



Public Health
England



Primary prevention of dementia: barriers and facilitators

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London School of Economics and Political Science

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Executive summary

Public Health England commissioned the Personal Social Services Research Unit (PSSRU) at the London School of Economics and Political Science to conduct a study of primary prevention of dementia. The study included a literature review of midlife risk factors for dementia and a study of barriers and facilitators to primary prevention. This report presents the findings of the study concerned with barriers and facilitators. The literature review of midlife risk factors for dementia is published separately.

To promote primary prevention of dementia it is important to understand both the barriers to primary prevention and factors which facilitate primary prevention. Primary prevention of dementia is taken here to mean activities or measures pursued before any symptoms of dementia are manifest and, in principle, before even the asymptomatic stage. It may involve promotion and adoption of a whole system approach to healthier lifestyle (for instance, increased physical activity, smoking cessation and social engagement). It may be targeted to specific population groups or risk categories or be universal. Primary prevention is designed to reduce the risk of onset of dementia and thus to reduce the number of new cases.

PSSRU conducted a focused literature review on barriers and facilitators to primary prevention of dementia in England. It conducted an internet search to identify examples of schemes organised by English local authorities, clinical commissioning groups (CCGs) or other agencies where a core aim is the primary prevention of dementia. It also consulted commissioners and other experts through a range of events and one-to-one discussions.

The research team found evidence or received comments on the following barriers to implementation of measures to promote primary prevention of dementia.

Barriers

Time: lack of staff time (particularly consultation time) and competing work demands

Financing: limited funding and competition for funds with other services may be one of the most important barriers affecting primary prevention

Limited access to services: including transport, facilities and resources and, in rural areas, barriers relating to distance and isolation

Lack of resources: too few sufficiently knowledgeable staff as well as accurate information (limited awareness of, familiarity with, and compliance with, guidelines)

System organisational issues: poor system integration, lack of management and staff support, practice information systems not geared to support assessment and

management of smoking, nutrition, alcohol and physical activity, limited availability of referral services and poor feedback from agencies

Patient-oriented issues: low patient motivation, health conditions influencing the priority patients place on changing behaviour (for instance, use of tobacco and alcohol, management of blood pressure, following a healthy diet, being physical active), lack of time, financial costs, entrenched attitudes and behaviours, restrictions in the physical environment, low socioeconomic status, lack of knowledge, impact of culture on knowledge/awareness

Stigma associated with dementia: stigma could deter interest in dementia prevention

The research team found evidence or received comments on the following facilitators to implementation of primary prevention of dementia.

Facilitators

Time: Workload has to be kept manageable which can be achieved by developing:

- time-saving working tools short assessment tools
- short questionnaires to assess (for example) nutrition or physical activeness status

Good access to services:

- accessible programmes and information
- quick, short, focused and easy-to-access local programmes
- provision of primary prevention interventions at more convenient times and in easily accessible places (for instance in workplaces or local community settings)

Resources and information:

- provision of continuing professional training activities (for example webinars)
- establishment of information systems to support smoking, nutrition, alcohol and physical activity interventions
- provision of self-management resources
- accessible guidelines
- web-based interventions and online intervention tools

System integration and management:

- effective management and strong leadership
- better remuneration of GPs providing health promotion
- successful collaborative practice (for example, the integration of smoking, nutrition, alcohol and physical activity programmes within existing activities, particularly those relating to chronic disease management) and
- social support

Raising public awareness and reducing stigma:

- involvement of people living with dementia to change public perceptions

Improving patient motivation:

- giving patients vouchers for health promotion
- ensuring that health promotion programmes are enjoyable promoting a positive view of ageing
- focusing on health benefits including healthy ageing rather than on disease and
- integration of healthy behaviours into general lifestyle

Conclusions

The research team conducted a focused literature review, concentrating on primary prevention of dementia in midlife. Since the evidence on barriers and facilitators is limited, caution should be exercised in drawing conclusions for policy and practice. Nevertheless, a number of conclusions can be supported. The findings of this study suggest the following points for policy and practice:

- local government, the NHS and other stakeholders need to be well informed about the scope for primary prevention of dementia: they may want to consider additional training on this issue for a range of health and social care staff
- health and social care agencies will need to consider providing more information and advice for patients and the public about the risk factors for dementia in midlife
- health and social care agencies will also need to collaborate closely in commissioning measures to promote healthy lifestyles in middle age

1. Introduction and background

Public Health England commissioned PSSRU at the London School of Economics and Political Science to conduct a study of primary prevention of dementia. The study included a literature review of midlife risk factors for dementia and a study of barriers and facilitators to primary prevention. This report presents the findings of that part of the study concerned with barriers and facilitators. The literature review is published separately.

To promote primary prevention of dementia it is important to understand the barriers to primary prevention and the factors which can facilitate it. Primary prevention of dementia is taken here to mean activities or measures pursued before any symptoms of dementia are manifest and, in principle, before even the asymptomatic stage.

It may involve promotion and adoption of a whole system approach to healthier lifestyle (for instance, increased physical activity, smoking cessation and social engagement). It may be targeted to specific population groups or risk categories or be universal. Primary prevention is designed to reduce the risk of onset of dementia and thus to reduce the number of new cases.

Primary prevention of dementia in everyday practice is a challenging issue. However, there are some promising examples currently within CCGs and local authorities, with lessons for the future primary prevention of dementia.

