

Interpretation of dementia diagnosis and treatment trends in the UK over time



The study by Katherine Donegan and colleagues,¹ published in *The Lancet Public Health*, provides a powerful analysis of routine data for dementia diagnosis rates and prescription practices over a period during which policies and practices have changed in the UK. The analysis presented in this Article uses the presence of codes in routine datasets indicating a dementia diagnosis during a 10 year period from 2005 to 2015. These data were extracted and examined in relation to prescribing practices and then linked to policy developments in the UK during this time. The policies relate to closing the estimated gap in dementia diagnosis and the emerging evidence of adverse outcomes in people with dementia who are prescribed antipsychotic medication. Increased recorded dementia diagnosis rates and reduced antipsychotic medication prescription were observed during this period in the present study. The rise in recorded diagnosis is moving closer at a national level to reaching the levels of prevalence from current estimation of dementia in the population from epidemiological studies. Background factors should be taken into consideration when interpreting the meaning of such changes.

The UK has a substantial set of primary care providers whose electronic data are available over several decades. These data can be related to the underlying geographical population estimates because of the nature of the country's comprehensive National Health Service (NHS) and the historically place-based nature of its primary care provision. The Clinical Practice Research Datalink (CPRD), used in this study, is available to approved researchers wishing to test specific hypotheses. Necessarily, the data are limited to what is coded and available, with interpretation required about how the coded data relate to an underlying truth. The data include dementia-related diagnoses communicated between primary care and secondary care and the analysis by Donegan and colleagues assumes the diagnoses in primary care reflect an accurate diagnosis and that prescribing data also reflect what medications people take on a regular basis. This study is an important contribution to our understanding of time trends

in diagnostic practice and prescribing despite these caveats, which affect interpretation.

The study links observed routine record changes to the UK's and its devolved nations' policy initiatives^{2,3} during the same period. These included ageing and specific dementia-related policy documents aiming to create more compassionate and effective approaches for an ageing population, including those with dementia, within the NHS. Raising awareness of dementia in the population and its importance to society, including costs, was also part of this drive. These activities, closely linked to attention from many sections of the society including media and media personalities, all political parties, charities, researchers, pharmaceutical companies and other business sectors, and health and social care sectors, have resulted in the fact that dementia is now rarely out of the headlines. The media activities included hard hitting campaigns (and some would argue the language and imagery used could reinforce stigma although evidence either way is limited⁴), with a substantial emphasis on seeking help at an early or timely stage if an individual or their loved ones were concerned about a person's memory or related behaviours. Beyond these media campaigns, there has been a top-down drive for general practitioners to seek out dementia diagnoses, with use of a carrot^{5,6} and stick approach with money in some localities for diagnosis and, across England, a heavy central diktat to primary care bringing in targets originally based on estimates of prevalence derived from 20 year old epidemiological studies of dementia in the UK, now updated using contemporary estimates (Cognitive Function and Ageing Studies in England and Wales⁷⁻⁹) as well as introducing screening for dementia for some admissions in hospital settings. Such carrot and stick approaches have not been universally welcomed, but they are likely to have substantially affected practice during this period. Part of these policy drives included specific actions resulting from evidence about the harms of antipsychotic prescribing to people with dementia leading to dedicated streams of efforts from centre to periphery to vigorously pursue reduction of such prescribing, particularly in care settings, through the structures of the NHS.

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The description of the recorded changes in practice is the strength of this study¹ and represents a major contribution. Whether there is a societal benefit from such policies and changed practice is less easy to assess. This requires a different type of analysis and a different type of evidence. Many would argue that the specific policies relating to targets and prescribing should have been underpinned by at least some implementation science to estimate evidence of size of benefit, potential harms, costs, and opportunity costs before a heavy handed system roll out. At the local level, the pressures for physicians, the health-care sector, and systems to behave in particular ways will have cost (with consequent opportunity costs at all levels) a great deal in specialist and NHS system professional time and resources throughout the health-care sector at a time of major reorganisation and austerity. There is also a concern that the reduction in prescription of antipsychotics has been accompanied by increases in the prescription of other, potentially harmful, medications because the underlying reason for the prescription in the first place has not been addressed, and cannot be, within current resourcing. Evidence on this concern has produced mixed findings.^{10–12} Holistic evidenced compassionate approaches with highly trained staff are alternative methods but not affordable or available to substantial proportions of people with dementia.

Future policy implementation should be preceded by a full exploration of the possible unintended consequences and their implications, through service testing methods (such as pilots in more usual sites, staggered roll out, rigorous publishable evaluation of natural experiments, no innovation without evaluation, modelling using various types of datasets, and simulation with different assumptions) wherever possible. Donegan and colleagues¹ have done an excellent analysis and their cautious attempt to link these changes with the timing of specific policy initiatives is not entirely without a prior sense of assumed benefit. The clear message of this study is

strong evidence that it is possible to examine practice changes across time and relate them in a non-causal manner to societal changes. This is undoubtedly a valuable exercise, but we too must be extremely cautious in interpretation.

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CB declares no competing interests.

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