

The Added Value of Linking Real-World Data Sources

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Background

Real-world data (RWD) sources are being extensively used for the evaluation of effectiveness and safety of medical treatments (1). While electronic health records (EHR) provide a valuable source of granular clinical and laboratory data (2), understanding the capabilities of linkage between EHR and other RWD sources is essential for designing studies that generate wider scope of evidence.

Objective

This review aims to identify cases in which the integration of electronic health records (EHR) with diverse real-world data (RWD) sources, including insurance claims data, physicians' notes, and patient reported experience data, is recommended to build a more comprehensive patient journey.




Methods

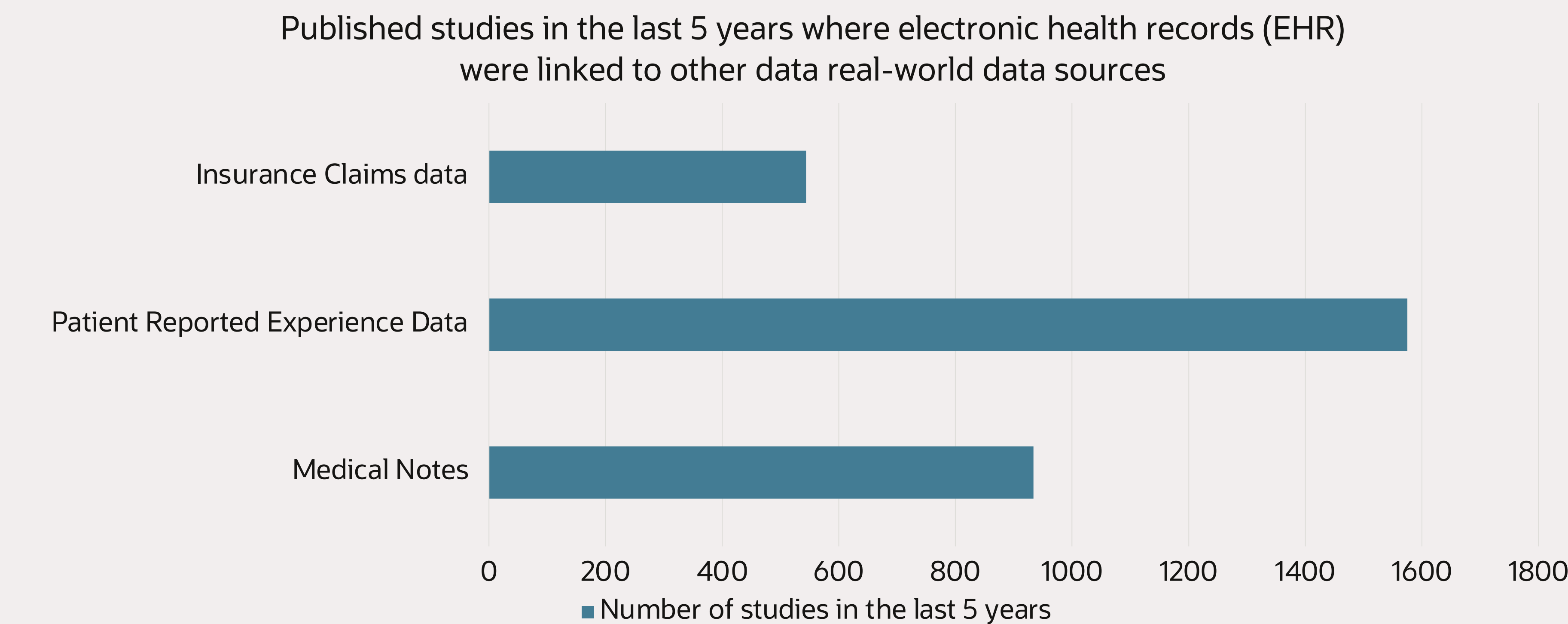
We reviewed published studies extracted from PubMed in the past five years and identified three cases where linkage of EHR with RWD sources should be considered as part of the design of a real-world study. We listed examples and benefits of each type of linkage.

