









INNOVCare - Innovative Patient-Centred Approach for Social Care Provision to Complex Conditions  
Workshop on Advancing Holistic and Innovative Care for Rare Diseases and Complex Conditions - Cluj-Napoca, 1-2 June 2017  
Breakout Sessions

Last update: 9 June 2017

**What we want to achieve in 5 years** (outcome of previous workshop Vienna 10/16): Awareness for Rare Diseases & Holistic care is the norm

**Breakout-session subjects & expected outcomes** (Results of research on cross-country issues - WP4, WP9; outcomes from previous workshops [Gothenburg](#) & [Vienna](#))

Discussion Subject & Outcome Tools		Chair & Rapporteur	Photos	
1	<b>Building the case of rare diseases</b>  <b>Outcome tool:</b> Fact-sheet on rare diseases and the need for holistic care	<b>Chair:</b> Raquel Castro, EURORDIS  <b>Rapporteur:</b> Aline Schnieder, EURORDIS		
2	<b>Steps to implement holistic care for rare diseases</b>  <b>Outcome tool:</b> Scheme on steps to implement integrated care for rare diseases	<b>Chair:</b> Ester Sarquella Casellas, Generalitat de Catalunya  <b>Rapporteur:</b> Valentina Rupel, Inštitut za Ekonomska Raziskovanja		
3	<b>Evaluation of social and economic impact</b>  <b>Outcome tool:</b> List of elements and instruments to consider when planning social and economic evaluation	<b>Chairs:</b> Juliet Tschank, Zentrum für Soziale Innovation; Vibeke Sparring, Karolinska Institutet  <b>Rapporteur:</b> Ersida Mansoor, Karolinska Institutet		
4	<b>Case management role and training</b>  <b>Outcome tool:</b> Outlines of roles and training for case managers for rare diseases	<b>Chair:</b> Dorica Dan, NoRo resource centre  <b>Rapporteur:</b> Zsuzsa Almasi, NoRo Resource Centre		

## 1. Building the case of rare diseases

Chair: Raquel Castro, EURORDIS; Rapporteur: Aline Schnieder, EURORDIS

First Name	Last Name	Organisation	Profile	Country
Alexandra	Toporan	Romanian Prader Willi Association - NoRo Resource Center	Social Service	Romania
Aline	Schnieder	EURORDIS - Rare Diseases Europe	Patient Representative	France
Emilia	Severin	Universitatea de Medicina si Farmacie (University of Medicine and Pharmacy)	Public Body	Romania
Gábor	Pogány	Hungarian Federation of People with Rare and Congenital Diseases (HUFERDIS)	Patient Representative	Hungary
Helena	Kääriäinen	National Institute for Health and Welfare Helsinki	Public body	Finland
Isabel	Fernandez	Federación Española de Enfermedades Raras (Spanish Rare Disease Federation, FEDER)	Patient Representative	Spain
Matilde	Munk	National Board of Social Services	Public body	Denmark
Raquel	Castro	EURORDIS - Rare Diseases Europe	Patient Representative	France
Tiina	Stelmach	Estonian Ågrenska Foundation Resource Centre	Social Service	Estonia
Veronika	Himlová Burešová	Ministry of Labour and Social Affairs	Public body	Czech Republic
Vlasta	Zmazek	Debra Croatia, Croatian Alliance for Rare Diseases	Patient Representative Service Provider	Croatia

### Expected outcome tool:

- Fact-sheet on rare diseases and the need for holistic care: strong case and compelling narrative.

**Challenges** (outcome of previous workshops Gothenburg 09/16 & Vienna 10/16):

- Lack of awareness on rare diseases; lack of political will.

**Strategies** (outcome of previous workshop Vienna 10/16):

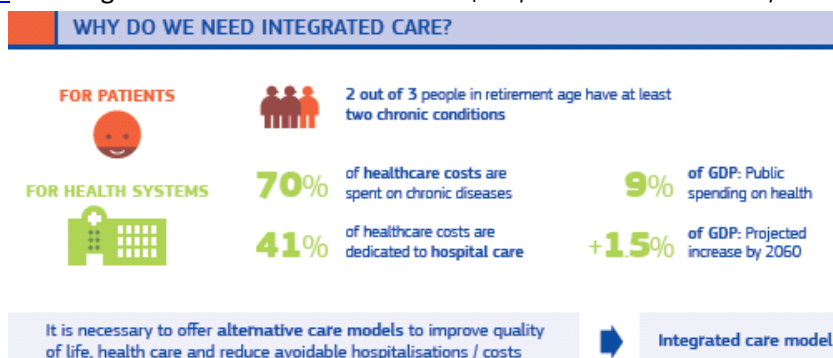
- Raising awareness of realities of people with a rare disease & need for holistic care (make it personal!; story-telling, media, pictures, narratives, emotional arguments);
- Bottom-up: involve stakeholders and influencers (champions) besides politicians (that change often).

