Designing a Dementia Fund

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ACKNOWLEDGMENTS

The SMF was commissioned by Alzheimer’s Society to carry out an independent assessment of how to commission a Dementia Fund and how much it would cost. Thanks goes to all those involved in helping develop the ideas presented within this paper.

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EXECUTIVE SUMMARY

Over 850,000 people in the UK are living with dementia. The current health and social care system treats dementia very differently to other health conditions. There is no cure or long-term treatment for dementia and those with dementia are treated as part of the social care system. Therefore, unlike individuals with cancer or other long-term illnesses, people living with dementia must cover the (often very high) costs of care unless they qualify for means-tested support. Not only are those with dementia treated differently to those with cancer or diabetes they are often treated differently to those with other social care needs. Dementia-related care can cost significantly more than care for those without the disease, often reflecting the complex nature of the care and support required.

This report sets out how a Dementia Fund, as suggested by Alzheimer’s Society, could be set up to cover the additional social care costs faced by people living with dementia. This would create a level playing field so that such individuals do not pay more for their care than social care users without dementia in similar settings.

The Dementia Penalty

The report defines the Dementia Penalty as the average difference between the costs of care faced by people living with dementia versus those with other social care needs. This average proportional difference would be calculated at a national level for different settings (domiciliary, residential home and nursing home) and then applied to the local base cost faced by social care users in the same settings who do not have dementia.

Commissioning the Dementia Fund

The report draws on an analysis of how social care and dementia services are commissioned as well as of similar Funds to make recommendations for how the Dementia Fund should be commissioned. The report proposes that:

- The Dementia Fund would be jointly commissioned by health and social care. This would help align incentives for local authorities and NHS.
- Individuals with a dementia diagnosis would have the right to access this funding through a Personal Budget. The NHS is looking to expand Personal Health Budgets and individuals living with dementia are one of the priority groups.
- Funding would be drawn down from the Dementia Fund into the Personal Budget and available to be spent on the individual’s care plan.
- Funding would be made available to self-funders and to local authority social care clients. The level of funding would vary according to the individual’s care needs.
- The Dementia Fund should be set up as an independent Fund with legal status.
- Spending through the Dementia Fund should be overseen by the OBR and outcomes monitored and reported on annually.

Estimating the cost of the Dementia Fund

The report estimates that the Dementia Fund would cost £468m in 2018 to cover costs of the dementia penalty for all those with dementia (self-funders and local authority clients). This is based on a 66% diagnosis rate. Based on forecasts that the number of people with dementia will increase over time, we estimate that the cost would grow to £915 million by 2040. The report also calls for a full evaluation of the penalty in advance of applying the policy as the evidence base is currently incomplete.
CHAPTER 1: MOTIVATION FOR THE DEMENTIA FUND

Over 850,000 people in the UK are living with dementia.¹ It is estimated that the number of people with dementia will increase to over 1 million in 2025 and to over 2 million by 2050.²

The current health and social care system treats dementia very differently to other health conditions. There is no cure or long-term treatment for dementia and as a result those with dementia are treated as part of the social care system. This means that those with dementia are treated very differently to those living with cancer or diabetes. Those with cancer or other long-term illnesses can access support services on the NHS without charge, but the same is not true for those with dementia. As a result, those who live with dementia can find themselves paying significant amounts of money towards their care in later life, with research by Alzheimer’s Society suggesting that those with dementia typically pay £100,000 for the care they need.³

Not only are those with dementia treated differently to those with cancer or diabetes, they are often treated differently to those with other social care needs. Research by Alzheimer’s Society estimates that dementia-related care can cost up to 40% more than care for those without the disease, often reflecting the complex nature of the care and support required.⁴ This drives cost and quality penalties. Self-funders face large costs when paying for dementia care and recipients of local authority funded social care may face demands for top-ups to ensure their complex care needs are met. Under-funded local authorities struggle to find sufficient money for good-quality care for dementia and this can have a negative impact on the level of quality, for instance only 70% of nursing homes are rated good or outstanding.⁵ Family members face disproportionate burdens of care either through the financial pressure to fund high quality care to meet the care needs of those with dementia or provide unpaid care to loved ones.

