

Neuroendocrine Cancer Advocacy and Policy Toolkit

AN ADAPTABLE TOOLKIT TO SUPPORT INCA
MEMBER USE OF EXISTING AND EMERGING
DATA TO MEET POLICY OBJECTIVES

developed by



Patvocates



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LIST OF ABBREVIATIONS

EMA	European Medicines Agency
HCPs	Health Care Providers
HTA	Health Technology Assessment
NET	Neuroendocrine Tumour
NEN	Neuroendocrine Neoplasm
PO	Patient Organisation
GP	General Practitioner
PCP	Primary Care Physician

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FOREWORD

Advocacy is something that we all engage in through our involvement in patient organisations. Advocacy is at the heart of what we do; we all want improved services for patients, better healthcare systems and equitable access to diagnostics, treatment and care. Whatever way we try to achieve these goals, it requires us to convince others that there is a need, and that there are better ways to do things. This is advocacy.

INCA is the Global NET Patient Voice and we want to help you with your advocacy work. We developed this toolkit to provide ideas, suggestions and tips on how you can advocate for your objectives. Whether your organisation is small, big, volunteer or professional with staff, I hope that you will find this toolkit useful in your efforts to improve the lives of neuroendocrine cancer patients. Thank you for all your work on behalf of patients.

Mark McDonnell
President INCA



Health Technology Assessment



HTA - Reimbursement authorities



In most countries with public healthcare systems, there is a process where it is decided what costs the public system will cover. These processes are to ensure that the future of the public healthcare system is sustainable and has enough resources to fulfil its remit of providing universal healthcare to citizens with a vast range of conditions.

It is the politicians (usually the ministry of finance) that decide how much resources are spent on healthcare and it is politicians (usually the minister of health) that decide how those available resources should be spent.

Once budgets and resources are set, there needs to be a process that takes a look at any treatment or medical tool and determines if it should be paid for within the public system. In most countries, this process is called **Health Technology Assessment (HTA)**. A health technology is any medicine, device or intervention that has been developed to improve a health outcome.

What is the goal?

The goal of HTA is to inform national, local, or even hospital policy regarding a specific health technology within a public healthcare system (note that if a treatment is not available in the public system, it may still be available through private healthcare, where available).

How does it work?

For a medicine, in essence, the HTA body is asking the question "What health and quality of life benefits does this new medicine bring that we don't have already with current treatments?" The assessors look at the evidence of the new medicine and compare it to the evidence of existing medicines to do this. Many then ask a second question: "Do the extra health benefits and quality of life improvements justify the cost of investing in this medicine?"

HTA - Reimbursement authorities



One important area to focus on, in HTA, is patient involvement in the process. Many HTA bodies have a process of asking patient organisations to give input to an HTA. If your country has no HTA, then there will probably be a 'reimbursement committee' within the Ministry of Health that performs a similar role. The tips below apply to both.



- 1:** Understand your local system. Search on the internet to find out how decisions are made in your country. If it is a HTA body, look at their website and search for any pages on patient involvement or public involvement. If it is a reimbursement committee search to see which organisations and people sit on that committee.
- 2:** Let them know that you exist. HTA bodies often find it difficult to identify patients to take part in patient involvement processes. Many keep a database of active patient groups that they can search when a new treatment in a disease area is being assessed. Look for a webpage within the HTA body that allows you to apply as a registered patient group. If that does not exist, write an email to the HTA body letting them know your contact details and the areas of your work. (Don't wait until there is a new treatment for neuroendocrine cancers to do this, that is too late).
- 3:** In the INCA network, there will be other patient groups that have built experience of inputting into HTA and/or reimbursement committees. Ask for advice, tips and evidence that other patient groups have used.

HTA - Reimbursement authorities



HTA processes follow different protocols around the world, which include the level of patient involvement. Here you find a graphic representing the HTA or reimbursement bodies within the countries INCA has members. This provides a visual on the variety of bodies and whom to contact based on the country. Nevertheless, keep in mind to check this information at a national level, since this information can change quite quickly, especially in developing countries. Depending on the country or region, engagement in HTA can differ greatly.

The world atlas shows examples of HTA / reimbursement bodies in countries where INCA has members.



HTA - Reimbursement authorities

Reaching out to your HTA or reimbursement body

Below you can find a draft email to contact HTA or reimbursement bodies at a national level.



Dear (contact person) or To Whom it May Concern,

I am writing as a representative of [patient organisation name], a registered patient organisation in the field of neuroendocrine cancers and would like to be added to your list of patient associations eligible to participate in HTA processes.

- Introduce your patient organisation
 - Highlight what you have done so far, how many members, and your memberships (E.g., Member of INCA),

Our members are currently [not involved / slightly involved / partially involved] in HTA processes. We would be delighted if we could establish contact with your agency to enable our members to share their experiences, needs, and opinions. We would highly appreciate information on how our members can participate or provide advice on HTA evaluation related to neuroendocrine cancers. Our organisation consists of patients with cancers and tumours in a variety of areas of the body as neuroendocrine cancers can have different sources.

Looking forward to hearing from you

Kind regards,

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Useful Links

HTA

<https://www.neuroendocrinecancer.org.uk/wp-content/uploads/2021/01/Patients-and-Public-health-technology-assessment.pdf>

Health Technology Assessment/Reimbursement Decision-Making: Simone Leyden, INCA President

<https://www.nlm.nih.gov/nichsr/hta101/ta10103.html>

https://www.euro.who.int/__data/assets/pdf_file/0018/90432/E87866.pdf

<https://pubmed.ncbi.nlm.nih.gov/35513309/>

Links to HTA / reimbursement bodies:

- Argentina: <http://www.iecs.org.ar>
- Australia: <http://msac.gov.au/>
- Australia: <https://www.pbs.gov.au/pbs/industry/listing/participants/pbac>
- Australia: <https://www.health.gov.au/committees-and-groups/prostheses-list-advisory-committee-plac>
- Belgium: <https://kce.fgov.be>
- Bulgaria: <http://ncpha.government.bg>
- Canada: <http://www.cadth.ca>
- Canada: <http://www.inesss.qc.ca>
- Denmark: <http://www.defactum.net>
- France: <http://www.has-sante.fr/>
- Germany: <http://www.iqwig.de>
- Germany: <http://www.g-ba.de/>
- India: <https://htain.icmr.org.in/>
- Ireland: <http://www.hiqa.ie>
- Italy: <http://www.agenziafarmaco.gov.it>
- Japan: <https://www.mhlw.go.jp/english/>
- Netherlands: <http://www.zorginstituutnederland.nl/>
- Norway: www.legemiddelverket.no
- New Zealand: <https://pharmac.govt.nz/>
- Portugal: <http://www.infarmed.pt/>
- Singapore: www.ace-hta.gov.sg
- South Africa: <http://www.htasa.org.za/>
- Spain: <https://www.aemps.gob.es>
- Sweden: www.tlv.se
- Switzerland: <http://www.snhta.ch/index.html>
- Taiwan: <http://www.cde.org.tw>
- UK: <http://www.nice.org.uk/>
- USA: <https://www.effectivehealthcare.ahrq.gov>

General

https://www.eu-patient.eu/globalassets/library/publications/epf_added_value_report_final.pdf

<https://www.bmj.com/content/368/bmj.l6925>

<https://www.iapo.org.uk/working-partners-and-stakeholders-toolkit>

home - Patient Engagement for Medicines Development (patientfocusedmedicine.org)

<https://academy.wecanadvocate.eu/>

<https://www.share4rare.org/es>