

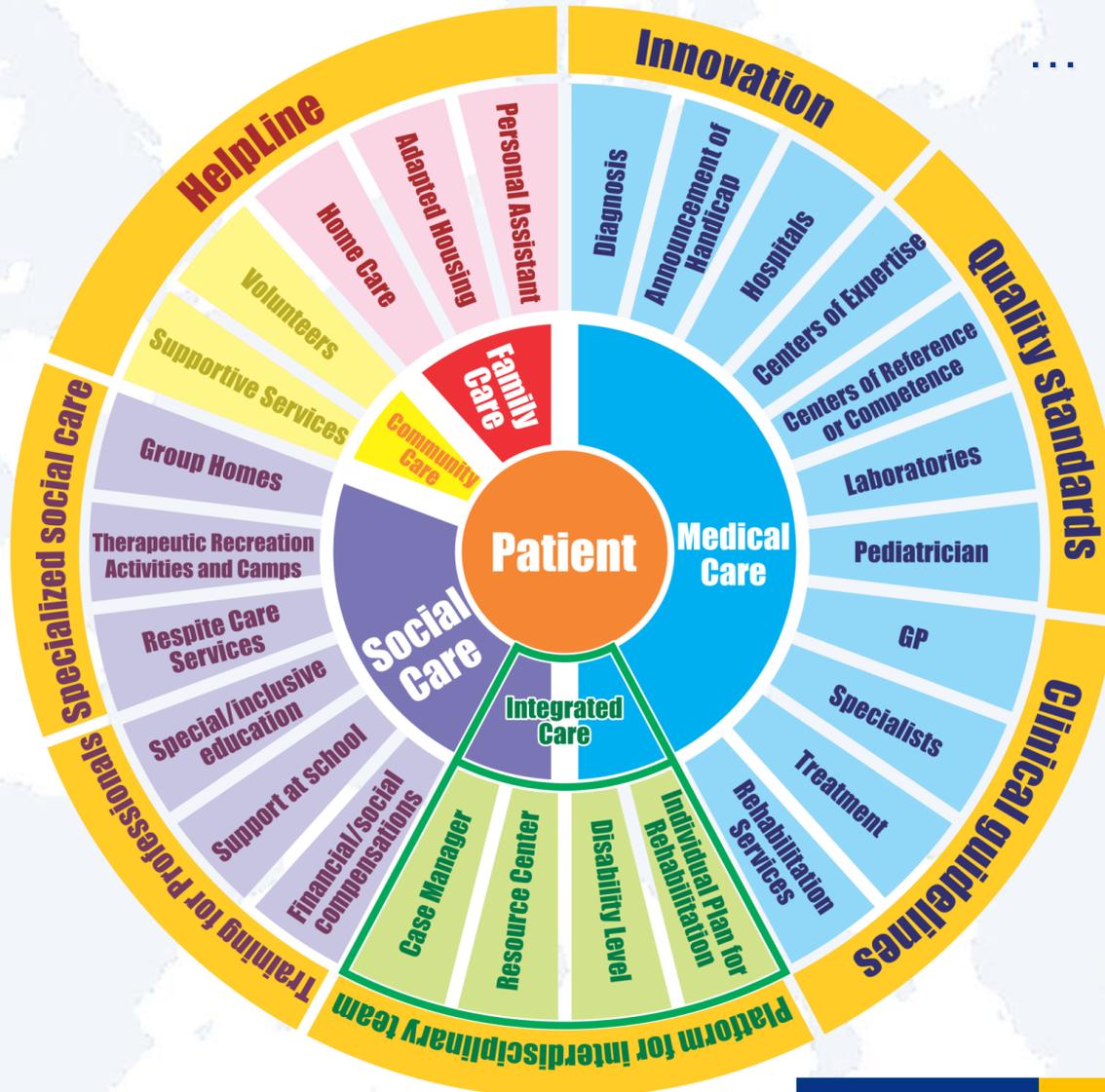


## Hele vejen rundt om patienten

Terkel Andersen, formand  
EURORDIS & Danmarks Bløderforening

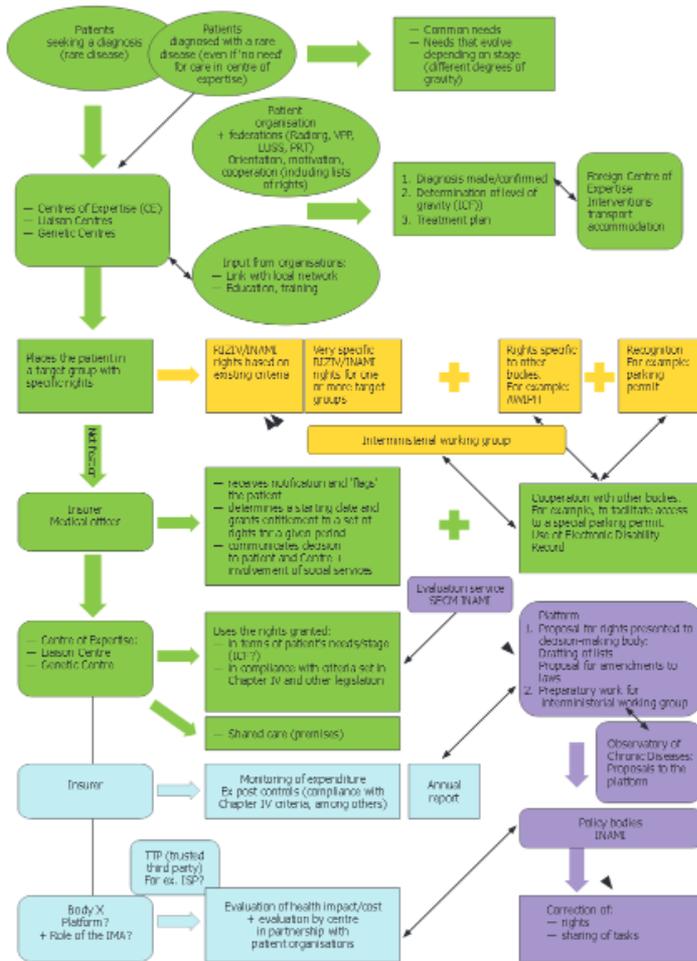
Europlan Conference København 23 januar 2015

