

INNOV Care

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

Special Needs and General Developments: Directions of Scaling the INNOV Care Pilot

Ursula Holtgrewe, Nicol Gruber

INNOV Care Workshop on Scaling Innovative Care Delivery for Rare Diseases and Complex Conditions, Vienna, 6-7 October 2016

www.innovcare.eu



 This project is co-funded by the European Union

The Social Innovation angle on Scaling

Social innovations have scaled when “their impact grows to match the level of need” (Gabriel 2014, BENISI 2016).

- More beneficiaries
- Wider geographical area
- Wider-adopted methodology
- Extension to other areas

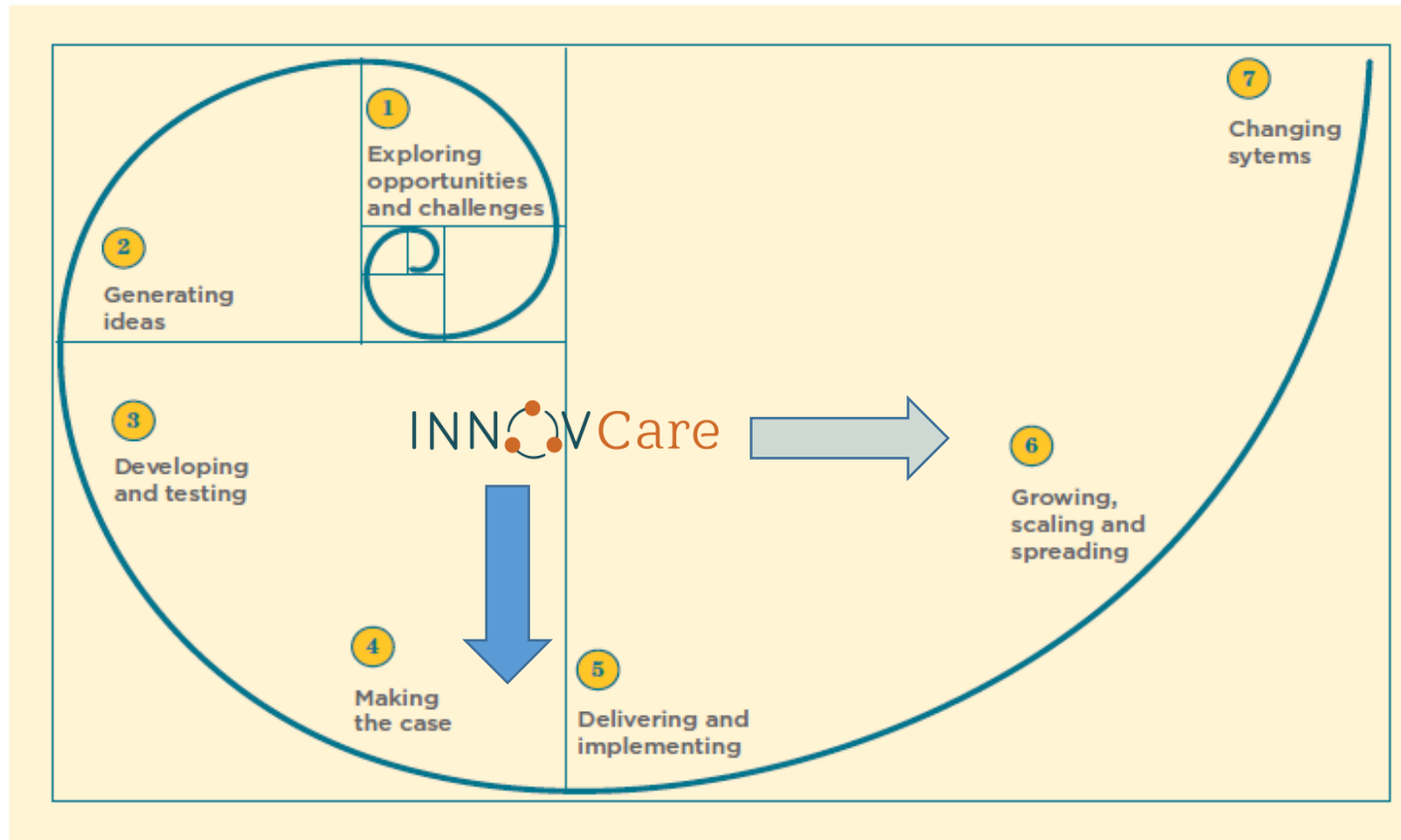
AND

- Hopefully economies of scale
- Partnerships
- After proof of concept in original “market”/context

Also “iterate, build on and add to social innovations” to increase impact on need (Gabriel 2014), complementary, re-combined social innovations

The Social Innovation angle on Scaling

SOCIAL INNOVATION SPIRAL



Source: Murry, R., Caulier-Grice, J. and Mulgan, G. (2010) 'The Open Book of Social Innovation.' London: NESTA and the Young Foundation.

Scaling something complex

A somewhat linear story – in the health and social care context?

Wider trends and developments into similar directions:

- Ageing societies
- Deinstitutionalisation
- Patient empowerment and autonomy
- Social inclusion
- Resources: “doing more with less”

In very varied national and regional contexts of health and social systems.

Where can INNOVCare contribute to better health and social service delivery and what can be scaled?

Health and social care and rare diseases – the general and the specific

- Fragmented health and social care organisations, offering highly specialised services - **Specialisation**
- Need to integrate health and social care services, especially for people with complex health and care needs - **Integration**
- Rare Diseases: varied, complex, progressive and rare: access to specialists and continuity in care – **(specialisation + integration)²** - a liminal case for health and social care?

Directions of scaling up INNOV-Care

- Incorporate needs of patients with rare diseases into **universal strategies** to provide integrated and innovative care to those who need it (a kind of “mainstreaming”) ?
