking meaningful patient input are not widely adopted, it is important that patient input through established approaches maximises the impact of the information shared in relation to patient needs, experience and perspectives.

Patient organisations have always had a very important role in improving migraine services, either directly, or indirectly through support for patients. Key to this has been success in ensuring that the important messages are communicated and that they are supported by real-world evidence from patients.

If there are limited, or no opportunities for patients to get involved in how their migraine services are delivered, other approaches to informing decision-makers have been shown to drive positive change.

Resources

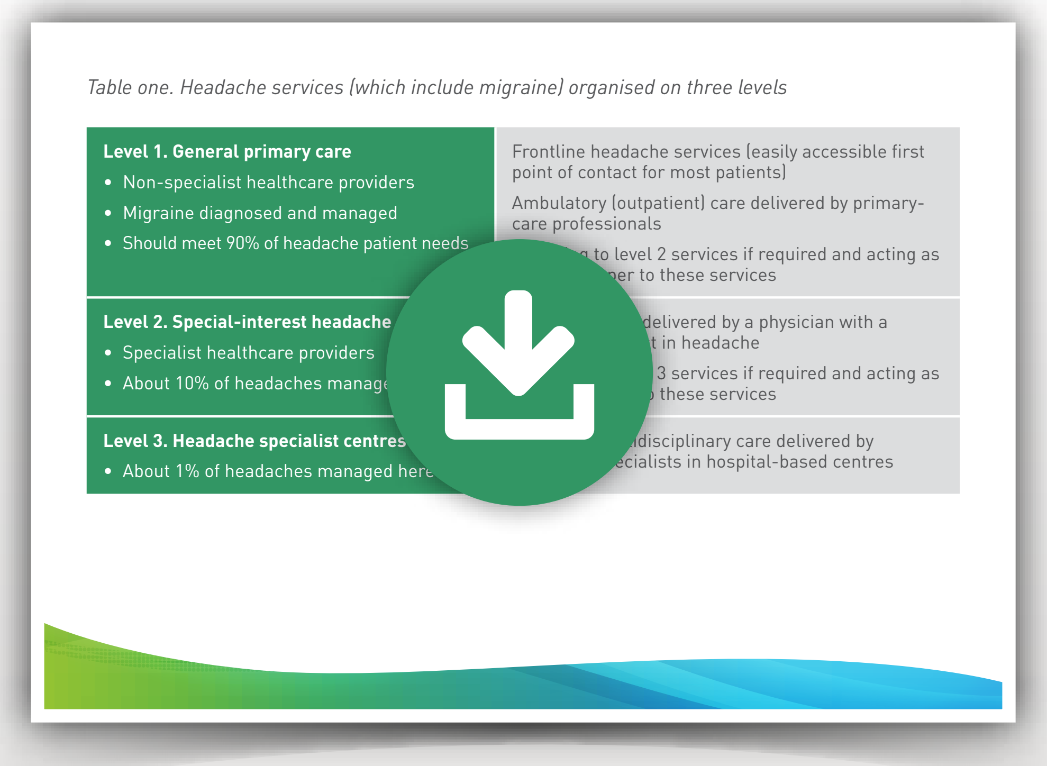


Table one. Headache services (which include migraine) organised on three levels

Level 1. General primary care • Non-specialist healthcare providers • Migraine diagnosed and managed • Should meet 90% of headache patient needs	Frontline headache services (easily accessible first point of contact for most patients) Ambulatory (outpatient) care delivered by primary-care professionals g to level 2 services if required and acting as per to these services
Level 2. Special-interest headache • Specialist healthcare providers • About 10% of headaches manage	delivered by a physician with a t in headache 3 services if required and acting as these services
Level 3. Headache specialist centres • About 1% of headaches managed here	disciplinary care delivered by ecialists in hospital-based centres

Source and format

Comprehensive Toolkit – Table 1, Patient Involvement in Improving Migraine Services Section

Resource title

Headache services organised on three levels

Direction for use

Download and use this to help benchmark services against a basic framework.