# Integrated care for RD patients?

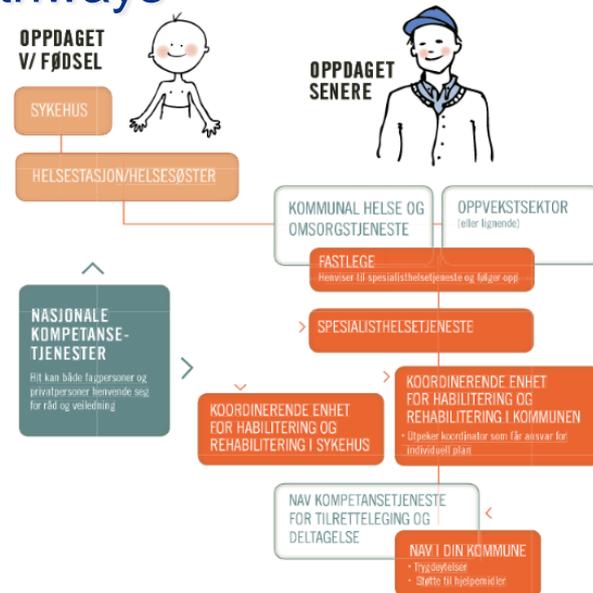


# Why integrated care for RD patients?

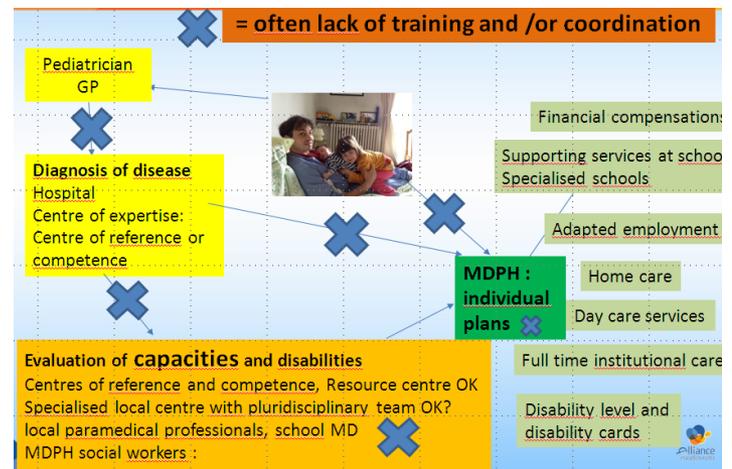
Patients need to go through complex care pathways



