EUROPLAN
European Project for Rare Diseases National Plans Development
Coordinated by the Italian National Centre for Rare Diseases
Italian National Institute of Health
2012-2015

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INDICATORS SELECTION according to the Delphi technique (EUROPLAN "A"): presentation of results

Rita M. Ferrelli, Amalia Egle Gentile, Marta De Santis

EUROPLAN 2012-2015 Coordinating Team

Italian National Centre for Rare Diseases
Italian Institute of Health
Rome, Italy

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Two processes for selecting a limited number of indicators:

- **Delphi process:**

  - *participants*: MoH representatives of 27 MS, 10 EURORDIS Advisors and 4 experts, *carried out by ISS (EUROPLAN "A").*

- **EURORDIS approach:**

  participants: 7 EURORDIS Advisors in conjunction with their MoH lead contacts on NP/NS,

  carried out by EURORDIS (EUROPLAN "B").

The results of both processes are discussed during this meeting

THE DELPHI PROCESS

- 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

<u>Round 1:</u> 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: 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.

METHOD

- **PARTICIPANTS**

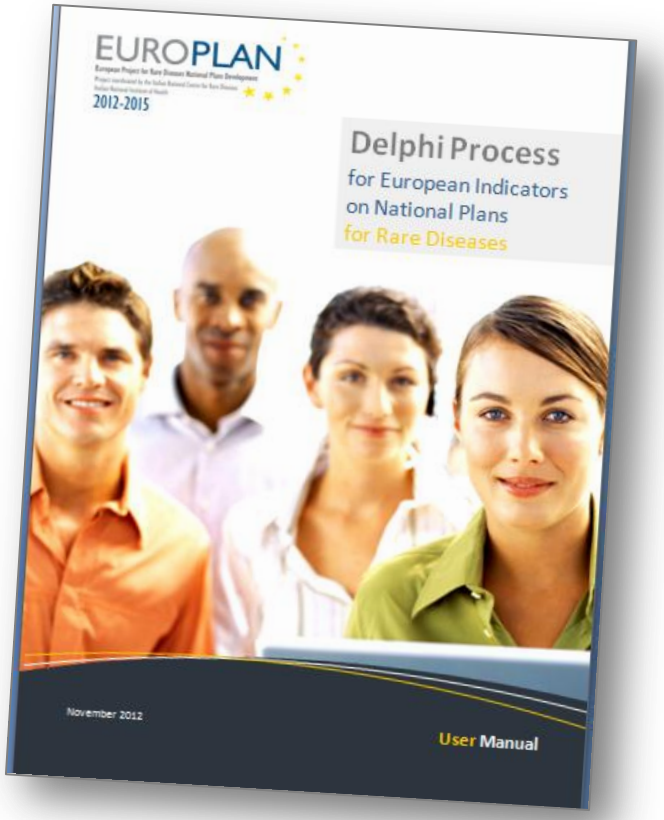
  MoH representatives from 27 MS, + MoH representatives from **Norway and Croatia**, **10 EURORDIS Advisors**, and **4 experts in RD and indicators development.**