Mapping existing evidence, including factors such as the socio-demographic characteristics of the target population, mode of delivery, incentives and reward, and the institutional framework within which interventions are implemented, provides a clearer picture of the primary prevention of dementia in practice.

2. Methods

Literature review

The research team carried out a literature search for papers published in English between 2006 and 2016. Initial mapping searches were carried out to identify the range of available evidence relating to the topic. The research remit predominantly focused on barriers and facilitators to primary prevention of dementia, as the literature on this proved to be very limited. However, the research team expanded its search to prevention of other long-term conditions (for example, diabetes) relevant to the causes of dementia.

Although the time available for this study did not allow the research team to conduct a systematic literature review, the following electronic databases for peer-reviewed primary studies, systematic reviews and economic evaluations published since 2006 were searched: MEDLINE (including MEDLINE – in-process); (Ovid); EMBASE (Ovid); PsycINFO (Ovid); CINAHL (EBSCO host); Health Management Information Consortium (Ovid); and Social Science Citation Index (Web of Knowledge) were searched.

Two additional databases were searched for systematic reviews published since 2006: The HTA database and the Cochrane Collaboration databases.

In addition, the research team conducted a ‘grey literature’ search to identify publications that might provide relevant information. The websites searched were: NHS Evidence Search: www.evidence.nhs.uk, Open Grey: www.opengrey.eu, Public Health Observatories: www.apho.org.uk, Health Evidence Canada: www.healthevidence.org, Alzheimer’s Society: www.alzheimers.org.uk and the British Library: www.bl.uk.

The research team also employed lateral search techniques, such as checking reference lists, performing keyword searches in Google Scholar and using the ‘cited by’ option in PubMed.

The following search terms were used: ‘primary prevention’ AND barriers (or) AND facilitators AND dementia AND CCGs (or) Local Authorities; ‘primary prevention’ AND barriers (or) AND facilitators AND smoking AND dementia; ‘primary prevention’ AND barriers (or) AND facilitators AND alcohol AND dementia; ‘primary prevention’ AND barriers (or) AND facilitators AND ‘physical activity’ AND dementia; ‘primary prevention’ AND barriers (or) AND facilitators AND hypertension AND dementia; ‘primary prevention’ AND barriers (or) AND facilitators AND diabetes AND dementia.

Overall, 21 papers were identified. However, only six of them focused on dementia primary prevention services and only one of those six focused on the UK.

Internet search for current examples in the UK

In addition to the literature search, the research team conducted an internet search in order to identify some key examples of primary prevention of dementia in the UK. The following search terms were used: 'primary prevention' AND dementia AND CCGs; 'primary prevention' AND dementia AND Local Authorities; 'primary prevention' AND dementia AND workplaces; 'primary prevention' AND dementia AND middle age AND CCGs (or) Local Authorities; smoking 'primary prevention' AND dementia; 'alcohol primary prevention' AND dementia AND CCGs (or) Local Authorities; 'physical activity' AND 'primary prevention' AND dementia AND CCGs (or) Local Authorities; hypertension AND 'primary prevention' AND dementia AND CCGs (or) Local Authorities; diabetes AND 'primary prevention' AND dementia AND CCGs (or) Local Authorities.

Information from this internet search helped to identify a small number of examples of primary prevention of dementia, mainly linked to CCGs, local authorities, and Health and Wellbeing Boards.

Consultation with stakeholders

PSSRU consulted commissioners and other experts in the following ways:

- discussions with the Director of Public Health and colleagues in one London borough
- discussions at a meeting in April of the Dementia Commissioners Network in London
- discussions at a meeting of the PHE Dementia and Ageing Well Centre Network
- a workshop held at LSE in May 2016 which related to PSSRU studies commissioned by Public Health England on primary prevention of dementia and mental health promotion/disorder prevention, and attended by 30 people from a range of public and voluntary bodies, as well as researchers

At these meetings, commissioners and other experts discussed their experiences of barriers and enablers in relation to the primary prevention of dementia and the sort of tools that would be likely to be helpful.

3. Literature on barriers and facilitators

This section provides a broad overview of the literature on barriers and facilitators to implementing projects or interventions aimed at the primary prevention of dementia.

As noted in the previous section, an evidence search was conducted which identified 21 articles. The research team found limited and mixed evidence in terms of detail and methodological quality, which made it difficult to identify information on barriers and facilitators. Reflecting the focused topic of the report, we considered six out of 21 papers to be related to dementia or making reference to dementia.

The research team excluded papers focusing on primary prevention in general, or on the ageing population but without any reference to dementia, and papers that described midlife risk factors but without any reference to interventions or implementation of those interventions in everyday practice. An additional two studies were retrieved from the internet search to identify some key examples of primary prevention of dementia in the UK (1, 2). Those studies are also included in our reference section.

Most of the excluded studies focus on the description of risk factors (3), specifically on how the reduction of risk factors can have an impact on prevalence of dementia (3, 4, 5) and on behavioural or other interventions to prevent or delay the onset of dementia (5, 6). Additionally, the research team identified five studies related to health promotion and social care services in older age and the promotion of healthy ageing practices and behaviours (7, 8, 9, 10, 11). Finally, the research team identified six papers that are mostly related to the implementation and delivery of primary prevention, systems barriers and facilitators in public health, on collaboration between primary care and public health, and on health promotion of ethnic minority groups but without specific reference to ageing or dementia (12, 13, 14, 15, 16, 17).

