Neuroepidemiological guideline

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Background and rationale

- During 1st ICCN conference,in Munich August 2009 approaches to “bridge the gap” between neuroepidemiological research and practice were discussed.

- It emerged that there were issues with the reporting of neurological research and this was a reason for gaps between evidence and practice for both clinicians and health policy decision makers.

Background and rationale

- Many reporting guidelines exist for different types of study design or different disease areas
- They have two main purposes:
  - they help researchers design and undertake robust studies;
  - they help reviewers and potential users of research outputs assess validity, reliability, and generalisability.
- Examples include:
  - CONSORT for randomised controlled trials; AGREE for clinical guidelines; STROBE for observational epidemiological studies

Background and rationale

- However, based on an examination of the STROBE explanation and elaboration statement there is a need for a new guideline pertaining to the conduct of descriptive health policy research in neurological disorders.
- This project aims to:
  - devise some guidance based initially on stroke
  - produce a set of quality criteria and comparable reporting guidance specifically for common neurological disorders.

Objectives

- Collate and summarise the existing literature on the principles of reporting both clinical and methodological aspects of incidence and prevalence studies of stroke ;
- Produce a draft set of items and principles that exemplify the reporting of incidence and prevalence studies;
- Identify:
  - the extent to which these principles have been followed by published incidence and prevalence studies of stroke
  - how rigour may be lost and how existing reporting could be improved;

Methods

- Identified reporting guidelines for incidence and prevalence studies in general.

- Identified reporting guidelines that are specific to stroke.

- Identified consensus reports, published reporting guidelines using PubMed and Medline (from inception to August 2012).

Methods

- Cochrane Methodology Register, Enhancing the Quality and Transparency of Health Research (EQUATOR) Network website and The US National Guideline Clearing House (up to August 2012).

- Reference lists and bibliographies of published systematic reviews of guidelines or checklists for incidence and/or prevalence studies.

Methods

- Information from the systematic review was used to identify the key pieces of information that:
  - must be included in order to assess potential sources of bias.
  - could be reported as it would be useful for policymakers.
- Created an initial checklist of these key items.

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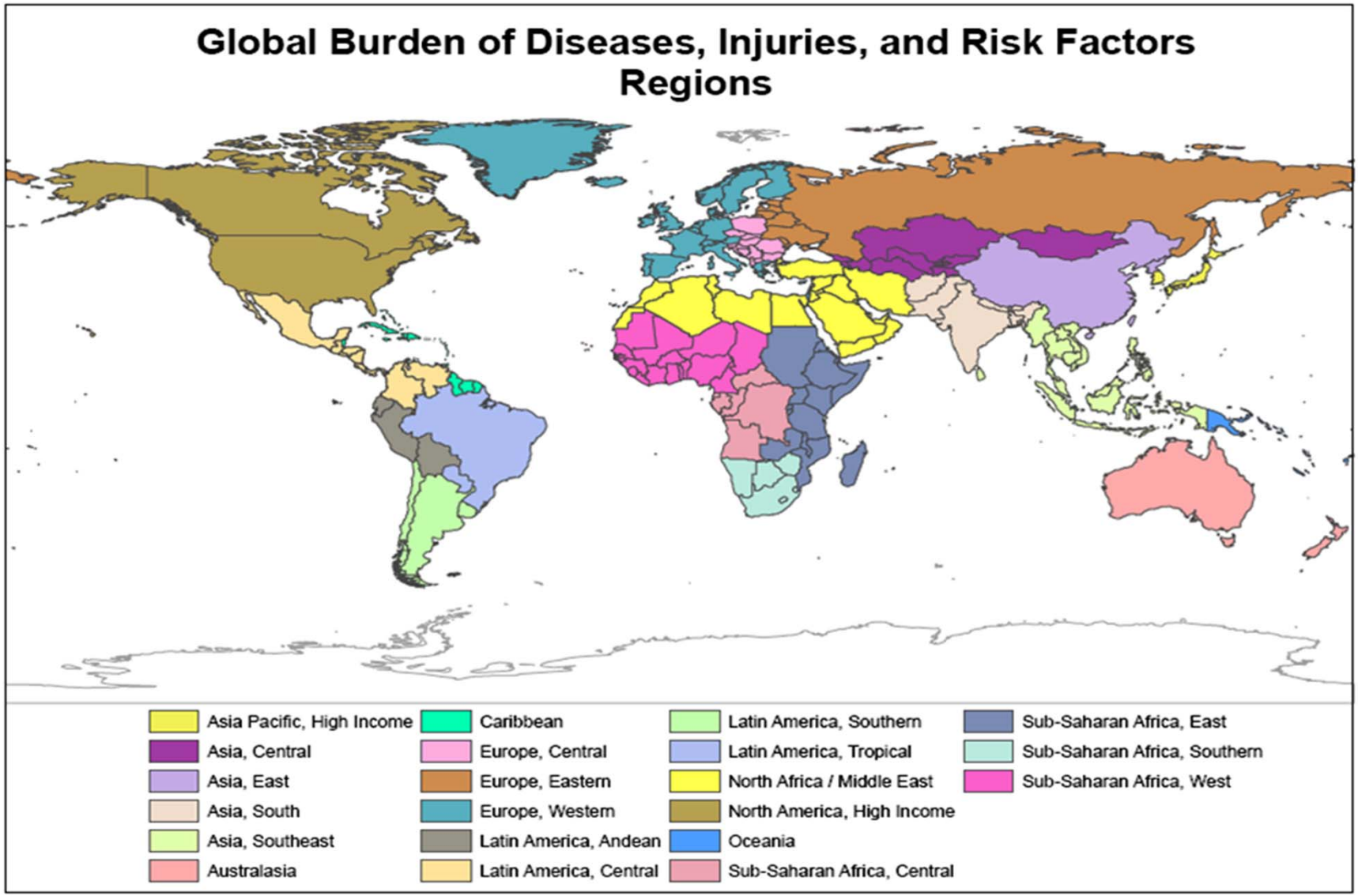


