



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

Up-scaling challenges & opportunities

*Findings of INNOVCare's work to develop
up-scaling roadmaps for selected MS*

Irina Vana, Ursula Holtgrewe, Barbara Glinsner
ZSI - Zentrum für Soziale Innovation

Conference: Advancing person-centred and integrated care for rare diseases and
complex conditions across Europe— Brussels, 5th September 2018

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This project is co-funded by
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Upscaling social innovations

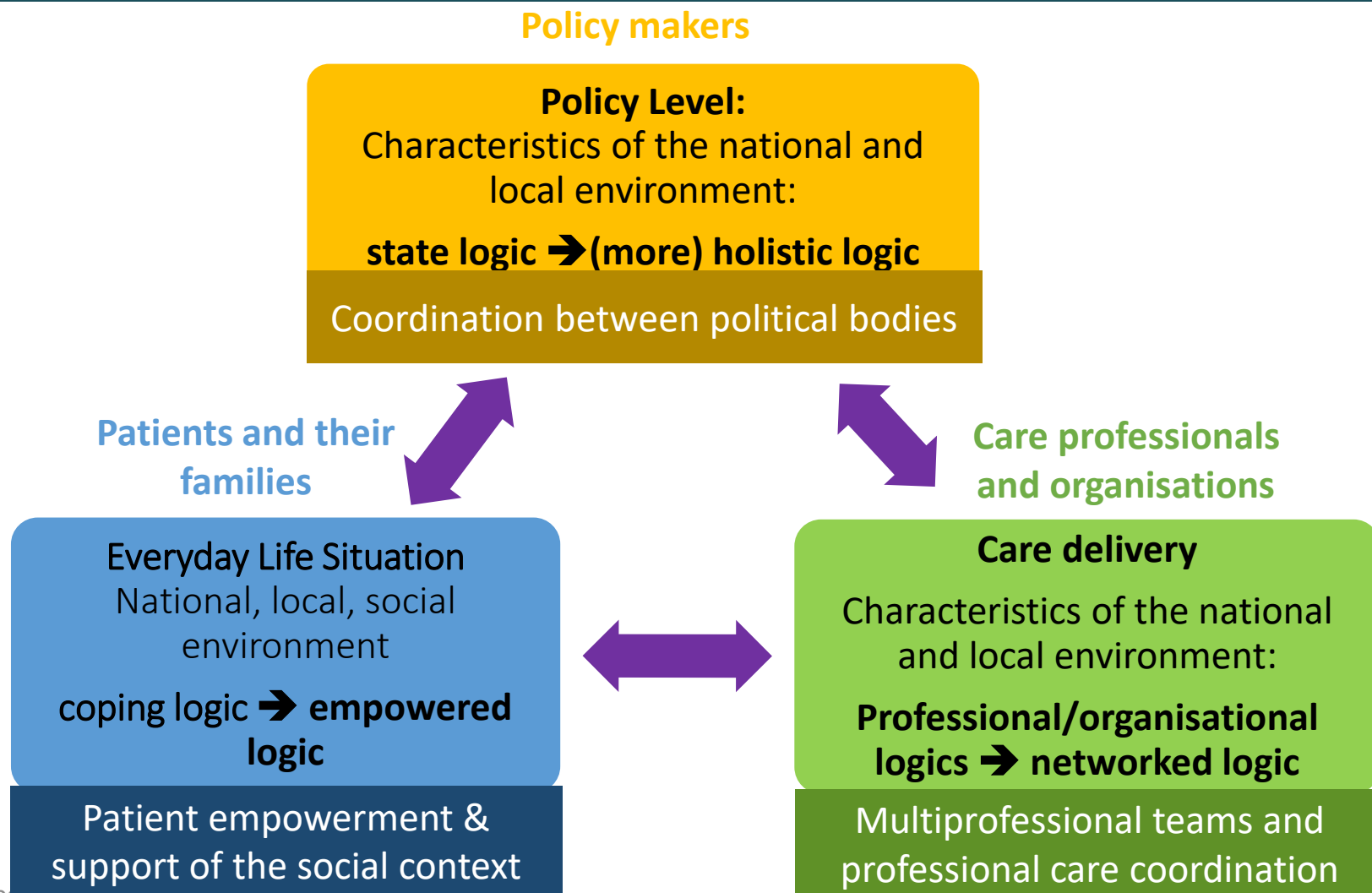
*“... **deliberate efforts** to increase the impact of health service innovations [...] in pilot or experimental projects so as **to benefit more people and to foster policy and programme development on a lasting basis.**” (WHO)*

- 1) Identifying “**opportunities and barriers** at broad institutional scales” (Westley et. al. 2014, 4) using a comparative perspective (**AT, ES, RO, SE**)
- 2) Stakeholder Involvement
 - Identify relevant stakeholders
 - Share knowledge and establish (strong) relations
 - Create a shared vision of integrated care

Methodology

- Interviews with 32 experts from **Austria, Romania, Spain and Sweden**:
 - **Policy**: national and regional policy makers and administration (health and social)
 - **Service providers and care giving professionals**: Social and health care
 - **Patient representatives**
- (Online) group discussions with experts to discuss the first results
 - Discussion and validation of findings
 - Connecting experts
 - Trying to discuss possible next steps in the up-scaling process

Interrelated levels of intervention and their stakeholders



Structural coordination & cooperation: Coordination between Political Bodies

- **Challenges**

- Fragmentation of political domains, federal states and regions
- Legal frameworks and different funding schemes
- Dependency on personal engagement of decision-makers

