

Patient Organisation Database Registration Form



Record of Updates

Version	Date	Description of changes
1.0	August 2018	

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



Patient Organisation – Database Registration Form

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. We believe that patients have perspectives and experiences that can uniquely contribute to the decision making process. We also consider that patients should have the same opportunity to contribute to HTA as other stakeholders, and this requires processes to enable effective engagement. With this in mind, 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;

- (i) To allow the NCPE to readily notify Patient Organisations when a relevant HTA evaluation is commissioned by the HSE.
- (ii) To allow the NCPE to maintain a list of interested partners so that we can communicate proposed changes to the process,



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provide training to participating organisations and provide annual reports on the Patient Organisation Submissions Process in the NCPE.

- (iii) 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.



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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

Question 4: Contact details

Please provide the names of at least one, and preferably two contacts within the organisation, including telephone numbers and email addresses

- 1.
- 2.



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Question 5: 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

Question 6: Please provide details if you have ticked 'Other'

Question 7: Please provide a short description of the nature and purpose of your organisation

Question 8: Please state the therapeutic area(s) of interest to your organisation, e.g. rheumatoid arthritis, breast cancer, multiple sclerosis etc.

Question 9: If you are a membership-based organisation, please indicate the number of patients you represent and geographical spread



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Question 10: 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 11: Does your organisation follow a code of conduct for engaging with the pharmaceutical industry? Please provide any relevant details.

Question 12: Consent for use of data

**Additional information on data protection is
provided at the end of this document**

1. Do you consent to the NCPE retaining a record of contact details for your organisation, for the purposes of communicating with you when relevant drugs are undergoing evaluation, in line with the process described on the NCPE website? If you refuse consent, the NCPE will not enter your details into the database, or use the contact details for your organisation beyond the duration of this HTA.

Yes, I consent

No, I refuse consent

2. Do you consent for the NCPE to occasionally contact you for input to reviews of the Patient Submission Process, to communicate any changes to the submission process, and to notify you of training opportunities which may be of interest?

Yes, I consent

No, I refuse consent

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. The data is kept solely for the purpose of communicating with organisations regarding ongoing and upcoming pharmacoeconomic evaluations of drugs which may be of interest to the registered groups, training opportunities and notification/consultation on changes to the process.



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Notes: Organisation Type ([www.governance .ie](http://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.