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A Scoping Review exploring data linkage needs to maximize the potential of Luxembourg's National Cancer Registry

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BACKGROUND

Population-based cancer registries (PBCR) provide international standardized indicators (e.g.: prevalence, incidence, and survival) and evaluate public health actions including prevention, screening, and quality of care.

Further significant benefits are obtained by linking PBCR data with appropriate secondary sources such as biobanks, socioeconomic or genomic data.

AIM

- To outline the current situation of Luxembourg's National Cancer Registry (RNC), and
- To evaluate RNC's potential linkages with data coming from the Integrated BioBank of Luxembourg (IBBL) and from sociodemographic data sources.

METHODOLOGY

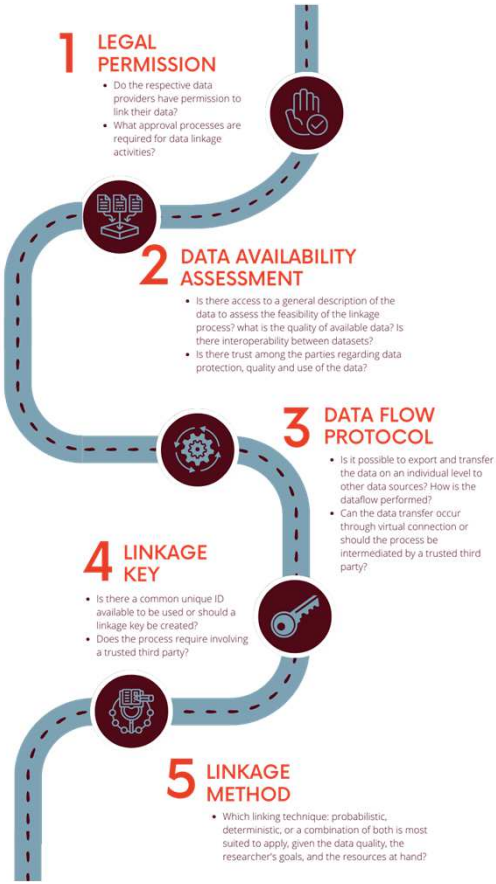
- A scoping review using PubMed and Embase databases was performed, followed by applying a backward snowballing literature search approach in Google Scholar.
- English guidelines, reports, and qualitative and quantitative studies on hospital-based cancer registries, PBCR, and site-specific registries were included.
- For population-based studies involving registries, data linkage methodologies used were also analyzed.
- No limitations were applied to geolocations or year of publication.

RESULTS

1005 articles were identified. After scanning, eight met the inclusion criteria. Moreover, 13 articles were included following the snowball search approach (N=21).
Significant differences between countries were observed, including data availability and harmonization, confidentiality, access to data, exchange, and linkage methods.
Results underline that PBCR's potential, efficiency, and cost-effectiveness are maximized thanks to linkage activities with secondary data sources.

CONCLUSION

This scoping review enabled to identify key questions to be analyzed prior to establishing data linkage being:



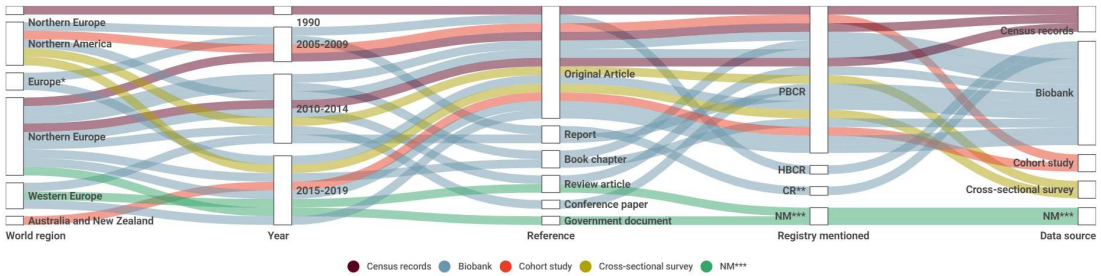


Figure 1. Scoping review results scheme. * more than one world region; ** cancer registry mentioned, but not defined; *** not mentioned.

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