Alzheimer’s Society has proposed an ‘NHS Dementia Fund’ to establish a fairer outcome for people living with dementia and to improve the quality of care. The Dementia Fund would help to cover the additional costs of social care faced by individuals who have dementia compared to other social care needs. This would help to move towards a system where all individuals with social care needs find themselves on a level playing field when it comes to paying for social care.

The fund would cover the additional costs faced by a user of social care with dementia compared to a social care user without dementia. The additional amount paid by an individual with dementia compared to other users is the “dementia penalty”.

This research will make recommendations for how best to design and structure a Dementia Fund and seek to estimate the cost of a Dementia Fund, now and in the future. The report is structured as follow:

- Chapter 2 outlines the way in which the fund should be commissioned to ensure the best outcomes for those with dementia
- Chapter 3 focuses on the cost of the Dementia Fund now and in the future
- Chapter 4 discusses the wider impact of creating a Dementia Fund
CHAPTER 2: COMMISSIONING A DEMENTIA FUND

This chapter asks:

- What is the aim of the Dementia Fund?
- What is the existing commissioning landscape for dementia services?
- What lessons can we learn from other similar funds and commissioning arrangements?
- How should money in the Fund be distributed and how should services be commissioned?

Aims of the Dementia Fund

The aim of the Dementia Fund is to cover the penalty that people living with dementia pay for their care compared to non-dementia care users. To be clear, the intention is not to cover the total social care costs of individuals living with dementia. The Dementia Fund would be available in England, and this work does not consider costs associated with Wales, Scotland or Northern Ireland due to their differing health and social care systems.

Chapter 3 provides further detail on the level of penalty faced, but our analysis suggests that individuals living with dementia pay an average of between 2% and 7% more than patients without dementia depending on the setting of their care and whether they are self-funders or local authority clients. For instance, a self-funder in residential care without nursing faces a 2% penalty compared to a 7% penalty for a local authority-funded individual.

The existing commissioning context for dementia

Commissioning is the process by which public funding is converted into services. How it is carried out can establish incentives for commissioners themselves, clinicians, people living with dementia, professional carers, unpaid carers and providers. How a service is commissioned also affects whether money is vulnerable to leaking away to other causes.

The first point to note is the complex commissioning landscape currently for people living with dementia and their services. Eligibility and assessment processes for health and social care services differ markedly:

- **NHS care**: Services are free-at-the-point of use, but individuals typically rely on referral from general practice (or memory clinics) to receive secondary care, medicines or other additional care. Services are commissioned by CCGs.

- **Publicly-funded social care**: People qualify by going through a social care needs assessment with their local authority as well as passing a financial means-test. Services are commissioned by local authorities.

- **NHS Continuing Healthcare (NHSCHC)**: Some patients with long-term complex health needs qualify for free social care arranged and funded solely by the NHS. Eligibility is dependent on assessed needs, rather than a particular diagnosis or condition. Many people with dementia do not qualify for NHSCHC. Services are commissioned by CCGs.
Designing a commissioning regime that is successful needs to navigate its way through this existing territory. Otherwise it will only further complicate an already very complex health and social care system – this is likely to be bad for people with dementia, their families and for the wider integration agenda.

This chapter explores a range of potential ways of structuring a Dementia Fund and commissioning care through it. Each of these has advantages and disadvantages.

Our starting position is that a well-designed Dementia Fund should ensure:

- That funding is accessible to those who need it at the level they need it (eligibility and assessment).
- That the commissioning structure promotes collaboration between health and social care (collaborative system).
- Flexibility so that individuals can use funding in different ways that best match their needs and drive quality care (purchasing).
- That the fund is resilient and sustainable as a concept and initiative (structure).

