The Portuguese Model of Reference Centres

1st Conference on European Reference Network

Brussels, June 23th, 2014
1. FRAMEWORK

“To proceed with the development of a network of Centres of Reference /Expertise, namely, as regards the definition of the concept of Reference/Expertise Centre, the identification and recognition criteria of those Centres by the Ministry of Health, as well as their implementation, models of financing, integration in the hospital network and reference networks.”
2. AIMS

- Define the concept of Reference Centre (RC)
- Establish criteria for identification and recognition
- Propose the implementation model
- Propose general criteria for financing
- Define the integration model of RC in the national hospital network and European Reference Network (ERN)
- Frame and adequate national policy in terms of rare diseases and propose the review of an already existing legislation package, regarding organizational models comparable to RC, further adequating them to the working group proposals, as to the creation of RC
- Present priority areas, pathologies and procedures, that will constitute the first phase of RC in Portugal
3. METHODOLOGY

METHODOLOGY IS BASED ON FOLLOWING MAIN PILLARS

- Directive 2011/24/EU, of March, 9
- Major Options of the Portuguese Government Plan (2012-2015)
- Programme of the 19th Portuguese Constitutional Government
- Final Report Technical Group for Portuguese Hospital Reform
- Portuguese Health Plan (2012-2016)
3. METHODOLOGY

- Review of Literature
- Analysis of the state of art of the RC development, at the EU Member States level
- Information of the European Committee on Cross Border Health Care and of the Expert Group on ERN
- Hearing and collecting of inputs from national experts
## 4. Priorities and Accomplished Activities

<table>
<thead>
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<th>Priorities</th>
<th>Accomplished Activities</th>
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<tbody>
<tr>
<td>Introduction, Aims and Methodology</td>
<td>Framework of working methods in presence of the Work Group aims</td>
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<tr>
<td>Historical framework</td>
<td>National and European state of art on RC</td>
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<tr>
<td>Reference Centres in Portugal</td>
<td>Contextualization of the national and European framework, and transposition into national context of basic definitions</td>
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<tr>
<td>Historical, normative and legal framework</td>
<td>Contextualization of the national and European framework, analysis of the Directive and other legal instruments, having an impact on the design of the RC Network in Portugal</td>
</tr>
<tr>
<td>Identification, Recognition Process and General Rules for the financing of RC</td>
<td>Criteria definition tending to the constitution, functioning and underlying principles to the financing of RC</td>
</tr>
<tr>
<td>Integration of RC in the National Hospital Network and European Reference Network (ERN)</td>
<td>Definition of RC integration model in the Portuguese Hospital Network and ERN, as well as governance and coordination elements of ERN.</td>
</tr>
<tr>
<td>Priority areas for intervention</td>
<td>Organs transplantation, oncology, (pediatric cancers and others), metabolism hereditary diseases, hemophilia, hemodynamics and intervention cardiology and refractory epilepsy</td>
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</tbody>
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### Recommendations
5. DEFINITION OF REFERENCE CENTRE IN PORTUGAL

REFERENCE CENTRE

Healthcare providing Unit, with recognized knowledge and expertise to provide high-quality healthcare to patients, who have conditions requiring a particular concentration of resources or expertise, due to the low prevalence of the disease, to the complexity in the diagnosis or treatment, and to the high costs of those same conditions.
5. **Definition of Reference Centre in Portugal**

- Experienced multi-disciplinary and highly qualified Teams
- Highly specialized structures and equipment
- Healthcare provision according to the highest possible quality criteria
- Competences in the areas of education, training and research

Reference Centres
5. Definition of Reference Centre in Portugal

Establishing of synergies in the scope of health

ERN → RC

- Scale Economies
- Efficiency maximization
- Cost-effective guarantee
- Best Practices dissemination
- Innovating potential of medical science maximization
5. **Definition of Reference Centre in Portugal**

<table>
<thead>
<tr>
<th><strong>Structural features</strong></th>
<th><strong>Acting principles</strong></th>
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<tbody>
<tr>
<td>Differentiation</td>
<td>Quality improvement</td>
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<tr>
<td>Attractivity</td>
<td>Access improvement</td>
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<tr>
<td>Consulting</td>
<td>Effectiveness improvement</td>
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<tr>
<td>Innovation</td>
<td>Outcomes centred</td>
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<tr>
<td>Education and Training</td>
<td>Transparency</td>
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<tr>
<td>Research</td>
<td>Safety improvement and decrease of clinical risk</td>
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- **Acting principles**
  - Quality improvement
  - Access improvement
  - Effectiveness improvement
  - Outcomes centred
  - Transparency
  - Safety improvement and decrease of clinical risk
6. **Integration in the Portuguese Hospital Network**

**Integration Model of Centres of Reference in the Portuguese Hospital Network**

Hierarchy of competences

**Hospital Organization and Hierarchy of Competences**
Portuguese Centre that does not fulfill the conditions and criteria to be officially recognized as a National RC, but possesses the knowledge and expertise in a certain specific area of competences recognized by the Ministry of Health. This Centre, based on its range of services, should be connected to a RC of the same area of expertise.
7. Integration in the European Reference Network - ERN

Integration Model of RC in the ERN

Highly Differentiated Centres that fulfil the whole of the recognition criteria for RC

Yes

Reference Centres

Integrates

ERN

Adopts the Designation

Full right Members of the Network

European Context

Portuguese Hospital Network

National Context

Integrates

ERN

Collaborates

ERN

Adopts the Designation

Associated National Centre
8. Financing Model

Intrinsic Principles to the Financing Model and Contractualization of Care

Assure the covering capacity, at national level, for the treatment of the pathologies and procedures considered at the selected reference areas.

