



EMIF Deliverable 12.4: Report on data linkage

Executive summary

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This report presents the results of investigative work to establish the current state of record linkage within twelve EMIF data source partners and develop a better understanding of the challenges that each face when they perform linkage of health records. The goal of this work is to develop a set of linkage good practice guidelines that will help EMIF partners with current and future linkage work. Through this set of guidelines and the details of this report, the work aims to help encourage record linkage and good practice across Europe, where needed and appropriate.

The report commences with an introduction to record linkage challenges that are faced across EMIF partners and more widely outside of Europe. It describes the methodology used to conduct the investigation using semi-structured interview, and the approach used to analyze and note the results. It presents the results as a “snapshot” of the state of record linkage for the participating partners, describing population coverage, linkage techniques, timescales, challenges and areas for improvement.

The report reveals common challenges across the partners, which emphasize timescales of approvals processes and correlations with civic and political anxieties around use of health records. It proposes linkage good practice guidelines that focus on the need for sound technical processes and information handling, meaningful civic engagement to show the importance of linkage, and civic involvement in its governance. It suggests further work around including harmonization with the development of the EMIF Ethical Code of Practice, capitalizing on existing public engagement activities, and testing the guidelines during the establishment of a proposed new mother and child linkage initiative.

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