In the European Union, more than 36 million people (patients and families) are affected by rare diseases. They often lack support from mainstream social systems. The INNOVCare project, which is piloted in Salaj, uses an innovative patient-centred approach to care by linking health services to social and support services.

For that, it appointed 4 case managers, whose role it is to listen, inform, support and empower patients and their families. They also identified resources for services and facilitated the coordination between different services and networks of service providers.

The project is a great success: for more than 120 patients and their families the care coordination became easier, the knowledge of care needs increased while the burden on family care givers decreased, and partnerships between the different services were strengthened.

“It is a terrible feeling of being so lonely and not understood. My case manager answered to my needs and helped me to get my family back and to become more responsible for my care.”