

EUROPLAN

European Project for Rare Diseases National Plans Development

Project coordinated by the Italian National Centre for Rare Diseases

Italian National Institute of Health

2012-2015

Delphi Process for European Indicators on National Plans for Rare Diseases



November 2012

User Manual

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Introduction

Delphi Process for European Indicators on National Plans for Rare Diseases

The Delphi method is a qualitative research technique for consensus building. Communication is organised in a group of experts in order to achieve their opinion in a systematic way and to group subjective judgments. Every expert can express his/her own opinion anonymously.

The Procedure

Delphi proceeds in a series of rounds:

Round 1: Experts are invited to provide opinions on a specific matter, based on their knowledge and experience. These opinions are grouped together under a limited number of headings and statements drafted for circulation to all participants on a questionnaire;

Round 2: Participants rank their agreement with each statement in the questionnaire. The rankings are summarised and included in a repeat version of the questionnaire;

Round 3 (if needed): Participants rerank their agreement with each statement in the questionnaire, with the opportunity to change their score in view of the group's response. The rerankings are summarised and assessed for degree of consensus: if an acceptable degree of consensus is obtained the process may cease, with final results fed back to participants; if not, the third round is repeated.

Methodological Issues

- Experts selection: the potential bias in the selection of participants can be overcome by using a different mixture of participants.
- Accuracy of the answer: because of the danger of deriving collective ignorance rather than wisdom (consensus does not mean finding the “correct” answer), the literature recommends that the results should, when possible, be matched to observable events (pilot study in EUROPLAN II)

Results Feedback

Agreement with statements is usually summarised by using the median and consensus assessed by using interquartile ranges for continuous numerical scales.

Feeding back the group's response enables participants to consider their initial ranking in relation to their colleagues' assessments, but it is not compulsory to conform to the group view.

Outliers (e.g. those in the lower and upper quartiles) must comment/provide written justification for their responses.

EUROPLAN Indicators Selection

Usefulness and feasibility of data collection are the two main criteria that EUROPLAN 2012-2015 identified for selecting a limited number of indicators among those produced by EUROPLAN 2008-2011.

Authentication procedure (log-in)



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Username:
Password:

Fig. 1 –Log-in

To access the system, you must visit the website
<http://www.iss.it/site/cnmr/privato/indicatorsv2>

Type in your *Username and Password*, both assigned by the coordinators of the Europlan 2012-2015 project.

Press “Enter” to access the System.

Home



Figure 2- Home page

After the log-in phase, the system's home page is accessed.
The connected user's data appear at top left.
After the heading is the list of enabled functions.

In detail:

- Indicators: returns to page with list of indicators for scoring
- Working group: returns to page with list of participants in the working group
- Logout: to exit the system.

USING THE BROWSER'S BACK/FORWARD BUTTONS IS HIGHLY DISCOURAGED.

Indicators

User: BACHNERFlorian
[Delphi Process for European Indicators on National Plans for Rare Diseases](#) - Delphi 1 - Indicators

Indicators

[AREA 1 - Plans and strategies in the field of Rare Diseases](#) Go to scoring

Aims	Actions	Indicators
To establish National/Regional plans and/or strategies on RD	Development of Regulations/Laws	1.1.Existence of regulations/laws that support the creation and development of a RD plan 1.2.National/regional (percentage of regions)
	Establishment of Coordination mechanisms	1.3.Existence of a coordination mechanism 1.4.Existence of an expert advisory committee
	Establishment of an external evaluation of the plan/strategy procedure	1.5.Existence of an external evaluation body/procedure
	Degree of comprehensiveness	1.6.Number of priority areas included in the plan
	Establishing of a budget for developing the plan/strategy	1.7.Budget of plan/strategy

[AREA 2 - Adequate definition, codification and inventorying of Rare Diseases](#) Go to scoring

Aims	Actions	Indicators
Use a common definition	To officially adopt the EC RD definition (No more than 5 cases / 10,000 inhabitants)	2.1.Adoption of the EC RD definition
Ensure that RD are adequately coded and traceable in the health care information system	To include the best RD diseases classification currently existing into the public health care related services	2.2.Type of classification used by the health care system 2.3.Developing policies for recognising RD by the care information systems
Support registries for better epidemiological knowledge	Defining a surveillance system based on a patient outcomes registry	2.4.Registering activity 2.5.Number of diseases included

Figure 3 - Indicators

In addition to the connected user’s data, the path for facilitated access to the sections also appears at top left.

For each area, the title and link for downloading the pdf document is at left, and access to the scoring of the “Indicators” is at right.

The table beneath contains the structured information regarding the section.

Click on “Go to scoring” for the system to go to the scoring page.

The “Home” button returns to the home page.