**Inspiring & provocative quotes from country visits** (WP9, up-scaling)

- "To have patient-centered services in health care it needs nice people who want to understand and are emphatic with the patients – that's all." (public administration, national)
- "It is about empowerment. You need a place for people to meet and talk to each other. Somewhere, you can feel normal. You meet others in the same situation. You have someone to talk to, someone who understands you. If you have a child, you have a dream. But how to handle it, if this dream turns out to be very different, how to adopt to the situation. You need a place to belong to." (resource centre)
- "If you put the information together, the government is more comfortable to do it" (patient representative)
- "We cannot afford case management. You cannot put money into a small group. With the small budget for health you have to finance everyone" (public administration, national)

**Inspiration sources – Factsheet for integrated care for chronic diseases**

- [Fact-sheet](#) on integrated care & chronic diseases (European Innovation Partnership on Active and Healthy Ageing)



### Outcomes of breakout session discussion & work

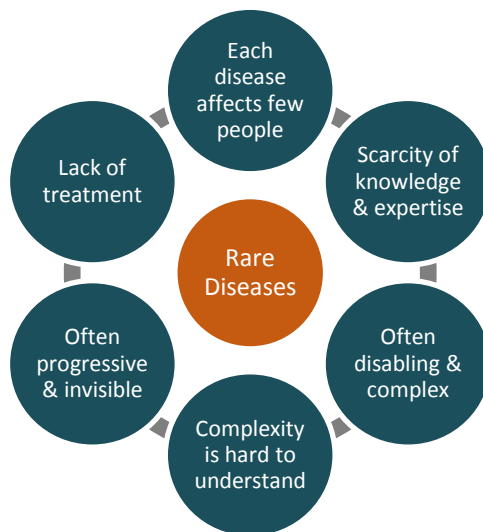
#### ✓ Fact-sheet on RD and the need for holistic care

#### Issues to keep in mind:

- Policy makers/stakeholders don't have time; **reduce information to 5'**; [elevator pitch](#); teaser;
- The person carrying the fact-sheet can then further elaborate on specific solutions regarding "how to" achieve integrated/holistic care according to national policy and social contexts;
- There are many rare diseases; avoid giving the impression that people should know them from the beginning; give tools for them to learn; **include contact points & provide information**;
- **"Selling point"**: if services/solutions work for rare diseases, it works for common diseases;
- Leading questions for factsheet:
  - **What is the difference with a rare diseases?** Special needs? Or common needs which required added support to be obtained?
  - Health policy makers may ask are we more ill than the other people living with chronic diseases? Social policy makers may ask do all rare diseases generate disability?
  - **Why are we looking into integrated care?**

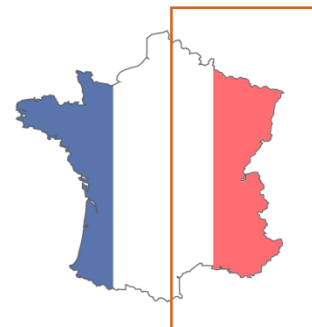
#### Outline for fact-sheet:

- **Person living with a rare disease and their carers are at the centre/departure of fact-sheet**;
- **Key facts** on rare diseases, presented in a visually attractive way:



#### But collectively rare diseases affect:

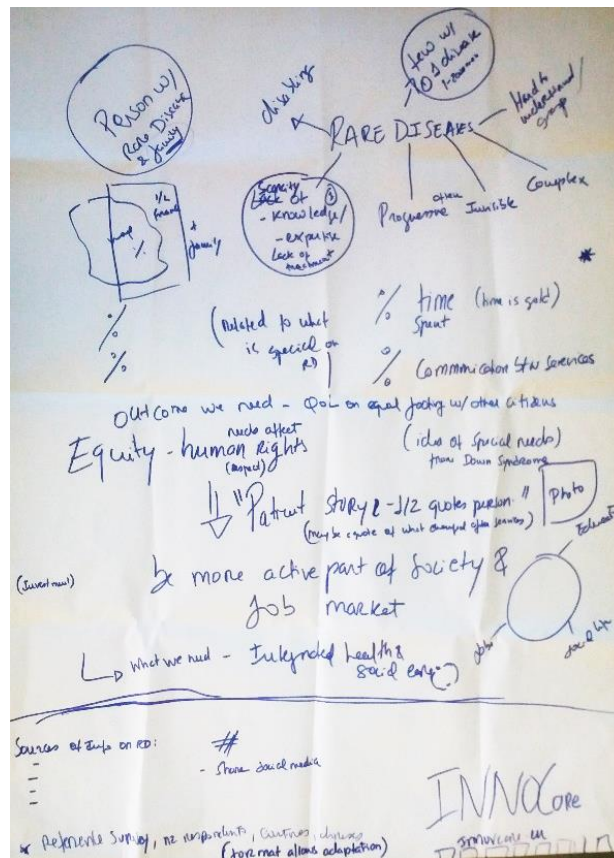
30 million people in Europe  
~1/3 of the population of France



