Inspiring actions & good measures from National Plans/Strategies - Conferences

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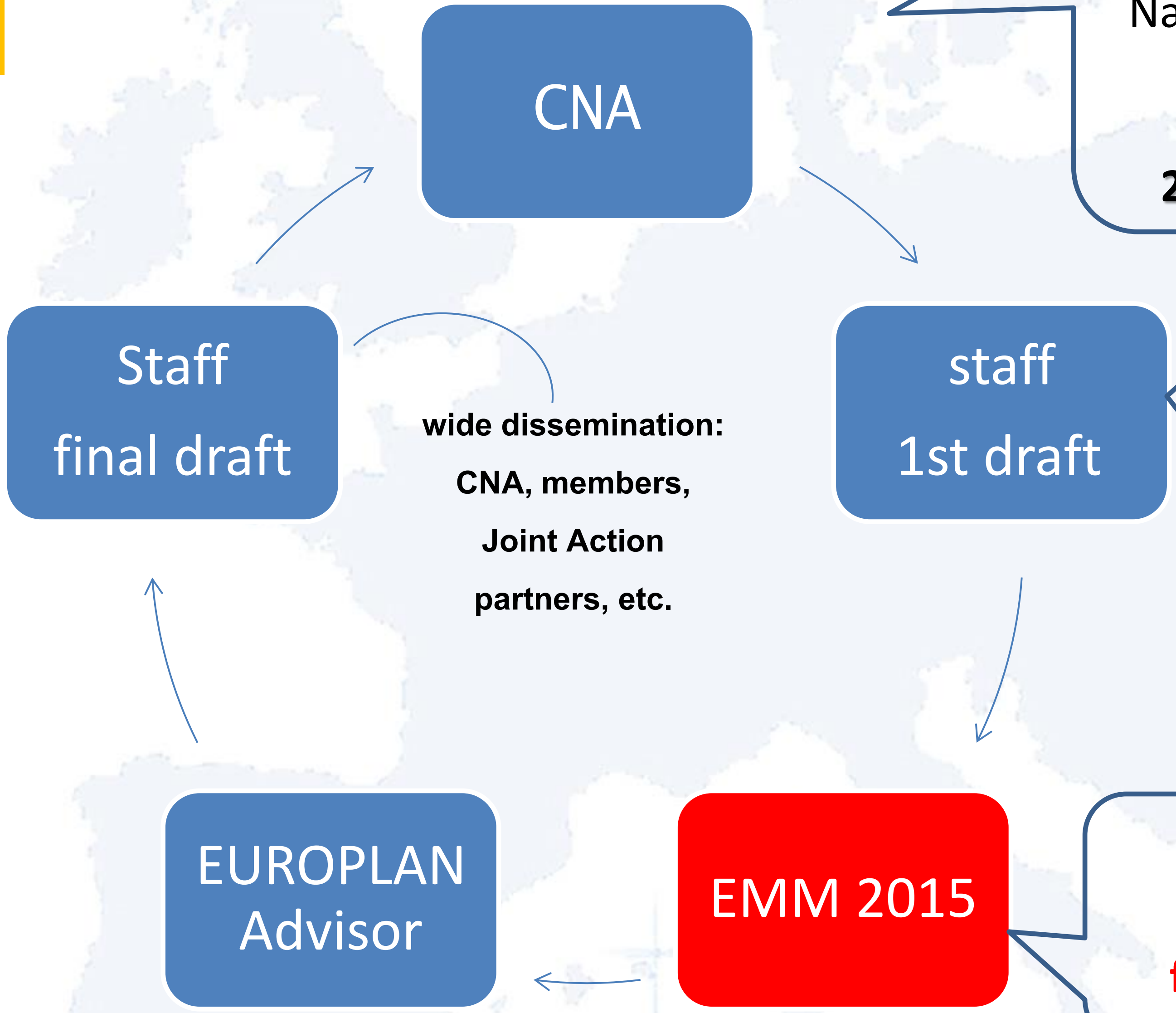
EURORDIS

What are we doing today ?

Sharing good practices
on **Centres of Expertise** in Europe
so that patients' advocates can be well
equipped for the

decision-making process around
implementation / monitoring / of their
National Plans or Strategies on RDs
and other relevant national policies

GOOD PRACTICE Reports



CNA

staff
1st draft

EMM 2015

EUROPLAN
Advisor

Staff
final draft

wide dissemination:
CNA, members,
Joint Action
partners, etc.

