



High Level Group on health services and medical care

Definition of a framework for ERN

Questions to Pilot Networks
European Commission
DG Public Health

Set of questions (February 2008)

- 1. Establishing and development of the network**
- 2. Governance of the network**
- 3. Quality and continuity of care**
- 4. Involvement of patients and other stakeholders**
- 5. Sharing of knowledge, best practice and dissemination of expertise**
- 6. Financial issues**
- 7. Practical and administrative issues**
- 8. Legal issues**
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Establishment and development of the network

- How were partners of the network identified in the initial stage and how was the network formally established? Were the principles and criteria developed by the High Level Group so far taken into account ?
- Is the network open for new partners and how are the potential new partners being identified or selected?
- What are the criteria to become a partner in the network?
- How is a centre and its capacity to become a partner in the network being assessed?
- How does the information about the network get to the potential partners, to the patients and other stakeholders (health professionals, patient associations, health authorities)?
- How is patient participation being ensured in the process of establishing and running the network?
- Can the network easily be expanded/transferred to other diseases?

Governance of the network



- Is there a hierarchy among the participating centres/nodes in the network?
- Who is responsible for supervising continuous compliance of the network partners with the membership criteria established by the network and how are the quality standards of care (including diagnostics, other tests or procedures in case the patient is referred only to the consultation or diagnostics) being continuously assessed within the network?
- Is the continuing compliance with criteria and evaluation ensured in a similar way as described in the High Level Groups document 'Options for a procedure for identification and development of European reference networks (see attached)?
- Is an external independent evaluation foreseen?
- Are there contacts established with other European networks of reference?

Quality and continuity of care

- Is there any quality management program established within the network?
- Have quality goals been assigned?
- Is there a benchmarking process established within the network? If so, who is getting the results?
- How is the continuity of care ensured for patients who are referred to the network from other countries or from centres outside the network or from the network back to the home country?

Involvement of patients and other stakeholders



- What is the involvement of other stakeholders, including patients, health professionals, health care administration and public authorities and health insurers, in the work of the network?
- What is the network's contribution to patient empowerment?
- How patient and professional satisfaction with the existence and operation of the network is being assessed?
- Which of the stakeholders will be able to receive network's results (outcome variables)?

Sharing of knowledge, best practice and dissemination of expertise

- How is the transfer of knowledge and sharing of best practice ensured within the network?
- How is the visibility of the network's results ensured?
- How is/can be the expertise and best practice disseminated outside the network in the relevant area (disease)?
- Can the expertise and best practice gained within the network be also disseminated to and used for other areas beyond the particular disease (for example for common diseases)? If yes, how?
- Are there arrangements in place within the network for mobility of health professionals between the network members?

Financial issues



- What is the overall budget of the network and what is its structure (including exact figures where possible)?
- How is the long-term financial sustainability of the project ensured (i.e. what happens after the first three years of the project)?
- What are the other sources of funding provided to the network?
- Are there any links to other sources of Community funding, for example to projects funded from the Framework Research Programmes?
- What are the arrangements in place for reimbursement of costs of services provided as part of the network activities (i.e. services for patients from other centres or countries)?
- Based on your practical experience with the network, what can be done at both, European and national level, to improve the situation related to financial issues?

Practical and administrative issues



- What are the practical problems and difficulties that the network has to face?
- What is the language regime of the network? Do the language differences cause any problems (between the network partners, but also in relation to patients)? How are these language problems being addressed?
- Are there any arrangements in place for transfer of patients from other centres or countries in case of need?
- What are the financial arrangements in place for transfers of patients from another Member State?
- Based on your practical experience with the network, what can be done at both, European and national level, to improve the situation related to practical and administrative issues?

Legal issues



- Are there any legal difficulties and obstacles hindering the work of the network?
- Have there been any difficulties related to data protection rules identified within the network?
- If clinical data are generated, who possesses the data? Is there any patient participation in the control of the data gathered by the network?
- Have issues of professional medical liability arisen in the context of the network and are there any arrangements in place in this respect?
- Based on your practical experience with the network, what can be done at both, European and national level, to improve the situation related to legal issues?

General Comments



- Which are the public health outcome variables (e.g. utilisation of healthcare resources)?
- Can the results of the project help in solving problems for other rare or common diseases? Which specific elements of your project can be adapted or transferred to other rare and/or common diseases?
- How can the network in your project be used as a model for European reference networks?
- Which impact does the network in your project have on the health care system in the different participating and not participating countries?
- Are there any other comments that you wish to make?

Conclusion

- The concepts have to be clarified
 - Confusion between mission of CE and mission of Networks
- A network to share resources and expertise
- or a networks of care in different clinical centres ?
- EU added-value ?
- Indicators ?
- Time frame to learn from CE and from ENCE