

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



Table of Contents

Introduction

| | |
|----------------------------------|-----|
| Introduction to the toolkit..... | 1 |
| Areas needing attention? | 2 |
| Advocacy..... | 3-6 |
| How do we make a change?..... | 17 |

Policy and Evidence

| | |
|--------------------------------------|-------|
| What is health policy?..... | 8 |
| Who is involved in health policy?... | 9 |
| Who are policy-makers?..... | 10 |
| Policy recommendation..... | 12-16 |
| Evidence..... | 17-18 |

Health Technology Assessment

| | |
|------------------------------------|-------|
| HTA reimbursement authorities..... | 19-22 |
|------------------------------------|-------|

How to work with others?

| | |
|--|----|
| How to work with others?..... | 23 |
| Working with patient organisations.. | 24 |
| Working with governmental organisations..... | 25 |
| Working with medical and professional societies..... | 26 |

Policy initiatives directed at the patient pathway

| | |
|---|-------|
| Policy initiatives directed at the patient pathway..... | 27-29 |
| Onset of symptoms and investigation by GP and secondary care..... | 30-32 |
| Diagnosis by neuroendocrine cancer specialist..... | 33-36 |
| Treatment and care..... | 37-39 |
| Monitoring and palliative care..... | 40-41 |
| Rare condition..... | 42 |

Closing remarks

| | |
|----------------------|----|
| Closing remarks..... | 43 |
| References..... | 44 |
| Useful links..... | 45 |



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



Policy Initiatives directed at the Patient Pathway



Ideal Patient Pathway



ONSET OF SYMPTOMS

Symptoms trigger the patients to visit the PCP in earlier phases and the patient keeps insisting on their symptoms.



INVESTIGATION BY PCP AND SECONDARY CARE

Suspicion of symptoms related to neuroendocrine cancer, timely referral to secondary care for appropriate investigations.



REFERRAL TO SPECIALIST MDT

Specialist MDT review to plan treatment and care pathway with the patient



TREATMENT AND CARE

All treatments are available in close proximity to the patient and delivered in a multidisciplinary care setting.



MONITORING

HCPs and patients follow up nationally tailored guidelines as part of the expert MDT treatment and care pathway. Access to specialist team, liaison with local PCP and PO support



PALLIATIVE CARE

Palliative care and support are available to all patients at the appropriate time.

Yet, most patients are far away from this pathway encountering numerous different challenges, for example:

- Onset of symptoms:



- Patients are not aware of the symptoms of neuroendocrine cancers and might not understand the connection of symptoms to the neuroendocrine system.
- The diversity of symptoms does not cause a direct feeling of “urgency” in the patient or the HCP or PCP.

- Investigation by PCP and secondary care



- PCPs are not fully aware of neuroendocrine cancer symptoms.
- A high percentage of neuroendocrine cancers are misdiagnosed
- Complex referral pathways and barriers to accessing appropriate specialists.
- Confusion is caused by the different terminologies used (NETs vs NENs vs neuroendocrine cancers).

- Referral to specialist MDT



- Lack of common neuroendocrine cancers guidelines implemented in all countries.
- Inequality in access to specialised scans.
- Few multidisciplinary expert teams are available for neuroendocrine cancer diagnosis.
- Other specialists are not aware of neuroendocrine cancers
- Very difficult to find neuroendocrine cancer specialists.

- Treatment and care



- Inconsistency in access to treatment.
- Inequality in access to clinical trials and novel therapies.
- Limited multidisciplinary care is available.
- No shared care models, where neuroendocrine cancers are integrated.
- Very limited funding or inexistent funding to support patients.

- **Monitoring**

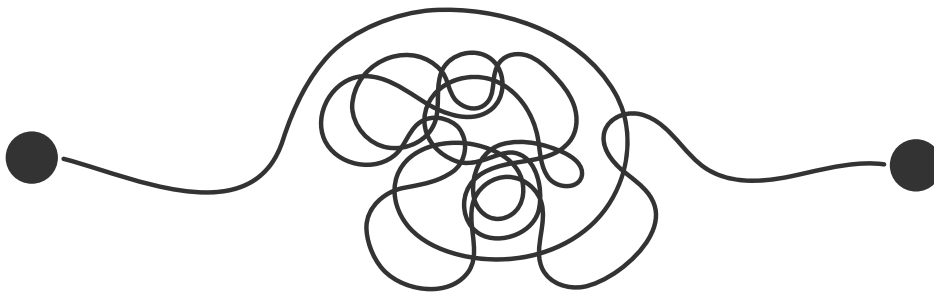


- No general monitoring guidelines are available.
- Lack of local guidelines on how to implement monitoring within a health system.
- Science gap in research of neuroendocrine cancer biomarkers.
- Very low implementation of biomarkers into monitoring practice guidelines.
- Lack of support for specialised centres.
- Few official channels by which patient organisations can help input into and shape monitoring.

