

Background

- Quality of life is a multidimensional concept consisting of subjective and objective measures (Schalock et al. 2002).
- The life expectancy of adults with Down syndrome has improved from 25 years in 1983 to over 50 years, particularly in developed countries (Glasson et al. 2002; Asim et al. 2015).
- There is dearth of literature on the quality of life of adults with Down syndrome. Most studies have focused on the quality of life of adults with intellectual and developmental disabilities rather than Down syndrome alone.
- Studies on quality of life have relied on parent proxy-reporting instead of adults with Down syndrome themselves.

Objectives

- To synthesize the evidence relating to the assessment and experience of the quality of life of adults living with Down syndrome.
- To identify instruments used to measure the quality of life for adults living with Down syndrome.

Methods

- Searches were conducted using the keyword combinations: ("Down*syndrome" OR "Trisomy 21" OR "Mongolism") AND ("Quality of Life" OR "Wellbeing" OR "Well-being" OR "Well being") on eight databases: MEDLINE, CINAHL, PsycINFO, SocINDEX, Scopus, ScienceDirect, Web of Science and the Cochrane Library.
- Quantitative, qualitative and mixed-method studies that focused on the quality of life of adults with Down syndrome from 1980 till date written in the English Language only.
- The registration number of the review on PROSPERO is CRD42019140056.
- Selection of studies were organised using the Population, Exposure and Outcome (PEO) framework (Bettany-Saltikov 2012) as shown below in Figure 1.