- **Opportunities**

- Building capacities for collaboration: budget, qualified personnel, learning to collaborate across domains
- Joint Policy Boards for Rare Diseases

- **Tools**

- Relating top-down and bottom-up approaches: stronger involvement and accountability of local administration and patient organisations
- Coordinated budget for health and social care provision beyond co-funded pilots

Multiprofessional teams and professionalized care coordination

- **Challenges**

- Doctors-centered health care systems
- Coordination of care is a burden on doctors, patients and patient carers
- Risk for the continuity of care

- **Opportunities**

- Case Management professionalises care coordination & helps patients navigate the system and the bureaucracy
- Building on existing resources & other health care innovations
- Recognition of the competences of various health and social care professionals in an occupational and interactive sense

- **Tools**

- Public tenders to require collaboration and coordination across domains
- Multidisciplinary intervention plans/protocol of treatments
- Training, knowledge, information for different professionals (teachers, social worker, doctors,..) together with patients

Empowerment of patients & Support of the social context

- **Challenges**

- Professionals lack confidence in the patients' abilities to decide on their care needs (medical paternalism)
- Limited opportunities for family members to obtain support
- Lack of awareness of and support for teachers, day-care teachers, work colleagues and school mates
- Empowerment is considered a domain of patients' organisations

- **Opportunities**

- General awareness raising
- Legal frameworks supporting inclusion in social and economic life
- Connecting agendas of disability and Rare Diseases where appropriate
- Involvement of patients' organisations in European Patient Advocacy Groups

- **Tools**

- Smart combination of professional and peer-to-peer support
- Timely and preventive support for patients and family members
- Targeted information and support for teachers, social workers and other social care professionals

Conclusions

RD as a „liminal case“
for better-quality health
and social services

Also well-organised,
well-networked,
experienced example

Policy makers

- * RD fosters joint efforts in different policy fields at political planning
- * European pilots contribute to the distribution of multidisciplinary expertise across contexts

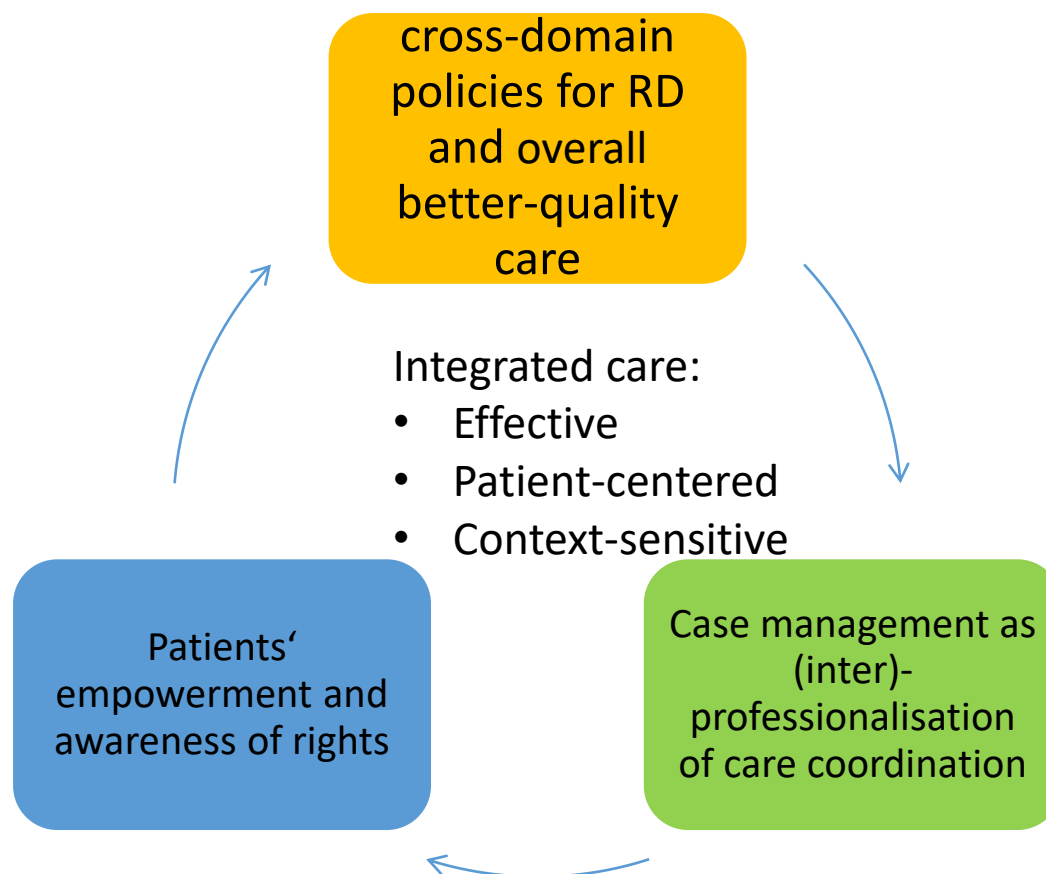
Patients and their families

- * Awareness of rights as one immediate effect of case management
- * Empowerment is not only the job of patient organisations - wider vision to keep care innovations “on track”

Care professionals and organisations

- * Getting the right mixture of tailored RD services and the integration of RD into mainstream services
- * Finding the best point of service for CM and similar services in different environments
- * Case Management as one way to move towards integrated care

A positive loop –INNNOVcare and many other efforts



Aiming at more “really” inclusive facilities contributing to an open-minded and responsive society



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Thank you

Irina Vana | vana@zsi.at

Ursula Holtgrewe | holtgrewe@zsi.at

Barbara Glinsner | glinsner@zsi.at

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