Can primary care electronic health records facilitate the prediction of early cognitive decline associated with dementia? A systematic literature review

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Background

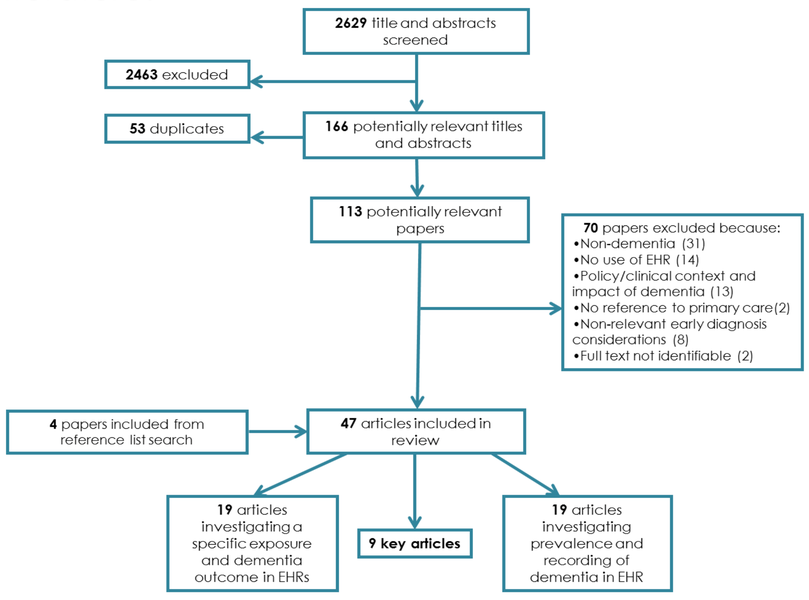
Though we have no cure at present, identifying the early stages of dementia is key in care management, clinical trial recruitment and mitigating the impact of cognitive impairment. Cognitive tests are most commonly used to investigate early stages of dementia. There is potential to harness routinely collected data from electronic health records (EHR) to elucidate novel markers of cognitive decline, both in their cognitive and non-cognitive presentations. Phenotyping the prodromal dementia trajectory is a critical step needed to design effective interventions.

Aim

To systematically review the literature to investigate the of use EHRs in early diagnosis of dementia

Methods

Publications up to September 2016 relating to "dementia", its subtypes, "electronic health records" and "primary care", were searched for in Scopus, Web of Science, PubMed and grey literature.

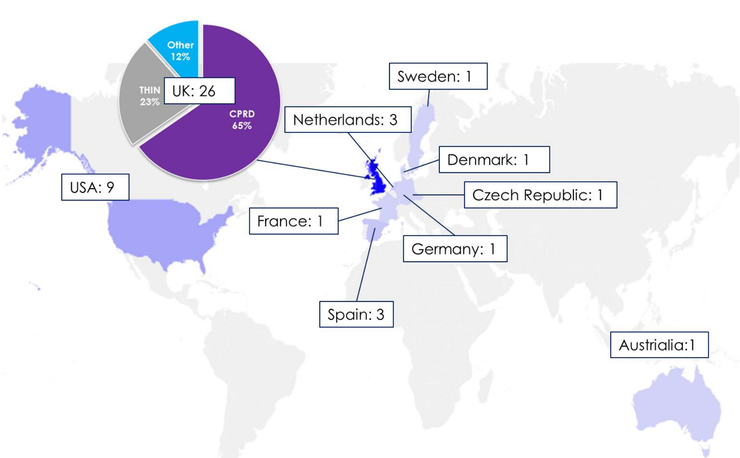


The inclusion criteria were 1) Studies investigating pre- diagnosis using data captured in EHR, at least in part, in a primary care setting 2) Articles in all languages (English abstract).
Studies were excluded if only post-diagnosis was investigated, studies in the UK were solely set in secondary care and qualitative, policy, social and ethical aspects of early dementia investigation were the focus.

