Draft Process for Patient Organisation Submission of Evidence

# Public Consultation

The National Centre for Pharmacoeconomics (NCPE) performs detailed reviews of the clinical effectiveness and cost-effectiveness of new and existing drugs at the request of the Health Service Executive (HSE).

In 2016, the NCPE launched the Patient Organisation Submission of Evidence process. The purpose of this process is to supplement our health technology assessment reports with information collected directly by patients, from patients, detailing the real-life experience of living with the disease in question and how the new treatment may address the challenges arising from the disease.

To date, we have received 16 patient organisation submissions which we have included in full with our report to the HSE. Towards the end of 2017, we undertook a review of the process with input from HSE decision makers, submitting patient organisations and participants in the IPPOSI Pilot Patient Education Program. Based on the feedback provided, we have developed new guidelines, processes and updated our Patient Organisation Submission of Evidence template.

Now we would like to hear the views of potential users of the updated documents, to ensure they are relevant, patient focused and user-friendly. Your comments will be considered and will inform the development of the Patient Organisation Submission Process.

Your comments can be submitted by downloading and completing the consultation feedback form and emailing your completed form to us at [info@ncpe.ie](mailto:info@ncpe.ie) . Alternatively you can post the completed form to us at The National Centre for Pharmacoeconomics, Old Stone Building, Trinity Centre for Health Sciences, St James Hospital, Dublin 8.



Draft Process for Patient Organisation Submission of Evidence

# Public consultation feedback form

## 29th March 2018

In 2016, the NCPE launched the Patient Organisation Submission of Evidence process. The purpose of this process is to supplement our health technology assessment reports with information collected directly by patients, from patients, detailing the real-life experience of living with the disease in question and how the new treatment may address the challenges arising from the disease.

The NCPE have undertaken a review of the Patient Organisation Submission of Evidence process. We have developed new guidance documents, information sheets and templates to aid patient organisations through the submission process.

We are holding a public consultation to give interested parties an opportunity to provide their feedback on these draft documents. Your input is essential, and we will assess all feedback received and use it to develop the finalised process and documentation. We welcome responses to all questions as well as any additional general comments you would like to make.

# How to complete this form

**The draft documents are available for review on our website, www.ncpe.ie. There are 4 documents available for review as part of this consultation:**

1. **The Patient Organisation Submission Process**
2. **The Patient Organisation Database Registration Form**
3. **The Patient Organisation Submission of Evidence Template**
4. **Guidance document on completing the Patient Organisation Submission of Evidence Template**

**The closing date for the consultation is 5pm on 30th April 2018**

### Data protection

The NCPE will not collect any personal information during this consultation. All information received will be treated as confidential. Responses may be collated and presented anonymously as part of research and education programmes.

### Instructions for submitting feedback

* If you are commenting in a personal capacity, there is no need to provide your name or any other personal information
* If you are commenting on behalf of an organisation, please combine all feedback from your organisation into **one** submission form
* Your comments can be submitted by downloading and completing the consultation feedback form and emailing your completed form to us at [info@ncpe.ie](mailto:info@ncpe.ie) . Alternatively you can post the completed form to us at The National Centre for Pharmacoeconomics, Old Stone Building, Trinity Centre for Health Sciences, St James Hospital, Dublin 8

# About You

Please tick as appropriate-are you providing feedback as:

An individual

On behalf of an organisation

Please provide the name of the organisation:

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# Feedback on the draft process

In this section, we would like to find out what you think of the content of each of the draft documents. You do not have to comment on all documents

Please consider the following as part of your review:

* Do you think all important areas have been covered?
* Is the language used appropriate and easily understood?
* Is the layout of the document clear and easy to follow?

Patient Organisation Submission Process

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Patient Organisation Database Registration Form

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Patient Organisation Submission of Evidence Template

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Guidance Document for completing the Patient Organisation Submission of Evidence Template

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# General feedback

Please let us know if you have any other general comments to make about the Patient Organisation Submission Process.

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Thank you for taking the time to give us your views, we appreciate your feedback