

## Debate & Analysis

# The pros and cons of early diagnosis in dementia

Dementia is an undeniable concern for ageing societies. If the predicted increases in life expectancy continue unabated, this will lead to a near doubling of the numbers of people with dementia in the UK within a quarter of a century,<sup>1</sup> with a doubling of numbers expected every 20 years globally.<sup>2</sup> The challenge this 'failure of success' poses has only relatively recently been fully recognised at the societal level. In 2012 the US announced a national Alzheimer's plan to prevent and effectively treat dementia by 2025, provide higher quality care, provide more support for patients and their families, enhance public awareness and engagement, and deliver improved data collection to understand its impact.<sup>3</sup> In the UK this attention has led to first a highly influential stocktaking of dementia in the UK,<sup>4</sup> stimulating governmental recognition of the importance of dementia and to the Prime Minister's Dementia Challenge. The areas of focus are those in which the government and their advisors perceive to be tractable and which may stimulate economic benefit through innovation, trying to create positive outcomes from a condition that is generally held as a tragedy.

### PUBLIC AWARENESS

The many awareness campaigns have been perceived to be successful, although the consequence of heightened population awareness, particularly for those in later life, has also been rising fear. This has been fuelled by the use of estimates based on true population-based studies to support the widely-stated estimates of the proportions of people living in the community with 'undetected' dementia or 'cognitive impairment', since these are larger numbers than those known to the appropriate caring agencies. One of the results of this societal fear, as with cancer, is an emphasis on what can be done to prevent and detect the 'disease' earlier.

Unfortunately, dementia is not a disease but a syndrome. The clinical features that, when seen together, make up the diagnostic criteria are all continuous and affected by many other factors; in other words, there is no magic test. Cognitive performance is affected by education, conditions such as depression, delirium, and proximity to death, and the ability to live independently is affected by physical conditions as well as social expectations. An individual with

changes which may herald dementia needs insight to recognise them — or their families will need to do so — and then, crucially, to perceive that there is a value to seeking help. This is very important. That value is often clear at the point of a crisis, when what may have been a relatively stable situation is disrupted by an event, such as illness of a carer or the person with dementia. At this point understandably, the health, social, and societal systems see a costly and distressing situation which early detection may have averted. So there is a pressure from society and health systems for action which prevents this and, failing this, detects this syndrome 'early'. This is not at all the same as reported delays in diagnosis when expressed problems are dismissed or ignored. As with prostate cancer, breast cancer, abdominal aortic aneurysm, and diabetes and its complications, only a trial can reveal whether there is a benefit to actively screening for dementia within the population or selected populations within particular health and social care settings.

To prevent and to detect dementia early we need to understand what the disorder is. Yet the diagnostic criteria for dementia remain controversial and are still changing,<sup>5</sup> with the actual diagnosis relying on societal norms for cognition and function. Even for Alzheimer's disease — the most frequent pathology underlying the dementia syndrome — clinical diagnosis is only confirmed through autopsy.<sup>6</sup> To complicate things further, population studies have established that people over 80 years (that is, most of those with dementia) have a mixture of pathologies in their brains, and that these changes are also common in those who die without dementia. So, essentially, there are no features within the brain that can be reliably said to 'cause' the dementia syndrome, neither 'necessary' nor 'sufficient',<sup>7</sup> despite the fact that many such features are strongly and consistently associated with dementia.

Primary care physicians are often castigated for not recognising dementia; many reports have suggested that greater education, more awareness, and other exhortations will 'improve' the gap between estimated numbers of dementia within any given population and the actual number a GP may diagnose or have on a register. Reasons have been given for this gap, which is assumed to have some real meaning<sup>8,9</sup>

in terms of people suffering. However, the most compelling of the reasons may also fit the role of the GP: the judgement that, on the basis of evidence and experience, available interventions, if any, for that individual will do more harm than good.

Harm can include raising expectations of effective treatments, which are not there. Some would argue that before creating more expectations (that is, reducing the 'gap') it may be wise to help GPs assess those with whom they are in contact who clearly are expressing concerns and have clear problems, and for whom the best current support and evidenced services are available. Dementia symptoms will often be seen as part of the normal ageing and dying process by carers, patients, and professionals, which indeed they can be as shown in numerous population longitudinal studies. The skill of the GP, as with so many other conditions, is to recognise with the least distress to their patients those for whom the evidence and their experience indicates a benefit is possible from the potential diagnosis of dementia.

### SERVICE CHANGES LACK EVIDENCE

Such discussions bring us into the arena of the introduction of new services or change without evidence. While much service change is indeed introduced without good evidence and built-in evaluation, systematic screening of specific populations in the UK has been an exception to date. The UK has an envied evidence scrutiny system — the National Screening Committee — which has developed an internationally accepted set of criteria building on the Wilson and Jungner criteria of the last century. This committee, and its equivalent in the US, has reviewed the evidence for the introduction of dementia screening and it has failed at pretty well every hurdle, particularly for the dementia syndrome in the older old (Box 1).