These objectives are described in fuller detail below. To help assess the potential options, this section draws on lessons from other Funds and commissioning regimes which have some parallels to, or lessons for, a Dementia Fund. Details are provided in Annex 1.

Key attributes of an effective commissioning structure for a Dementia Fund and how to achieve them.

Here, we describe in more detail commissioning objectives and how they could be achieved.

**Objective 1: Funding should be accessible to those who need it at the level they need it**

*Why this matters in a Dementia Fund*

People living with dementia may present with needs either through NHS channels (e.g. GP surgery, memory clinic, in hospital or through NHSCHC) or through social care (local authority social care assessment). Alzheimer’s Society notes that ‘the symptoms of Alzheimer’s disease worsen over time, although the rate at which the disease progresses varies’. Typically, this is separated into mild, moderate and severe, with symptoms varying markedly across the different stages. The needs of individuals also change over time, and therefore funding would have to alter to match changes along the care pathway.

*How this could be achieved*

<table>
<thead>
<tr>
<th></th>
<th>Strengths and opportunities</th>
<th>Weaknesses and challenges</th>
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<tbody>
<tr>
<td>NHSCHC</td>
<td>Already in place</td>
<td>Assessment is often protracted and outcomes uncertain. This leads to delay in care and false expectations.</td>
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<td>The NHSCHC can fund all aspects of care (including board and lodging), so channelling the Dementia Fund through it would be confusing and potentially ‘unfair’.</td>
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<td></td>
<td></td>
<td>Would mean two-stage assessment for individuals.</td>
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<tr>
<td>NHS diagnosis only</td>
<td>Research has shown that clinicians under-diagnose dementia for a wide range of reasons. One of these is that GPs are not confident that there is value in diagnosis given the poor availability of care. Access to a funding for dementia care could encourage prompter diagnosis.</td>
<td>Those assessed through social care may miss out.</td>
</tr>
<tr>
<td>Social care assessment only</td>
<td>Many people with dementia will have co-morbidities and undergo a social care assessment.</td>
<td>People who have had a diagnosis but are relying on unpaid support or would benefit from social prescribing (outside of the social care system) would miss out.</td>
</tr>
<tr>
<td>Assessment via social care or NHS</td>
<td>Could increase the opportunities for individuals to be diagnosed with dementia.</td>
<td>Would require an integrated commissioning process.</td>
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Based on this analysis we propose that eligibility for funding from the Dementia Fund could be triggered by a dementia diagnosis in the NHS or by a new/refreshed care needs assessment for those already living with dementia in the social care system. This would categorise individuals into ‘mild’, ‘moderate’ or ‘severe’ dementia and establish what banding of funding they should be eligible for. This would lead to a care plan being drawn up or revised to reflect the individual’s needs.

Clear links could be built in to the CCG Improvement and Assessment Framework (CCGIAF). The CCGIAF scores CCGs against their dementia diagnosis rates and on their use of care plan reviews, as a route to better diagnosis rates and more appropriate care. As noted elsewhere, the Government hopes to increase dementia diagnosis rates; meanwhile, establishing and regularly reviewing care plans can help ensure that the care plan is personalised and reflects changes in the condition that may have taken place. Reviewing plans regularly would help ensure that the care plan and the support available to the individual are reflective of the severity of their dementia and their support needs.

Eligibility to different levels of funding support would change as the individual progresses along the care pathway and when / if the person’s dementia becomes more severe. The penalty would be calculated as a national percentage applied to the base cost of average social care services in that local authority area, and allocated accordingly. In a perfect world, the national penalty would vary by the severity of dementia, ideally by mild, moderate and severe needs. However, this may be impossible to achieve. Alternatively, (as in our modelling), the penalty could be based on the settings – such as residential care home and nursing home. The information on the dementia penalty in domiciliary care is very incomplete and hard to estimate. Further information on the difference in hourly costs of dementia carers versus other social care workers may help estimate this penalty.

