

The challenge and promise of regional secondary data analysis for rare diseases - the EMRaDi project

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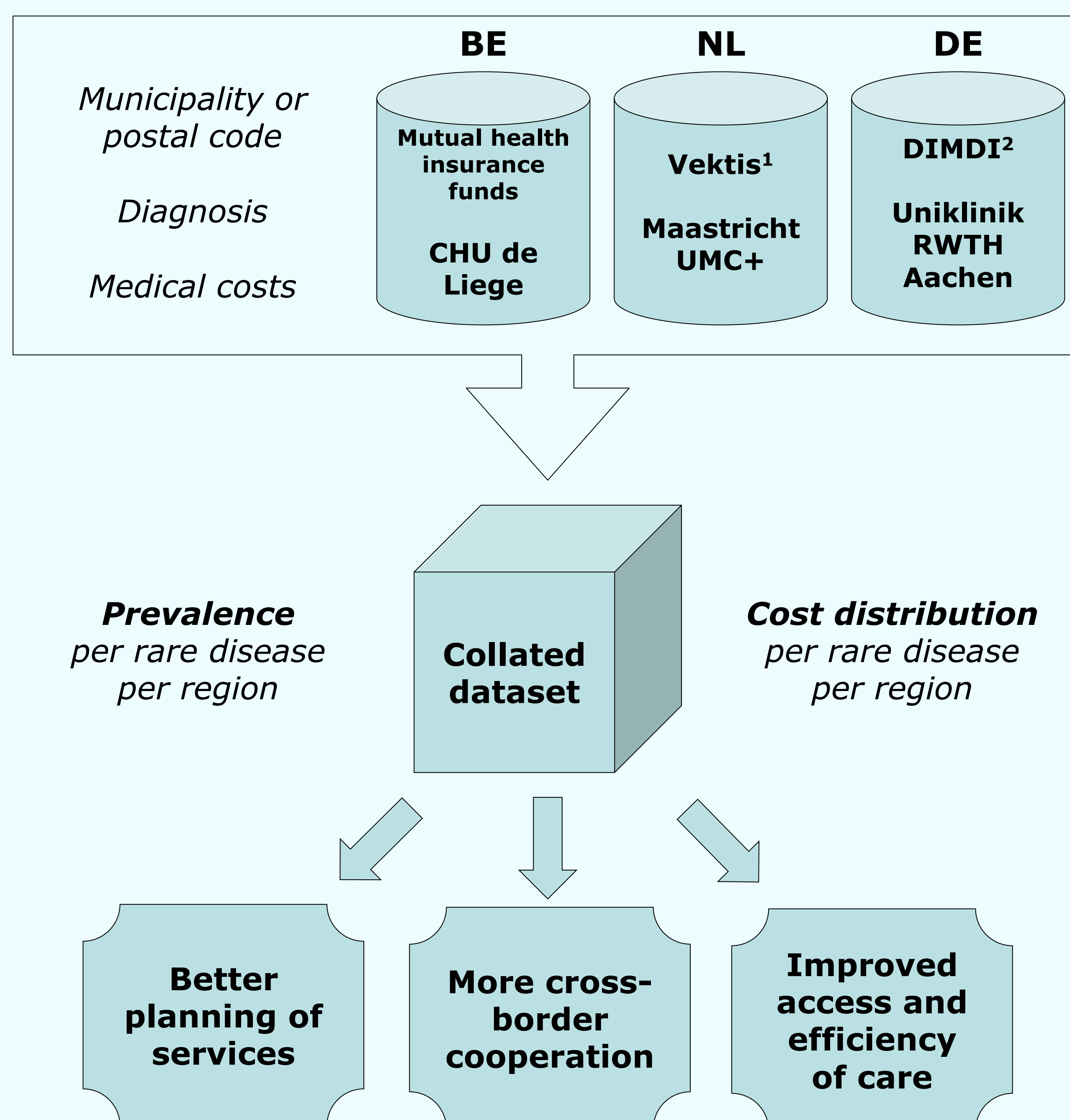
Summary

- Regional data on rare diseases is scarce. In the EMRaDi project, we are filling this gap for the five regions of Euregio Meuse-Rhine at the borders of Belgium, Germany and the Netherlands.
- The key challenges were data access barriers, case definition and risk of deanonymisation.
- Partnering with data holders, performing the analysis *in-house* and exchanging best practices were helpful in overcoming these challenges.