- **Palliative care**



- No end-of-life services are available or provided to patients.
- Limited tools to provide and evaluate the quality of life, not necessarily end-of-life services.
- Patients are not properly informed about palliative care, when to get it and where.

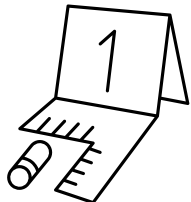


In this section of the toolkit, the authors will try and tackle the main challenges neuroendocrine cancer patients encounter and offer tools and recommendations on how to advocate for the specific initiative.

For simplicity of this toolkit, the authors have unified the onset of symptoms with the investigation by the GP as well as the Monitoring and Palliative Care phases.

In the following sections, the authors will highlight the main evidence of that specific pillar and will suggest how you could take action towards reducing the impact of the challenge patients encounter.

Onset of symptoms and investigation by GP and secondary care



Globally it takes a mean of 5 years to get diagnosed with neuroendocrine cancer.









Develop a symptoms diary log and make it available for patients.

Currently, self-diagnosis algorithms are still in development and are a bit controversial for the associated problem of self-diagnosis without medical supervision. Hence even though this could possibly help undiagnosed neuroendocrine patients, the authors recommend your organisation brings awareness to the use of symptoms diary logs for patients that are having symptoms but are having trouble being diagnosed. The authors suggest using a symptoms diary log, capturing:

- Symptoms: enter which symptoms were experienced and to what magnitude.
- Dates - Entering a date next to the symptoms will help to keep track of them. Knowing if the symptoms have a cycle to them can also help to predict when they may occur again or if they follow a pattern.
- Times - If hot flushes appear mainly at night, then a note can be made of this. As with the dates of the symptoms and the timing can give some useful information.
- Additional information - Patients may get asked to keep a record of their diet, exercise, or significant events that are happening in their life to understand the whole problem rather than the symptoms on their own. Their GP will let them know if they need to track additional information.

Onset of symptoms and investigation by GP and secondary care

Here is a template you can make available for the general public when raising awareness of neuroendocrine cancers:

| | | | |
|--|---|---|---|
|  | Date: _____ |  | _____ |
|  | Time: _____ |  | _____ |
|  |  |  |  |
| How am I feeling? | | | |
| Which symptoms did I have? | | | |
| Scale of pain experienced? | | | |
| How often do I have the symptoms? | | | |
| What was I doing when I had the symptoms? | | | |
| What did I eat today? | | | |
| Did I carry out physical exercise? | | | |
| Additional information? | | | |
|  | |  | |

Onset of symptoms and investigation by GP and secondary care

How to adapt the tool?

Validated tools such as the [EORTC QLQ GI.NET21](#), provide more specific questions which guide you towards adapting the template provided to a more specific neuroendocrine cancer subtype your organisation has more focus on. The authors want to highlight, that they are providing you with a template to base the symptoms log on, but this should be discussed within your patient organisations and the PCPs you have the most contact with.

Since neuroendocrine cancers have such a wide array of symptoms, the authors believe it is important to provide a tool that is flexible and adaptable and that will trigger your creativity to capture concepts or issues that have been missed.

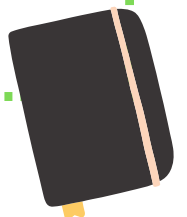
How to use the tool?

At this time, many apps and software provide help to log the information online or on smartphones, like Apple Notes or specific apps targeted to record symptoms. When using a symptom tracker app, please be aware of how the data is utilised and if data is sold for profit.

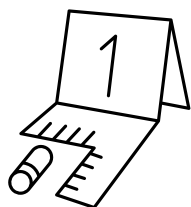


Be fully aware of the data usage on the App you use, some Apps collect patient data and sell it to pharmaceutical companies, so keep an eye out for that!

You can never go wrong with a hard copy which can be presented to the PCP and help them in the diagnosis process.



Diagnosis by neuroendocrine cancer specialist



44% of neuroendocrine cancer patients were misdiagnosed at least once and 26% were incidentally diagnosed. Only 27% were diagnosed at the first attempt. The correct diagnosis was made by, surgeons (46%), medical oncologists (40%), gastroenterologists (39.1%) and General practitioners (39.1%).

Most neuroendocrine cancers are misdiagnosed as gastritis, other digestive disorders, irritable bowel syndrome, or others. Yet it is not established with which conditions specific neuroendocrine cancer subtypes are being misdiagnosed.