As stated above, in view of the focused topic of this report, the research team restricted the included papers to dementia-related studies and to studies that mentioned dementia. This was to make the report feasible within available resources and because the primary aim of the report was to inform public health policy specifically about primary prevention of dementia. Consequently, the focus here is on the six papers that are most relevant to this report. Two are dementia-focused and the others focus on the older population in general with reference to dementia.

Knowledge and awareness among the public health workforce in the UK about the prevention of dementia

Only one study explored knowledge and awareness among the public health workforce in the UK in relation to primary prevention of dementia (18). The UK Health Forum conducted an online survey of the public health workforce between December 2013 and

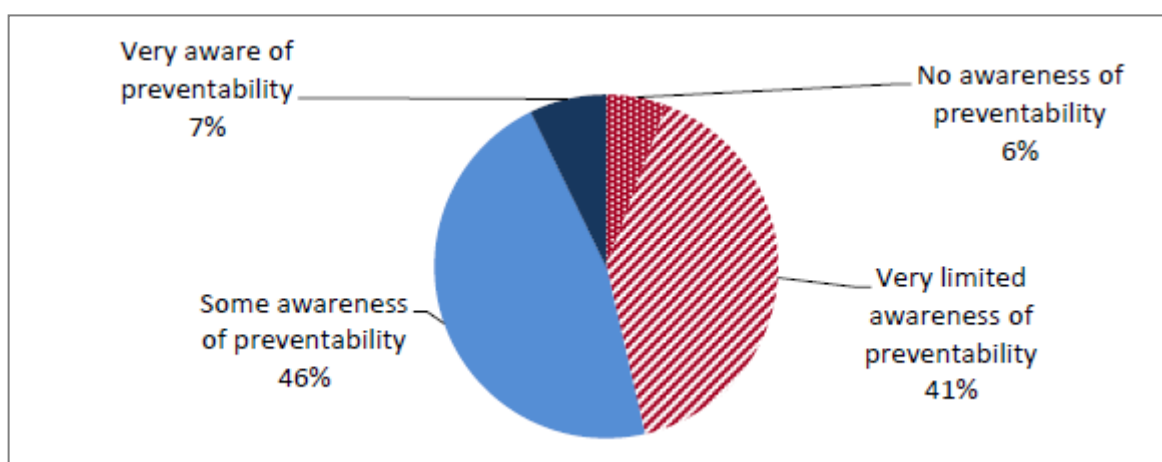
January 2014 with the support of Public Health England. The aim of the survey was, principally, to evaluate perceptions and knowledge of dementia prevention and, secondly, to identify the needs and the essential ingredients to support and implement primary prevention of dementia in practice. The findings of the survey were the focus of a high-level meeting that followed. 60 dementia and non-communicable disease experts discussed the survey results in depth. They summarised their final key findings in 'UK Health Forum report: Knowledge and awareness among the public health workforce in the UK about the prevention of dementia' (18).

Key findings from the Health Forum Report survey and discussion at their expert dementia meeting were (18 p.4):

- nearly 300 participants responded to the survey between December 2013 and January 2014
- half of respondents thought their colleagues were not aware that dementia is preventable
- the respondents reported self-awareness of the risk factors for dementia was highest for the non-modifiable risk factors of age (99%) and heredity (88%)
- reported awareness of behavioural risk factors of physical inactivity, tobacco, alcohol and poor diet was also high (78 to 88%). However, awareness was lower for the related intermediate risk factors such as hypertension, obesity, and diabetes (29 to 39%)
- there was low awareness of non-vascular and protective factors for dementia. 63% of respondents were not aware that education level was associated with dementia and 40% were not aware of the association of dementia with depression and social networks
- the majority of respondents (68%) do not currently include dementia prevention in health improvement or promotion activities
- a wide variety of information sources on dementia prevention are used, ranging from google and official government websites to journals and third sector sources
- evidence (85%), national guidance (65%) and training and support (>50%) were reported to be most useful for supporting future work in the area of dementia prevention
- barriers to dementia prevention include lack of evidence and official advice, lack of official strategic priority and resources, and public opinion and fear of stigmatising patients

