

RD-ACTION and INNOVCARE Workshop:

Creating a Sustainable Environment for Holistic & Innovative Care for Rare Diseases & Complex Conditions

Dates: 12th (from 9am) and 13th April 2018 (until 1:30 pm)

Venue: Frambu Resource Centre, Norway

Ethos of RD-ACTION workshops

A key objective of the RD-ACTION Policy WP workplan is to continue to provide support to the rare disease community in conceptualising, implementing and evolving robust ERNs capable of meeting the needs and expectations of people living and working with conditions requiring a specific concentration of expertise. As the ERNs evolve, shared consensus guidance and policy documents - generated with the ERNs, for the ERNs- is important to support the Networks but also to ensure a baseline compatibility and interoperability (at various levels) between the ERNs. These workshops are collaborative events, for which input is sought from RD-ACTION Partners, DG Sante, the ERN Coordinators (particularly via the Working Groups), the Board of MS of ERNs, and more.

Ethos of INNOVCare Workshops

The EU-funded INNOVCare project voices the everyday challenges of people with RD and aims at bridging the gaps in coordination between health, social and support services in EU MS. The project is developing and testing a holistic, person-centred care pathway: using a [resource centre](#) for RD and regional case managers, to centralise the coordination of care and to ensure the link between care providers. This care pathway aims at: relieving the care burden; promoting the transfer of information/expertise between providers; creating efficiency gains for national authorities; strengthening partnerships between public, private and civil society organisations; and supporting the EU and MS in implementing structural reforms in care systems. INNOVCare's multi-stakeholder workshops focus on identifying key elements and co-creating collaborative strategies to advance multidisciplinary and integrated health-social care for people with RD and other complex conditions. The project Advisory Group, composed of 17 representatives of national authorities from 14 EU countries, attends the workshops. Previous project workshops: [Improving Integrated Care for People Living with RD](#) (2016, Sweden); [Scaling Innovative Care Delivery for RD](#) (2016, Austria); [Advancing Holistic & Innovative Care for RD](#) (2017, Romania). More information on INNOVCare: [Summary](#) (activities, partners, Advisory Group); [PowerPoint presentation](#).

Context for this workshop

Over 3,000 people living with a RD and carers responded to the first Europe-wide survey on the impact of RD on everyday life: ['Juggling care and daily life: The balancing act of the rare disease community'](#) (2017, 42 countries, 800+ RD). The survey's results show that RD have a severe impact:

- The time and care burden is substantial for a majority of patients and carers;
- RD have a strong impact on work-life balance, leading to absence from work, hampered professional activity, and economic burden;
- Patients and carers are faced with complex and hard to manage care pathways, which include for example the need to visit different services in a short space of time and lack of communication between service providers;
- Patients and carers feel badly informed about their rights and feel that social services are badly prepared to support them; and
- RD have a significant impact on the mental health of patients and carers.

The survey was conducted via [Rare Barometer Voices](#), the EURORDIS survey initiative, in 23 languages across 42 countries and was carried out in the scope of the INNOVCare.

The implementation of multidisciplinary and integrated health and social care pathways is essential to overcome these challenges, leading to increased quality of life for patients/carers and to efficiency gains for the national health and social care systems.

The [Commission Expert Group on Rare Diseases Recommendations to Support the Incorporation of Rare Diseases into Social Services and Policies](#), adopted unanimously by all MS in 2016, state the important role of ERNs and CEs (recommendations 2 and 3) in supporting and facilitating integrated care for people with a RD in line with the principles defined in the [EUCERD recommendations on Quality Criteria for CoE on RD](#) and in the [EUCERD recommendations on ERNs for RD](#) i.e.:

- *CE bring together, or coordinate, within the specialised healthcare sector multidisciplinary competences/skills, including paramedical skills and social services CEs provide education and training to (...) non-healthcare professionals (such as school teachers, personal/homecare facilitators);*
- *CEs contribute to and provide accessible information adapted to the specific needs of patients and their families, of health and social professionals;*
- *RD ERN need to collaborate with each other, as well as with patient groups, health and social care providers;*
- *RD ERNs follow a multi-disciplinary approach;*
- *RD ERNs could function as a platform to share experiences and promote cooperation between MS, to develop precise descriptions of the services required and elaborate common guidelines.*

Aims of the Workshop

- To affirm the role of Centres of Expertise/ERN Healthcare Providers can play, in providing integrated and holistic care for RD, and to present case studies of Centres demonstrating effective and innovative practices

- Explore how ERNs can add value by expanding/improving the provision of integrated care for people living with RD: both in terms of upskilling practices at constituent CEs/HCPs and more widely, as a Network.
- To exchange on the progress of INNOVCare's pilot of case management for RD (ongoing in Romania), with a focus on implementation and evaluation;
- To discuss a range of key issues to support the implementation of integrated health-social care for people living with a RD across Europe, with a focus on sharing/upscaling good practices and on sustainability

Preliminary Thoughts: How might ERNs positively impact the quality and availability of integrated, holistic for rare disease and complex conditions requiring a concentration of expertise?

ERNs could perhaps:

- Spread understanding of the benefits of joined-up, holistic care pathways for patients (encompassing less strictly medical professionals, such as physiotherapists, psychological therapists, and social support appropriate to the specific needs of people with rare diseases and their families)
- Support and propel the drive to identify how best to provide care for patients with rare and complex conditions and define patient pathways (e.g. ERNs may help to define best practices and support their inclusion to comprehensive clinical practice guidelines or care guidelines)
- Create personalised health and social care plans for people with rare diseases, possibly both those receiving virtual referrals and the patients visiting constituent HCP
- Engage in tertiary prevention activities, including the creation of dedicated guidance from the ERN for patients and families and for local health and social actors (some activities may of course sit more logically with the actual Centres of Expertise i.e. the HCPs here)
- Embed good practices to support integrated care for patients in their constituent HCPs (and eventually 'affiliated' partners), and in time help to diffuse good practices to broader health systems
- Contribute to the collection and integration of data, to improve knowledge and understanding of rare diseases and the impact of patients and wider society

Expected Outputs (to be adapted as workshop participants recommend):

- A Workshop Report
- Summaries of the breakout sessions
- An output (perhaps 'Recommended practices' document) elucidating the added value ERNs might play in promoting integrated, holistic care for rare diseases and conditions requiring a concentration of expertise
- A 'best practices' resource list, composed of useful outputs from INNOVCare and related initiatives which could be useful for ERNs (e.g. Case Manager factsheet, case studies on exemplary Centres of Expertise and their approach to integrated care provision)

Participants will include:

- Policy makers - including national/regional competent authorities e.g. INNOVCare Advisory Group and former members of the Commission Expert Group on Rare Diseases/Board of Member States of ERNs
- Representatives European Reference Networks
- Patient representatives (including an ePAG contingent)
- EC: DG-EMPL and DG-SANTE
- RD-ACTION Partners
- Social services and resource centres for RD

For more information on this workshop, please contact aline.schnieder@eurordis.org or victoria.hedley@ncl.ac.uk (ERN contact)