Define the range of healthcare service to be provided by RC and Affiliated Centres in the scope of patients follow-up.

Contract and finance defined procedures and pathologies exclusively with the entities to be constituted as RC.

Contract with the entities to be constituted as Affiliated Centres, the procedures and pathologies that integrate the range of healthcare services in the reference area.

Allocate the financing to the RC and Affiliated Centres, in conformity with their respective range of healthcare services, applying the most suitable payment modalities in presence of the defined aims for the areas involved.
9. RECOGNITION PROCESS
9. Recognition Process

Proposal of entities to be constituted for the recognition process of Centres of Reference

Medical and Scientific Committee for Centres of Reference

Directorate-General of Health

Technical Specifications Expert Group

Technical and Evaluation Group

Central Administration of Health System

Financing Support
9. Recognition Process

Proposal of entities to be constituted for the recognition process of Centres of Reference

Medical and Scientific Committee for Centres of Reference

<table>
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<tr>
<th>Competences</th>
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<tbody>
<tr>
<td>Identify major areas of intervention</td>
</tr>
<tr>
<td>Ellaborate a proposal of pathologies and procedures</td>
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<tr>
<td>Define ratios of national implementation</td>
</tr>
<tr>
<td>Ellaborate a final proposal of specific criteria and indicators for the pathologies and procedures</td>
</tr>
<tr>
<td>Propose to the Minister of Health the eventual decision of official recognition of centres, candidate to RC</td>
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<tr>
<td>Ellaborate a model that materializes the establishing and functioning of Affiliated Centres</td>
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9. RECOGNITION PROCESS

PROPOSAL OF ENTITIES TO BE CONSTITUTED FOR THE RECOGNITION PROCESS OF CENTRES OF REFERENCE

**Technical Specifications Expert Group**

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<tr>
<td>Propose specific criteria and indicators for pathologies and procedures</td>
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<tr>
<td>Identify the requirements to be considered, when evaluating the candidate centres</td>
</tr>
<tr>
<td>Clear up doubts and validate RC evaluation aspects, whenever requested by the Technical and Evaluation Group</td>
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9. RECOGNITION PROCESS

PROPOSAL OF ENTITIES TO BE CONSTITUTED FOR THE RECOGNITION PROCESS OF CENTRES OF REFERENCE

TECHNICAL AND EVALUATION GROUP

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<tr>
<td>Evaluate, documentally, the self-assessment process</td>
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<td>Check the quality of the submitted proposals.</td>
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<tr>
<td>Make visits to the candidate units for validation of all received information.</td>
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<tr>
<td>Prepare the final report to assess the submitted applications.</td>
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<tr>
<td>Promote an audit model.</td>
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9. RECOGNITION PROCESS

- Organization and management (11)
- Research and training capacity (3)
- Quality, safety and best practices (7)
- Patient empowerment and patient centred care (6)
- Information Systems (2)

GENERAL CRITERIA (29)

SPECIFIC CRITERIA
10. Threats to Recognition Process

- Misuse of RC Concept
- Local/Regional Pressures
- Social Pressures
- Inadequate Financing

Loose the opportunity of concentration of hospital services
Loose the opportunity to integrate the Portuguese RC in ERN
### 11. Priority areas, pathologies and procedures - 2014

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<th>Priority areas of intervention</th>
<th>Pathologies and procedures</th>
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<tr>
<td>Organ Transplantation</td>
<td>Renal, hepatic, pancreatic, cardiac and pulmonary</td>
</tr>
<tr>
<td>Oncology</td>
<td>Paediatric cancers</td>
</tr>
<tr>
<td>Rare Diseases</td>
<td>Testicle, hepatobiliary, pancreas, rectum, esophagus, stomach, breast and skin cancers</td>
</tr>
<tr>
<td>Cardiology</td>
<td>Metabolism hereditary diseases, hemophilia and refractory epilepsy</td>
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<td></td>
<td>Hemodynamics and intervention cardiology.</td>
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12. IMMEDIATE ACTIONS

1. Publish the legal framework of Centres of Reference (final inter-ministerial audition).

2. Approve priority areas for the constitution of Centres of Reference in Portugal for 2014.

3. Assume a specific financing model for Centres of Reference and Affiliated Centres.

4. Define the integration model of Centres of Reference in the Portuguese Hospital Network.
12. **Immediate Actions**

5. Ensure a transitional period for adequacy of already existing centres in the first phase, into the new legal framework of Centres of Reference and Affiliated Centres.

6. Consider the public, private and social sectors, as potential candidates to the statute of Centres of Reference and Affiliated Centres.

7. Start, at once, the recognition process of national Centres of Reference and respective Affiliated Centres.
12. IMMEDIATE ACTIONS

8. Develop the internal competences, as well as the organizational model at the central administration of the Ministry of Health, in order to give an effective, complete response to the creation and development process of Centres of Reference in Portugal.

9. Establish evaluation processes and periodic auditing of Centres of Reference and Affiliated Centres.

10. Clarify and integrate in the concept of RC and Affiliated Centres, the Highly Differentiated Centres and Treatment Centres already existing in Portugal, as well as the National Programme for Rare Diseases.