The “Logout” button allows the user to exit the system.

Scoring

ser: Admin
[Delphi Process for European Indicators on National Plans for Rare Diseases](#) > Delphi 1

Delphi 1

AREA 2 - Adequate definition, codification and inventorying of Rare Diseases

USEFULNESS = The indicator is useful to develop and monitor National Plan implementation.
 FEASIBILITY = The indicator can be collected easily
 On a 0 to 10 scale, where '0' means "completely DISAGREE", '10' means "completely AGREE", and '5' is "exactly in the middle", for each indicator, select which score you choose about its USEFULNESS and FEASIBILITY in your Country. Please, note that comment is obligatory if score is less than or equal 7.

Action	Indicator	Usefulness		Feasibility	
To officially adopt the EC RD definition (No more than 5 cases / 10,000 inhabitants)	2.1 - Adoption of the EC RD definition	Delphi*: <input type="text"/>	Comment: <input type="text"/>	Delphi*: <input type="text"/>	Comment: <input type="text"/>
	2.2 - Type of classification used by the health care system	Delphi*: <input type="text"/>	Comment: <input type="text"/>	Delphi*: <input type="text"/>	Comment: <input type="text"/>
To include the best RD diseases classification currently existing into the public health care related services	2.3 - Developing policies for recognising RD by the care information systems	Delphi*: <input type="text"/>	Comment: <input type="text"/>	Delphi*: <input type="text"/>	Comment: <input type="text"/>
	2.4 - Registering activity	Delphi*: <input type="text"/>	Comment: <input type="text"/>	Delphi*: <input type="text"/>	Comment: <input type="text"/>
Defining a surveillance system based on a patient outcomes registry	2.5 - Number of diseases included	Delphi*: <input type="text"/>	Comment: <input type="text"/>	Delphi*: <input type="text"/>	Comment: <input type="text"/>

[previous area](#)
[next area](#)

[Logout](#)

Figure 4 – Scoring

In addition to the connected user's data, the path for facilitated access to the sections also appears at top left.

At the centre of each area is the link for downloading the pdf document. In the portion beneath is the legend for guidance in scoring. The table beneath contains structured information regarding the area.

Scoring instructions

The scoring system has two phases: the free saving of the data, and definitive validation. In both phases, the user is called upon to provide his or her opinion of the Usefulness and Feasibility for each individual Indicator of the area.

For each of the Indicators, a score and a comment are respectively requested. The ranges from 0 to 10. For scores less than or equal to 7, the comment is obligatory.

While saving, the user is free to enter and/or edit his or her data with no verifications by the system.

In the validation phase, on the other hand, certain data and certain constraints on relations between them are obligatory. All the scores are obligatory.

AFTER VALIDATING THE DATA, THE USER WILL NO LONGER BE ABLE TO EDIT THEM.

The “Next area” button to the right of the table leads to the next area.

The “Previous area” button to the left of the table returns to the previous area.

When both buttons are clicked, a message reminds the user to save the data prior to changing page (“Are you sure to go to the previous/next area? If you have entered or changed data without saving the entered data will be lost”).

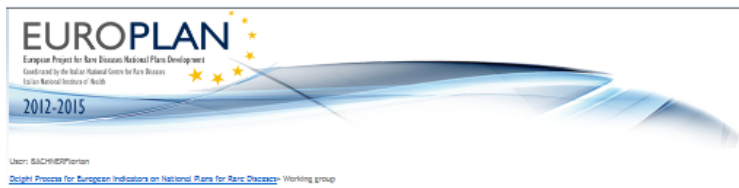
The “Save your data” button allows all the entered data to be saved without implementing checks. The “Validate” button, on the other hand, checks that the obligatory data have been entered, and permits the definitive saving of all the data. **A message requests confirmation of the operation: once validated, the data can no longer be edited.**

The “Indicator” button returns to the previous page.

The “Home” button returns to the home page.

The “Logout” button allows the user to exit the system.