- Or do concepts of integrated and innovative care need to be adapted and **tailored** to the particular needs of this group of patients?
- Or: a bit of both, recombining and complementing innovative care elements?

Methodology

- A literature review on „neighbouring“ approaches (integrated, innovative, holistic care, SI in health and social care)
- Expert Interviews with researchers and professionals from existing integrated care projects
 - Prisma, Québec, Canada
 - Esther, Sweden
- Focus group with patient representatives and service providers(Gothenburg, Sweden) „Making it happen in other countries“
- Workshops/focus groups with patient representatives, experts and policymakers NOW
- *To come:*
 - *information on possibilities of EU structural funds*
 - *Identification of likely upscaling contexts*
 - *Country visits with stakeholder discussions*
 - *Devlopment of roadmap for upscaling*

Findings: General Advice from integrated care etc.

- Individual care plans and holistic care assessment to ensure continuity of care
 - multiple uses to connect patients, professions, providers
- Case management: personal relationship between case managers and recipients/ families
 - But pay attention to professional networks
- Multifunctional teams with well-defined roles
- Well-connected provider network
- Implementation of round-tables between stakeholders at all levels
- Political leadership and commitment

Findings: initiatives in rare diseases

- Integration: „if all that exists would work better, it would be good“
- Technical solutions (platforms, helplines) smartly combined with f2f contacts, training, regional expertise
- Role of volunteers: peer-to-peer support among patients, student volunteers in helplines, summer camps etc – also to disseminate RD knowledge in professional education
- Policy: Importance of sound, concrete evidence: budgets, value-added, social investment
- networking and dissemination, active role of empowered patients (policy, media)
- Getting knowledge on rare diseases into professional education (medical, social, also teachers) – the more inclusion, the more bureaucracies to contend with!