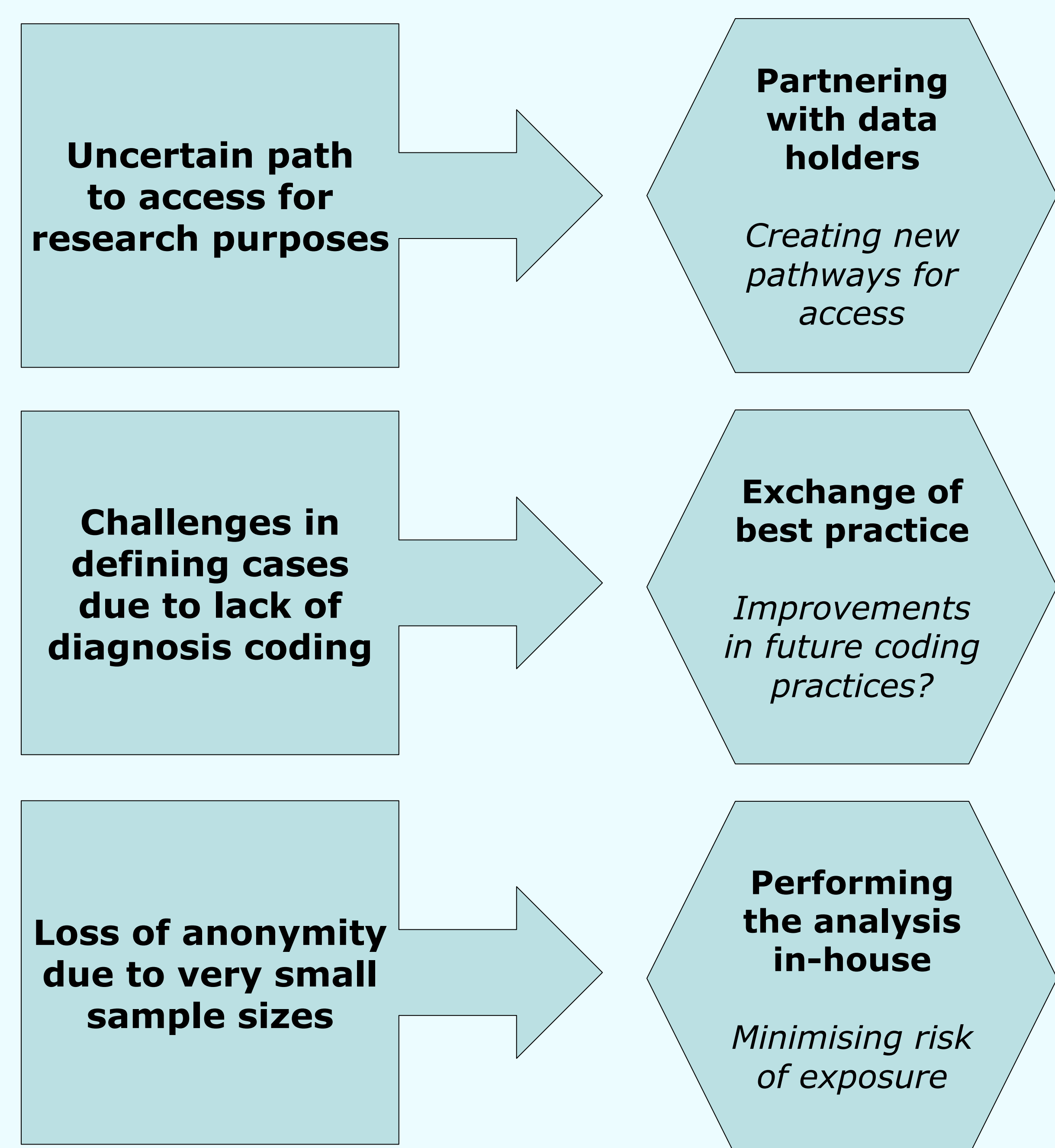
Introduction

- Enhancing regional service provision is just as important as EU-wide or national efforts to improve rare disease care, especially in border regions.
- There is a lack of regional data on prevalence and cost of managing rare diseases.
- Our objective was to mobilise, collate and analyse hospital and insurance claims data on rare diseases in five regions of the Euregio Meuse-Rhine.

Designing regional data collection and use



Challenges to data collection and our solutions



Acknowledgments

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For more information about the EMRaDi project, visit www.emradi.eu.

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