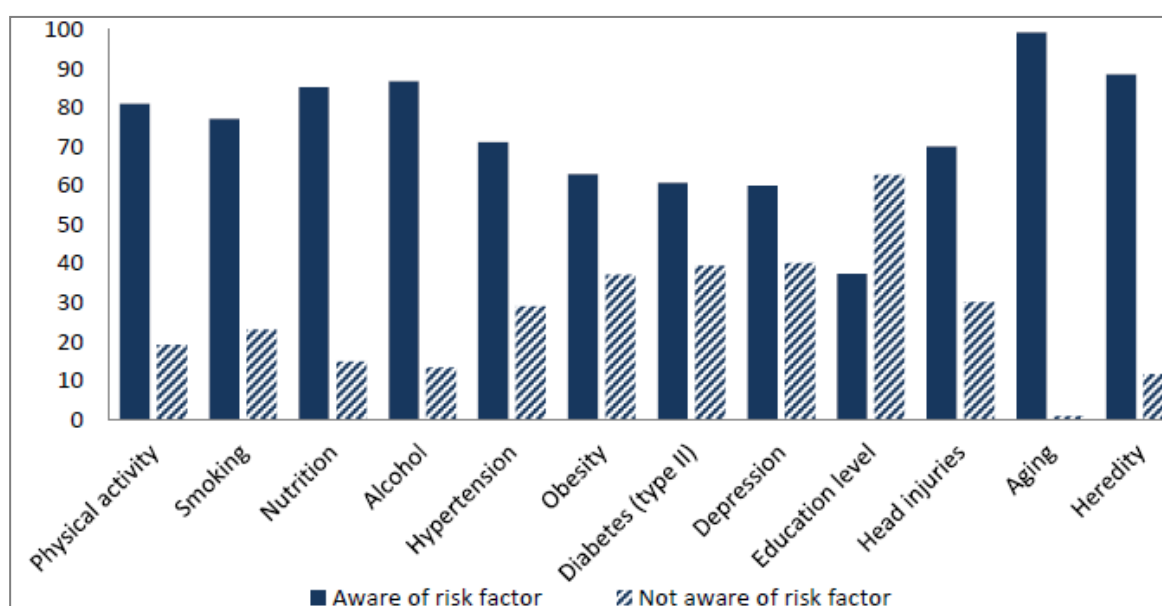
The UK Health Forum report (18) provides information suggesting that public health workforce is divided in their perceptions of how their colleagues understand prevention of dementia with 41% of respondents to a survey thinking that their colleagues have limited awareness of preventability (Figure 1). The reported awareness of risk factors varies considerably by risk factor (Figure 2): awareness of behavioural risks factors (physical activity, diet, smoking, alcohol) among public health staff is high (77 to 88%); but a significant proportion of respondents (29 to 39%) were unaware of the impact that some other factors (for example, hypertension, obesity, diabetes) can have on the development of dementia.

Figure 1: Perceptions of colleagues' awareness that dementia is preventable



Source: 18, p.8, reproduced with kind permission of the UK Health Forum.

Figure 2: Reported awareness of dementia risk factors (%)



Source: 18, p.8, reproduced with kind permission of the UK Health Forum.

The absence of a defined strategic priority for dementia prevention within health care bodies and government was identified as a barrier to primary prevention of dementia (18). Insufficient funding and limited resources to support work in this demanding area were seen as among the principal constraints on prioritising and applying primary dementia prevention in practice. The experts included in this study reported absence of coherent advice and guidance from official, evidence-based sources on what behaviours and other factors can protect against dementia (18).

The survey also found that many health care staff (including general practitioners) held the view that dementia is not preventable. In addition, it was suggested that stigma and fear of communicating a dementia-related risk or diagnosis adds emotional pressure and creates a more challenging environment for professionals working in dementia and mental health in general, compared to physical health (18).

The availability of evidence-based and updated national guidance with comprehensive information related to modifiable risk factors (diet, physical activity, tobacco, depression, alcohol, education) was identified by experts as a priority in facilitating primary prevention of dementia. One respondent quoted in the report commented that ‘the current guidance ignores many sources of information that are known to a few researchers’ (18, p.10).

Another important aspect of enabling primary prevention of dementia is professional education and training within the health care and public health workforce, and for policy-makers. This is not simply a need for access to training. The data from the survey suggests a need for in-depth research within the health and social care system in order to identify and thereby help creatively to manage concerns, issues, challenges and facilitators to implementing primary prevention of dementia across the health and social care system (18).

Evidence from the experts’ survey clearly suggests that education and training programmes, as well as communication regarding dementia, should challenge established myths about dementia being an inevitable part of ageing. Dementia is not inevitable nor simply an integral part of healthy ageing. The experts called for more action concerning the stigma surrounding dementia.

Better-integrated policies and programmes on dementia and non-communicable diseases would effectively support primary prevention of dementia. Dementia and cardiovascular disease, for example, share risk factors such as smoking, inactivity, diabetes and high blood pressure. Understanding this can motivate a shift from disease focused prevention to prevention based on promotion of healthy behaviors, independently of the disease. This should include, for instance, developing mental health and brain health programmes and strategies across the life stages, from early years (even maternal health) to old age (18; p. 11).

Dementia risk reduction in primary care: what Australian initiatives can teach us

Travers, Martin-Khan and Lie (19) conducted a comprehensive literature review aiming to identify and classify research evidence regarding barriers to and facilitators of dementia risk reduction in the Australian health care system. Their focus was on the elderly population, and a secondary aim of their study was to use the existing evidence to inform and enrich the Australian national dementia prevention strategy. They identified 116 titles (not only journal papers but policy reports too) that met their inclusion criteria and they finally focused on 68 titles that fully met those criteria. Despite the limited evidence, they concluded that health promotion strategies which are quick and easy in terms of administration seem to be more effective.

Reducing dementia risk by targeting modifiable risk factors in mid-life: study protocol for the Innovative Midlife Intervention for Dementia Deterrence (In-MINDD) randomised controlled feasibility trial

The In-MINDD study by O'Donnell et al. (20) is an ongoing clinical trial which aims to identify, in depth, the impact of modifiable risk factors in the development of dementia. The researchers are mainly interested in developing online interactive tools that may help middle-aged people to sustain healthy behaviours. For example, to be more active, reduce smoking and alcohol consumption. Moreover, the In-MINDD research team developed an online personalised profiler based on individualised demographic, clinical and self-reported information on health related behaviours. The aim of this online profiler is to calculate an individual's dementia risk modification score (LIBRA global score) and monitoring any changes.