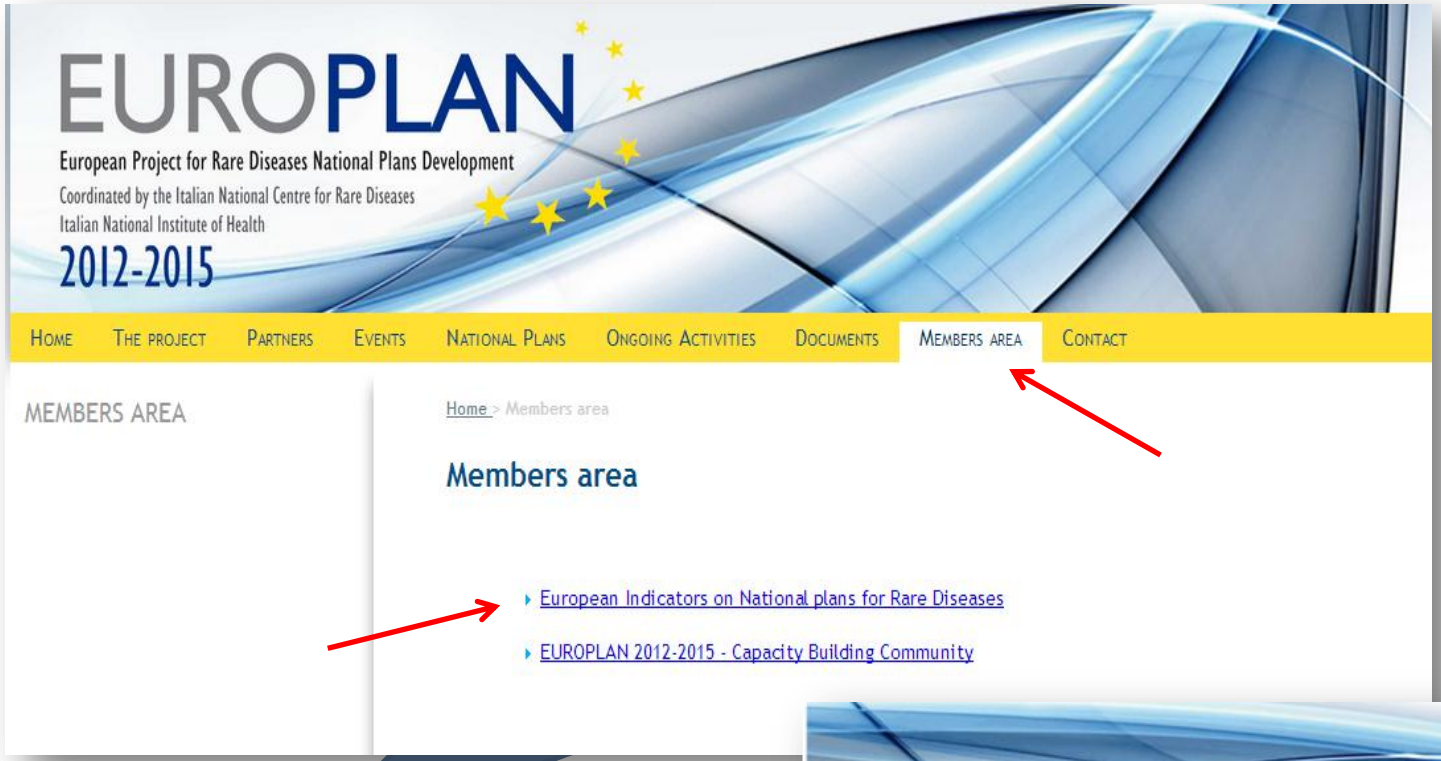
- **CRITERIA FOR SELECTING INDICATORS:**

  USEFULNESS and FEASIBILITY

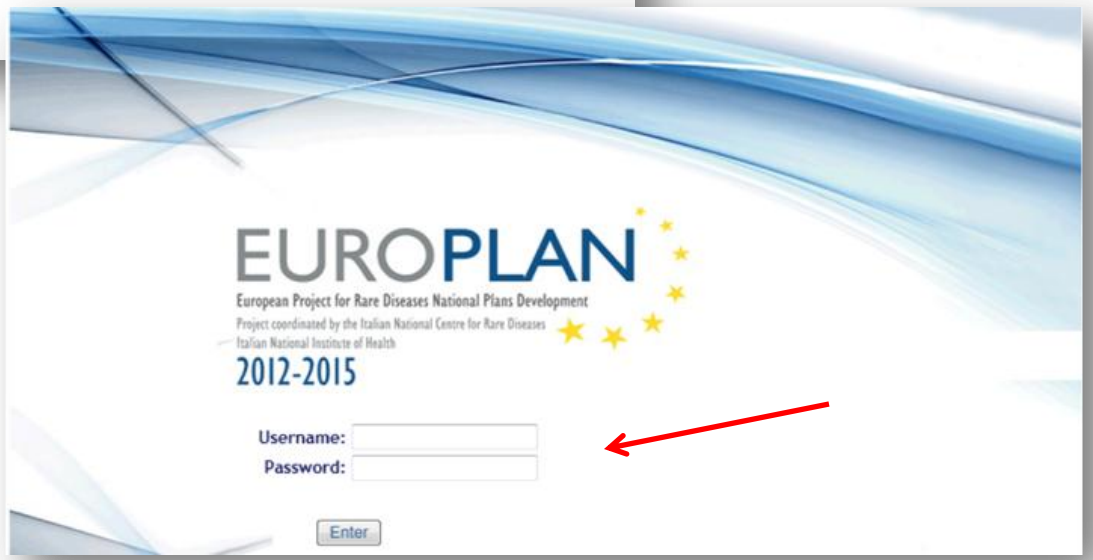
- **METHODOLOGICAL HOMOGENEITY**

  we prepared an ***USER MANUAL*** to facilitate the process and to ensure homogeneity.