- **Key figures** from the [survey conducted within INNOVCare via Rare Barometer Voices](#) or other surveys e.g. Time burden; lack of communication between services; time to diagnosis;
- Include a **patient story and photo** to make it more compelling;
- **Focus on outcome** desired: **quality of life (QoL)** in equity with other citizens; human rights;
- **Mention the societal benefits** of supporting people living with a rare disease: they'll be more active in society, job market, as consumers, etc.;
- **Conclude with what we need to achieve the outcome**: integrated health and social care;
- **Include sources of information/contact points** (footer which can be adapted): EURORDIS, Orphanet; national alliances for rare diseases; helplines; resource centres for rare diseases, etc.
- Include icons and **links to share on social media** (for online version);
- Include **reference to INNOVCare** (logo, website, partners' logos)

### Draft scheme of Fact-sheet:

To be followed up on by INNOVCare project to produce the final fact-sheet



- ✓ **Other issues referred during the discussion:**
- **Distinction between rare diseases and chronic common diseases;** need to:
  - Stress that the goal is not to compete between diseases; it's to achieve **equity** not equality;
  - Explain **why** are **complementary care solutions** and **"disease specific knowledge"** necessary to facilitate care pathways within mainstream systems; stress what services are needed;
  - Clarify that **patients and families only want services that they need;**
- **Difficulties before receiving diagnosis;** risk of exclusion from the health and social care pathways;
- Importance of a **common language for social and health services:** patient pathway – client pathway;
- Risks of **disability assessments not taking into account** certain very disabling aspects of many rare diseases i.e. **time and care burden**, variability of the disease symptoms, rapid degeneration;
- **Importance of informing** and educating **people living with a rare disease and professionals;**
- Need for **resource centres and trained professionals close to the person** with a rare disease and family;
- Different solutions for case management: social workers, patient organisations, nurses, etc.; our **fact-sheet focuses on "what to achieve" (QoL) and not "how to" do it**, which will differ according to national/regional contexts/legal frameworks;
- **Importance of evaluating the impact** of services on patients and carers;
- **Funding** remains an issue;
- **Good practice examples:**
  - Denmark: guidelines for processes for social services in municipalities for blind children and families; no timeline, but model of who should be contacted and need for early intervention;
  - Finland: health reform promotes sharing of information between services and authorities.



## 2. Steps to implement integrated care for rare diseases

Chair: Ester Sarquella Casellas, Government of Catalonia; Rapporteur: Valentina Rupel, Inštitut za Ekonomska Raziskovanja

First Name	Last Name	Organisation	Profile	Country
Andreia	Bernardo	Raríssimas; Casa dos Marcos Resource Centre	Patient Representative Service Provider	Portugal
Anica	Ježić	Ministry of Social Policy and Youth	Public body	Croatia
David	Koubi	Finovatis	Academic	France
Ester	Sarquella Casellas	Government of the Spanish Region of Catalonia	Public Body	Spain
Florina	Breban	Romanian Prader Willi Association - NoRo Resource Center	Patient Representative Service Provider	Romania
Mirja	Heikkilä	Association for physically disabled people	Patient Representative Service Provider	Finland
Lavinia	Ghilea	Salaj County Council	Public body	Romania
Silvia	Manea	University of Padova	Health Service	Italy
Stein	Are Aksnes	Norwegian National Advisory Unit on Rare Disorders	Public body	Norway
Valentina	Rupel	Institute for Economic Research	Academic	Slovenia

### Expected outcome tool:

- Scheme on steps to implement integrated care for rare diseases.

### Challenges (outcome of previous workshops Gothenburg 09/16 & Vienna 10/16):

- Lack of policies; separation of budgets;
- Lack of collaboration between care providers; fragmentation; lack of clear responsibilities;
- Need to look wider at the whole system to find gaps; let's not make a case-manager another silo.

### Strategies (outcome of previous workshop Vienna 10/16):

- Promoting integration of care & integration of budgets.

### Inspiring & provocative quotes from country visits (WP9, up-scaling)

- "You can reach out to people in two ways: top-down or bottom up. Top-down policies need key-players who promote best practices and ask for their implementation. [...] But we also need to work from the bottom up, because the authorities on the local level need to be engaged." (Public administration, regional)
- "You need to work broadly so as not to be so dependent on one person, but it takes time; it really is a matter of cooperating with the authorities [...] Cooperation is better than fighting. [...] If you want to adopt to the system you cannot focus on RD only" (resource centre)
- "Establish a committee that is composed of multidisciplinary teams, clinicians, pharma, researchers, social workers, teachers, patient representatives and public administration. The main goal for us was to find a president who is respected by all the clinicians and who is involved in the change of RD. The president must be recognised also by public authorities and needs to have good connections." (patient representative)
- "Another very important step that needs to be taken at the beginning is the implementation of multidisciplinary teams to implement a holistic view of the patients' needs and to design services tailored to their specific needs (health, social, housing, transport, economic)." (public administration, national)
- "Public funding takes too much time. Private funded centres are dependent on the personal engagement of some interested people. [...] The NP does provide a political guideline but it does not include any budget plan for the Expertise-centers. Therefore it is worthless." (resource centre, patient representative)

### Inspiration sources – Quote on integrated care

- "Without integration at various levels [of health systems], all aspects of health care performance can suffer. Patients get lost, needed services fail to be delivered, or are delayed, quality and patient satisfaction decline, and the potential for cost-effectiveness diminishes." (Kodner and Spreeuwenburg, 2002, p2)

## Inspiration sources – 10-Step Integrated Care Framework for Older Persons

Implementing integrated care in the Irish context: the example Integrated Care Programme for Older Persons. PJ Harnett, Health Service Executive (HSE) Ireland; International Conference on Integrated Care, Dublin 8-10 May



Inspiration sources – Report by the EC Expert Group on Health Systems Performance Assessment: [‘Tools and methodologies to assess integrated care in Europe’](#) (2017).

