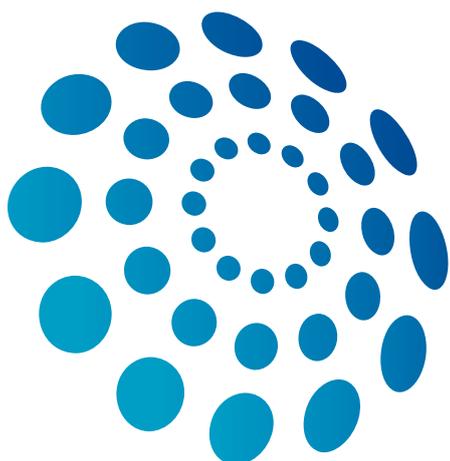




2nd CONFERENCE ON



European Reference Networks

SATISFACTION
SURVEY RESULTS

8-9 OCTOBER
2015, LISBON



GOVERNO DE
PORTUGAL

MINISTÉRIO DA SAÚDE

GRAND DUCHY OF
Presidency of
the Council of the
European Union  Luxembourg

Health and
Food Safety

Methodology

We asked participants to complete onsite the satisfaction survey by evaluating their satisfaction degree from 1 to 5 (5 = Very satisfied; 4= Satisfied; 3 = Undecided; 2 = Dissatisfied; 1 = Very Dissatisfied; 0 = Not applicable).

Executive summary

109 participants completed the survey out of +/- 400 participants. Comments and suggestions from respondents are included in the present document after the results to the questions.

Note: Survey results are based a self-selecting sample of 109 individuals from a total of 400 participants. As this group may not be a representative sample, the results must be interpreted with due caution.

1. Conference preparation

	5	4	3	2	1	N/A	Response count	Average
Conference registration was efficient and straightforward	66.05%	27.52%	2.75%	1.83%	1.83%	0%	109	4.54
Documentation was made available in a timely manner	56.88%	27.52%	9.17%	3.67%	0.92%	0%	109	4.38

Respondents found the conference registration process and preparation to be efficient.

2. Practicalities on the day

	5	4	3	2	1	N/A	Response count	Average
Conference was generally well organised	56.88%	27.52%	9.17%	3.67%	0.92%	0	109	4.40
The venue and its location met my expectations	35.78%	39.45%	14.68%	8.26%	1.83%	0	109	3.99
Sound quality in the meeting room was good	44.95%	33.94%	13.76%	5.50%	1.83%	0	109	4.14
Conference staff/officials were generally helpful	59.63%	33.03%	2.75%	2.75%	1.83%	0	109	4.45
Internet access was good and reliable	43.12%	25.69%	14.68%	8.26%	5.50%	0	109	3.95

Participants said the conference was well organised, giving an average rating of 4.4 out of 5. Conference staff also scored highly (4.45 out of 5) and the conference facilities were generally well received. The venue location and internet access were weak points, relatively speaking, with scores slightly below 4 out of 5.

3. Conference content

	5	4	3	2	1	N/A	Response count	Average
In general, the conference lived up to my expectations	33.03%	45.87%	14.68%	3.67%	0%	1	108	4.11
The conference sessions offered valuable insights	33.94%	49.54%	11.01%	3.67%	0%	1	108	4.15
The conference outputs will be useful to my work/ research	34.86%	43.12%	14.68%	4.59%	0.92%	1	108	4.08

Conference participants generally felt that the event lived up to their expectations and would be useful for their work.

4. Conference expertise

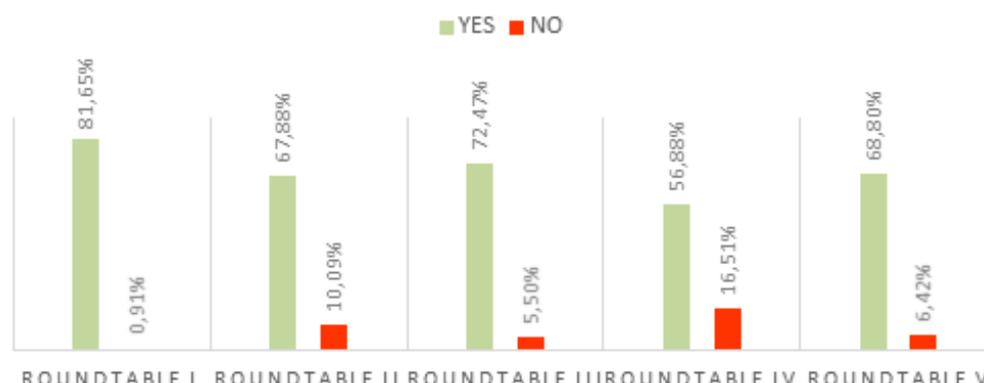
	YES	NO	N/A	Response count
Do you agree that the conference speeches are being well presented and are informative?	85.32%	2.75%	13	96
Do you agree that the conference chairs are doing a good job of moderating the panels and discussions?	88.07%	1.83%	11	98
Do you agree that the panellists are articulate and knowledgeable?	84.40%	4.59%	12	97

5. Conference agenda

1. Do you agree that the five roundtables have proven to be interesting and useful?

	YES	NO	N/A	Response count
Roundtable I: Framework for the establishment of European Reference Networks	81.65%	0.91%	19	90
Roundtable II: European Reference Networks: Strategic value for the Member States	67.88%	10.09%	24	85
Roundtable III: Network organisational challenges and experiences: Issues, solutions and lessons learned	72.47%	5.50%	24	85
Roundtable IV: ERN and better health outcomes: Good clinical practices	56.88%	16.51%	29	80
Roundtable V: Network Challenges: eHealth and IT solutions	68.80%	6.42%	27	82
2. Do you agree that you and other delegates had plenty of opportunities to ask questions and become actively involved in discussions?	60.55%	19.26%	22	87

DO YOU AGREE THAT THE FIVE ROUNDTABLES HAVE PROVEN TO BE INTERESTING AND USEFUL?