In-MINDD is a multi-centre, primary care-based, single-blind randomised controlled feasibility trial currently being conducted in four European countries (France, Ireland, the Netherlands and the UK). Participants are middle-aged people (between 40 and 60 years old) with at least one modifiable risk factor for developing dementia (including diabetes, hypertension, obesity, renal dysfunction, current smoker, raised cholesterol, coronary heart disease, current or previous history of depression, self-reported sedentary lifestyle, or self-reported low cognitive activity). Results from the study are not yet published.

What is currently available is a paper describing the research protocol and the risk factors associated with dementia. The paper identifies some barriers to scaling up the implementation of primary prevention of dementia in middle age. According to O'Donnell and colleagues (20), overloading in clinical practice and the busy daily routine of middle-aged people are among the most important factors limiting implementation of primary prevention programmes.

Attitudes, barriers and facilitators for health promotion in the elderly in primary care

Badertscher and colleagues (21) carried out a qualitative focus group study to examine the self-perceived attitudes, barriers and facilitators experienced by GPs in their efforts to provide health promotion in the older population. They conducted 37 focus groups with general practitioners. The GPs reported that there are different definitions of health promotion and, moreover, that the effectiveness of primary prevention seems not to be homogeneous. However, according to Badertscher et al., the two most essential barriers for GPs in implementing health promotion in an elderly population were lack of time and insufficient reimbursement for prevention and health promotion campaigns. Despite the barriers, Swiss GPs suggested that by including health promotion in postgraduate training, involving practice nurses in health promotion and introducing counseling, health promotion for older people could be increased.

Barriers and enablers of health promotion, prevention and early intervention in primary care: Evidence to inform the Australian national dementia strategy

Travers, Martin-Khan and Lie conducted a second comprehensive literature review (22) focused on initiatives that encouraged primary care practitioners to implement a primary prevention programme. The programmes and campaigns covered were based on lifestyle factors. For example, smoking, healthy eating and physical activity. They extended their search from bibliographical databases to a wider search including health care in Australian-focused websites. Their aim was to identify barriers and facilitators in primary prevention.

Their findings suggest that financial issues (lack of effective reimbursement) and limited time within an extremely demanding environment were the most important barriers. However, they concluded that there are some important facilitators in adapting and running a primary preventive programme. These included integration of interventions, the existence and specific role of the practice nurse and the support of the Australian General Practice Network. They concluded that these factors should be considered for inclusion in the Australian National Prevention Strategy for the implementation of a successful primary prevention strategy for dementia (22).

Barriers and facilitators to the uptake and maintenance of healthy behaviours by people at mid-life: a rapid systematic review

Finally, Kelly, et al. (23) conducted a systematic review of literature reviews and qualitative or longitudinal cohort studies in order to identify barriers and facilitators to healthy behaviours in middle life (40 to 64 years). Being physical active, following a healthy diet, and stopping smoking and drinking sensibly, were among the included factors. From 16,426 titles reviewed, only 28 qualitative studies, 11 longitudinal cohort

studies and 46 systematic reviews met the full inclusion criteria. The evidence from this systematic review suggested that among the main barriers holding middle-aged people back from following healthy rather than unhealthy behaviours are: lack of time (due to family, household and occupational responsibilities), access issues (to transport, facilities and resources), financial costs, basic attitudes and behaviours, restraints in the physical environment, low socioeconomic status and lack of knowledge (23). On the other hand, key facilitators include focusing on the positive part of life, on enjoyment and on healthy ageing; having an active social network and thus social support; having clearly communicated primary prevention messages; and integration of behaviours into lifestyle (23).

From these six papers we can pull out the key barriers and facilitators.

Barriers

Staff

- lack of staff time (especially consultation time) and competing work demands. Staff time was also required to arrange referrals, follow-up, recall and reminders (21, 23, 19, 22)

Financing

- inadequate funding: limited funding seems to be one of the most important barriers effecting primary prevention in many ways. Health promotion strategies generate high costs and there is competition for funds with other services (21). The absence of specific funding for smoking, nutrition, alcohol and physical activity programmes means that those interventions have to be incorporated into the consultation for which the patient had presented, and payment (in the Australian context at least) was not commensurate with the increased consultation time (19). Further, no additional staff costs are covered (21, 23, 19, 22)
- insufficient reimbursement can be a barrier for GP health promotion for older people (21)

Limited access to services

- access issues, including transportation, facilities and resources (21, 23, 19, 22)
- in addition, in rural areas there are barriers relating to distance and isolation, heavy workloads and limited access to services and training (21, 23, 19, 22)

Lack of resources

- unavailability of staff with the appropriate knowledge (22)
- accurate information (lack of awareness of guidelines; lack of familiarity with guidelines; lack of agreement with guidelines (19, 18)

System organisational issues

- poor system integration (for instance, difficulty navigating the system; lack of consistency throughout the system; inconsistent follow-up care; poor communication with health professionals and instructors) (21, 19, 22, 18)
- lack of management and staff support (beliefs, attitudes, motivations; unachievable targets) (19, 18)
- practice information systems not geared to support smoking, nutrition, alcohol and physical activity assessment and management (for instance, barriers to information exchange) (22, 18)
- limited availability of referral services and poor feedback from agencies (22)