Assessment of relevance of this checklist

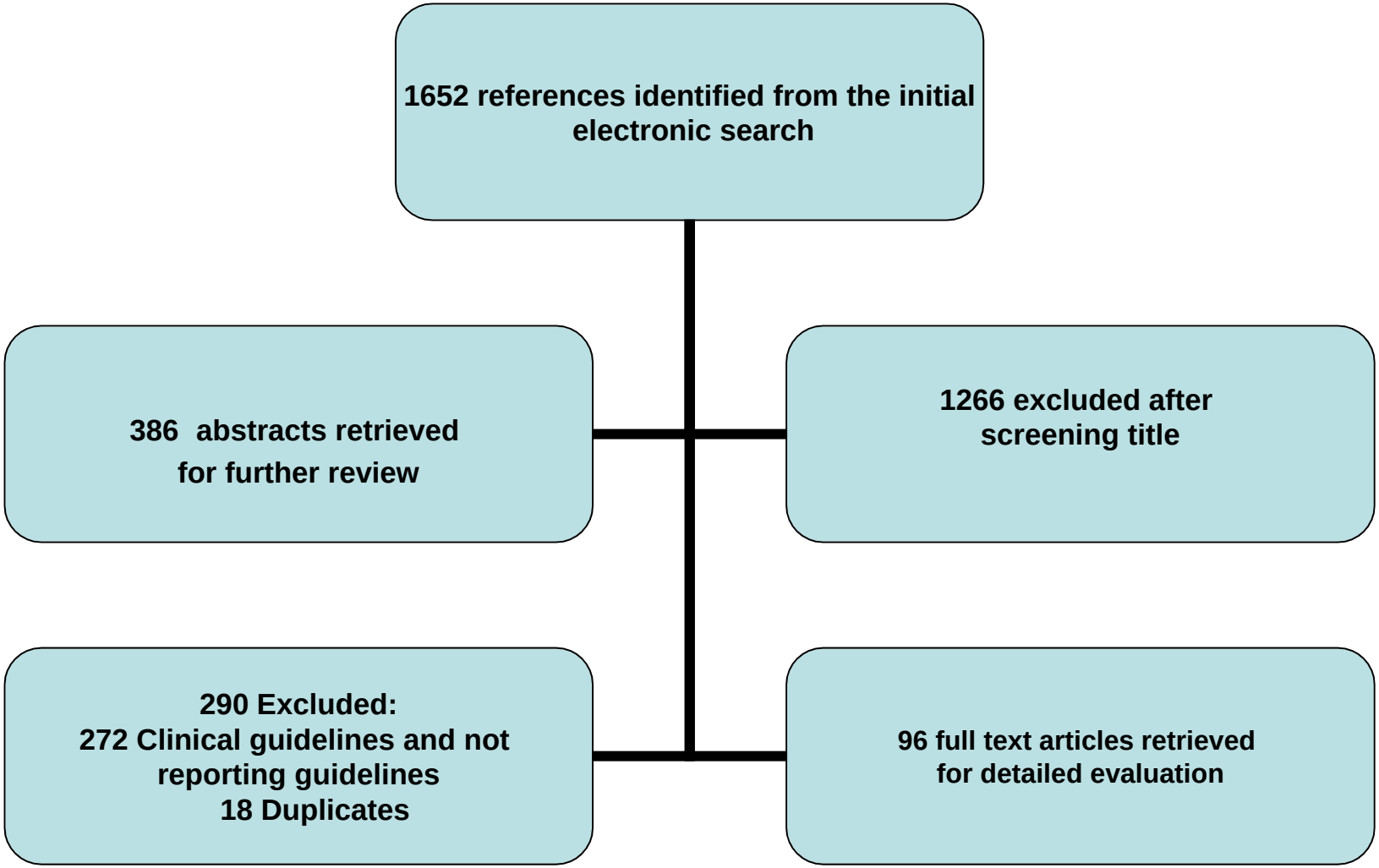
- Reviewed of a random sample of ~30 incidence or prevalence studies of stroke published between 2005 and the end of 2010 identified by the Global Burden of Disease and Injuries (GBD) Stroke 2010 project for inclusion.

