

Privacy regulations for the National Prevalence Measurement of Care Indicators

Paragraph 1 General definitions

Article 1 Comprehensive description

In this regulation one understands under:

1. *Registered*: the public health institution with registered institutional particulars.
2. *Institutional particulars*: particulars on the occurrence, the prevention and the treatment of care problems at an individual institution.
3. *Untraceable particulars*: an untraceable particular is a particular that requires disproportionate amount of time, money and manpower for tracing it back to an individual person or an individual institution.
4. *Registration*: the coherence collection of institutional particulars lodged with the Landelijke Prevalentiemeting Zorgproblemen.
5. *Holder*: the one who has the authority for the registration: Maastricht University.
6. *Processor*: the one under whose responsibility the particulars are compiled into a national registration: the project leader LPZ
7. *Coordinator*: the one who is actually responsible for providing the institutional particulars, is responsible for the data collection within the institution, but does not belong to the holder's organisation.
8. *Providing particulars to a third party*: Providing the particulars from the registration to a person or an agency outside the holder's organisation, with the exception of the registered.
9. *Client*: all persons who are under care at a health institution are understood under client. Client/resident can thus also be read for those in home care, nursing homes and homes for the elderly.
10. *The regulation*: this regulation including the 2 appendixes.
11. *Client particulars*: particulars of individual clients collected for the registration (see appendix 1)

Article 2 Suitability of the regulation

This regulation is in use for the Landelijke Prevalentiemeting Zorgproblemen beginning on 1 January 2007 and replaces the earlier privacy regulation of the then National Prevalence Study Decubitus (NPSD).

Article 3 Aims of the organisation

De Landelijke Prevalentiemeting Zorgproblemen (LPZ) is an annual data collection on the prevalence of care problems within the Dutch Health care. The institutions receive the particulars through this data collection that are necessary for the fulfilment of the client-related performance indicators which must be collected at an individual level. Moreover, one may gain insight into the prevalence, the prevention, the treatment and the policy (quality indicators) of specific care problems, whereby directed measures can be taken for improving the quality of care for these care problems.

Aims of the registration are:

1. Obtain an insight into the occurrence of care problems both at national as well as institutional- and departmental levels.
2. Obtain an insight into the differences in the occurrence of the care problems between institutions, departments and client groups.
3. Obtain an insight into the occurrence of care problems during the course of time.
4. Obtain an insight into the coherence between care problems.
5. Obtain an insight into the affectivity of the undertaken actions in the prevention of the care problems.
6. An aid for the registered to receive particulars desired by the Public Health Authorities.

Article 4 Participation in the registration
Participation in the registration is voluntary and applies to both the registered as well as the client.

Article 5 Nature of the submitted particulars in the data collection
The registered annually provides institutional particulars for registration on the national data collection day. The particulars consist of:

1. A profile of the institution and the department providing the particulars
2. General client particulars and specific particulars of care problems on which data was collected from all participating clients of the registered.
3. Preventive and curative measures that were taken for the care problems in the individual client.

Article 6 Submission of the collected data

1. Employees of the institution are responsible for an adequate and reliable registration of the particulars on the standard forms provided by the LPZ. The coordinator gathers the forms and registers the particulars via the internet registration programme of Flycatcher Internetresearch that sends the particulars to the processor.
2. The coordinator then files the filled in forms. These remain the property of the institution. The forms can only be seen by the processor after permission from the institution.
3. The registered receive the results of their own institution in the form of Tables distinguishing the actual departments from the types of departments from the processor within a week.
4. The institution also receives the results at the national level from the processor two months after the national data collection.

Article 7 Storage of particulars
The particulars of the institution are stored conform to its guidelines with the understanding that these will be stored for at least a year.

Article 8 Privacy of the individual client
The processor has the computerised particulars of all the participating institutions and processes these for the purpose as mentioned in article 3. The particulars in the registration cannot be traced back to the individual clients

Paragraph 2 Rights of the registered

Article 9 Providing information
The processor is responsible for the written information to the registered. The information in each case consists of:

1. Aim of the registration
2. The manner in which access is obtained for the registration
3. The procedure of the registration
4. The nature of the particulars that will be included in the registration
5. The presence of this regulation
6. Participation in the registration implies restricting to the regulation
7. The right of the registered to inspect, to change and to destroy own institutional particulars
8. The right of the registered to object to providing the particulars to a third party

Article 10 Request for the destruction of institutional particulars in the registration

1. Requests by the registered to inspect, to change and to destroy the institutional particulars in the registration are directed to the processor in writing. The processor ascertains the identity and the authority of the requestor.
2. The processor informs the registered in writing on the processing of the request within 4 weeks after receiving it.

Article 11 Complaints regulation

1. The registered may lodge a complaint concerning the functioning of the registration and the implementation of this regulation with the processor without losing the right to turn to a judge.
2. The processor has the duty to deal with the complaint immediately and to settle it within a period of 4 weeks after receiving it. The complainer is granted an opportunity to provide additional verbal or written information on the complaint.
3. The processor corrects the shortcomings and takes appropriate measures to prevent recurrences once the complaint has been declared as justified.
4. The registered still has a right to turn to a judge after the internal complaint procedure has been concluded.

Paragraph 3 Providing data to a third party by the holder

Article 12

The processor provides the institutional particulars to a third only after permission from the registered.

Article 13

The registration (or parts thereof) may be used without permission from the institution for scientific investigation by the processor and a third party according to the agreement in appendix 2.

Paragraph 4 Other definitions

Article 15

The registration is not related to other registrations of the institutional particulars.

Article 16

The processor decides in all cases in which this regulation does not suffice or in the case where the accuracy of the explanation of this regulation is doubted.

Article 17

The processor is responsible for any changes in this regulation and for sending the revised version immediately to the coordinator of the registered.