Patient-oriented issues

- low patient motivation associated with comorbid medical conditions influences the priority that patients place on changing their behaviour (23, 22)
- lack of time (due to family, household and occupational responsibilities) (21, 23)
- financial costs facing individuals (23)
- entrenched attitudes and behaviours (23)
- restrictions in the physical environment (21, 23)
- low socioeconomic status (23)
- lack of knowledge (23)
- impact of culture and religion on knowledge/awareness, beliefs and lifestyle behaviours (23, 14)
- older people misunderstanding health promotion as discrimination (21)

Facilitators

Staff

- workload has to be kept manageable (for instance by developing time-saving working tools, short assessment tools, short questionnaires to assess the nutrition or physical activeness status) (21, 19, 22). However, it is important to note that any new instrument must easily integrate in daily work (19, 9)
- the role of practice nurses is very important and they could be a target group for training in primary prevention of dementia (22)

Good access to services

- good accessibility of programmes and information (21, 23, 19, 22), such as quick, short and focused easy-access programmes with a local character (23)
- health promotion at workplaces: better primary prevention can be achieved by providing primary prevention interventions at more convenient times and in easily accessible places. For example, in workplaces or local community settings (23)

Resources and information

- provision of continuing professional training activities (22, 18)
- establishment of information systems to support smoking, nutrition, alcohol and physical activity interventions (22, 18)
- self-management resources (18)
- easily accessible guidelines (attractive presentation and clear messages) (23, 19, 22, 18)
- web-based interventions and online intervention tools (20, 18)

System integration and management

- a defined strategic priority for dementia prevention within health care bodies and the Government (18)
- mental health and brain health programmes and strategies across the life span from the early years (even maternal health) to old age (18)
- social marketing campaigns to promote healthy lifestyles amongst people in middle age (20)

- increased remuneration for GPs providing health promotion: according to a qualitative focus group study, one of the most crucial prerequisites for the majority of the GPs to provide health promotion in the elderly population is sufficient reimbursement by the healthcare system in terms of time and effort spent on health promotion (21)
- successful collaborative practice, such as the integration of smoking, nutrition, alcohol and physical activity programmes within existing activities, particularly those relating to chronic disease management (23, 22, 18)
- social support, for example, supportive family, friends or partners to act as a facilitator in people's effort to adopt and maintain healthier lifestyles (physical activity, healthy eating) (23)
- integration: For some GPs, integration is a key element for the promotion of primary prevention, and health promotion activities by GPs could be made more effective by building integrated services together with other stakeholders and with practice nurses, specialised nurses and other health professionals (21)

Patient-oriented issues

- reward based health promotion, for instance giving people vouchers (21)
- health promotion programmes should be enjoyable – focus on enjoyment (21, 23)
- promoting a positive view of ageing and focusing on health benefits including healthy ageing rather than on disease (21, 23). Promoting an overall positive view of ageing can be one of the most important initiatives and a key facilitator for healthy middle-aged people to increase their physical activity (23)
- integration of behaviours into lifestyle (23)

4. Key themes arising from discussions with commissioners

Primary prevention services aimed at reducing the risk of dementia for middle-age.

Barriers

- attributing some of the symptoms of dementia to stress, particularly by younger men who have a higher rate of early-onset dementia than women
- stigma associated with a dementia diagnosis
- social isolation and loneliness in older populations
- lack of motivation to engage in healthier life-styles
- lack of information and resources (for instance, NHS Choices pages are not well known; lack of strong and clear evidence)
- lack of staff training
- some services experience difficulty engaging with black, Asian and minority ethnic populations

Facilitators

- strong links between partner organisations
- strong engagement by senior management

Recommendations

Recommendations from people we consulted included:

- partnership working should be promoted as a facilitator to improve incentives
- improved evidence should be a priority, but a trusted source is needed, as there is a great deal of misleading advice available on the web
- segmentation of recipients of information and advice is needed so that appropriate help can be targeted on different groups
- proper training required for staff involved: webinars by experts would be valuable
- technology can be valuable in providing feedback on physical activity

- strong leadership is required, to match resources to priorities
- involvement of people living with the condition in media campaigns to change public perceptions would be valuable
- more resources should be provided for risk reduction activities

5. Primary prevention of dementia – current examples

Primary prevention services aimed at reducing the risk of dementia for middle-aged people are rare. The existing paradigms can be categorised broadly into local/regional and national campaigns. This section describes these types of services. The material below is drawn from the websites of CCGs, local authorities and Health and Wellbeing Boards. Most of the examples do not specifically mention dementia. However, we selected these examples as they were the only ones identified by use of our search terms (see section 2 for current examples in the UK).

Local programmes

Wellbeing coordinators in Cheshire

Public health aims to prevent or at least delay the onset and impact of dementia via interventions that protect a person's health. A partnership between Age UK, the local CCGs and the local acute trust in Cheshire developed a team of wellbeing co-ordinators who together with the local integrated teams direct people towards services that might have a positive impact on their wellbeing. For example, if someone would like to feel less lonely, to lose weight or to help out in their local community, the wellbeing coordinator can direct people in the right direction.

Source:

www.mylifeafulllife.com/Downloads/Publications/Leading%20local%20partnerships_WEB.pdf (p18)

Health coaching in practice – Salford City Council

'Being Well, Salford Health coaching' is a central action of 'Being Well Salford', a primary prevention programme commissioned by Salford City Council and coordinated by Big Life Centres.