- These studies used as a preliminary starting point in order to assess what is actually reported and the quality of reporting of these types of study.

- The aim of this process is to identify areas of deficiencies in reporting using contemporary sample of stroke incidence and prevalence studies.

Results

Results of search strategy



Summary of checklists and scales retrieved

Characteristics of tool	Checklist	Checklist and scale	Scale
Developed	12	0	5
Modified	18	0	27
No information about development of the tool	20	1	13
Can be applied to incidence/prevalence studies	8	0	14
Unlikely to be used for incidence prevalence studies	40	1	27
Created for incidence / prevalence studies	4	0	3
Validated	2	0	8
Reliability reported	4	0	17
Conflict of interest included	3	0	1
Levels of evidence	14	0	7
Grading	18	1	15
Total	*50*	*1*	*45*

Checklist items identified: clinical issues

- *Case-finding and sample size*
  - Evaluate all eligible members of the population using multiple overlapping case-finding procedures (hospitals, outpatient clinics, death certificates).
  - Assessment of completeness of case-ascertainment described.
  - Assessment of whether completeness of case-ascertainment is adequate.
  - What is the rate of admission in the particular population.

Checklist items identified: clinical issues

- *Case definition*
  - Cases of first ever in a lifetime event reported for incidence studies.
  - Clearly defined and consistent with globally accepted criteria.
  - If the disease under consideration is heterogeneous (as stroke is) then it should be reported how pathological subtypes are distinguished.
  - Prevalence should be defined as the number of cases existing in a specific time point.

Checklist items identified: clinical issues

- *Source of diagnosis*
  - Fully validated source or “gold-standard” criteria applied.
  - Define and justify severity.
- *Functional outcomes*
  - Measures of disability reported (such as modified Rankin scale for stroke).
  - Quality of life reported using a recognised measure.
- *Organization of healthcare*
  - Details of the health care system in country.
  - Description of how a person with stroke gets referred (with the filters).

Checklist items identified: methodological issues

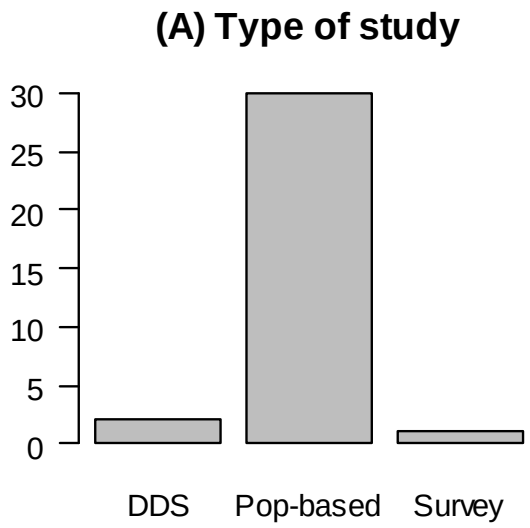
- *Time-frame and population*
  - Data should refer to some specified time period (usually whole years).
  - Population should be clearly defined (usually, but not always, on a geographic basis) and stable, with limited in- and out-migration.
  - Details of the sampling method (is the population representative).
  - Well-defined denominator.
  - Prospective study design for incidence studies.
  - Sources of data (e.g. administrative database, medical records).
  - Response rate/ Exclusion rate.