Figure two. Approaches to patient input

Surveys
Often used to obtain input from lots of patients through their response to a number of pre-determined questions

Market research
A more formal approach to undertaking a survey, often facilitated by an expert in market research. This can be one-on-one or with a group and all participants are asked the same questions

Patient P
Often a 'yes' respon few qu such a you ha our se toda

ry telling
ts telling ry of graine ment n or in ng

Patient pathways
Patients creating a picture of their management pathway, or commenting on a pre-developed picture

Focus groups
A demographically diverse group of patients who participate in a guided discussion

Source and format

Comprehensive Toolkit – Figure 2, Patient Involvement in Improving Migraine Services section

Resource title

Approaches to patient input

Direction for use

Download this to help you understand some of the ways that decision makers obtain patient input.

Figure three. Some approaches to raising awareness of unmet services needs

What	Description
Patient survey and launch	A patient survey that uncovers the unmet needs in services and the impact that these have on patients. Written up as a formal report and sent to decision-makers.
Expert Report and launch	A multi-stakeholder velops an Expert Report on the need for improved services. The to decision-makers.
Media awareness campaign	Using the ed by patient case studies, to run a media awarene
On-line petition	An on- on, while encouraging patients and carers umber of signatures and forward the petitio
Migraine and employment media campaign	A partne ganisation to identify the cost to industry of the con ign for enhanced services and better support by e
Social media campaign	A social media campaign that encourages patients and their carers to use their social media channels to mobilise family and friends behind a call to action.
Lobbying	Reaching out to elected officials with evidence on the unmet needs in services and the consequences of this on individuals, their families and the economy.

Source and format

Comprehensive Toolkit – Figure 3, Patient Involvement in Improving Migraine Services Section

Resource title

Approaches to raising awareness of unmet services needs

Direction for use

Download this to better understand some of the approaches that have been used across different therapy areas to raise awareness of unmet needs in services.

Next steps:

- Use the downloads above to see how your organisation might be able to contribute to patient involvement in improving migraine services
- Consider what groups or organisations you could partner with

Module six - STAKEHOLDER ENGAGEMENT AND COMMUNICATIONS

Throughout the world, patient organisations are working with other individuals who support them in delivering on their mission.

Many of these will be decision-makers who don't work for the organisation. In securing their support, many organisations will have an established approach to stakeholder development and management.

The practical aspects of stakeholder (decision-maker) engagement and communications are covered in detail within the comprehensive version of the Toolkit. It provides an overview of a rational step-by-step approach to support decision-maker engagement.

This includes information about identifying and building relationships with relevant stakeholders, as well as the role of communications including media, social media and public affairs.

Given the importance of stakeholder engagement and communication, we hope that you will revert to the comprehensive Toolkit to support your activities in this area.

Evaluation and feedback

We Would Value Your Feedback!

To ensure that future activities meet your needs, and to understand how useful you found your Summary Resource, where it can be improved and to identify additional information we can incorporate into future updates, we would very much value your feedback.

We have tried to keep this as simple as possible and there are two ways you can feedback.

Download the attached word document and return this to us via email.

Thank you for your support!

A Word copy of the evaluation form can be downloaded **here**

Summary Resource Evaluation

Your feedback is important to us. Please complete the questions below and return this to (TBC). We anticipate that this will take no more than five minutes.

1. How useful did you find your Summary Resource in introducing you to the subject of patient involvement in improving migraine services and access to appropriate medicines?

Not at all useful	**Somewhat useful**	**Useful**	**Very useful**	**Extremely useful**
☐	☐	☐	☐	☐

Additional comments:..

....

2. Having read your Summary Resource, do you feel more confident in considering whether to get involved in advancing the role of patient involvement in improving migraine services and access to appropriate medicines?

Not at all confident	**Somewhat confident**	**Confident**	**Very confident**	**Extremely confident**
☐	☐	☐	☐	☐

Additional comments:..

....

3. As a result of reviewing your Summary Resource, did you, or will you use the comprehensive Toolkit?

☐ **YES**

☐ **NO**

If no please explain why:...

....

4. As a result of reviewing your Summary Resource, are you more likely to reach out to other patient organisations in support of patient involvement in HTA?

☐ **YES**

☐ **NO**

If no please explain why: ....

....

5. Any other comments?

....

....

....

....

....

Please return your completed form to: (tbc)

Thank you for taking time to complete evaluation of your Summary Resource.

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This resource was created by KYNE Communications in partnership with the European Migraine and Headache Alliance (EMHA), the European Federation of Neurological Associations (EFNA) and Migraine Action (MA). The development of the Toolkit was funded by Novartis.*

NOVARTIS

**As of June 2018, Migraine Action has closed.*