The first roundtable, addressing the framework for establishing ERNs scored highest of the five sessions with more than 4 out of 5 respondents stating that it was useful and interesting. The weakest session was roundtable IV on clinical guidelines which was positively reviewed by 56.88%. The proportion of participants agreeing that there was sufficient opportunity to ask questions was low at just 60.55%.

6. Personal satisfaction

6.1. The conference provided me with a good opportunity to:

	YES	NO	N/A	Response count
• Learn more about the subject matter	83.48%	3.66%	14	95
• Network with colleagues and other interested parties	77.98%	8.25%	15	94

6.2. What I learned from the conference will be useful to my work/research?

Participants at the ERN 2015 conference in Lisbon reported that they learned how to prepare for the first call and how to establish or join European Reference Networks. There was praise for the plenary session on day two for providing detailed and practical advice on the steps to take in answering the call.

Roundtable IV on clinical guidelines received mixed reviews. It was singled out for praise by one participant and for criticism by another. The overall survey results suggest it was the least popular of the five sessions.

Several respondents to the survey said the meeting was beneficial, although it was noted that some questions remained unanswered at the end of the event – particularly questions about funding of ERNs and the number/scope of networks.

- “Concerning other experiences in other EU countries”
- “A lecture about guidelines was not needed”
- “Miss much more concrete plan at this stage, Plenary presentation on day 2 was perfect”
- “Step back in 3 years would be important to evaluate the impact on inequity and to avoid it continuing”
- “Generally yes. However, no clear answer was given to the most important question: how many networks will be recognised? Shall they be focused on individual disorders, clusters of diseases, or wide spectra of disorders - like: rare skin disorder”
- “Importance of ERN building, eHealth, No funding through ERN (not direct), indirect impacts. A lot of technical tools/methodologies/advices were given but the agenda is short and the process quite

heavy because at the end we don't have more people/help to take care of the patients, do the research part (epidemiological, clinical trials, fundamental) and write the guidelines/fill all these databases/follow all these processes... We stay a bit afraid of the road"

- "Please share the PPTs"
- "Learn of how to participate in ERN as a member"
- "Have a better perspective on how to prepare the future"
- "Structure of network (network needs to learn & coordination)"
- "How to prepare for an application for an ERN"
- "Contacts for eventual EU networking in endocrine rare diseases"
- "Update of current status"
- "Round table IV was outstanding, very helpful in improving understanding of guidelines"
- "It is important to dialogue, share and cooperate for rare diseases. "
- "Need more coordination among EU states."
- "ERN could be organised directly by DG SANTE without calls. Only working on data and with the ministries."
- "Yes it does, but many questions ... On how to build up ERN"
- "Agenda depends on previous knowledge. Didn't receive any new information, some points were clarified. Workshop 3 was interesting but not enough time to go in depth. Would be useful having information regarding the opportunities to interact with other possible partners."

6.3. Keys conference objectives were to discuss and raise awareness on the state of the art on the organization of highly specialised networks and centres of expertise across the EU, to present the draft assessment manual and toolbox to be used for assess the Network proposals and to help prepare Health Care Providers for the call for proposals. Do you agree that these objectives will be achieved going forward?

A number of participants said the key objectives were met but there were also some criticisms. Among these were the lack of involvement of patient representatives, insufficient networking time, and a perceived lack of clarity on the role of Member States in the process.

- "I miss national authorities clear and definite implication in the organisation of highly specialised networks"
- "Very interesting/eHealth projects and associations point of view - Oncology experience ++ But: not so clear concerning the added-value of ERN for countries that already have a rare diseases programme... example France"
- "Yes. It is still not clear the role of patients organisations and how will be the National endorsement be set up"
- "It will depend on the outcomes of the workshops as well as of the ongoing work in the following months!"
- "See forward but generally yes"
- "Many experiences presented are not refined to an ERN"
- "Yes but we ask for make it as simple and concrete as possible with many thanks."
- "Patients representation and involvement is missing and the patient is the center of all this work. Be aware of this and includes patients representatives in ALL steps of the network development."
- "I would like more networking time"
- "How to position our own clinical issue/network into a bigger "ERN umbrella", how to proceed?"
- "EC and National Ministry already know which are the reference centres, you complicate what could be simple - not all rare diseases have 10 good centres in countries"

7. Suggestions and comments

- The event was informative and well-attended by highly-engaged participants.
- Attendees learned how to prepare for the first call for ERNs. Practical sessions were appreciated.
- More networking time and opportunities for questions could be built into future event programmes.
- Patients were frequently discussed by various stakeholders but input from patient representatives was low.
- The Commission could publish an updated FAQ addressing some of the key questions raised (where possible) such as funding and number/scope of ERNs.