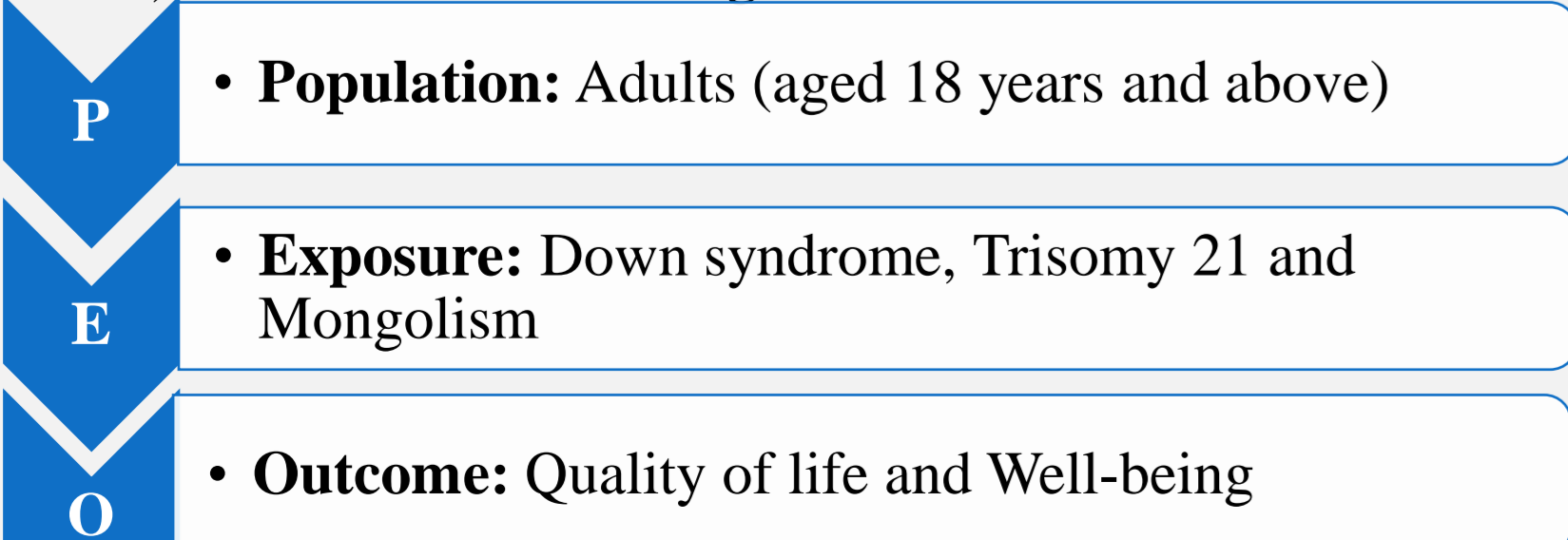


Figure 1: Population, Exposure and Outcome strategy

Results

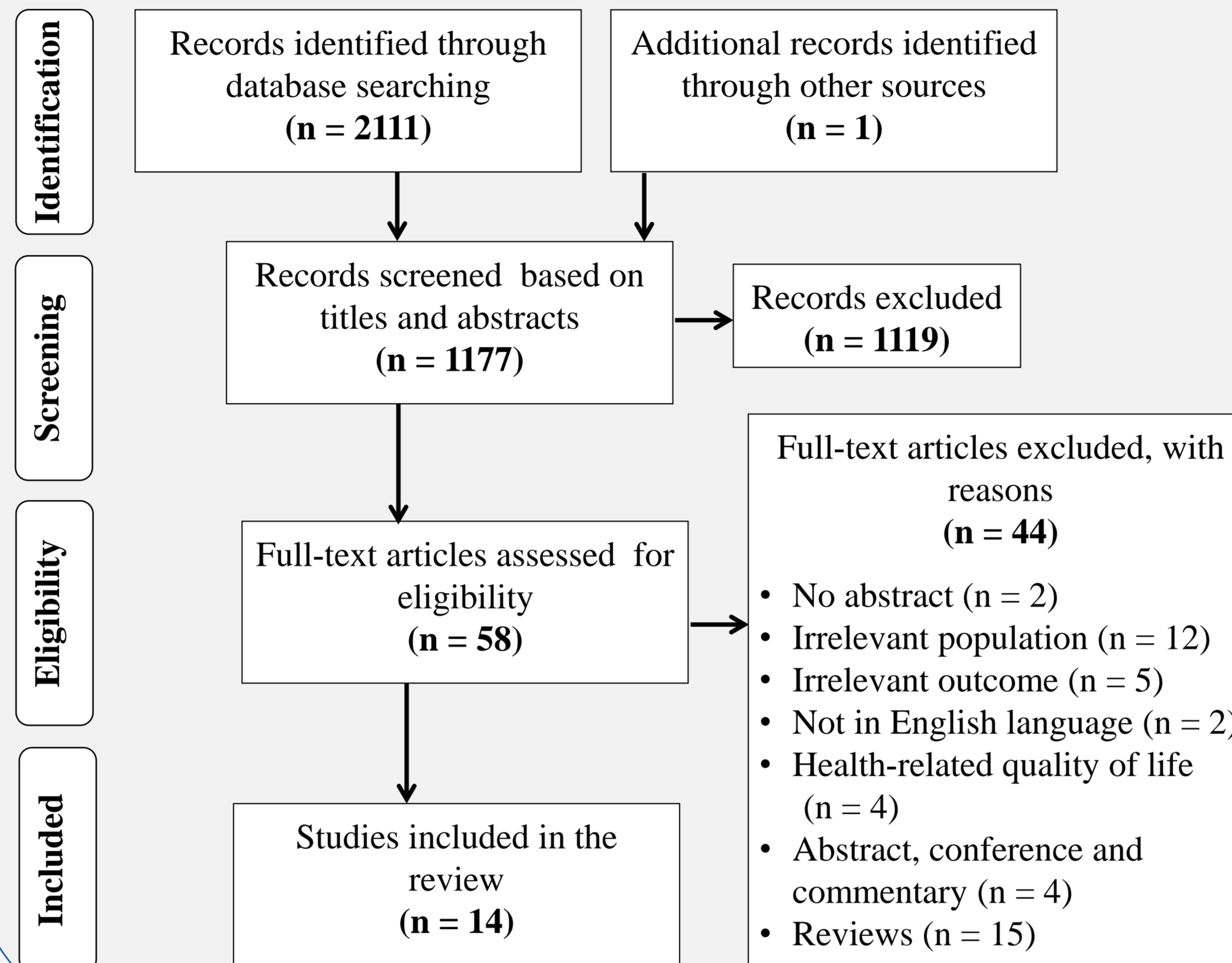


Figure 2: PRISMA flow chart of paper selections

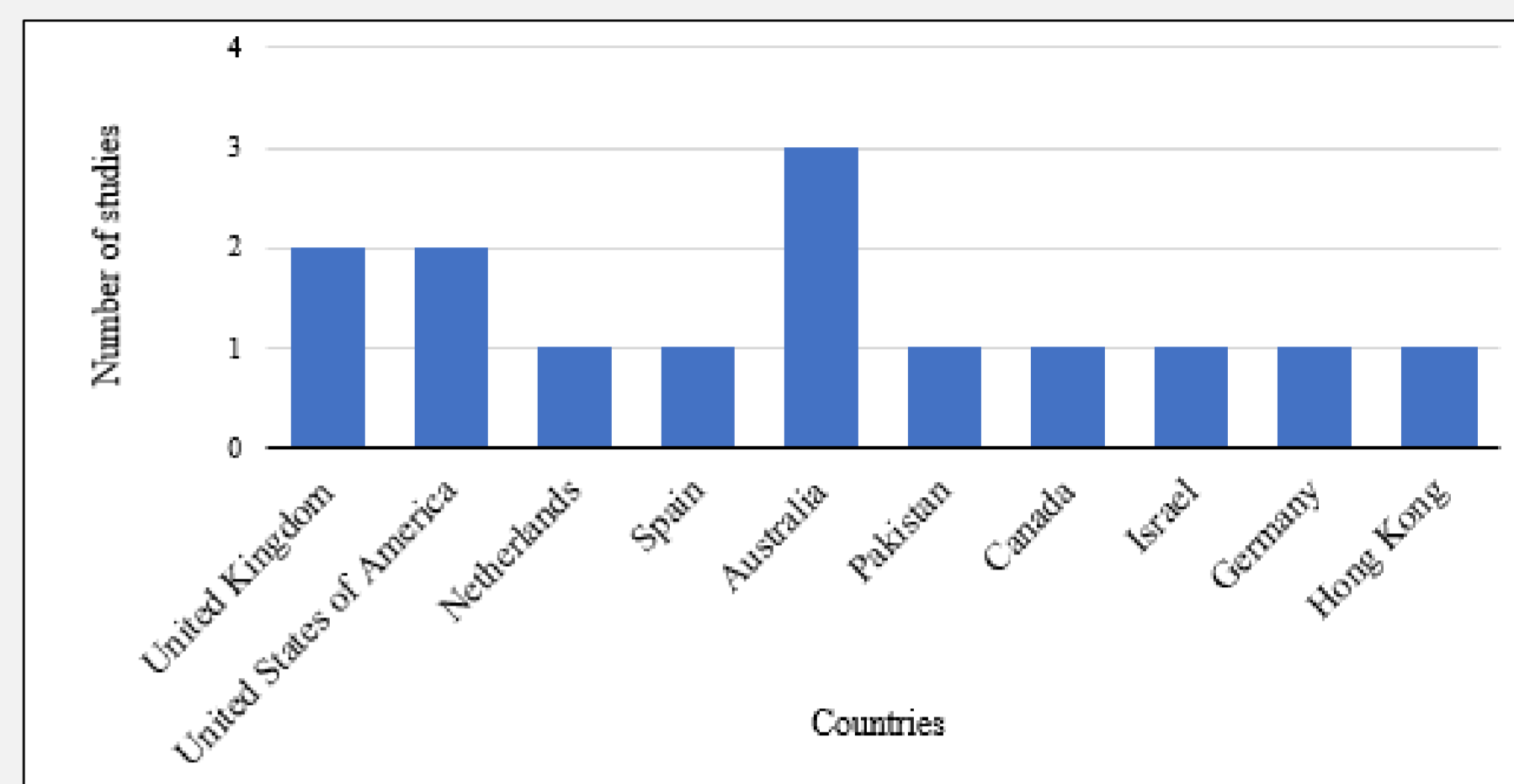


Figure 3: Countries included in the review

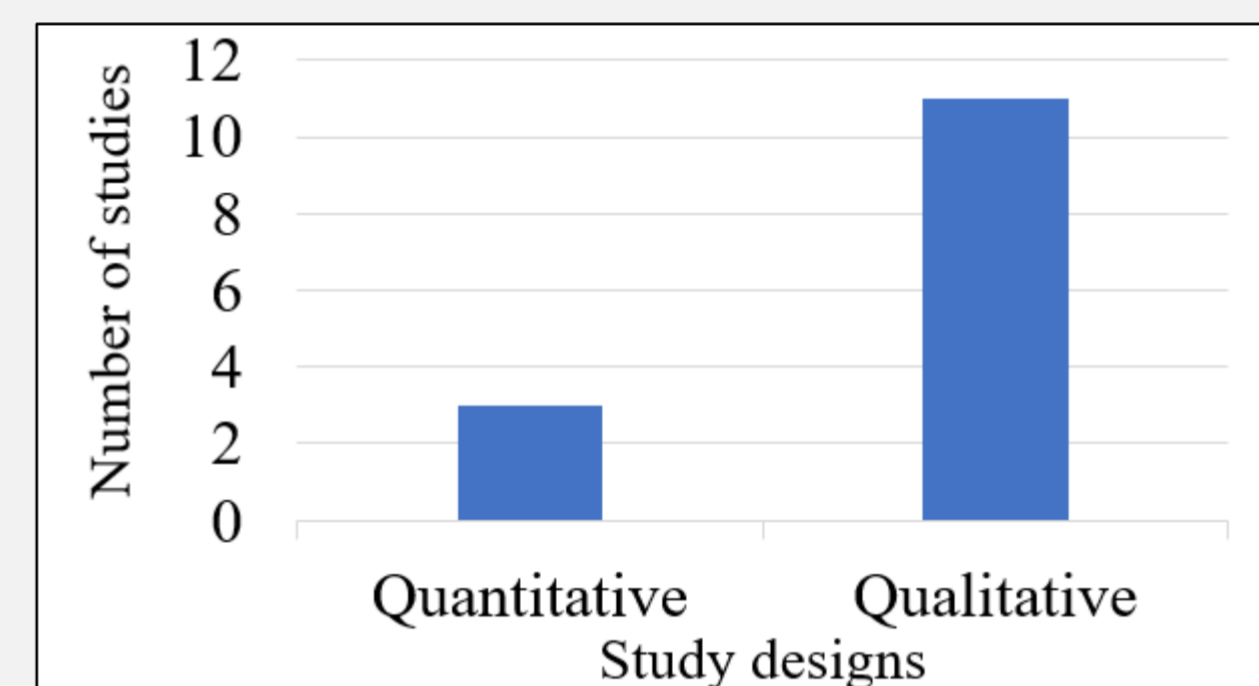


Figure 4: Number of study designs included in the review

Preliminary findings

- There is a methodological gap in the literature concerning assessing the quality of life of adults based on objective and subjective measures.

Next steps

- Currently undertaking data extraction using a standardised piloted form for extracting qualitative and quantitative studies.
- Quality assessment will be conducted using the Critical Appraisal Skills Programme (CASP) tool.
- A narrative synthesis will be used to combine the outcomes that will be identified in the included studies. Key themes will be identified, and data will be presented narratively using tables and graphical displays.

Acknowledgement

- Professor Roy I. Brown for providing useful information on some of the studies for the systematic review.

References

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- Bettany-Saltikov, J., 2012. *How to do a systematic literature review in nursing: A step-by-step guide*. McGraw-Hill Education (UK).

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