### 11 Building blocks of successful integration

- |                                     |                                      |
|-------------------------------------|--------------------------------------|
| 1. Political support and commitment | 7. Workforce education and training  |
| 2. Governance                       | 8. Patient focus / empowerment       |
| 3. Stakeholder engagement           | 9. Financing and incentives          |
| 4. Organisational change            | 10. ICT infrastructure and solutions |
| 5. Leadership                       | 11. Monitoring / evaluation system   |
| 6. Collaboration and trust          |                                      |

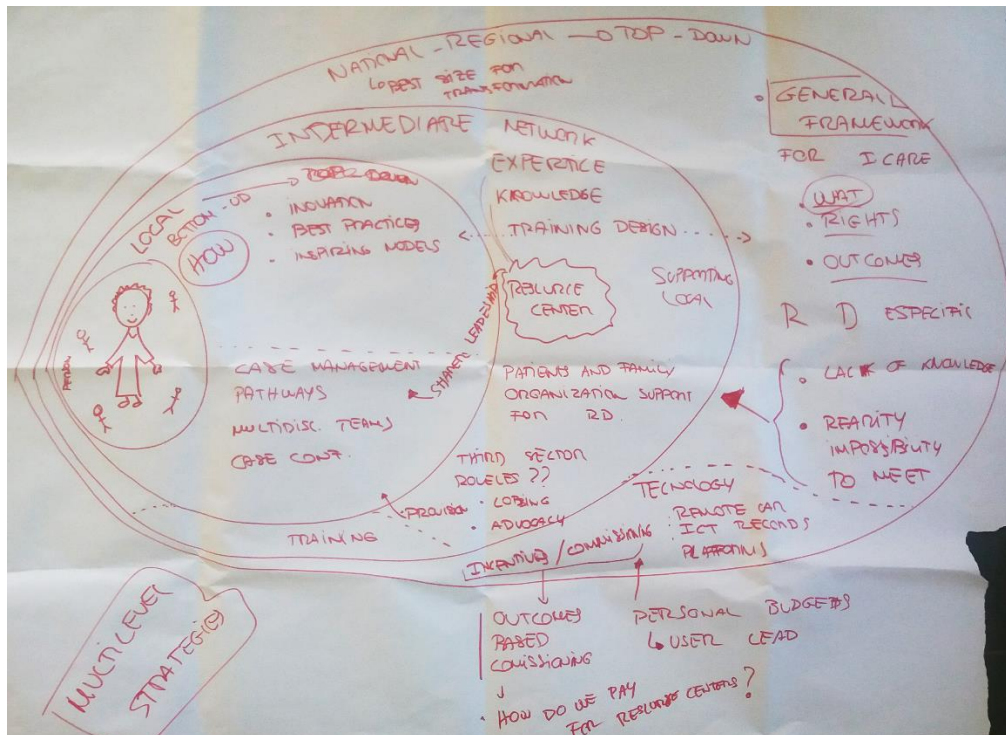
Inspiration sources - [Lessons from transforming health services delivery: compendium of initiatives in the WHO European Region](#) (2016)

### Overview of lessons learned

- |   |   |
|---|---|
| 1. Put people and their needs first           | 6. Align incentives                             |
| 2. Reorientate the model of care              | 7. Develop human resources for health           |
| 3. Reorganize the delivery of services        | 8. Uptake innovations                           |
| 4. Engage patients, their families and carers | 9. Partner with other sectors and civil society |
| 5. Rearrange accountability mechanisms        | 10. Manage change strategically                 |

Outcomes of breakout session discussion & work

- ✓ Scheme on steps to implement integrated care for rare diseases



- ✓ Other issues referred during the discussion:
  - Focus on specifics of integrated care necessary for rare diseases;
  - Difference between rare diseases and other diseases:
    - **Rarity** (difficulty to meet other with the same disease);
    - **Lack of knowledge** about the diseases (difficulty to find information);
  - For these reasons, it is **necessary to use multilevel strategies** in the integrated care implementation;
  - **Top-down and bottom-up** approaches:
    - **National or regional level: top down** approach is most appropriate; the rights of the patients need to be defined as well as outcomes and training programs for resource centres;
    - **Local level:** where the patients reside, a **bottom up** approach will provide innovative methods, best practices and inspiring models of care;
    - **Intermediate level: rarity and lack of knowledge require this to connect the local and national level;** offer experience, knowledge and organizational support;
  - **Incentives/tools needed** to promote integrated care for rare diseases:
    - **National level: financial or non-financial**, while experience, support and training can be transferred throughout community using technology, remote care, ICT record, platforms, etc.;
    - **Intermediate level: coordination and patient training, advocacy and active hearing;**
    - **Local level: provision of services uses case management**, supported by pathways; care is provided in **multidisciplinary teams**; leadership is shared.
  - Discussion on **funding**:
    - **Value based commissioning does not seem appropriate** for rare diseases;
    - **User led personal budgets that transfer responsibility for care to patients do not seem appropriate** in case of rare diseases;
    - **Resource centres need to be financed as part of the system**, publicly. Their payment shall be according to the outcomes and goal achievement.

