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A doctrine, what for ?

The initial motivations of the DGOS :

Recurring requests from patients and from professionals

(they ask for the recognition of an expertise, the perpetuation of a funding...)

Diversity of models and namings in France

(reference networks or centers, ressource centers...)

The EU directive 2011/24 of March 9, 2011 to be transposed on October 24, 2013...

A doctrine, what for ?

The initial motivations of the DGOS :

To place, to situate « reference centers » among other existing national schemes/systems :

- Inter-regional authorizations for coordinated and highly specialized care facilities (e.g., severe burns, grafts)
- Expertise and epidemiology surveillance centers for infectious diseases (no patient care delivery)
- Institutions dedicated to translational research and bringing together university-hospital
- Dedicated funding tools for rare and expensive medical acts not yet included in standardized tariffs

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A Doctrine, what content ?

Our objectives :

Harmonize concepts, definitions, appointment procedures for reference centers (RC)...

To suggest procedures about :

Justification, designation, missions of RC

Setting up and labellising a RC

Financial support, evaluation

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Setting up a reference center or a specialized care center.

When and what for?

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Possible justifications for a RC

- **Complexity of medical care/management**
- **Scarcity of Expertise** (patients and health professionals « wander about »)
- **Pre-existing technical equipments and skills** (= RC is not created from scratch)

To a lesser extent :

- *Low prevalence(<1/2000) (or rare clinical expression of a common illness) (+/-)*
 - *A health plan exists (+/-)*

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Five reference assignments

The proposed missions listed below are in fit with the directive's propositions :

- **Coordination** (information and communication to the public / to professionals, link with associations / government administration, maintain a directory of health care providers, set up courses of treatments)
- **Expertise** (quality follow-up, epidemiology studies, set-up of guidelines and of professional's formation, organization of multidisciplinary advice for complex cases)
- **Highly specialized, referral level, global care delivery** at the national or inter-regional level
- Involvement in **University teaching**
- Participation to **Research** (clinical, translational, basic)
- « *RC should be clearly identified and visible* »

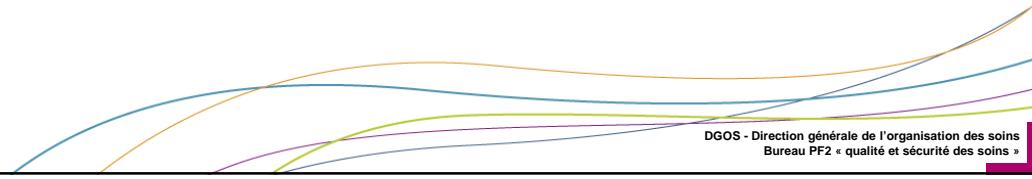
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What specialists of industry/services standards say :

- Conformity to a government/state regulation is mandatory ;
- *Conformity to a standard (terms of reference) in order to get approved, is optional*

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Proposed terminology for the reference center concept

The structure

High level structures

- Reference center

2nd level

- Corresponding/associated center

The labelization

Strong

- **label**
- To be distinguished from state-level accreditation, certification

weaker

- **Identification...**

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What about specialised or referral facilities ?

- They do not meet all the criteria requested for the reference centers : e.g. the disease is complex but not rare (pain...)
- These structures are in charge of a part only of the 5 classes of missions assigned for the RC
- They are more numerous and they may take part to the regional or local networking of care providers

Yet the main steps described in the forthcoming slides should apply.

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Creating a reference center, or a specialized care facility.

Propositions for an implementation procedure

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Key steps

- Set up the specifications

What are the **standard care** pathways for this pathology and for these patients ?

1

> **What missions** should be assigned ?
> Are different **referral levels** needed ? Are there **density** specifications ?

2

Write down the **terms of reference**
Is an **additional funding** needed ?
Can a pattern of funding be set up ?

3

- Set up the RC (or RC network) and evaluate it

Call for projects and selection
(at national or régional level)

4

Design the **governance**/
steering committee or other

5

Evaluate the RC itself
Evaluate the whole public policy

6

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Defining the specifications

As a rule, recent and acknowledged recommendations/guidelines should be referred to.

Otherwise a working group including professionals and patients representatives should brainstorm and produce shared guidelines

1. Define the appropriate standard care pathways

- They may vary with the kind of target population

2. Define the needs/missions to fulfill, and thus to be assigned to the RC

- E.g. choose between high specialisation or wide distribution ; are several levels needed ?

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Draw up the terms of reference

The validity of these terms/specifications is nationwide

A call for projects is drawn/published at the national or regional level

Centers are acknowledged for a limited period of time (e.g. 5 years, renewable upon evaluation)

- The terms of reference for RC should contain a synthesis about the pathology, its treatment, the overall organisation scheduled, the missions to be fulfilled, quality criteria...

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Granting a financial support

At the start, the project leader may estimate its needs

- Only extra/additional costs should be considered for granting
 - This excludes sums already granted for previously identified missions, all fees received for act payments...
- Funding should be allocated after a defined and mutually agreed model, and be traceable
- Funding should be renewed subject to evaluation : results, service, cost-efficiency. A contract may be signed.

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Tips & tools for funding

1. Acts and tariffs

- Attributing a label to a structure already enhances its activity, thus its per act earnings
- Special/dedicated tariffs may be drawn for complex (long, multidisciplinary...) acts and allowed under controlled conditions

2. Other allocations

- They may be « one-shot » (e.g. for setting up an information system...) or annually renewable,
- They should be subject to modelisation (model based upon levels/volume of activity, cost of extra workforce needed...)

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Implement and follow-up

- A steering committee or an appointed person may be in charge at the national level
- The follow-up includes :
 - Selection of the candidate projects, regular evaluation, meetings between RC representatives and communication to RC
 - Tools : Contracting, annual reporting, standardised activity reports, information systems, annual surveys
- The overall system should be explained and advertised to the general public
 - Website pages for professionals and patients
 - Directory of RC and facilities
 - Smartphone apps...

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Evaluation (not annual)

- **Evaluating centers and facilities**
 - This may be performed by an independent authority
 - This evaluation may impact the next fundings
- **Evaluating the overall system, the public policy**
 - Parliament-issued body, public health authority, independent inspection body...

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Thanks for your attention.