There is a gap in evidence regarding the most common misdiagnoses of neuroendocrine cancer subtypes. Hence, this could be a research project to be developed on a national or international level. The present data from INCA SCAN Survey provides very valuable information on the percentage of misdiagnoses, but the authors suggest digging a bit deeper and identifying the main misdiagnoses. Here you can see a table that is lacking relevant information. Unfortunately, the data does not exist at this point.

Carry out a research project to gain evidence on the most common misdiagnoses of neuroendocrine cancer subtypes.

Diagnosis by neuroendocrine cancer specialist

| Neuroendocrine cancer subtype | % of misdiagnose | Most common misdiagnoses |
|---|------------------|--------------------------|
| Adrenal | | |
| Appendix | | |
| Breast | | |
| Cancer of unknown primary site | | |
| Duodenal | | |
| Female reproductive system | | |
| Goblet cell | | |
| Large Bowel | | |
| Lung | | |
| Pancreas | | |
| Pheochromocytoma and Paraganglioma (PPGL) | | |
| Prostate | | |
| Rectum | | |
| Secondary | | |
| Skin Merkel cell carcinoma | | |
| Small bowel | | |
| Stomach | | |
| Testicles | | |
| Thymus | | |
| Thyroid | | |

EVIDENCE GAP

How can I fill in the evidence gap?

One possibility is to carry out a survey within the neuroendocrine community targeting the issue of misdiagnosis.



Sample Survey template

Neuroendocrine cancers are commonly misdiagnosed. Some of the most common misdiagnoses are gastritis, other digestive disorders, or irritable bowel syndrome. We [Name of your organisation] aim to find out more about misdiagnosis patterns.

Please fill out the survey and help us to advocate for timely and correct diagnoses. You can also participate if your first diagnosis was correct. The survey consists of 10 questions and can be finished in under 5 minutes. This survey is anonymous and we will make sure your personal information will not be given to a third party.

1. How old are you? Choose one.
 - a. 20 to 40
 - b. 40 to 60
 - c. 60 to 70
 - d. Above 70
2. What type of neuroendocrine cancer have you been diagnosed with? (Include "Other option")
3. What year did you receive your neuroendocrine cancer diagnosis?
 - a. *Drop down list preferably or open ended answer*
4. What year did you first start having symptoms? (open-ended)
5. When seeing your family doctor for the first time about these symptoms, what did the doctor conclude?
 - a. *Open ended answer*
6. Have you been misdiagnosed?
 - a. *Open ended answer*
7. What was the first diagnosis for your symptoms? What was the second diagnosis for your symptoms? What was the third diagnosis for your symptoms? Etc.
8. How many misdiagnoses have you received before the correct one? (Please enter a number)
 - a. *Open ended answer*
9. What type of health care professional diagnosed you with neuroendocrine cancer?
 - a. General Practitioner
 - b. Oncologist
 - c. Internist
 - d. Surgeon
 - e. Gastroenterologists
 - f. Other
10. Was your neuroendocrine cancer diagnosis incidental (Incidental means that your tumour or mass was found during scans that were made for another reason)
 - a. Yes
 - b. No
11. What aspect of your diagnosis journey could have been improved (open-ended)

Diagnosis by neuroendocrine cancer specialist

How to adapt the tool?

In order to capture the evidence on misdiagnoses and make the case for better patient pathways through the diagnosis journey, the authors suggest conducting a survey of people already diagnosed with neuroendocrine cancer. The survey in this tool is just a starting point, the authors strongly advise you to work with patients and medical professionals to finalise the survey and ensure all the terminology is correct and understandable to those completing the survey. Furthermore, you can work with professional firms that help with the development of surveys to ensure the questions are useful for evidence purposes.

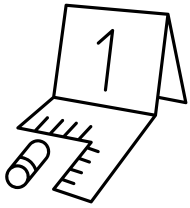
How to use the tool?

The outcome of this evidence-based research can bring awareness to HCPs about the problems of misdiagnoses of neuroendocrine cancers and help reduce the misdiagnosis rate. HCPs would gain a better understanding of what to look out for in terms of symptoms and potential misdiagnoses when examining new patients.

To ensure high-quality outcomes for this project, it is important to include HCP's insights during the creation of the survey targeting the misdiagnosis. So that the evidence generated matches their concerns. The authors suggest engaging and collaborating with a medical society for this.

Make sure to share the resulting evidence with INCA, so that an international overview comparing regional differences can be generated.

Treatment and care



56.7% of patients do not have a NET specialist involved in their initial diagnosis and in 11% of patients, a NET specialist was not involved in the treatment.