### 3. Evaluation of social and economic impact

Chairs: Juliet Tschank, Zentrum für Soziale Innovation; Vibeke Sparring, Karolinska Institutet

Rapporteur: Ersida Mansoor, Karolinska Institutet

First Name	Last Name	Organisation	Profile	Country
Annette	Dumas	EURORDIS - Rare Diseases Europe	Patient Representative	Belgium
Dominique	Bonneau	PRIOR (Regional Platform for Information and Guidance on Rare Diseases)	Social Service	France
Edmund	Jessop	National commissioning Group, National Health Service	Public Body	UK
Ersida	Mansoor	Karolinska Institutet	Academic	Sweden
Juliet	Tschank	Zentrum für Soziale Innovation (Centre for Social Innovation, ZSI)	Academic	Austria
Lidia	Onofrei	Ministry of Health Romania	Public body	Romania
Maud	Le Graët	Finovatis	Academic	France
Monica	Solomie	Ministry of Work, Family, Social Protection and Elderly	Public body	Romania
Pierre	Sarda	Réseau Maladies Rares Méditerranée (Mediterranean Rare Diseases Network)	Social Service	France
Vibeke	Sparring	Karolinska Institutet	Academic	Sweden

#### Expected outcome tool:

- List of elements and instruments to consider when planning social and economic evaluation.

**Challenges** (outcome of previous workshops Gothenburg 09/16 & Vienna 10/16):

- Lack of political will;
- Economic crisis.

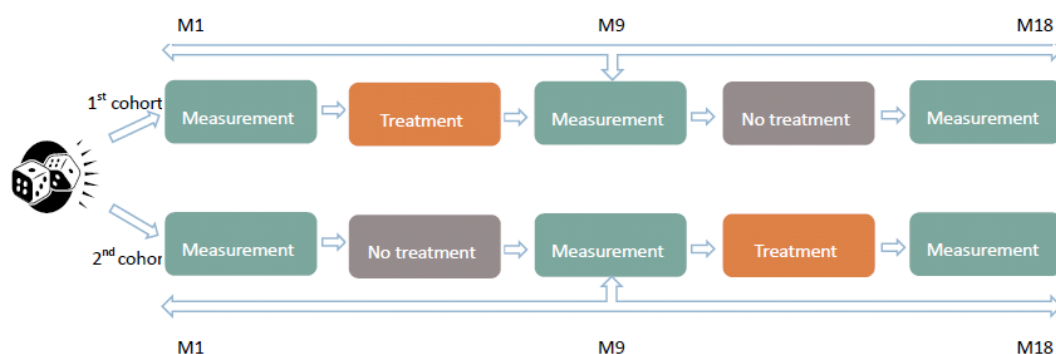
**Strategies** (outcome of previous workshop Vienna 10/16):

- Use pilots to show to policy makers what can be done;
- Use health economics as a tool to provide evidence;
- Raise awareness: quality of life of patients, broadly speaking not health based, must be evaluated.

**Inspiring & provocative quotes from country visits** (WP9, up-scaling)

- "We did a query with associations in RD together with the clinicians. After the first round we did a cluster of personal information that we share to make visible what patients shared e.g. 'the doctor doesn't look at me' or 'the doctors don't talk to each other'. It sounds like stupid things, but in the end it makes people's life more difficult. With the results of this study, we pressured the administration to develop a committee that is composed of different clinics, representatives of people with a rare disease, teachers, researchers, social workers and public administration. [...] In the meetings we develop things to improve, on the basis of our survey. With the results we can work on how to develop solutions" (patient representative)
- "We cannot afford case management. You cannot put money into a small group. With the small budget for health you have to finance everyone" (public administration, national)

Inspiration sources - INNOVCare's evaluation model





- **Evaluation design:** a basic two-condition repeated measures design, also known as rotation design;
- **Sampling:** random proportionate stratified sampling; stratifying variables: type of patient (NoRo or external), age group (nine levels) and sex;
- **Randomisation:** stratified random assignment (random allocation of participants into the 1st and 2nd cohorts) based on the variables: type of patient (NoRo or external), age group (three levels), sex and location (urban or rural) as well as simple random allocation of participants to the four case managers;
- **Ex-post assessment of the randomisation procedure:** checking balance of the two cohorts based on the following variables -age, age group, type of patient, sex, location, disease cluster, degree of disability.
- **3 points of measurement:** March 2017, November 2017, July 2018