The dedicated website was accessible in the private area of the EUROPLAN website



www.europlanproject.eu

PARTICIPANTS

- **26 EU MS** MoH Representatives (instead 27)
- **2 non-EU Countries** MoH Representatives
- **4 Experts**
- **6 EURORDIS Advisors** (out of a total of 10)

…about 27 EU MS…

- **23 provided all data**
- **3 provided data partially**
- **1 did not participate (Germany)**

	Country	AREA 1	AREA 2	AREA 3	AREA 4	AREA 5	AREA 6	AREA 7	Status
26 EU MS	Austria	✓	✓	✓	✓	✓	✓	✓	COMPLETE
	Belgium	✓	✓	✓	✓	✓	✓	✓	COMPLETE
	Bulgaria	✓	✓	✓	✓	✓	✓	✓	COMPLETE
	Cyprus	✓	✓	✓	✓	✓	✓	✓	COMPLETE
	Czech Republic	✓	✓	✓	✓	✓	✓	✓	COMPLETE
	Denmark	✓	✓	✓	✓	✓	✓	✓	COMPLETE
	Estonia	✓	✓	×	✓	✓	✓	✓	Incomplete
	Finland	✓	✓	✓	✓	✓	✓	✓	COMPLETE
	France	✓	✓	✓	✓	×	✓	✓	Incomplete
	Greece	✓	✓	✓	✓	✓	✓	✓	COMPLETE
	Hungary	✓	✓	✓	✓	✓	✓	✓	COMPLETE
	Ireland	✓	✓	✓	✓	✓	✓	✓	COMPLETE
	Italy	✓	✓	✓	✓	✓	✓	✓	COMPLETE
	Latvia	✓	✓	✓	✓	×	✓	✓	Incomplete
	Lithuania	✓	✓	✓	✓	✓	✓	✓	COMPLETE
	Luxembourg	✓	✓	✓	✓	✓	✓	✓	COMPLETE
	Malta	✓	✓	✓	✓	✓	✓	✓	COMPLETE
	Netherlands	✓	✓	✓	✓	✓	✓	✓	COMPLETE
	Poland	✓	✓	✓	✓	✓	✓	✓	COMPLETE
	Portugal	✓	✓	✓	✓	✓	✓	✓	COMPLETE
	Romania	✓	✓	✓	✓	✓	✓	✓	COMPLETE
	Slovakia	✓	✓	✓	✓	✓	✓	✓	COMPLETE
	Slovenia	✓	✓	✓	✓	✓	✓	✓	COMPLETE
	Spain	✓	✓	✓	✓	✓	✓	✓	COMPLETE
	Sweden	✓	✓	✓	✓	✓	✓	✓	COMPLETE
	United Kingdom	✓	✓	✓	✓	✓	✓	✓	COMPLETE
plus	*Germany*	*This Country did not participate: too early*							
Non EU	Croatia	✓	✓	✓	✓	✓	✓	✓	COMPLETE
	Norway	✓	✓	✓	✓	✓	✓	✓	COMPLETE
	4 Experts (France, Italy, Spain)	✓	✓	✓	✓	✓	✓	✓	COMPLETE
EURORDIS Advisors	Belgium, Denmark, Portugal	✓	✓	✓	✓	✓	✓	✓	COMPLETE
	Finland, Sweden	✓	✓	✓	✓	✓	✓	✓	COMPLETE
	France, Switzerland	✓	✓	✓	✓	✓	✓	✓	COMPLETE
	Georgia, Russia, Ukraine	✓	✓	✓	✓	✓	✓	✓	COMPLETE
	Hungary, Romania, Slovakia	✓	✓	✓	✓	✓	✓	✓	COMPLETE
	Italy, Greece, Spain	✓	✓	✓	✓	✓	✓	✓	COMPLETE

RESULTS

- **PARTICIPANTS** respondent rate = **100%** (38/38).
- **COMPLETED AREAS** rate = **99%** (265/268).