There is a clear lack of awareness about the availability of treatments, for example, 32% of HCPs stated that transarterial chemoembolisation (TACE) was not available in their country and 21% of the neuroendocrine cancer patients were not aware of its availability in their country. Similar results were found for intravenous chemotherapy or endoscopic ablation. There is also a large difference in the availability of treatments in advanced economies compared to emerging and developing economies. For example, peptide receptor radionuclide therapy is available for 57% of patients in advanced economies but only 33% of those living in emerging and developing economies.



Considering the alarming evidence encountered at this stage of the patient pathway, the authors want to remark on the importance of providing patient-focused evidence to policy makers (see pages 17 and 18). Ensuring that the patient voice is heard and captured is of priority. To ensure that the patient perspective is being captured, we need a two-way dialogue and agree on actions forward with all relevant stakeholders.

A key way to address the issue is to divide into the following 3 stages:

1
Awareness of the issue
You need to make the policy makers aware of the existing problem

2
Understanding the issue
You need to ensure that the policy makers understand the dimension and complexity of the problem

3
Taking action on the issue
You need to trigger motivation of the policy makers in order to address the problem and take action.

Treatment and care

Examples of issues which need to be addressed with policy makers:

- Access to specialists
- Knowledge on treating neuroendocrine cancers
- Access to appropriate diagnostics, imaging and monitoring
- Access to appropriate procedures and treatments

Understanding the concept of patient experience data and the use of it, is also very important when advocating for policy changes. Patient Experience Data (PED) is data that:

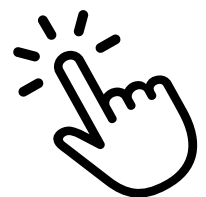
1. are collected by any persons (including patients, family members and caregivers of patients, patient advocacy organizations, disease research foundations, researchers, and drug manufacturers);
2. are intended to provide information about patients' experiences with a disease or condition, including:
3. the impact (including physical and psychosocial impacts) of such disease or condition, or a related therapy or clinical investigation on patients' lives; and
4. patient preferences with respect to the treatment of such disease or condition.

The term 'patient engagement' (PE) refers to the active and meaningful involvement of patients in developing medicines and healthcare management.

Combining the PED with PE is fundamental to ensure that the patient is the central pillar when designing, generating, collecting and analysing patient experience data. The [Global PED Navigator](#) from the PFMD organisation provides an extremely useful tool to navigate through this landscape.

They provide 4 levels of a PED matrix:

1. Tool to identify select approaches that could be used to determine what outcomes matter most to patients & families
2. Tool to select appropriate measurement methods of outcomes that matter to patients & families
3. Tool to identify PED use per stakeholder throughout the product development cycle
4. Tool to identify PED use per stakeholder throughout the healthcare process



Treatment and care



You can download and use each of these tools separately or combined. For example, for the first tool, to identify what outcomes matter most to patients & families, the global patient experience data navigator provides a matrix of the areas of impact and the corresponding specific impacts versus the prioritisation approaches like having individual interviews or survey, online bulletin boards etc... So, this tool provides you with a first stepping stone onto how to approach the different stakeholders for the areas you as a patient organisation want to tackle.

Evidence regarding patient preference can be very useful when engaging with pharmaceutical companies and discussing clinical trial plans so that patients' priorities and preferences are met by their treatments. Furthermore, the data can be used to inform HTA processes to highlight the need for specific treatments or care tools for patients.

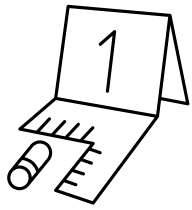
There is a lack of patient preference studies and adherence to medication data in the neuroendocrine cancer landscape.

Generating evidence in neuroendocrine cancer due to the nature of the neuroendocrine system, the data will vary greatly between neuroendocrine cancer subtypes. Hence, to have robust data, patient preference and treatment adherence should be analysed in correspondence with the neuroendocrine cancer subtypes and grades.

The reality of adherence to a certain medication can depend on different reasons, attitudes and expectations toward the medication. Evidence on medication adherence can support HCPs to identify these expectations and attitudes and address and discuss them with their patients in order to improve adherence.

Here is one example of a [patient preference study](#) carried out by Myeloma Patients Europe (6) and one [adherence to medication study](#) carried out in Chronic Myeloid Leukemia (CML) (7).

Monitoring and palliative care



There are several consensus guidelines for the treatment and management of neuroendocrine cancers, for example (9,10).



