

Interface management concepts in the health care for rare diseases in Germany: A mixed-methods study to develop best practice recommendations

Maja Brandt, Ramona Otto, David Zybarth, Laura Inhestern, Martin Härter & Corinna Bergelt

BACKGROUND

Patients and families affected by a rare disease are burdened in multiple ways and face specific challenges¹. It can take several years until patients receive the accurate diagnosis². Additionally, receiving appropriate health care might be difficult in the home area of patients due to the rarity of the diseases and specialized treatment centers³. Intersectional communication and coordination are crucial to enable continuity of disease management.

OBJECTIVES

- 1) Systematic inventory and analysis of existing concepts and instruments regarding interface management of rare diseases
- 2) Development of recommendations for implementation of a cross-sectional best-practice model

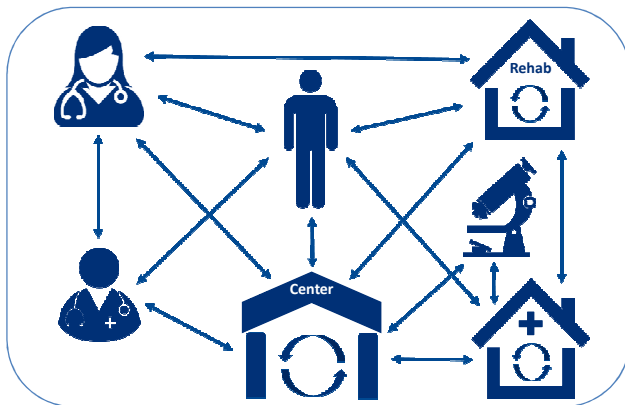


Figure. 1: Example for intersectoral interfaces in the care for people with rare diseases

Flowchart of the study phases

Start 06/2019

Phase I

Analyses of existing concepts of interface management

- Literature research
- Expert workshop and on-site visitations of centers for rare diseases
- Development of an assessment tool for interface management
- Telephone survey of centers for rare diseases and practitioners⁽¹⁾
- Selection of concepts

Phase II

Evaluation of selected interface management concepts

- Interviews with practitioners⁽¹⁾
- Survey of patients with rare diseases or parents/legal guardians
- Interviews with patients with rare diseases or parents/legal guardians

Phase III

Integration of results and development of best practice recommendations

- Integration and aggregation of results from phase 1 and phase 2
- Expert workshop
- Finalisation of consented best practice recommendations

(1) referring and cooperating primary and specialized caregivers

End 05/2021

EXPECTED RESULTS & RELEVANCE FOR CARE

The findings will provide a systematic assessment of the current state of interface management in the context of rare diseases in Germany. A structured assessment tool to evaluate the interface management will be developed. The tool will focus on processes regarding the access to centers for rare diseases and information transfer to and from other health care providers.

At the end of the study, consented best practice recommendations will allow health care institutions to improve their interface management. This results in an improved journey through the health care system for affected patients and their relatives.



Do you have any **questions** about the project?

Please contact us at: ese-best@uke.de

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¹ von der Lippe, C., P.S. Diesen, and K.B. Feragen, *Living with a rare disorder: a systematic review of the qualitative literature*. Mol Genet Genomic Med, 2017. 5(6): p. 758-773.

² (EURODIS), E.O.f.R.D., *The voice of 12.000 patients - experiences and expectations of rare disease patients on diagnosis and care in Europe*. 2009: Paris.

³ Reimer, A., L. Bruckner-Tuderman, and H. Ott, *Mapping health care of rare diseases: the example of epidermolysis bullosa in Germany*. Orphanet J Rare Dis, 2018. 13(1): p. 197.