TABLE 3: PRE OR POST VERSIONS OF THE QUESTIONNAIRES ACCORDING TO COHORT AND MEASUREMENT TIME

	1 <sup>st</sup> Measurement (March 2017)	2 <sup>nd</sup> Measurement (September 2017)	3 <sup>rd</sup> Measurement (June 2018)
1 <sup>st</sup> cohort	PRE Patient-SMILEY	POST Patient-SMILEY	POST Patient-SMILEY
	PRE Patient-8+	POST Patient-8+	POST Patient-8+
	PRE Patient-SOLO	POST Patient-SOLO	POST Patient-SOLO
	PRE Family questionnaire	POST Family questionnaire	POST Family questionnaire
2 <sup>nd</sup> cohort	PRE Patient-SMILEY	PRE Patient-SMILEY	POST Patient-SMILEY
	PRE Patient-8+	PRE Patient-8+	POST Patient-8+
	PRE Patient-SOLO	PRE Patient-SOLO	POST Patient-SOLO
	PRE Family questionnaire	PRE Family questionnaire	POST Family questionnaire

- **Questionnaires:**
  - **Soft items** based on the 8 main goals of the intervention as defined in the logic model of intervention
  - **Hard items** based on demographical information of household & use of healthcare resources
  - Also include existing question batteries or whole questionnaires e.g. DISABKids, EQ-5D, Zarit Burden Interview (ZBI), etc.

TABLE 1: OVERVIEW OF THE DIFFERENT DATA COLLECTION INSTRUMENTS AND THE TARGET GROUP

Patient questionnaire					Family questionnaire
DISABKIDS SMILEY	DCGM-12	EQ-5D-Y	'Soft' items [Q3 – Q49 & Q71 & Q72]	'Hard' items [Q50 – Q70]	
<ul style="list-style-type: none"> <li>▪ Patients <b>4 to 7 years old</b></li> <li>▪ Older patient with serious cognitive difficulties</li> </ul>	<ul style="list-style-type: none"> <li>▪ Patients <b>8 years and older</b></li> </ul>	<ul style="list-style-type: none"> <li>▪ Patients <b>8 years and older</b></li> </ul>	<ul style="list-style-type: none"> <li>▪ Patients <b>8 years and older</b></li> </ul>	<ul style="list-style-type: none"> <li>▪ Adult patients, living alone and managing their own care</li> </ul>	<ul style="list-style-type: none"> <li>▪ Family members most closely involved or informed about the care of patients selected to take part</li> </ul>

### Outcomes of breakout session discussion & work

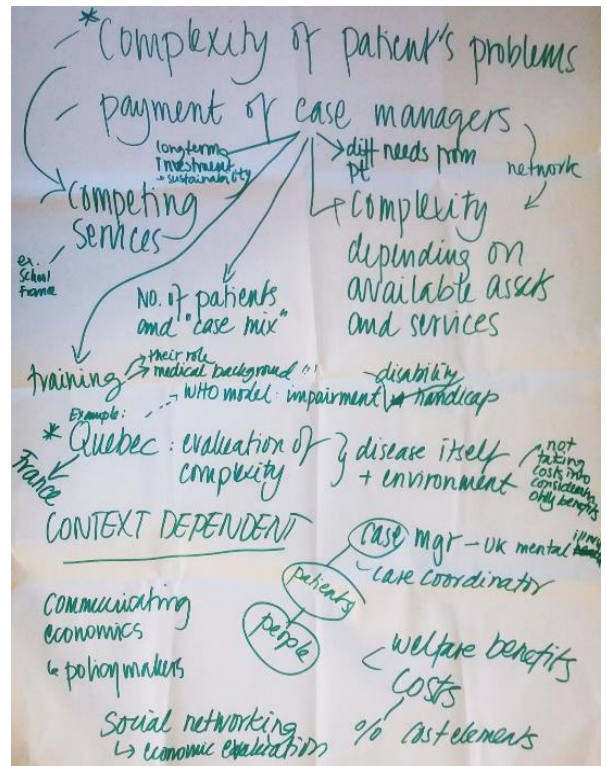
- ✓ List of elements and instruments to consider when planning social and economic evaluation

### Issues to keep in mind:

- Take into account **previous studies and questionnaires** developed for other complex conditions;
- **Evaluation and service design need to be aligned** to take into account e.g. lines of intervention addressing the needs of the person with a rare disease; services already provided; competing services;
- Important to **evaluate the true benefits for the person**;
- **Evaluation is contextual:**
  - Case management is contextual **to patients'/families' individual needs**: evaluation instruments taking into account the **complexity** are key; there may be added challenges for undiagnosed;

## Breakout Sessions

- Evaluation to be based on **country's context** to take into account different starting points, available assets/ and expectations;
- **Time frame** for evaluation: tackle the time accessing case management;
- **Control group** e.g. at NoRo an external group of beneficiaries is recruited to allow comparison with those already benefiting from NoRo's services;
- Interest of **comparing impact of case managers with different profiles** e.g. social worker, lawyer, nurse;
- Case managers can also have **negative impacts**;
- Measuring the case manager's effort when supporting 30 people with different complexity: **tracking frequency of contact with families and social services**;
- Remember to address **ethical issues**;
- Consider **data management**: ensure **data protection** by providing data in aggregated form; ensure an adequate management of data;
- **Assessing long-term social and economic impact is key**.