Given the current attention to, and fear of, dementia in the population what is likely to happen? There are two sets of scenarios: activity within a system such as the NHS and what may happen in the private sector. We will examine each in turn. What would happen when those who are keen to 'screen' systematically do so on a large scale in primary care attendees or particular groups within lists? The first test is usually of cognitive performance: the evidence from screening programmes more generally and

## Box 1. Evidence for introducing dementia screening

- A. The condition is important and common — Yes.
- B. Its natural history is well understood — No. It is a syndrome not a disease. The syndrome has very many underlying associated pathologies. Those pathologies do not always lead to manifest clinical syndromes.
- C. There should be an effective treatment which, if given early enough, changes the natural history — No. There is no such evidence as yet.
- D. There must be a relatively simple, cost-effective, reliable, and valid test — No. Not tested in relevant populations with sufficient follow-up and establishment of harms/benefits.

the extensive knowledge of cognitive scores in older populations suggests that a large proportion of people aged  $\geq 80$  years will score in the intermediate levels. But has the test been validated in that particular age group, comorbidity, and educational level? What will people be told? If individuals performing below some threshold are then referred for imaging, which will incur considerable costs and concern, many will have 'positive' scans showing atrophy, vascular lesions, and, if advanced scanning, could show build up of Alzheimer-related proteins. What is to happen to these people? Can we really tell them what their risk of developing dementia within 1, 2, 5, 10 years is with higher probability than we already know based on age? Do we have evidence-based therapies to offer them? Do we have services ready to counsel them before and after their testing? How do we handle the increased demand for support: the feature which is most cited as being the reason for early diagnosis, which itself has never been tested in randomised controlled trials over reasonable periods? Will there be an inevitable diversion of resource away from other areas with a consequent impact on other services? It is likely that some people will benefit, but others will be harmed.

Turning to the private sector. It is quite possible that considerable 'market' can be generated through capitalisation of fear of dementia and cognitive decline. Direct-to-consumer advertising already exists for cancer (specific insurance schemes) and

stroke (carotid and risk screening). Taking the example of stroke risk 'screening', individuals may receive, through population listings, materials that promote testing in centres sometimes hosted by primary care settings, which gives an apparent endorsement that this is evidenced practice. Could this happen with cognition? It seems likely, including the online potential. Does this matter? It depends on the outcome of the testing. If positive in some way where will these individuals turn for support? How much investigation will reassure them? How many people will be tested unnecessarily and for those who are identified as having a problem will there be sufficient resources to support them? In a publicly-funded system this will fall to their GP, who will therefore have less time for those who attend with existing concerns. In a private model these individuals may seek help elsewhere, paying for imaging and further tests. These may or may not provide reassurance or further indication of problems, but doing such tests is not, at present, justified on the basis of evidence. For some a remediable condition may be found, but as with general health screening, it will be impossible to say who has been harmed and who helped by such efforts.

Such questions can only be addressed through systematic research (Box 2) which does take time. The need for this has been clear for a while and requires a strategic approach to where research for ageing populations will really provide tangible benefit over given time scales. There is no

## Box 2. Recommendations for dementia screening: a road map of when it should be introduced

1. Research in representative patient groups including full assessment of perceived benefits and harms of the process of screening, impact of diagnosis using the existing evidence to guide the specific questions.
2. To scrutinise whether stratification on the basis of easily available data could identify those most likely to benefit, and those where harm/benefit may reverse. To conduct careful trials if the question does not have sufficient existing evidence to answer.
3. Learning from current clinical and funded future research about the characterisation of early dementia and pre-dementia patients is likely to provide benefit, and how this may translate into population settings including recognition of multiple causes of underlying syndrome and proximity to death (that is, value of diagnosis in last years of life in a frail older population). From the above continue search for biomarkers that reflect the person and their individual prognosis better.
4. Develop screening diagnostic aids with sufficient robustness: appropriate for setting/age group/comorbidity.
5. For any technology or diagnostic boundary change with potential to 'creep' into usual clinical practice conduct economic studies which are appropriate to specific clinical settings and their particular populations.

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high quality research evidence for the benefit in diagnosing patients before the usual point of presentation. The surveys which are quoted as suggesting that the population is ready for screening miss an important fact. The answers have been given without the provision of the state of current evidence and when questioned, many survey responders say they believe treatment and screening to be effective in terms of prevention. If a patient's health is not enhanced by early diagnosis then this should not be forced on them.<sup>10</sup> Now that the cart is rolling along independently there is a critical need to get the research horse out of the paddock and not only aligned but back in the traces. It is not too late to undertake research which could overcome the evidence gaps. Such research must be rigorous and must, if associated with potential commercial or vested interests, be independently evaluated. Only then can evidence presented be relied on and considered in healthcare reorganisation.

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