The focus here is to enable the participants to improve their lives. They collaborate with seven other Voluntary Community and Social Enterprise (VCSE) organisations in Salford; Social Adventures, Unlimited Potential, Langworthy Cornerstone, Salford Community Leisure, YMCA and People's Voice Media.

'Being Well' is emphasising the value partner site for health coaching. The participants, who are supported by coaches, are urged to take control and think carefully how they can make positive changes to their lives. The service offers support to people who want

to make changes to several of the following areas in their life: weight, smoking, alcohol, physical activity, low mood or depression.

The service is offered to participants for up to 12 months and their engagement is then reviewed. Some results on leaving the service:

- 48% of smokers had stopped smoking
- 70% had increased their self-efficacy significantly
- 21% reduced their weight by more than 5%
- 88% had adopted at least three behaviour change goals within six months
- 93% said they had greater awareness of opportunities and services

Source: 2.

Intelligent Health – Reading

The Intelligent Health programme, which started in 2012, is described on the NESTA (National Endowment for Science Technology and the Arts) website.

'Intelligent Health' was founded by GP Dr William Bird MBE and is focused on campaigns to make physical activity a way of life.

One radical element of the Intelligent Health programme is 'Beat the Street' (BTS), where the participants earn points as they walk, cycle and run around their town. It is like a game where 'Beat Box' sensors are placed on lampposts around the town for players to tap their card against, scoring points for the distance they walk, cycle or scoot.

BTS focuses on community in order to change behaviour. The whole community, schools, GPs, local authorities, community organisations and local media, are united and encouraged to join in. In order to keep this game interesting, social media are used and incentives are given to make the game engaging and fun for the residents. Results show 175,000 people played in 2015 in 21 different areas, with a projected figure of more than 300,000 by the end of 2016.

BTS has long-term results since it acts as a catalyst for behaviour change, while at the same time creates a social norm around walking and cycling. Statistics highlight that 48% used their car less and 9 out of 10 participants said that it helped them be more active. There is both a personal impact on wellbeing and a financial incentive too as councils recoup long-term savings as people make physical activity a habit.

Source: www.nesta.org.uk/news/new-radicals-2016/beat-street

See also: www.intelligenthealth.co.uk

National programmes

PHE 'One You' campaign

In March 2016, Public Health England launched a health campaign called 'One You' which focuses on middle-aged adults (40 to 60 years old) living healthier and longer. One You is the first campaign in England focusing on middle-aged adults in a holistic way that tries to encompass and integrate physical activity, nutrition, smoking cessation, management for drinking and psychological wellbeing. It is also the first time that dementia is included in a primary prevention campaign targeting adults in middle life.

The One You campaign stresses that healthier choices today. For example, eating better and less, stopping smoking, being active, and drinking sensibly can have a positive influence on present and future health, and can also have a proactive role in areas such as type 2 diabetes, cancer and heart disease. Moreover, adoption of a healthier lifestyle in middle age can reduce the risk of suffering a stroke or living with dementia, disability and frailty in later life.

One of the One You campaign innovations is its integrated nature, taking into consideration that people in their 40s, 50s and 60s are usually active and working.

According to Public Health England, the London Borough of Hounslow is a good example of how to adopt and promote the One You campaign making it relevant, accessible and thus acceptable to the local community. As 70% of middle-aged adults are in employment, the workplace is one of One You targets. Some employees have already adapted the campaign in their workplaces. For example, Travis Perkins, Britvic Soft Drinks, NHS England and Crossrail.

Source: www.nhs.uk/oneyou#Lrjj4ict4xpDazo1.97

A local authority example of implementing 'One You' campaign

Since April 2016, the health and wellbeing services in the Borough of Hounslow united under one single hub service known as One You Hounslow.

One You is one of the largest Public Health England campaigns to be launched since Change4Life and it will be the biggest campaign that focuses on the adult population in leading a healthier life.

The hub service provides various information and support from healthy lifestyle specialists through a devoted website, and online services, telephone and face-to-face support.

One You Hounslow, also supports locals in their efforts to stop smoking, lose weight, eat healthily and exercise more.

The service will provide local people with advice on how to improve their health and the services combining them under one roof.

In addition to help with making their lifestyle healthier, residents can access local leisure centre facilities and other local health services.

People find information about Hounslow wellbeing services through a dedicated website and online services, telephone and face-to face support. The community NHS Trust at Hounslow is working in parallel with the local voluntary sector (the Hounslow Wellbeing Consortium and Age UK).

Source:

www.hounslow.gov.uk/news_mod_home/news_mod_year/news_mod_month/news_mod_show?year1=2016&month1=3&NewsID=73381

Workplace examples of implementing the 'One You' campaign

NHS England healthy workforce

It was important for the NHS Five Year Forward View (24) to ensure that the NHS will set, as an employer, a good national example in terms of the support it offers to their own staff to stay healthy. Simon Stevens announced further plans to support this commitment, which includes a major drive to improve the health and wellbeing of NHS staff. These web pages detail the offer made, and how this work is being taken forward.