Belgium Care Pathway



Norway Care Pathway



France Care Pathway

# HÆMOFILJ

Organisation af forebyggelse  
og behandling

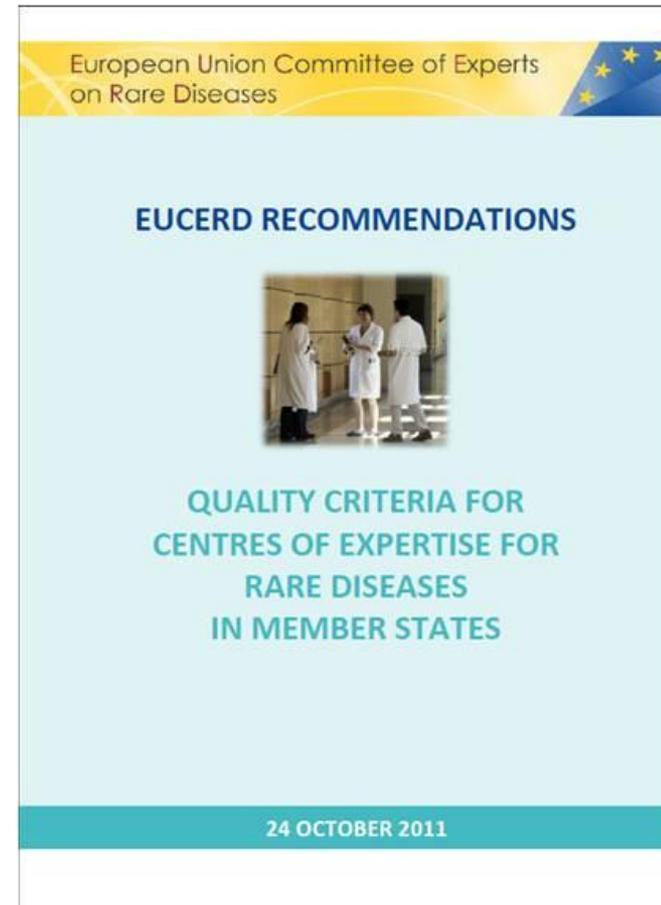
Redegørelse afgivet  
juni 1978 af et af sundhedsstyrelsen  
nedsat ekspertudvalg

Sundhedsstyrelsen 1978

# EUCERD quality criteria

## Centres of expertise

- Multidisciplinary approach – coordination with social services
- Contribute to building health care pathways from primary care
- Collaborate with patients' organisations
- Centres designated by Member States
- Organise collaborations for the continuity of care from childhood to adulthood and at all stages of the disease, produce guidelines. Referrals to other countries



# Recommendations: CEs' role in spreading information

- CEs contribute to the elaboration of good practice guidelines and to their dissemination
- CEs provide education and training to healthcare professionals from all disciplines, including paramedical specialists and of non-healthcare professionals (such as school teachers, personal/homecare facilitators) whenever possible
- CEs contribute to and provide accessible information adapted to the specific needs of the patients and their families in collaboration with the patient organisations and with Orphanet

[www.eucerd.eu](http://www.eucerd.eu)



## 2. European Reference Networks (ERNs) for RDs: the EUCERD Recommendations

### HIGHLIGHTS

- RD ERNs will link Centres of Expertise and specialised healthcare providers, social care providers, patient groups, diagnosis labs, research groups ...
- Flexible framework for healthcare pathways to patients
- Will facilitate mobility of expertise + cross border healthcare for RD-patients



# Possible Solutions to greater integration of care

## **Structural/ framework:**

- Greater integration of policy activities, communication and recommendations
- Supported by long-term funding and sustainable policies between health and social care
- Structured national integrated care pathways supported by integrated budgets

## **Integrated, multi-disciplinary, patient centred and continuous care:**

- Flexibility of care models, integrated multi-disciplinary and multi-system approach
- Capacity to coordinate care between providers and sectors (health, social, employment); between local, regional, national and international structures; between public, private and civil society partners;
- Proximity care, case managers (coordinators, handlers, case management teams)
- Individual care plans, life plans; the importance of active life, autonomy, dreams

*(Possible solutions have been identified in: Reports from EUROPLAN National Conferences (2012-2015), National Plans, Discussions at EUCERD Joint Action workshop on 'Social Care' for RDs)*