Ways to take the next steps towards holistic care

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General lessons for up-scaling so far

- Clear idea about the agenda of changing
- Identification of country specific policy issues, opportunities and obstacles
- Establishing a shared vision together with a strong strategy
- Definition of clear and ambitious goals on all levels
- Establishment of a common language between and within organisations
- Partnership with all relevant sectors and civil society
- Engagement of patients, families and carers from the beginning, always putting needs first

Selection of countries for up-scaling

✓ **Austria**
✓ France
✓ Hungary
✓ Luxembourg
✓ **Romania**
✓ **Spain**
✓ **Sweden**
✓ United Kingdom

- Selection made by the consortium (March 2017)

- Selection of countries was based on criteria of:

Diversity	Policy	Feasibility
✓ Type of welfare states	✓ National plan for rare diseases (RD)	✓ Country of INNOVCare partners
✓ Size of the country	✓ Reference to social issues in national plan for RD and in RD national multi-stakeholder conference	✓ Existence of National Alliances of RD patient organisations
✓ Size of the population	✓ Resource centres for RD	✓ Involvement in similar EU projects
✓ Type of public administration	✓ Pilot for case management	
✓ GDP per Capita		
✓ Geographic representation across the EU		

What does up-scaling mean in the INNOVCare context?

- *Up-scaling means ”… **deliberate efforts** to increase the impact of health service **innovations […]** in pilot or experimental projects so as **to benefit more people** and **to foster policy and programme development on a lasting basis**.” (WHO)*

- for INNOVCare that means

1) understanding the **regional and national potentials** for holistic care

2) looking for the potentials to **reach out to all who need it**

Who was interviewed and why?

- Different stakeholders at different levels
  - Policy: national and regional politicians and public administrators (health and social)
  - Service providers: Social and health care
    - Resource centres
    - Case managers
  - Patient representatives

- To identify different perspectives and understandings on
  - Needs
  - Barriers
  - Holistic care

- Are there common understandings? How do they differ?

Selection of interview partners

- **Decision power and competence** in the relevant policy fields
- Reaching out to stakeholders **so far not involved in holistic care approaches**/ projects
- **Expertise:** Recommendations of interview partners („snowball sampling“)
- **Continuity:** People interviewed before
- **Diversity:** Local and regional best practice examples as well as regional and national problems identified

Current debates adressed by stakeholders

Awareness:

- Patients and families: holistic view on patient AND family ("you have to see the whole family, not only the patient with RD") vs. narrow focus on the health need of the patients
- Policy level: lack of basic awareness of gaps in supplies "we have a great health and social care system […] what is needed are nice and empathetic people" vs. relatively high recognition of existing barriers "Awareness of all policymakers and public is necessary"

Current debates adressed by stakeholders

Awareness:

- Legal framework ("we have a law, they have to provide services") vs. good-will ("to make it work is dependent on nice people making an exception for your child")

- Special status or "alert" included in patient files for easier access to services and medication vs. special status as stigmatisation ("RD patients already have the same rights in the social insurance system [...] it would cause ethical and constitutional problems as it contradicts the principle of equality")

Current debates adressed by stakeholders

Competence share of politicians:

- EU policies and NAP as tools to raise awareness vs. NAPs as another “concept in a drawer”
- National frameworks (“To be honest, no one takes the ministry of health seriously”; “integration is a constant battle”) vs. regional obligation to organise care
  - Competencies at the local level, recommendations from the national level; both levels refer to the other level as responsible → fragmentation

Current debates adressed by stakeholders

***Health and social care provision*:**

- low-threshold facility vs. specialised expertise on RD
  - Health and social care system needs to be there for everyone, resource centres cannot provide that; specialized RC are necessary to provide for special needs, but how can access for everyone be reached → how to obtain equality?
- Offers to improve care for those who need it to achieve equal access vs. a lot of money for a small group (“The small budget we have for health care has to be for everybody”)?
- Case managers as “part of the system” vs. “another person to talk to”
- Clinical knowledge and training vs. personal aptitude
  - Supervision of case managers and working conditions?

Current debates adressed by stakeholders

- ***Patient representatives***
  - On the way to partnership in designing approaches to holistic care vs. lobbying without being heard and private engagement as a result „We are dependent on the personal engagement of some interested people."

- ***Patients and families***
  - Empowerment of patients and families to become experts of their own care needs "patients need to understand what is going on" vs. lack of recognition of patients and families as equal partners in the health and social care network "patients and families are not listened to at the moment, they are not taken seriously."

Approaches to holistic care (policy)

- Network involving different stakeholders sometimes including, sometimes excluding patient representatives, patients and families/ main care givers (regional and national policy makers)
- You need to have powerful, well-connected key-players and the right contacts to people in decision power (patient representatives; resource centres)
- Awareness raising through confrontation of people in charge with patients ("bring the patients with you") (patient representatives)

Approaches to holistic care (tools)

- Installing multidisciplinary teams with a clear division of responsibilities (resource centre)
- Case management within the system(resource centre)
- Mixed training courses including RD patients and professionals (case manager, resource centre)
- Guidelines (on different RD) that provide carers and professionals with information and help to establish care plans (resource centre, case manager)
- An “alert” informing on the special needs of RD to facilitate access to medical care (resource centre, patient representative)

How can we build on that?

- Develop a common understanding of **equality**
  - Why do we need different offers for different needs?

- Develop a common understanding of **inclusion**
  - Which steps to take towards inclusion?
  - Where are we now?
  - How to make clear to policy makers the multiple aspects of inclusion?

- Involvement of
  - Patients
  - Families, social network
  - Care givers (formal and informal)

INNOVCare

Innovative Patient-Centred Approach for Social Care Provision to Complex Conditions

Thank you

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