Outcomes of EUROPLAN
National Conferences &
National Plans/Strategies
to identify
1) good practices
2) inspiring proposals

5 reports
Good Practice
Reports on
Governance of NP,
research,
Centres of Expertise,
orphan drugs
social care

Discussions
and inputs
from workshops

Sources:

- **National plans**
- **EUROPLAN /Joint Action National Conferences**
- **State of the Art Report 2014**

But not exhaustive!

Good Practice Report EUROPLAN II – EUCERD Joint Action WP4

Theme 4 – Centres of Expertise
1. Overview of healthcare systems
2. National Accreditation Systems
3. Identification of Needs & Prioritisation
4. National Treatment Pathways and Therapeutic Policies

Good Practice – FR
Comitê de labélisation assessment of competency and accreditation of Reference Centres and Filières de Santé with Ministry of Health, regional and patient organisation representatives

Examples:
SW – National Commissioning Board is the decision-making body and has representation and advice from regions, experts, patient groups and medical societies

UK – 75 Clinical Reference Groups are grouped by medical speciality with experts, patient and carers representatives covering

Your feedback and comments today are absolutely essential

Centres of Expertise (CoE)

→ Centres of Expertise are **'expert structures for the management and care of RD patients in a defined catchment area, preferably national, and at international level if necessary'.** (EUCERD R2)

Objectives:

- **Improve the quality of care and equitable access** for their population, through the **concentration of expertise and resources** into a limited number of national centres.
- **Secure participation of experts** and promote collaboration between expertise to share and compare data to **drive improvements in knowledge**.

Centres of Expertise

1. **Overview of healthcare systems**
2. **National Accreditation Systems**
3. **Identification of Needs & Prioritisation**
4. **National Treatment Pathways and Therapeutic Policies**

Overview of healthcare systems

1. Overview of healthcare systems

→ Guiding principle in healthcare is **care is managed locally to ensure local needs are met by local services**

Rationale - Devolvement of decision-making and financial management locally to regions, to varying degrees.

Approach - National authorities prefer to promote national **'recommendations'** instead of national **'mandates'** to maintain regional autonomy.

NB: Access to national CoE can be restricted due to local decision-making by regions (IT, ES)

Proposal - Patient organisations can have a pivotal role in strengthening relationships with national expertise and local partners, bridging the spectrum of local, regional and national healthcare.

1. Overview of healthcare systems

➔ **Legislation and policies framework**, specifically outlining the coverage of rare diseases the population is entitled to access and gives the foundation stone to develop a national accreditation system for Centres of Expertise.

Spain

- The **autonomous communities** (no. 17) are responsible for providing health care to people with rare diseases.
- Equal access to care for those living with rare diseases must be guaranteed throughout the national territory, so Centres of Reference must be better identified and well-known in order to facilitate such equal access.
- There are variations in regional access policies.

Sweden

- Decentralised healthcare system, run by County Councils (no. 21) in **6/7 regions**.
- National catalogue of providers of specialist care, which provides recommendations on reference points for local administrators.
- Centres of Expertise are located at the seven university hospitals which are located in the 6/7 regions enabling equitable access.

NB: Not all countries have a specific legislation or policies for rare or complex diseases or highly specialised healthcare (SR)

1. Overview of healthcare systems

➔ **National Advisory committees** are established to secure ‘buy-in’ and engagement and promote access from regional referrals and advise on accreditation of Centres of Expertise**.**

PROPOSALS **SW, UK, FR**

SW – National Commissioning Board is the decision-making body and has representation and advice from regions, experts, patient groups and medical societies

UK – 75 Clinical Reference Groups are structured by medical speciality with multidisciplinary experts teams, patient and carers representatives developing national specifications and policies

DM – 35 Working Groups of experts advisors on the development of Centres of Expertise, with two groups ‘piloting’ patients involvement on the groups

Best Practice - FR

Comité de labélisation assessment of competency and accreditation of Reference Centres and Filières de Santé with MoH, regional and patient organisation representatives

1. Overview of healthcare systems

➔ Patient organisations play a role in establishment of national policy, the development of national accreditation systems and their delivery as they promote access to nationally recognised CoE working with autonomous regions.

Proposal

- **UK, NL, DM** – All have equitable access for patients from different regions, through **inter-regional agreements** for accessing care in line with national policies. Patient representatives are either members or advise national advisory groups.
- **IT** – Patient organisations advocated the **expanding the scope of rare diseases covered by legislation**
- **FR** – Patient organisations support the creation of transparency in the national accreditation and evaluation of Reference Centres, Filières de Santé and national care pathways

National Accreditation Systems

2. National Accreditation Systems

➔ Member States are required to **‘include, in their plans or strategies, the necessary conditions for the diffusions and mobility of expertise and knowledge in order to facilitate the treatment of patients in their population.’** (Council’s Recommendations)

- 10 / 28 MS have formal national or regional accreditation/designation process in place for rare, complex or highly specialised healthcare services.
- Most national accreditation processes in place are in alignment to the EUCERD recommendations.