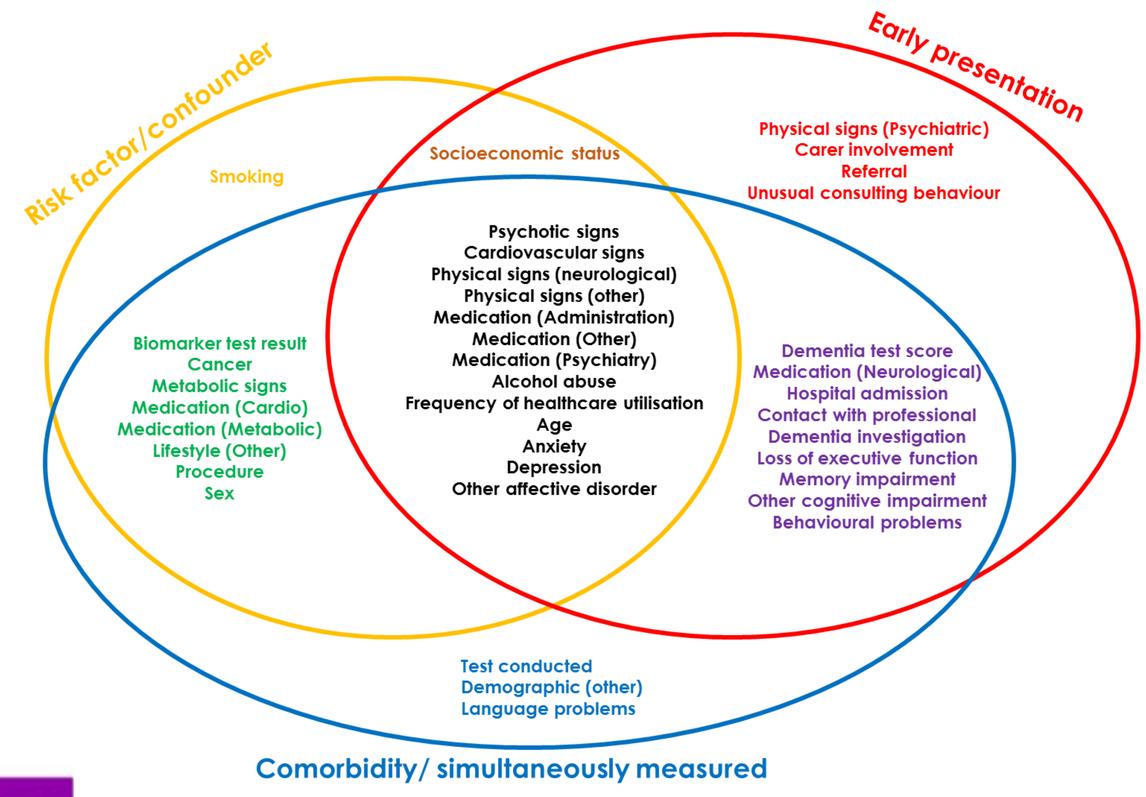
Results & Discussion

47 studies were included in the review. The studies varied considerably in their outcomes and methods, and as a result, a meta-analysis could not be conducted. 26 of the studies were from the UK, and of those 17(65%) used the Clinical Practice Research Datalink (CPRD) and 6 (23%) used The Health Innovation Network (THIN).

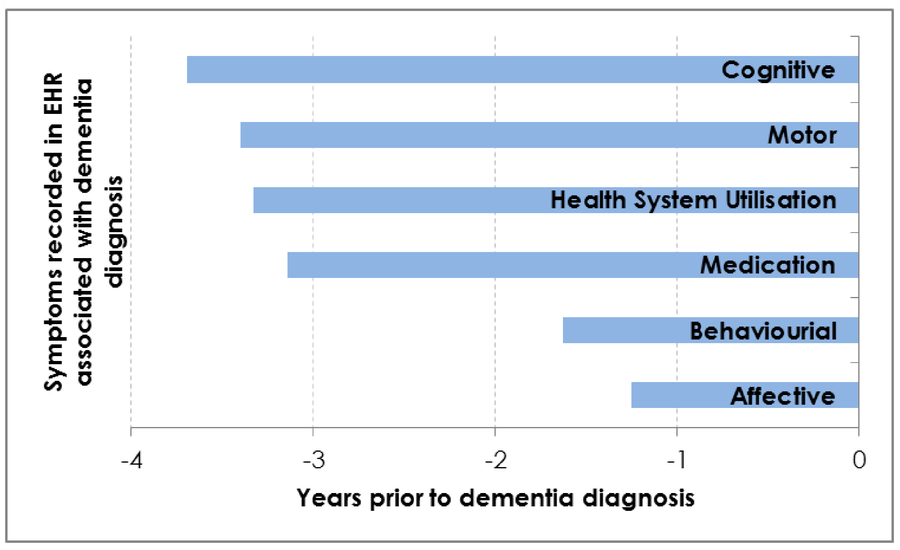
The size of the study population of dementia patients varied considerably, between 125 cases to ~55,000 cases.



The studies collectively included over 550 markers of dementia prediction, but varied in whether they were risk factors, confounders, predictors, co-morbidities, exposures or early presentations of dementia.



Cognitive symptoms, including executive function or memory impairment, were estimated to be the earliest predictors of dementia diagnosis, observable in EHR from an average of 3.7 years prior to diagnosis. Affective symptoms, such as mood disorders or problems with sleep were identified on average 1.25 years prior to diagnosis. Health system utilisation, such as frequency and type of consultation was investigated in a number of studies. However, as many of the authors discussed, this can be a challenging marker to use as those under investigation for dementia are likely to see a sharp rise in interactions with the health service, particularly in the year prior to diagnosis.



Conclusion & Future work

Use of EHRs to facilitate early diagnosis of dementia holds great potential, but evidence on the predictive accuracy of EHR data for early diagnosis is mixed. Due to the range of methodological approaches, definitional inconsistencies when categorizing predictive variables, setting and population size variability, direct extraction and comparison of early markers is challenging

This review forms the basis of future work in understanding the prodromal dementia trajectory in order to facilitate early dementia diagnosis, using EHR data. The prodromal dementia period is still ill-defined, and largely measured using cognitive test scores, such as the MMSE. There is therefore significant potential to use routinely collected data from EHR as a valuable source of information to investigate and phenotype prodromal dementia and shed new light on cognitive decline's both cognitive, and non-cognitive presentations in the health service, for early diagnosis of dementia.

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