Checklist items identified: methodological issues

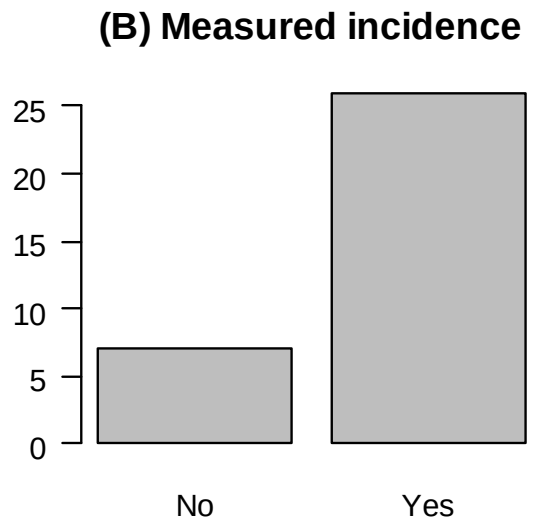
- *Statistical considerations*
  - Raw numbers should be reported in sufficient detail to calculate the appropriate rates (by age, gender, ethnicity).
  - Rates should be given for all pathological stroke subtypes separately and combined.
  - Any assumptions made in calculations should be described.
  - Explain how missing data was addressed.
  - Any sensitivity analyses should be reported.
  - Reliability of the estimates.

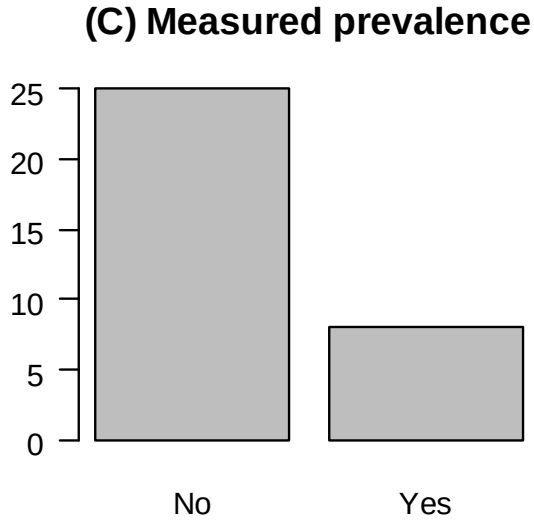
Random sample of ~30 GBD 2010 stroke studies

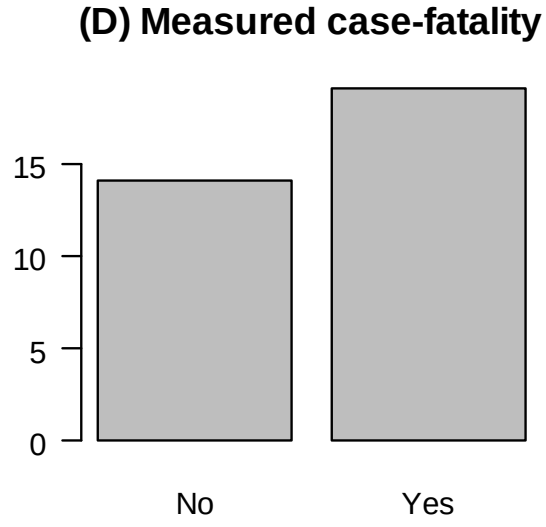
- The studies covered diverse regions of the world a
  - included low- and middle-income countries as well as high-income countries.
- Studies were published in a range of journals:
  - E.g. *Lancet Neurology, Stroke, Neuroepidemiology*
  - Mixture of open access journals and subscription based journals.
  - All published between 2006 and 2009.