26 MS (instead of 27)

- One Country (*Germany*) deemed the indicators process selection to be in a early stage (as no formal consensus on the different actions has been reached by the steering committee yet) and decided not rake part into the process.
- Three Countries (*Estonia, France, and Latvia*) answered partially in some areas. The incomplete areas were not evaluated.
- EURORDIS participated with 6 Advisors (out of a total = 10), selected upon a criteria of personal availability.

- Data analysis reports the mean, median and range of the values.
- Only the highest median has been taken into account for selecting the indicators.

The highest scored

PRELIMINARY OBSERVATIONS

- The Delphi process allowed for a selection of a limited number of indicators for national plans on rare diseases

- The literature recommends that the results should, when possible, be matched to observable events (pilot study in EUROPLAN II)

Working Group

- **Domenica Taruscio** - *EUROPLAN Leader*
- **Marta De Santis, Rita M. Ferrelli, Amalia Egle Gentile** - *EUROPLAN 2012-2015 Coordinating Team*
- **Manuel Posada** - *Institute of Rare Diseases Research, Instituto de Salud Carlos III*
- **Luciano Vittozzi** - *Italian National Centre for Rare Diseases Italian National Institute of Health*

“Overlapping” indicators between ISS & EURORDIS= 20 (DRAFT)

	USEFULNESS	FEASIBILITY
1.1 - Existence of Regulations/Laws that support the creation and development of a RD plan	9,5	9
1.4 - Existence of an expert advisory committee	9,5	10
1.7 - Budget of plan/strategy	9	9
2.1 - Adoption of the EC RD definition ≠	9	10
2.2 - Type of classification used by the health care system	10	9
2.4 - Registering activity	9	8
3.9 - There are specific public funds allocated for RD research	9	8
3.10 - Funds specifically allocated for RD research actions/projects per year since then plan started	9	8
4.1 - Existence of a policy for establishing centres of expertise at the national/regional level	10	10
4.2 - Number of centres of expertise adhering to the policy defined in the country	8	9
4.5 - Participation of national or regional centres of expertise into European reference networks	9	9
5.1 - Existence of a comprehensive national and/or regional RD information system supported by the government	10	9
5.2 - Help lines for professionals + 6.10 - Availability of Help line for RD	9	9
5.3 - Clinical guidelines	10	8,5
5.13 - Existence of a governmental program for compassionate use for Rare Diseases	9	9
6.5 - Permanent and official patients’representatives in plan development, monitoring and assessment	10	10
6.15 - Existence of programmes to support integration of RD patients in their daily life	9	8
7.1 - Existing policy/decision to ensure long-term sustainability of the RD plan /strategy ≠	10	9
7.2 - Amount of funds allocated for ensuring RD plan /strategy sustainability	9	8
7.3 - Existing policy/decision to ensure the contribution to support RD European infrastructure ≠	9	9

REFERENCES

- Jones J, Hunter D. Consensus methods for medical and health services research. BMJ 1995; 311: 376-380.
- Linstone HA. The Delphi technique. In: Fowles RB, ed. Handbook of futures research. Westport, CT: Greenwood, 1978.
- Moscovice I, Armstrong P, Shortell S. Health services research for decisionmakers: the use of the Delphi technique to determine health priorities. Y Health Polit Policy Law 1988;2:388-410.
- Oranga HM, Nordberg E. The Delphi panel method for generating health information. Health Policy and Planning. 1993;8:405-12.
- Pill J. The Delphi method: substance, context, a critique and an annotated bibliography. Socio-Economic Planning Science 197 1;5:57-71.
- Rowe and Wright. Expert Opinions in Forecasting. Role of the Delphi Technique. In: Armstrong (Ed.): *Principles of Forecasting: A Handbook of Researchers and Practitioners*, 2001. Boston: Kluwer Academic Publishers.
- Skulomosky G, Hartman FT, Krahn J. The Delphi method for graduate research. Journal of Information Technology Education 2007; 6:1-21.
- Wiener B, Chacko S et al. Delphi survey of research priorities. J Nurs Manag 2009; 17:532-8.