## Notes on economic evaluation of costs and benefits:

- Clarify what will be measured: the **hypothesis is that the intervention might be more costly but will provide better quality of life and societal benefits**;
- Measure **economic savings in health care**;
- **Other costs to be considered** e.g. pharmacy, respite care or other social services;
- It would be useful to **analyse the social network** from an economic impact point of view;
- Consider **case manager services also represent employment opportunities and job creation** for municipalities/regions/care providers; these employment opportunities may also be available to people living with a rare disease or family members (e.g. siblings);
- Take into account that for some services the overall budget is pre-defined, so it's **important to assess the cost of actual services provided**;
- **Salary of case management** to be evaluated in comparison to the national average wage.

## Example of evaluation instruments:

- **Quality of life impact:**
  - **Zarit** instrument measures the burden of caregivers;
  - **Barthel** index may be useful in cases where physical impairment is crucial;
  - Instrument to **measure the complexity** of disease and care pathway is important;
  - **Consider social evaluation** – difficult to find instruments that measure the right outcomes;
  - **Specific instruments to measure quality of life in children with cognitive impairment**;
- **Economic impact:**
  - **MAFEIP** "Monitoring and Assessment Framework for the European Innovation Partnership on Active and Healthy Ageing";
  - Model from **Canada (PRISMA)**.

#### 4. Case management role and training

Chair: Dorica Dan, NoRo resource centre; Rapporteur: Zsuzsa Almasi, NoRo resource centre

First Name	Last Name	Organisation	Profile	Country
Beatriz	Martinez-Lozano	Regional Ministry of Health-Region of Murcia	Public Body	Spain
Christine	de Kalbermatten	ProRaris (National Alliance for Rare Diseases Switzerland)	Patient Representative Service Provider	Switzerland
Dorica	Dan	Romanian Prader Willi Association - NoRo Resource Center	Patient Representative Service Provider	Romania
Dorisz	Veres	Romanian Prader Willi Association - NoRo Resource Center	Social Service	Romania
Gunilla	Jaeger	Ågrenska Resource Centre	Social Service	Sweden
Lisen	Julie Mohr	Frambu Resource Centre for Rare Disorders	Social Service	Norway
Marta	Fonfria	CREER (National Reference Center for people with a rare disease and their families)	Public body Service Provider	Spain
Monica	Lucia Avram	Salaj County Council	Public body	Romania
Ovidiu	Dragan	A smile for Mira	Social Service	Romania
Zsuzsa	Almasi	Romanian Prader Willi Association - NoRo Resource Center	Patient Representative Service Provider	Romania
Zsuzsa	Bojtor	Hungarian Federation of People with Rare and Congenital Diseases (HUFERDIS)	Patient Representative	Hungary

#### Expected outcome tool:

- Outlines of roles and training for case managers for rare diseases.

#### Challenges (outcome of previous workshops Gothenburg 09/16 & Vienna 10/16):

- Lack of clarity on responsibilities;
- Lack of communication between service providers & between services and patients.

#### Strategies (outcome of previous workshop Vienna 10/16):

- Exchange of good practices; using technology;
- Empowerment and training of organisations and services.

#### Inspiring & provocative quotes from country visits (WP9, up-scaling)

- “Case Management has to be part of the system, then it is a good way. The aim must be to make the ordinary system cooperate better so people can navigate better, get more empowered [...] a pilot we established once worked well – people were satisfied; but Case Managers were only able to handle 15 people, but that is not enough. It is only fair if it is for everyone who needs it” (resource centre)
- “A case manager needs a certain attitude and the will to engage for the good of the families and patients. You need a clear description of competences and you need to know your personal boundaries. You need to distance yourself as the families in need are naturally very demanding” (case manager)
- “It is all auto-training, I have no supervision, there is also no Case Management training included in nurse training, at the moment it is only through self-training. You have to have the right personality to be a Case Manager. But now I feel ready to train others”(case manager)
- The level of engagement is much higher compared to my previous job as a nurse, but it is also more satisfying as I can see immediate results. That is rewarding.” (case manager)

#### Inspiration sources - What matters to patients and their family?

([Workshop on Improving Integrated Care for People Living with Rare Diseases and Complex Conditions](#), 2016)

- Case manager:
  - Needs to be a facilitator and should not replace other professionals;
  - Supports and empowers patients/families, who always have ultimate decision power;
  - Should be neutral and independent in providing advice and referral;
  - Needs to have an added value to services already provided: not just another person to talk to;
  - Need to ask the patients (adults or children) and caregivers first what matters to them.