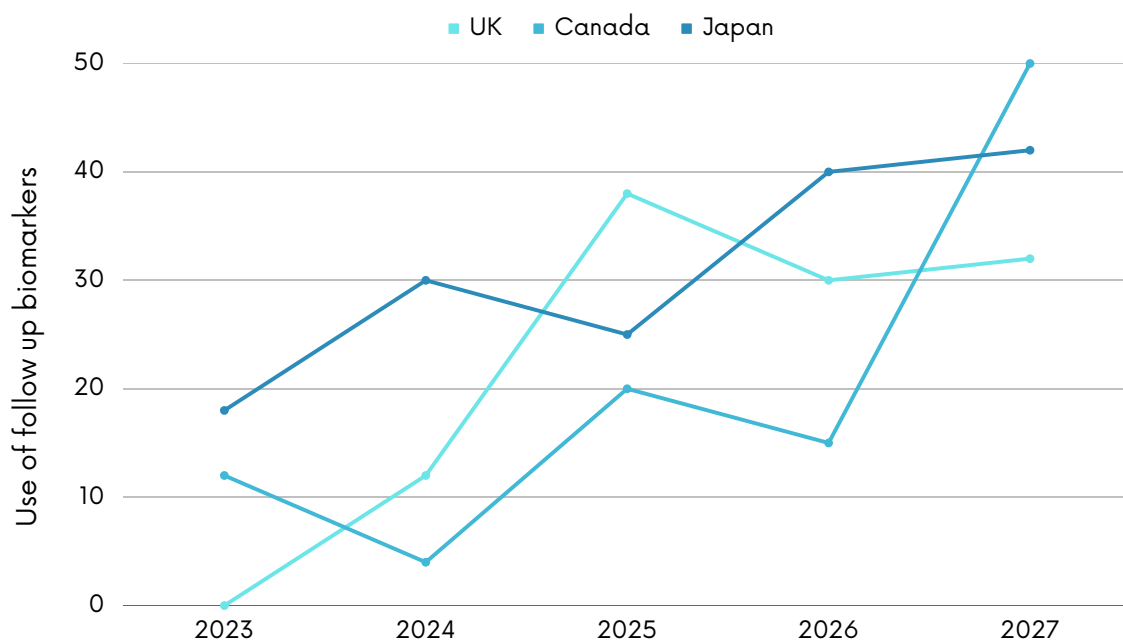
Yet, for this stage in the patient pathway, there is a big gap in the evidence. There is no available evidence on how patients are monitored after diagnosis from a patient perspective, hence how well the patient follows the monitoring guidelines suggested. The authors suggest trying to plan a research project to gather information on this.

Ideally, the authors would recommend creating a global monitoring registry with a live update of the data, providing a quick and robust snapshot of the monitoring situation of patients worldwide.

Yet, the authors realise this is quite ambitious so here is another suggestion to capture this data.

Producing a yearly bench-marking survey will provide a measuring tool to evaluate the situation in monitoring and if it's improving or deteriorating.

Example



Monitoring and palliative care

How to adapt the tool?

Monitoring can differ greatly at a national level hence it is crucial that at the beginning there should be a round table with HCPs to develop the survey which captures the main points neuroendocrine patients should follow in the monitoring phase of their pathway for example, how patients are being monitored, which methods are used, etc also taking into account the present protocol of monitoring neuroendocrine patients. Once the survey is developed, it should be standardised so it can be used on a yearly basis, yet it can maintain neuroendocrine subtype specificity. The survey and its outcomes will provide a stepping stone for the following yearly continuous surveys on monitoring.

The authors also want to point out that the survey can be carried out at a national level or international level, making sure the factors measured are at least available in all the participant countries to avoid bias.

How to use the tool?

With the outcomes of the survey, your patient organisation can do a reality check and identify the reality of the situation and identify gaps, challenges or golden standards. The resulting evidence can be used to advocate for improvement in the identified areas on a national and international level.

Closing Remarks and Further Readings



Closing remarks

Hopefully, this toolkit has provided you with useful tips and tools to develop local strategies to influence policies that improve the diagnostic and treatment pathway for neuroendocrine patients.

This is an INCA toolkit developed by Patvocates with guidance from patient leaders and NET experts from around the world to serve INCA members' purposes

Patvocates is a think tank, consultancy and social enterprise in the area of patient advocacy and patient engagement. Patvocates delivers unique insights, experience, connections and projects to empower all stakeholders to establish effective engagement frameworks, policies, processes and projects for the involvement of patients, patient advocates and patient organisations with the relevant stakeholders.

For any further questions or concerns, please don't hesitate to write to info@patvocates.net for general questions.

You can always seek input from [INCA](#) via an email to post@incalliance.org or isabella.oronova@incalliance.org.

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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>

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