Results

Review Findings

In the past 5 years, in addition to using HER:

-  **934 studies** extracted further data from medical charts/notes.
-  **1,575 studies** ran surveys/questionnaires to collect additional patient-reported data.
-  **544 studies** linked patients' EHR to insurance claims data.

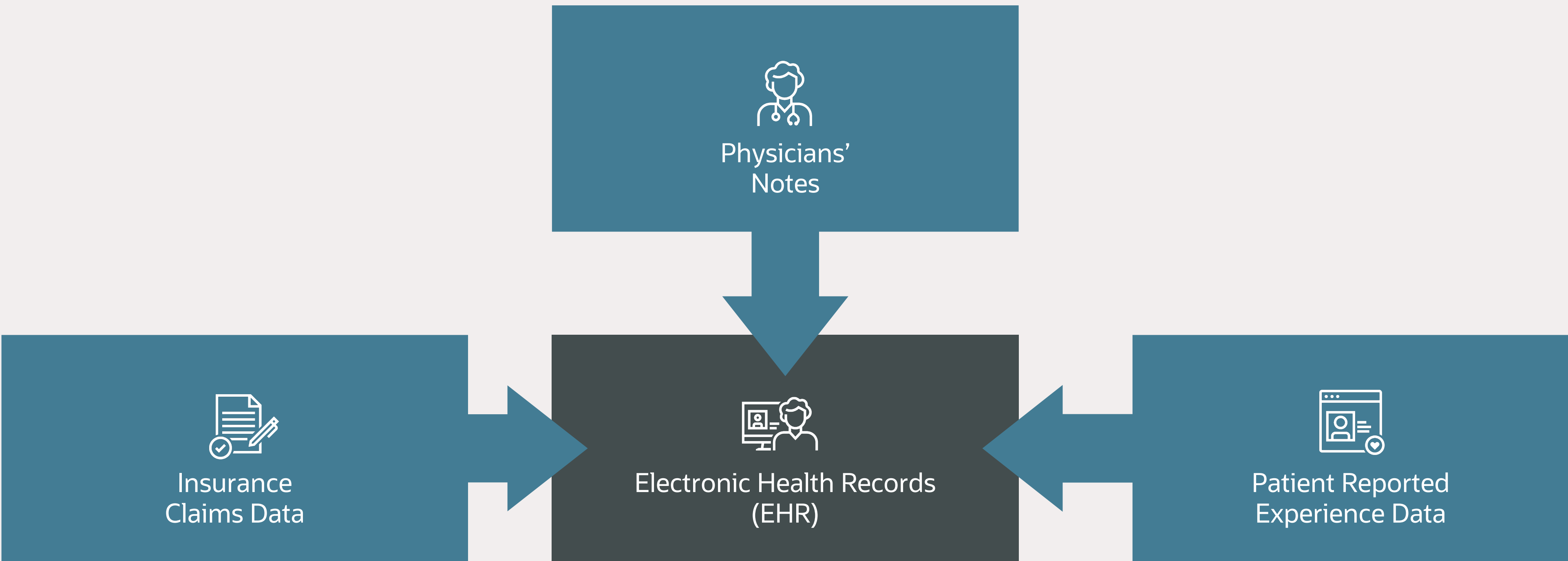


Results

Cases of Data Sources Integration

The use of EHR allowed to establish and measure clear clinical outcomes, as they include granular clinical and laboratory data. We identified the following three cases when linkage of EHR with RWD sources should be considered as part of the design:

- Case 1:** Medical notes and charts provided researchers with an even higher degree of granular details compared to EHR alone, granting access to information about the actual clinical context, such as standardized assessments scales for patients' motor functionality allowing to follow disease progression and symptoms intensity;
- Case 2:** Patient reported information allowed to complement EHR's unknowns or incompleteness, such as ethnicity, race, and patient experiences allowing the delivery of care to be both patient centric and evidence based; and
- Case 3:** Health insurance claims data allowed investigating economic burden of diseases including quantifying the use of the system, and the costs for this use, such as physician visits, which completes the humanistic burden information extracted from EHR.



Conclusions

Understanding the capabilities of linkage across RWD provides valuable opportunity to generate wider scope of real-world evidence, than using a single source separately, thus improving overall patient care.

References

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