Patient Organisation

Database Registration Form

Record of Updates

Version	Date	Description of changes
1.0	Feb 2019	

Please Note: This document may be updated periodically, therefore please refer to the NCPE website to obtain the most recent version

Patient Organisation Submissions

The National Centre for Pharmacoeconomics (NCPE) is committed to facilitating the inclusion of the patient voice in the Health Technology Assessment (HTA) process. The NCPE provide the Patient Organisation Submission Process, to enable patient organisations to communicate their experiences directly to the decision maker, the Health Services Executive (HSE).

The Patient Organisation Submission Process encourages Patient Organisations to gather information from their members for inclusion in the Patient Organisation Submission of Evidence Template. In particular, it includes information on the day-to-day experience of living with the disease and the ways in which the new drug may improve this day-to-day experience. This information can help the HSE Drugs Committee to understand the real-world impact a new drug may have on the quality of life and daily experience of patients and carers.

Patient Organisation Database

The NCPE maintain a database of Patient Organisations who have expressed an interest in submitting Patient Organisation Submissions of Evidence as part of the HTA process.

The purpose of maintaining this database is threefold;
1. To allow the NCPE to readily notify Patient Organisations when a relevant HTA evaluation is commissioned by the HSE.
2. To allow the NCPE to maintain a list of interested partners so that we can communicate proposed changes to the process, provide training to participating organisations and provide annual reports on the Patient Organisation Submissions Process in the NCPE.
3. Reduce duplication in the submission process for organisations who submit regularly, by retaining information on the organisation on file.

This database allows the NCPE to maintain the two-way communication required for effective patient engagement. The only information recorded in this database is the information provided by the organisations through this form. The database will not be shared with any other organisation. We record the information in compliance with data protection legislation, and as such, any Patient Organisation has the right to have their information removed from the database by emailing info@ncpe.ie with their request.

Patient Organisation – Database Registration Form

It is necessary to answer ALL of the questions in this form to be registered as a Patient Organisation.

Patient Organisation Details

Question 1: Name of Organisation

Please give the full name of your organisation as it appears in your governing document.

Question 2: Alternative/Previous Names of Organisation

Please advise of any alternative names by which your organisation is known.

Question 3: Organisation's main or registered address

Please provide the full registered address of the organisation

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Question 4: Type of Organisation *(please tick as appropriate)*

Type A – (see Note 1) ☐
Type B – (see Note 2) ☐
Type C – (see Note 3) ☐
Other ☐

Further information on organisation type is available on www.governance.ie and additional information is provided at the end of this document.

Please submit a copy of your governing document e.g. Memorandum of Articles or Articles of Association. *Unincorporated organisations must still provide a written governing document to demonstrate that they operate under a set of rules.*

☐ **Enclosed**

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Question 5: Please provide details if you have ticked 'Other'

Question 6: Please provide a short description of the nature and purpose of your organisation

Question 7: Please state the therapeutic area(s) of interest to your organisation, e.g. rheumatoid arthritis, breast cancer, multiple sclerosis etc.

Question 8: If you are a membership-based organisation, please indicate the number of patients you represent and geographical spread

Question 9: Please list any pharmaceutical companies that are corporate members of your organisation. What percentage of your organisation's overall funding came from pharmaceutical companies in the last financial year?

Question 10: Does your organisation follow a code of conduct for engaging with the pharmaceutical industry? Please provide any relevant details.

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Question 11: Contact Details

Please provide the name of one contact within the organisation, including a telephone number and email address. This contact should complete the data processing consent form below.

Name:
Telephone number:
Email address:

Data Processing Consent

Question 12: Consent for use of data

This section is for completion by the person outlined in Question 11 as the point of contact for the organisation. If necessary, it may be completed on behalf of this person but only if they have knowledge and understanding of the details outlined below and are content for their answer to be recorded on their behalf by a representative.

Processing your personal data
We ask for the name and contact details of a relevant person within the organisation to act as a point of contact for the Patient Organisation Submission Process. The NCPE will retain a record of your contact details for the purposes of communicating with you when relevant drugs are undergoing evaluation, in line with the process described on the NCPE website. The NCPE will also use these details to occasionally contact you for input to reviews of the Patient Organisation Submission Process, to communicate any changes to the process, and to notify you of training opportunities which may be of interest. The NCPE may present, in an aggregate manner, the number of Patient Organisations registered in our database for academic or organisational purposes but will not identify individual organisations or the personal details provided here.

We will not share your data with other third parties.

Storing your personal data
Your electronic data will be stored on a drive on the NCPE server. Any paper copies will be stored in a locked room within a secure building.
Personal data will be retained by us for as long as is necessary to operate the Patient Organisation Submission Process.

Additional information
You retain the right to enquire about your personal data.
You retain the right to request that we erase, anonymise or rectify your personal data.
You also retain the right to withdraw consent to use your personal data at any time.

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Please be aware that if consent is not granted or is withdrawn, we require details of an alternative point of contact in order for the organisation to remain on this database.

Please contact us at info@ncpe.ie should you have any enquires about the personal data NCPE hold on you.

Do you consent to your data being collected, processed and stored by the NCPE as outlined above?

Yes ☐   No ☐

Notes: Organisation Type *(www.governance.ie)*

Note 1: Checklist for Type A

This group is run by volunteers and do not employ staff. The members of the board are therefore responsible for:

1. Overseeing the work of the organisation (governance);
2. Organising the daily work (management), and;
3. Carrying out the work of the organisation (operations).

Many such groups operate on less than €10,000 a year although some may have a larger income. They may or may not have a CHY number. Type A groups are may be incorporated but some may be required to do so by funders.

Note 2: Checklist for Type B

These organisations usually employ a small number of staff and many may have a single member of staff. While the most senior (or only) member of staff may have a title such as manager, coordinator or administrator, the people who sit on the board will still have some management and operations responsibilities as well as their governance/oversight role.

Annual income may vary considerably from one organisation to the next in this category and many organisations may receive grants from statutory bodies and/or trusts and foundations. A 'Type B' organisation may tend to be incorporated, and may have a CHY number.

Note 3: Checklist for Type C

The main characteristics of these organisations are that the people who sit on the board focus solely on their governance/oversight role, delegating management and operational duties to

the staff. There is a clear division between the governance role of the board and the management role of staff.

These organisations tend to employ more than ten members of staff and may often have hundreds of staff which in turn, may require a structure based on functional or geographic departments. It is most likely that 'Type C' organisations will be incorporated and may have a CHY number, but this is not always the case.