Source: www.nhsemployers.org/your-workforce/retain-and-improve/staff-experience/health-work-and-wellbeing/copy-of-leading-the-way/whats-happening-nationally/nhs-england-healthy-workforce

Travis Perkins

Travis Perkins decided in April 2016 to restructure its health and wellbeing programme. Travis Perkins' comprehensive health services include discounts for gym membership, and on-site fitness classes, provided by British Military Fitness. Travis Perkins has collaborated with AVIVA in order to provide innovative insurance and health and wellbeing benefits, such as access to cutting-edge cancer treatment at the Sarah Cannon Research Institute. They have also initiated a virtual GP service, which empowers employees to consult with a doctor over the phone. These will be a part of the government's One You health campaign, which launched in March 2016.

Source: www.employeebenefits.co.uk/issues/may-2016/travis-perkins-unifies-its-benefits-offering/

The Richmond group of charities

The Richmond Group of Charities consists of 12 of the leading health and social care organisations in the voluntary sector. These organisations collaborate together and act as a collective voice for the 15 million people living with long term conditions. Their aim to influence health and social care policy and of course to improve the care and support for them. Prevention is one of their major priorities: 'There is now compelling evidence that physical activity has huge health benefits for everyone, including for people with long term conditions. As a coalition of charities, we are eager to engage with policies and initiatives that support people with long-term conditions to enjoy the benefits of physical activity. We are also keen to link our wider prevention influencing programme with practical solutions to get people active. With this in mind, the Richmond Group, in partnership with Sport England, are currently in the early stages of developing a collaborative programme of work which aims to get more people at risk of or living with long term conditions participating in sport and physical activity'.

Source: richmondgroupofcharities.org.uk

Ageing Well

The 'Ageing Well' programme, which was commissioned by the Department of Work and Pensions, was implemented in collaboration with the Local Government Association over a two-year period, which ended in March 2012. The initial objective of the programme was to support councils in their efforts to provide a better quality of life for older people by designing and developing services to meet their current needs, and in the future at a local level.

Source: www.gov.uk/government/publications/2010-to-2015-government-policy-older-people/2010-to-2015-government-policy-older-people. This webpage includes links to an evaluation report and summary.

The Newcastle West Clinical Commissioning Group Ageing Well Strategy

Oliver, Foot, Hamphries (2014) presented the Newcastle West Clinical Commissioning Group Ageing Well Strategy as an example of good practice concerning the Ageing Well programme which also focuses on middle age people.

Newcastle West CCG, in collaboration with Newcastle Council, have developed an ageing well strategy that not only targets mid-life but also the 'mature life cycle', encompassing the way the following age periods 'preparing for active old age' (50 onwards), 'active old age', 'vulnerable old age' and 'dependent old age'. The implementation of the strategy includes: health checks to identify risk factors such as obesity, physical inactivity and poor diet in those aged 40 to 74, and incorporates older people as volunteers and health champions with a focus on case-finding to identify older people who are vulnerable to deterioration or dependency. The overall aim of this

project is to ensure that older people will have access to proactive support services with particular focus on supported self-management (1; p.9).

Source: 1; p.9.

Age UK's 'Fit as a fiddle' campaign

Age UK runs a nationwide programme called 'Fit as a fiddle' to support healthy, active ageing and promote physical activity, mental wellbeing and healthy eating, to better meet the needs of older people. The programme is implemented and delivered in collaboration with regional and national organisations. This includes various initiatives such as participation in activities, telephone peer support, chair-based exercise programmes, and social networks for older men experiencing social isolation. The campaign's initiatives have had a positive impact on wellbeing, levels of happiness, physical activity and social engagement. An independent evaluation of the programme is being carried out.

Source: www.ageuk.org.uk/professional-resources-home/services-and-practice/fit-as-a-fiddle/

6. Conclusions

There is strong evidence that adopting healthier lifestyles in middle age. For example, maintaining regular physical activity and avoiding smoking, can reduce the incidence of dementia in old age (3, 4, 5). Primary prevention of dementia for the middle-aged population is a challenge that we cannot ignore – at individual, community and national levels. The existing national programmes promoting healthy lifestyles in midlife and healthy and active ageing – with their focus on physical activity, preventing obesity and smoking cessation – have vital roles to play in reducing the risk of developing dementia and improving the health and wellbeing of middle-aged and older people.

Primary prevention programmes relating to cognitive impairment and dementia, however, have tended to focus on people over 60 or 65 years. Local health and wellbeing strategies in England have tended not to prioritise middle-aged people in relation to (future risks of) dementia. Thus, there are a limited number of ‘good practice’ examples concerning primary prevention of dementia for middle-aged people. There is, it seems, a strong case for greater attention to prevention of dementia as well as other health conditions in promoting healthy lifestyles in middle age. This could include health promotion activities in the workplace.

Local authorities and CCGs, together with the voluntary sector, are currently delivering the majority of the primary prevention interventions discussed in this paper. There is a vital need for health and social care services and voluntary organisations to work together to help tackle the barriers and promote the facilitators to successful primary prevention. This will help to improve quality of life of both middle-aged and older people, and lessen their risk of developing dementia.

Since the evidence on barriers and facilitators is limited, caution is clearly required in drawing conclusions for policy and practice. Nevertheless, the evidence that we have assembled can inform the development of primary prevention efforts. The findings of this study suggest the following points for policy and practice:

- local government, the NHS and other stakeholders need to be well informed about the scope for primary prevention of dementia: they may want to consider additional training on this issue for a range of health and social care staff
- health and social care agencies will want to consider providing more information and advice for patients and the public about the risk factors for dementia
- health and social care agencies will also want to collaborate closely in commissioning measures to promote healthy lifestyles in middle age

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