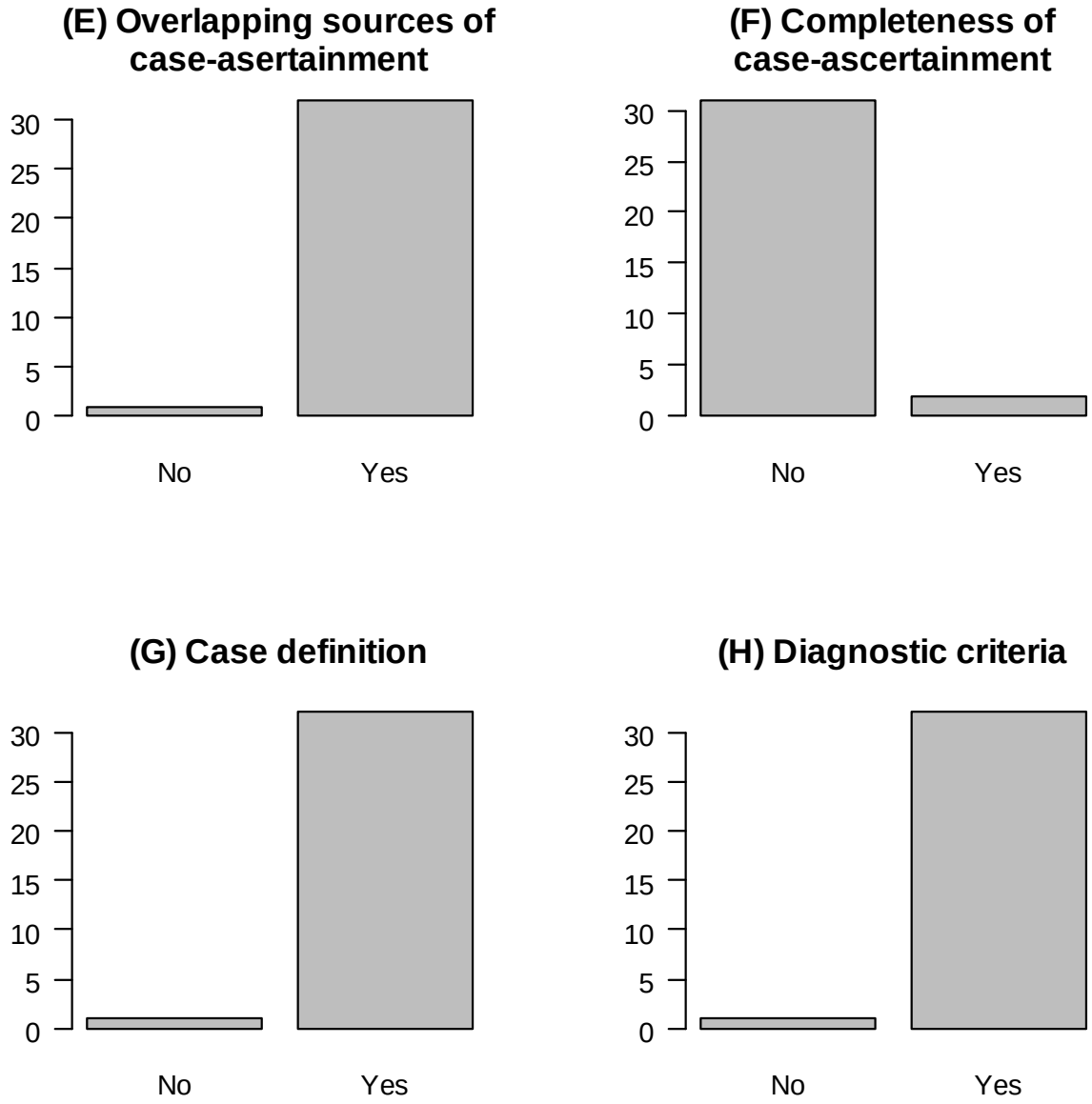


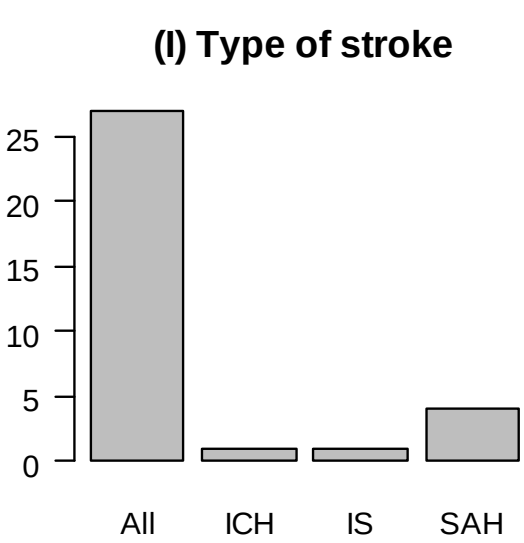
DDS: Door-to-door survey; Pop-based: Population-based

