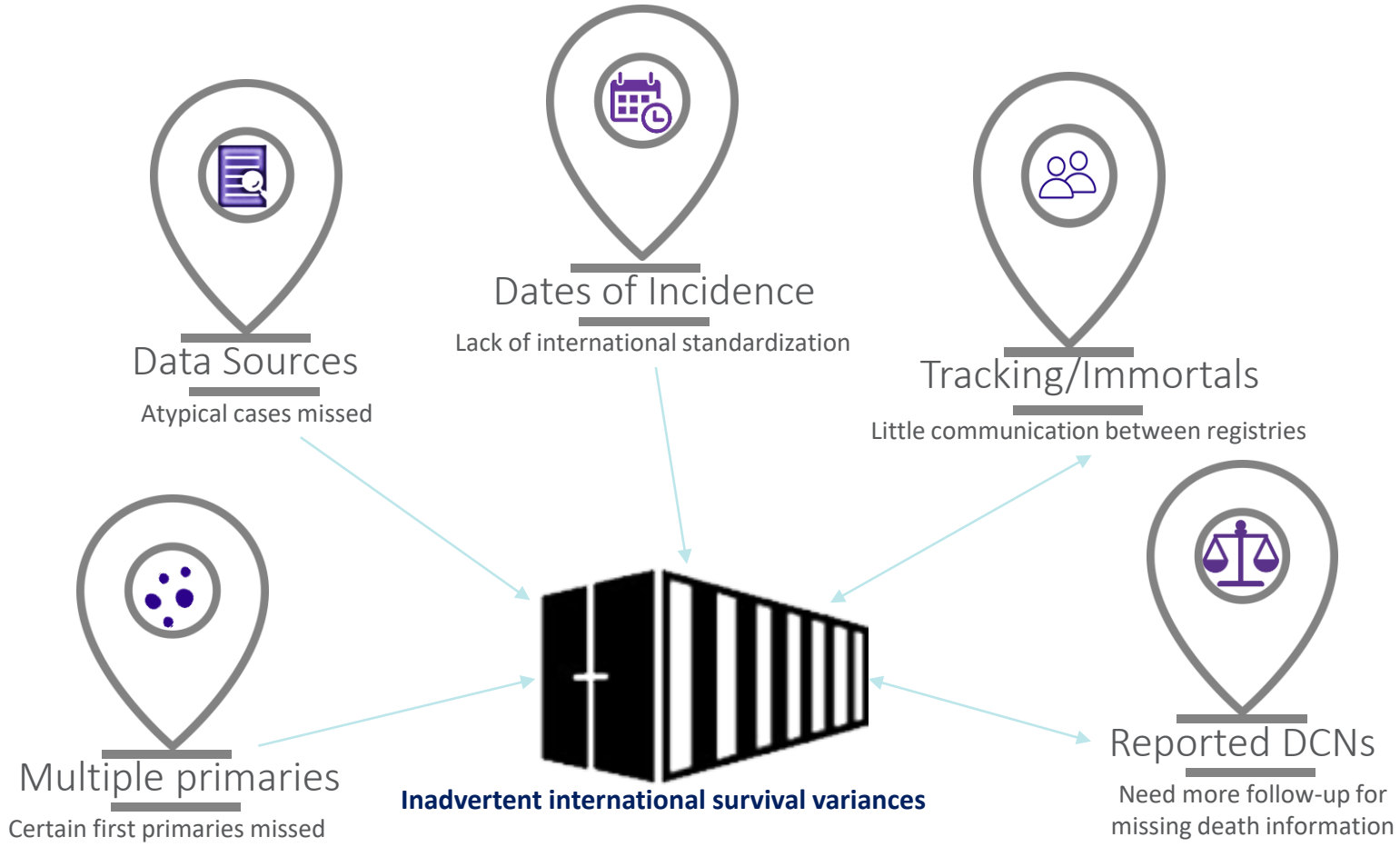
Five ways to improve international comparisons of cancer survival: lessons learned from ICBP SURVMARK-2

Therese M-L Andersson *et al.*

Factors Impacting Completeness of Cancer Registries*



*Impact of these factors is unlikely to fully explain the survival differences observed across jurisdictions, but should be mitigated where possible

Recommendations

1. Gain an understanding of the type of **individuals not obtained from routine sources**, and therefore missed or captured through death certificates
2. Record if a case is a DCI case, and **report the DCI proportion** along with the DCO proportion
3. **Record multiple dates of interest** for each case instead of only one date of incidence, e.g. date of first hospital admission and date of pathology
4. **Include the first primary within each site** in survival analyses, irrespective of previous cancers at another site
5. **Assess if death information is missed** for cases in the registry, especially in countries with subnational registries where death information can be hard to retrieve from other regions

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Data Sources
- Over reliance on pathology reports or hospital admissions may respectively result in overestimated or underestimated survival by missing atypical cases

Date of Incidence and Multiple Primaries
- Lack of international standardization for dates prioritized as DOI
- Mislabeling of recurring/secondary primary tumors as first primaries
- Exclusion of multiple primaries

Immortals
- Emigration out of cancer registry jurisdiction
- Lack of unique identifier/healthcare number

Proportion of DCNs
- Reliance in DCOs, which do not provide follow-up information
- Lack of reporting of DCIs

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Recommendations

Record the specific source/s in addition to describing the underling processes when registering or updating a case.

Record multiple dates of interest for each case instead of only the jurisdiction-defined DOI so it can be standardized between the datasets being compared e.g. include all of date of first hospital admission, date of pathology report, date of CT or MRI scan, etc.

Confirm and include only the first primary within each site in survival analyses, irrespective of previous cancers at another site i.e. exclude multiple primaries of the same site in survival analyses but not multiple primaries.

Mitigate potential missed and/or DCI cases by understanding and capturing atypical individuals/populations not captured from routine sources.

Complete routine assessment of vital status, especially for cancers with poor prognosis.

Review potential missed death information for cases in the registry, especially in countries with subnational registries where death information can be hard to retrieve from other regions.

Record and report complete DCO, including the DCI proportion along with the DCO proportion for completeness.