Approach - self-declaration or formal accreditation processes which vary in their model, from in-house to independent assessment.

Process - Self-assessment, desk-top review, with or without external audit.

Advice - Patients / patient organisations are part of these assessments to varying degrees (Best Practice – NL, FR)

2. National Accreditation Systems

→ National conferences for rare diseases recognise the **value of patients and patient organisation's** involvement in the accreditation process of Centres of Expertise

→ There are **significant variations** in approach and the extent of involvement between countries.

NL

NL: Patient perspective is used to inform the decision for full or partial accreditation, through patient organisations complete the same 'self-assessment' tool as the CoE applicants and compared.

Evidence: *Policy recommendations for rare disease centres of expertise*[1] outlines the value of patient representatives involvement in the performance management of Centres of Expertise.

NB: Patient organisations should continue to advocate the value of a more formal role in accreditation and operational delivery of CoE.

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[1] M. Syed, Camp, mischorr-Boch, Hauÿez (Oct 2015)

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Identification of needs & prioritisation

3. Identification of Needs & Prioritisation

Some countries separate out the identification or prioritisation of a condition **(the 'what')** to have a CoE from the application process for identifying the healthcare providers **(the 'who').**

- **IT** – Patient organisations successfully advocated for the extension of the list of rare conditions in the legislation. The political landscape changed at same time so work continues with some regions to recognise this new list of conditions
- **ES, SW** – Assess the needs of rare diseases or highly specialised healthcare before identifying potential expert centres – two step process
- **SW** – An impact and consequence assessment of the potential accreditation of a national centre is completed.

PROPOSALS

Patient organisations have a key role in advising on needs, prioritisation and where expert centres should be developed depending on the geography of their country

National Treatment Pathways and Therapeutic Policies

4. National Treatment Pathways and Therapeutic Policies

➔ National networks vary in maturity.

Proposal - National networks:
- Make it easier for all patients and GPs to navigate in the health system
- Bridge gaps and create a continuum between the various actors, those involved in medical care, diagnostic, therapeutic R&D and social care sector

FR – National care pathways and Filières de Santé

UK – National service specifications with care pathways including referral criteria, therapeutic policies

4. National Treatment Pathways and Therapeutic Policies

Visibility of expertise by clinicians, other experts and patients is key to ensure the system can be 'navigated' to improve access and reduce inequalities.

SW - The Swedish's Information Centre for rare diseases in 1999, is funded by the government. It is a database of 300 to 500 rare diseases with **detailed clinical information to aid clinicians with diagnosis and referral to specialist centres.**

PROPOSALS

NL

Patient Organisations should continue to develop close working relationship with experts, as they have a positive impact on shaping national networks, building relationships with local / regional hospitals and the development of shared care arrangements.

4. National Treatment Pathways and Therapeutic Policies

➔ Centres of Expertise hold annual face-to-face meetings to review clinical outcomes data from all centres, shared best practices and discuss complex cases.

DE - Federal Joint Committee (G-BA) that ‘fleshes out’ the relevant legal provisions through binding guidelines including specification of diseases, scope of treatment, technical resources and staff requirements, referral requirements and quality assurance measures.

UK – Centres providing Highly Specialised Healthcare are contractually required to hold face-to-face clinical annual meetings to share best practice and clinical outcomes, in some cases with international experts invited to attend

ADVOCACY OPPORTUNITIES SUMMARY

PATIENT ADVOCACY OPPORTUNITIES

- **Enabling clinicians and patients to navigate the national system** with universal coverage of services through sign posting where the expertise is nationally
- **Creating transparency of the national accreditation** and evaluation of expertise, focusing on a holistic approach to comprehensive care pathways
- **Promoting the exchange and collaboration of expertise + quality data** for peer review and benchmarking to develop best practice

CNA Meeting: 13 October 2014

Discussion on optimising results from EUROPLAN National Conferences

→ **Decision** to identify **1) good practices 2) inspiring proposals** on governance, research, access to care (CEs & ERNs), orphan drugs and social care

Mainly from EUROPLAN Conference Reports + current RD National Plans/National + State of the Art on RDs.

Membership Meeting 2015

- Team members produced a first draft of good practices / proposals stemming from Conferences, National Plans…
  - Research
  - Centres of Expertise/ ERNs
  - Orphan Drugs
  - Social care

- → to be discussed throughout EMM 2015 → EUROPLAN Advisors will input.
- Theme 4: Centres of Expertise → to be discussed here today