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VIEWS AND REVIEWS

Margaret McCartney: Looking for dementia—in the name of “awareness”

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How many sins must be committed in the name of “awareness”? The Department of Health in England has announced that it wants to extend to people under 65 the “mandatory dementia awareness raising” that the current NHS Health Check already includes for over 65s.

Three pilot sites will “enhance the evidence” (really, that’s what it says). “Social marketing” will “raise public awareness” of dementia risk reduction, and coming soon is a personalised brain age calculator to complement the heart age calculator currently available on NHS Choices.

Is this an unbiased randomised controlled trial capable of finding harms?

Scotland quietly got rid of its health checks for over 40s after realising that they’re expensive and don’t work. Let’s not go over the evidence again, but let’s consider that the Ministerial Advisory Group on Dementia Research contains several industry representatives.

They want more people to take part in research “including those at risk” of dementia but “without increasing bureaucracy.”¹ I sincerely hope that health checks are not going to be a facade for recruitment to clinical trials. We absolutely need trials, but we also need absolute transparency. Using a veil of “awareness” and hoping for absolution simply isn’t good enough.

A week before exams I used to ask students whether they worried about their memory: almost all did. We need evidence about harm. How many people should we expect to feel anxious or depressed about a memory problem that isn’t a true cognitive impairment or dementia? How often will information about “awareness” lead to meaningful benefits? What will the false positive rate of “early” diagnosis be? How many people will harm themselves after an early diagnosis of dementia? How

accurate is this “brain tool” in real life, and what risks and advantages does using it confer? Here, the literature is as a desert.

If we are going to have “awareness,” let’s look in the mirror. What sort of “awareness” do policy makers have of general practice on the ground, and the opportunity cost of this dementia policy? What are the effects on help seeking behaviours and quality of life? Do healthy people feel better about their brain age? Do people with modifiable risk factors feel despair or feel empowered? And the anxiety that this creates, so often overlooked as a minor inconvenience—how much of this do health professionals bring about, affecting day to day living, risk taking behaviours, and pleasure in life?

We’ve surely had enough of single issue awareness: we need a wider perspective. Stopping smoking will cut not only your risk of dementia but also of cancer and cardiovascular disease. Charities that insist on awareness of symptoms of one disease may not be aware of the dozen other diseases that can also cause those symptoms. Enough of “awareness”: is it too much to ask for fair, unbiased knowledge?

1 Prime Minister’s challenge on dementia 2020: implementation plan. Mar 2016. www.gov.uk/government/uploads/system/uploads/attachment_data/file/505568/dementia-implementation-plan.pdf.

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