Integration of Health and Social Care Systems – Key issues

- „Integrated care should center on people from birth to death“
- „The complexity of conditions people have requires a paradigm shift from hospital care to community based care“
- „We need to focus on fostering the autonomy of a person rather than measuring the burden of the disease“
- „Wiser way of using the resources“
- „Globality of the needs that require integrated care, but barriers are not the same [...] we have to account for particularities“
- Proactivity: „Action in health and social care needs to be taken before it is urging“

Patients' and families' needs

- Patients need to be actively involved from the beginning
 - Empowerment and engagement focused on autonomy
 - Also contributes to solution-orientation
 - „When patients are in the room, the focus is on how to help the patient. But when the patient is not in the room professionals stop seeing the person as a whole, professionals start to blame each other, they only see their part“
 - „Why not let patients be part of the solution?“
- Families and social networks of patients need to be included
 - „If you forget the family, you have 2 patients“
- Continuity of care through case managers working together with main care giver and family doctor
 - „If you know a patient very long, you might know what s/he wants and needs, even if s/he cannot express what s/he wants [...] continuity of care is an indirect way of giving power to patients“

Assessment tools and care plans

- Single assessment tool
 - Provides a common language
 - Informs local managers and policy makers
- Care plan written on paper
 - „If you have a plan and the wishes and needs of the patients are included in the plan, you can find strategies how to meet those needs“
 - Plan needs to be re-discussed over time: „Are this still your wishes and needs?“
 - „But you also need a Plan B [...] patients want to know what happens to them if Plan A isn't successful, which happens a lot“
- Creation of a common language between health and social care professionals
 - „A Care Plan is a very strong strategy to ensure fundamental continuity; it links the management and the clinical model“

Organizational aspects and professional roles

- Professional roles should be clearly defined
 - „Change is never easy [...] of course it was hard for everybody at the beginning, but the goal to improve patient care and patient satisfaction so that nobody falls between the gaps helped [...] a clear focus on why we had to change the way we were working and organized helped in those times when it was really hard“
- Define people who take over responsibilities
 - „At the beginning we thought it would all go by itself, but that did not happen“
- There needs to be a framework for the training of case managers
 - „The framework was created years later. That was too late“

Organizational aspects and professional roles

- Meeting places for professionals from different institutions
 - „A big part are meeting places for professionals to share information and knowledge [...]but professionals do not always have time to go to these meetings, their chiefs have to give them time, but time is money“
 - „Regular meetings including staff from different organizations helped to eliminate prejudices between organizations [...] during the meetings we always asked: How can we collaborate“

Policy and institutional level

- Power of law and change at clinical level have to happen at the same time
 - „There was a strong faith in the power of law but it is also about how local managers plan and understand change [...] they put a lot of energy in changing the law, but they put no energy in training“
- Budget should be an initial part of the innovation
 - „The capacity of local managers to take needs of the population into account is strongly a financial matter“
- Help-it happen rather than make-it happen and let-it happen
 - „It is essential to distinguish between top-down and bottom-up approaches“

What can we learn?

- **What is the agenda of changing?**
- What are the priorities in your country?
 - National and local contexts are extremely important
 - Give tools, but every context needs to find its own way
- General vision, but at the same time a strong strategy
- Definition of clear goals on all levels
 - What can be achieved in what time frame?
 - Goals need to be clear but ambitious at the same time and center on patients as well as their social networks
 - „What does Person xx need? What does s/he want?“
 - „How can we support the family/ the social network of Person xx?“

What can we learn?

- Communication is essential
 - How can a common language between (and within) different organisations be created?
 - „Build strong relationships and rely on these relationships“
- Working on different parts of the spiral simultaneously
- Sharing „work in progress“, incremental and tentative developments early and often

INNOV Care

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

Thank you

Ursula Holtgrewe, Nicol Gruber | holtgrewe@zsi.at, grubern@zsi.at

www.innovcare.eu



 This project is co-funded by the European Union

The information contained in this publication does not necessarily reflect the official position of the European Commission