**Breakout Sessions**

**Inspiration sources – Activities of case manager - [INNOVCare pilot](#)**

- |  |  |
|--|--|
| 1. Information about disease             | 5. Knowledge of available services           |
| 2. Information about rights as a patient | 6. Disease-related peer-to-peer learning     |
| 3. Self-management of care               | 7. Understanding and acceptance in community |
| 4. Better communication skills           | 8. Coordination of care among stakeholders   |

**Inspiration sources – [Training of case manager from “Pilot scheme TCC Valais”](#), ProRaris - National Alliance for Rare Diseases Switzerland**

**Module 1 - What is to be known about rare and/or genetic diseases?**

- Development of a large understanding of the issue, integrating strong data related to rare diseases and/or genetic diseases, treatment and interdisciplinary/interprofessional care of these diseases.

**Module 2 - To live with a rare and/or genetic disease: crossed approaches**

- Evaluation of the needs, the means and the resources of persons affected by a rare disease and/or genetic disease in order to ensure an accompaniment throughout their life and health course long.

**Other inspiration sources were edited directly below, to include the outcomes of the breakout session:**

- Role of case manager - INNOVCare project
- Training of case manager - INNOVCare pilot

**Outcomes of breakout session discussion & work**

✓ **Outline of role of case manager for rare diseases**

**1. Single and stable point of contact**

**2. Listen, inform, support and empower patients and families**

- Provide knowledge/tools for patients to be able to acknowledge their personal situation
- Develop individual long-term care and life plan with person with a rare disease and family
- Inform about existing resources (services, rights, compensations)
- Encourage and support health literacy, self-care, family resilience and compliance to treatments
- Develop working methods that support empowerment of patients and families

**3. Assess/monitor needs & be an observatory of those needs**

**4. Holistic and patient-centred care planning and care co-ordination**

- Identify resources available in the territory - services and support
- Refer to available resources and speed up access to services and support
- Simplify care pathways & support navigation for patients/families and professionals
- Support transition periods & deliver continuous structured support to prevent care ruptures and facilitate independent life
- Facilitate work of care providers as a multidisciplinary team: create the link/facilitate coordination between services & professionals; mobilise them to build networks

**5. Hub of information and knowledge**

**6. Inform, support, train and empower professionals involved in care provision**

**7. Facilitating networks of service providers**

**8. Prevention of avoidable high risk situations**

- Identify most vulnerable cases at risk of serious situations and possible prevention measures
- Follow up patient to avoid over-use of health services for lack of information



✓ **Outline of training for case management for rare diseases**

**1. Introduction**

- Project presentation
- Vision, definition of case management
- Skills, qualification and abilities for case managers
- Case studies – other national experiences

**2. Rare diseases - general information**

- Testimonials from patient and families
- Access to diagnosis/diagnosis tools
- Assessment of the degree of disability
- Access to education
- Employment
- Social inclusion

**3. Case management and communication**

- Communication
- Efficient communication: personal and virtual communication
- Developing communication skills
- Conflict solving & Networking

**4. Resilience**

- General information on family resilience
- Empowering patients and families
- Announcement of diagnosis and impact on family
- Personal development and self-esteem

**5. Development and coordination**

- Description, definition and possibilities
- Legislation - rights and obligations, health and social welfare and insurance system
- Finding the right information and accessible
- Available Services
- Organising trainings for professionals

**6. Work methodology**

- Methodology of case management for people with rare diseases and their families
- Ethics and data protection
- Tools used in case management for rare diseases
- Supervision of case managers

**7. Fundraising**

**Skills for Case Manager:**

- Positive approach
- Effective communication and negotiation skills
- Ability to perform ongoing evaluation
- Critical thinking and analysis
- Ability to plan and organise
- Ability to promote client autonomy and self-determination

✓ **Other issues referred during the discussion:**

- Case manager can be **any type of professional** with proper training; bachelor's degree advised;
- **Roles may vary according to country**, based on local reality and needs;
- It's good to have **different profiles in the case management team**: complimentary knowledge and expertise; it's an added value if the case manager has a personal experience with a rare disease;
- The **training curriculum has to be adapted** to the previous training of the case manager candidate;
- There should be a **system of protection for case managers**: peer support, supervision, resilience;
- **Local professionals' job description should include collaboration with case managers**;
- **Training of professionals** in the case manager's network is important: accredited courses should be used; different professional societies should endorse the case manager training; online trainings;
- **Virtual case management** should be considered for those using IT or having a busy schedule;
- **Networking** is key: it helps beneficiaries and works as support system for case managers;
- Case manager's **experience can be used to design services** which are not available in the region;
- **Helplines** can be a tool to support case management (via advice);
- **Case managers train and empower patients and family members**; and to see case by case if the patient/family can handle the tasks themselves or if the case manager needs to intervene;
- **Patients empowered may require fewer interventions** from case managers but the collaboration can be intensified in transition periods;
- **Case manager wording**: "case" is not human enough; proposals like "care coordinator for rare diseases" or "care facilitator" might be discussed in future development of this profession;
- **Sustainability of INNOVCare's pilot in Romania**: proposal of having a small team of case managers (2-3 people) in every region (county), trained to create the regional networks in their counties.