The power of administrative data in national studies:

Experiences from the Scottish Burden of Disease study

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#ScottishBurdenOfDisease

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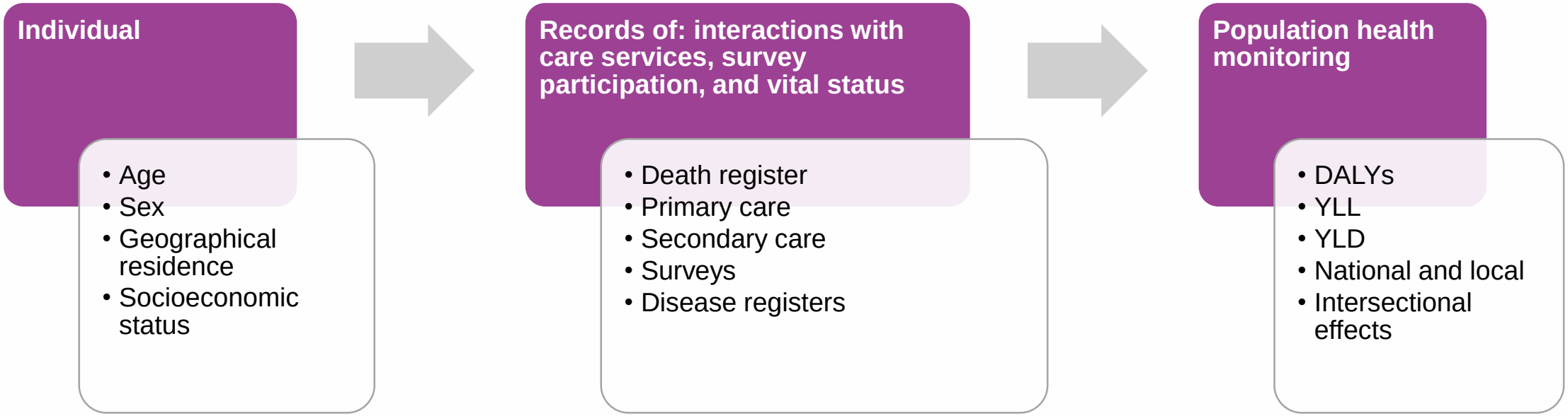
Administrative data in Scotland



- Individual data from cradle to grave ➜ timely availability
- Universal health system free at point of access ➜ full population coverage
- Ability to link across care services for wider searches
- Some structured data available for around 40 years

The benefits of using administrative data

- Autonomy, transparency and alignment with national and local policy needs

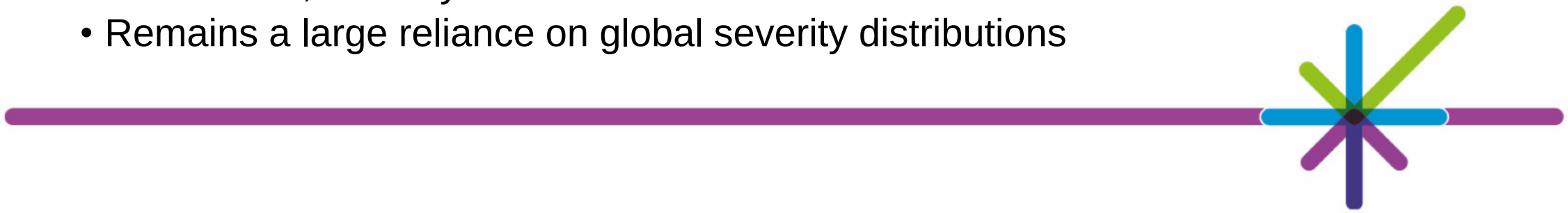
- Understanding and control over uncertainties around data and methodological choices
  - Recognition and endorsement of disease occurrence from stakeholders
  - Co-designing outputs to meet stakeholder needs (A)
  - Avoiding generalisations by generating health state prevalence (B)
  - Appreciation of the real differences: inputs versus method (C, D)

- Enables better appraisal of GBD estimates, and thus gains benefits from occupying a “the middle ground”

(A) – National, regional, health board and local authority level results: https://scotland.shinyapps.io/scotpho-burden-disease
(B) – Impact of national versus global severity distributions: https://doi.org/10.1371/journal.pone.0221026
(C) – Differences in redistribution of Ill-defined deaths: https://www.nrscotland.gov.uk/files//statistics/rgar-invited-chapter/rgar17-invited-chapter.pdf
(D) – Impact of age-standardisation: https://doi.org/10.1186/s13690-019-0383-8

The hidden costs of using administrative data

- Data governance can be time consuming
- National and local expertise is not always readily available
  - Data experts
  - Clinical networks
- Although data coverage is wide, available data is not always appropriate
  - Coding differences
  - Headaches, sensory conditions
  - Remains a large reliance on global severity distributions



Reconciling the costs and benefits

- Being involved in the full process allows us to be clearer about data capabilities and limitations
  - Timely assessment of COVID-19 occurrence and cause of death data to estimate DALYs
- Quantifying the impact of under-reporting and uncertainty, independent of methods
- Increased ability to synthesize knowledge from national and GBD efforts to facilitate clearer knowledge translation for maximum impact