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Report

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Why no reliable estimate can be produced for the rate of return on investment in primary prevention of dementia

A return on investment (ROI) analysis in health and social care would normally focus on a specific intervention and would analyse the return on the costs of the intervention from the flow of savings and/or monetised benefits accruing from the intervention. The initial plan for the Personal Social Services Research Unit (PSSRU) study of primary prevention of dementia was that it should include development of an ROI tool. This would enable local commissioners to estimate the return they could expect from investment in specific primary prevention interventions in mid-life to prevent, or reduce, subsequent onset of dementia later in life.

The research team planned to design and produce a user-friendly modelling tool to assist local areas to determine their population/need-specific primary prevention strategy and to quantify the dementia-specific return on investment of a given initiative in a local area. PHE asked the researchers to focus on primary prevention and not extend this project to secondary prevention.

We were not able to find, through our extensive literature review, any studies of the effectiveness or cost-effectiveness of primary prevention interventions relating to dementia. For example, a recent review of past and current interventions for dementia and cognitive decline did not list any trials that focused on health-related behaviours in midlife and reported results on dementia as an outcome (1). It is not surprising that evaluations have not been conducted for such interventions. They would require following up both treatment and control arms of the study for at least 25 years and preferably rather longer.

A long follow-up is necessary because the focus of primary prevention of dementia needs to be on risk factors in midlife (ages 40 to 64). Although dementia is typically developed in very late life, the processes leading to precursory health problems often start in mid-life.

In the absence of studies of the effectiveness of primary prevention interventions relating to dementia, we discussed use of a two-step process with the project Steering Group. This involved linking: (a) the findings of one or more evaluations of a specific intervention and its impact on (for example) participation in physical activity, and (b) the findings of other studies which explored the relationship between participation in physical activity and onset of dementia years later.

However, the two example analyses we produced were considered by the Steering Group as well as by ourselves to be unreliable. It was not possible to be confident that the evaluation of the intervention and the study of the risk factor for dementia were compatible. For the process to be reliable there would need to be compatibility in terms of the characteristics of those offered the intervention (especially age, health status), the nature of the intervention (eg exercise class), the definition of the outcome of the intervention (eg 20 minutes of moderate exercise five times per week), and the duration of participation in the intervention (eg exercise maintained over at least ten years).

In theory, one way forward could be to commission an evaluation of an intervention whose findings could be linked with the findings of an existing study of the impact on incidence of dementia in old age of the risk factor(s) to which the intervention relates. An issue is whether this would be sufficiently reliable to justify the cost of the evaluation. It is very doubtful that a tool developed through such a two-step approach would be regarded as robust as a tool based on direct evidence of the impact of an intervention on incidence of dementia.

We then suggested, following discussion with experts and with PHE, that we aim to produce a different form of tool. It would focus on the link between behaviours and conditions in mid-life and dementia onset in later life. It would present for individual areas an estimate of the current and projected future prevalence of dementia under current arrangements and under alternatives involving primary prevention. It became clear, however, that this too presented problems.

We discussed with the Steering Group the development of a form of 'ready reckoner' indicating the possible impact of changes in risk factors on numbers of older people with dementia in the future. Users of the tool would be enabled to enter their local objectives, eg 100 people in mid-life successfully enabled to give up smoking or take up physical activity (of given intensity) and continue it for an extended period. The tool would then provide an estimate of the proportion of this group who would be expected to experience onset of dementia in the future if they continued smoking or being sedentary, and if they gave up smoking or took up and sustained physical activity.

This again presented a range of challenges. First, the evidence on the association between risk factors in mid-life and subsequent dementia in old age has limitations; and estimates of relative risk, odds ratios and hazard rates are subject to wide confidence intervals, see our focused review (2). The tool could in principle have shown a range rather than a point estimate, but the range would have been wide. Wide confidence intervals are common in population based heterogeneous samples with long follow-up periods. A way to reduce the confidence intervals would be to conduct a new study with a substantially larger sample.

Second, there will be no/negligible effect of changes in mid-life on onset of dementia for many years and the biggest impact will occur after 2040 even from smoking cessation or commencement of physical activity in 2016. It seemed unlikely, in view of the comments we received in our discussions with commissioners, that projected impacts so far in the future would be of great interest or value.

Third, there are associations between the different risk factors: For example, smokers may be more likely than non-smokers to display other risk factors. This means that, if smokers gave up smoking but did not change other risk factors associated with smoking, their risk of dementia would not decline as much as suggested by relative risk estimates from observational studies.

The tool would have needed to use adjusted relative risk estimates which for some risk factors could be calculated using findings from existing studies but would need to be estimated for other risk factors. Norton et al (3) examine the association between a group of seven risk factors – diabetes, midlife hypertension, midlife obesity, physical inactivity, depression, smoking and low educational attainment - and present adjusted population-attributable risk estimates for them. We are not aware of similar analyses for any other risk factors.

Fourth, changes in smoking, physical activity and other risk factors affect future mortality rates as well as future incidence rates for dementia. Modelling in other studies - see (4) and our explorative modelling, suggested that people who give up smoking in mid-life increase their lifetime risk of dementia despite experiencing reduced age-specific incidence of dementia. A tool should ideally reflect this, but this would have required further detailed modelling which would have had considerable caveats.

While PHE found that that there is demand among commissioners for a tool that would support them identifying quick and reliable wins, there cannot be quick wins from primary prevention of dementia and there is insufficient evidence for reliability. We found a lack of obvious demand for a tool among the commissioners we consulted. This was on the basis that the tool would inevitably show that returns on investment would not be achieved for some 25 years and would inevitably be subject to wide uncertainty.

The Steering Group agreed with us that it would not be useful to proceed to prepare a tool in view of all these challenges. Experts advised that a tool would inevitably be unreliable, such that it would not be wise to use it or advocate its use.

References

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