Working group



Delphi Process for European Indicators on National Plans for Rare Diseases

Working group

Country	Role	Surname	Name	Institution
	Participant - Health Representative	OSUNAS	Miriam	Ministry of Health
Austria	Participant - Health Representative	SÄCHNER	Florian	Austrian Health Institute
Belgium	Participant - Health Representative	VAN DEN BOGERT	Saskia	Federal Public Service of Public Health
Belgium, Denmark, Portugal	Participant - Adviser	JENSEN	Lene	EURODIS
Bulgaria	Participant - Health Representative	TINCHEVA-YORDANOVA	Radka Stefanova	National Advisory Council on rare diseases
Croatia	Participant - Health Representative	BURISIC	Ingeborg	Children's University Hospital
Croatia, Poland, Serbia	Participant - Adviser	DHALCEK	Vlasta	EURODIS
Cyprus	Participant - Health Representative	ANASTASIOU	Violetta	Orthopaedic Halkentis III Hospital, the Cyprus Institute of Neurology and Genetics
Cyprus, Luxembourg	Participant - Adviser	CANNON	Lily	EURODIS
Czech Republic	Participant - Health Representative	HALCEK	Milan	University Hospital Motol
Denmark	Participant - Health Representative	JENSEN	Hanneke	National Board of Health
Estonia	Participant - Health Representative	YASUJÄE	Inna	Ministry of Social Affairs
Finland	Participant - Health Representative	AJTAN-COLLAN	Katja	Ministry of Social Affairs and Health
Finland, Sweden	Participant - Adviser	GÄRDSJÖTER	Maria	EURODIS
France	Participant - Expert	DONADIEU	Jean	Hopital Trousdale
France	Participant - Health Representative	GARCIS	Alain	Ministry of Health
France, Switzerland	Participant - Adviser	NOURISSIER	Christel	EURODIS
Georgia, Russia, Ukraine	Participant - Adviser	KVILVIDZE	Oleg	EURODIS
Germany	Participant - Health Representative	HÖHN-KLIN	Véronique	Federal Ministry of Health
Greece	Participant - Health Representative	TSALA	Lia	Historic Centre for Disease Control and Prevention
Hungary	Participant - Health Representative	BRUNNER	József Károlyné	Committee of Developing the Hungarian RD National Plan
Hungary, Romania, Slovakia	Participant - Adviser	DAN	Denica	EURODIS
Ireland	Participant - Adviser	O'LEARY	Áine	EURODIS
Ireland	Participant - Health Representative	DEVLIN	John	Ministry of Health
Italy	Participant - Health Representative	CONGLI	Maria Elena	Ministry of Health
Italy	Participant - Expert	SCHIEFFATI	Luigi	Clinical Research Center for Rare Diseases Aldo e Celia Daddi
Italy	Working group - Coordinating Team	GENTILE	Amelia Epic	EUROPLAN 2012-2015 Coordinating Team
Italy	Working group - Coordinating Team	FERRELLI	Rita Maria	EUROPLAN 2012-2015 Coordinating Team
Italy	Participant - Expert	GATTA	Gemma	Institute for Cancer Research and Treatment
Italy	Working group - Coordinating Team	DE SANTIS	Maria	EUROPLAN 2012-2015 Coordinating Team
Italy	Working group - Coordinator	TARUSCIO	Domenico	EUROPLAN Leader
Italy	Working group - Partner	VITTOLEI	Luciano	Italian National Centre for Rare Diseases Italian National Institute of Health
Italy, Greece, Spain	Participant - Adviser	BELLUGLIANI	Simona	EURODIS
Latvia	Participant - Health Representative	STRUJNE	Zane	Children's Clinical University Hospital
Lithuania	Participant - Health Representative	KAVYLAIUSKIENE	Simas	Ministry of Health
Luxembourg	Participant - Health Representative	WÄGNER	Yolande	Ministry of Health
Netherlands	Participant - Health Representative	SEEVERENS	Hendrieka Johanna Josephina	Ministry of Health
Norway	Participant - Health Representative	ÅKSHES	Stein Åne	Directorate of Health
Poland	Participant - Health Representative	GRALINSKI	Janek	Ministry of Health
Portugal	Participant - Health Representative	DINIZ	Alcander	General Directorate of Health
Romania	Participant - Health Representative	SEVERIN	Emilia	Ministry of Health
Slovakia	Participant - Health Representative	CISARIK	Prerast'ák	Hospital Žilina
Slovenia	Participant - Health Representative	HEDVED	Robert	Ministry of Health
Spain	Participant - Health Representative	SOLER-CRESPO	Pilar	Ministry of Health, Social Services and Equality
Spain	Participant - Expert	SERRANO	Pedro	Canary Islands Foundation for Health and Research (FUNCIIS)
Spain	Working group - Partner	POSADA	Manuel	Institute of Rare Diseases Research, Instituto de Salud Carlos III
Sweden	Participant - Health Representative	BERGMAN	Susanne	National Board of Health and Welfare
United Kingdom	Participant - Health Representative	JESSOP	Edmund	National Specialised Commissioning Team
United Kingdom, Netherlands	Participant - Adviser	HUTT	Stephen	EURODIS

Stroma

Figure 5 – Working group

At the top left, in addition to the data on the connected user, the page presents the path for facilitated access to the sections.

The table beneath contains the information on group members.

The “Home” button returns to the home page.

The “Logout” button allows the user to exit the system.

For information contact



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