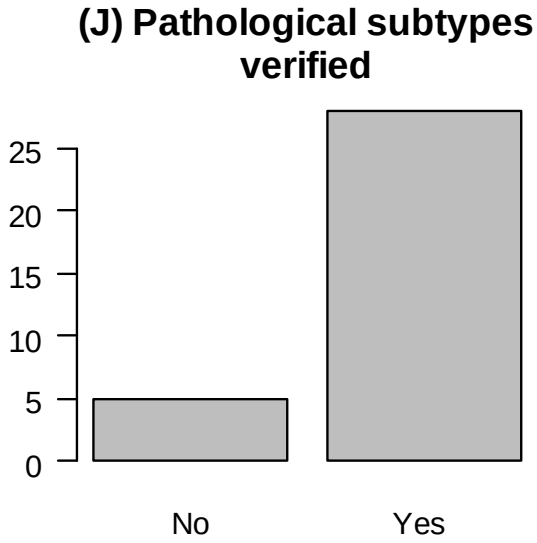


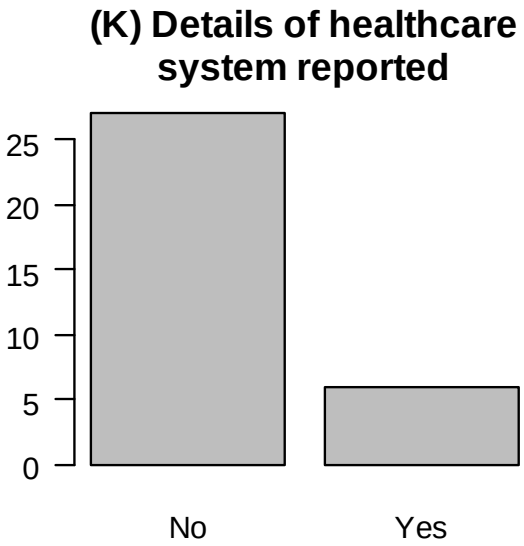





(E) Overlapping sources of case-asertainment
30
25
20
15
10
5
0
No
Yes
(F) Completeness of case-ascertainment
30
25
20
15
10
5
0
No
Yes
(G) Case definition
30
25
20
15
10
5
0
No
Yes
(H) Diagnostic criteria
30
25
20
15
10
5
0
No
Yes


(I) Type of stroke
25
20
15
10
5
0
All
ICH
IS
SAH


(J) Pathological subtypes verified
25
20
15
10
5
0
No
Yes


(K) Details of healthcare system reported
25
20
15
10
5
0
No
Yes


(L) Details of how person with stroke referred
25
20
15
10
5
0
No
Yes

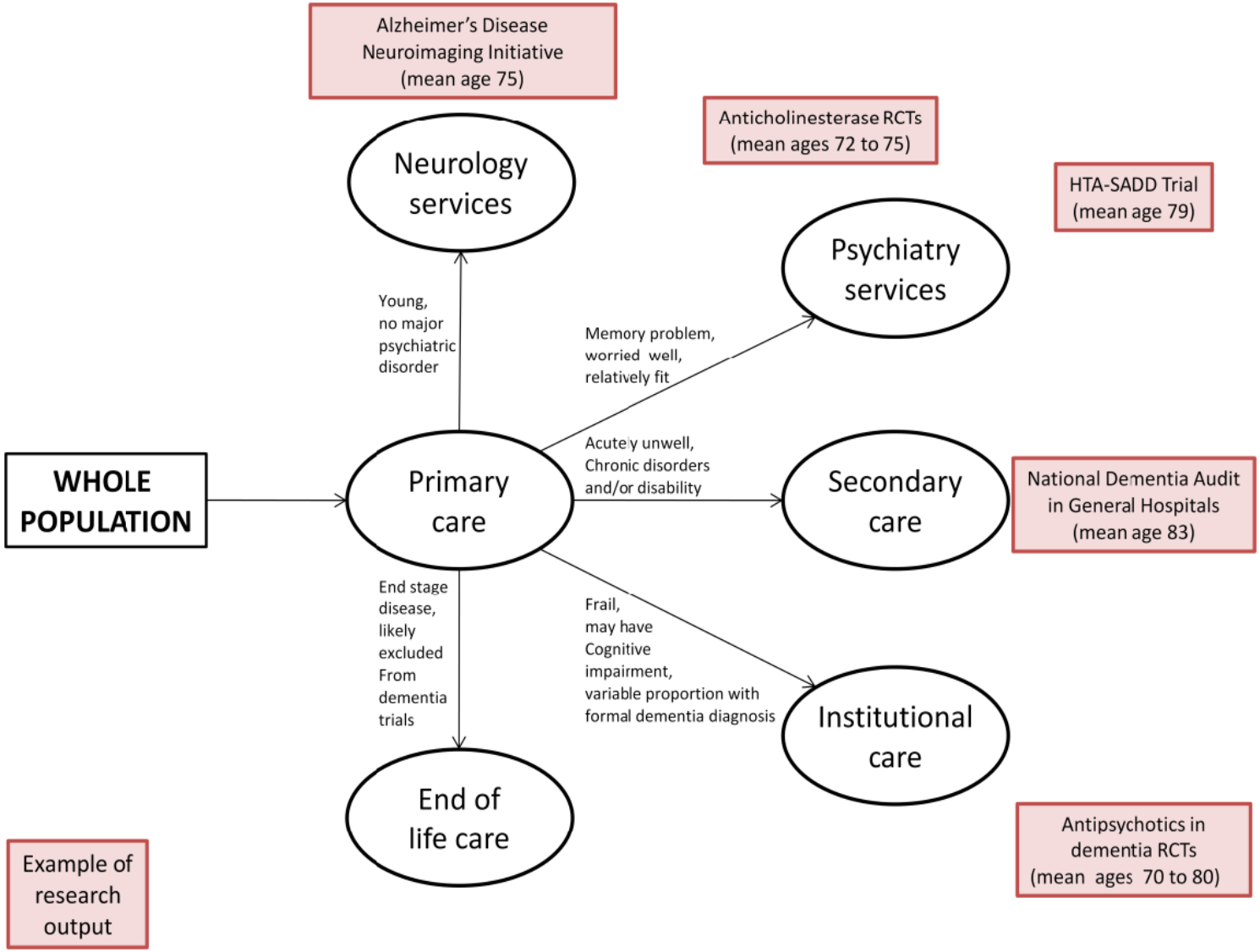
Summary of results

- All studies described the time-period of the study, sampling method and details of how cases were obtained via multiple overlapping sources.

- All studies reported case-definition, diagnostic criteria and verification of stroke sub-types extremely well.

- Many studies outlined details of how they arrived at the number of cases included in their study and discussing exclusions (e.g. outside the study period, or not a first-ever in a lifetime stroke for incidence studies).

UK Example: Different filters and routes for Alzheimer's and Dementia patients to healthcare/research



Summary of results

- Actual details of completeness of case-ascertainment was not explicitly reported (does not mean that it wasn't assessed!).
- None of the studies explicitly reported whether the number of cases ascertained was adequate as assessed by some specific criteria.
- Very few studies reported details of the healthcare system and how patients were referred (only 4 and 3 studies respectively).
- All studies reported age- and sex-specific results with appropriate confidence intervals.

Conclusion

- Our review (and that of others), have found that many tools did not:
  - provide a clear description of their design.
  - describe development or the empirical basis for item inclusion.
  - describe how they evaluated of the tool's validity and reliability.
- We intend to employ a rigorous development process in order to:
  - construct an appropriate guidance/reporting tool for use for health policy type research for neurological incidence and prevalence studies.

Future plans

- Conduct a Delphi study with an interdisciplinary panel of experts to:
  - further revise these draft set of items that are of importance to stroke
  - assess how transferable these items are to other neurological disorders.
- Synthesise expert input (via a workshop):
  - with the review of the evidence for stroke.
  - extend the scope to other common neurological disorders in order to devise a more definitive reporting standards.
- Disseminate outputs to interested parties (including journal editors and neurological societies).

How to get involved

- We invite anyone:
  - that is interested in taking part in the Delphi exercise
  - that is interested in the being part of reporting guideline development workshop
- E-mail : helen.mcdonald@aut.ac.nz
  - Stating “neuroepidemiological guideline” in the subject line
  - Stating your preferred level of involvement