Consideration should also be given to how Dementia Fund assessments and eligibility interact with NHS Continuing Healthcare and NHS-Funded Nursing Care. One approach would be for the Dementia Fund to be a gateway into NHSCHC for those with a dementia diagnosis. In other words, people living with dementia could initially be allocated support from the Dementia Fund, before onward referral to NHSCHC if they have other conditions that might make them eligible for funding through it. This would require more detailed
analysis to ensure that people with dementia had equal outcomes irrespective of which assessment channel they follow.

Given the incompleteness of data, we would expect the Treasury and DHSC to issue a call for data and evidence from local authorities and care providers so that the very best estimate can be made of the dementia penalty.

**Recommendation:** Eligibility for support from the Dementia Fund would be triggered by assessment either through the NHS or through social care assessment. This would categorise people living with dementia into different bandings of funding, depending on their care needs.

**Recommendation:** The penalty would be calculated as a percentage of the base cost of social care services for an individual without dementia in that local authority area. The funding would be higher for those with more severe dementia in the same setting.

**Recommendation:** The Government should give further consideration to how the Dementia Fund should interact with NHSCHC and NHS-Funded Nursing Care, including assessment and eligibility and distribution of funding.

**Recommendation:** The Government should carry out a full evaluation of the penalty in advance of applying the policy. It should then increase the Dementia Fund in line with inflation, before fully reviewing the scale of the penalty every five years.

**Objective 2: The commissioning structure promotes collaboration between health and social care**

*Why this matters in a Dementia Fund*

Due to the fact that social care is funded locally and eligibility is means tested, whilst NHS care is funded nationally and free-at-the-point of use, there is a history of cost shunting between the two. Cost shunting and lack of joined-up commissioning contributes to significant inefficiencies in use of resources and results in poor quality care for people living with dementia. For instance, between November 2014 and November 2016, delays in discharges from hospital increased by 37%, with lack of a care package and appropriate nursing home placement being the most significant contributors. The Dementia Fund will sit at this divide between health and social care: it will make public funding available for dementia care needs regardless of the means test outcome. Careful consideration therefore needs to be given to promote buy-in from commissioners in both the NHS and adult social care.

As it stands, people living with dementia can receive support from a very confusing range of sources (see Figure 1).
How this could be achieved

<table>
<thead>
<tr>
<th>Strengths and opportunities</th>
<th>Weaknesses and challenges</th>
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<tbody>
<tr>
<td><strong>NHSCHC</strong></td>
<td><strong>Already in place</strong></td>
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<td></td>
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<tr>
<td><strong>Better Care Fund</strong></td>
<td>Is already in place.</td>
</tr>
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<td></td>
<td>Has aim of reflecting health and social care integration.</td>
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<tr>
<td></td>
<td>Contains specific funds allocated for specific purposes already (e.g. Disabilities Facilities Grant). The DFG grant is paid directly to councils via a Section 31 grant from MHCLG. The Government attaches a set of conditions for how it is spent.</td>
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<td>A memorandum of understanding is signed by DHSC and MHCLG which governs how this money is used.</td>
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<tr>
<td><strong>Establishing a separate fund which can be co-commissioned by NHS and social care</strong></td>
<td>Could create a strong independent brand.</td>
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<td>This could be channelled through one of the four optional models of joint commissioning referenced in the NHS Plan (see below for more detail).</td>
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The most important commissioning principle is that the Dementia Fund is jointly commissioned between health and social care. This would ensure that there is an incentive for commissioners and professionals in social care and in the NHS to promote access to the Dementia Fund rather than to try and ration its use (as in NHSCHC).

Given the recently announced review into the Better Care Fund, it is unclear how it will be structured in the future. Consideration to the Dementia Fund should be given when officials review the BCF. There are other joint commissioning models, including: voluntary budget pooling between a council and CCG; individual service user budget pooling through personal health and social care budgets; and approaches where either a council or the NHS oversees a local pooled budget. Further detail on joint commissioning is expected in the Green Paper.

Any of these co-commissioning routes could be suitable for the Dementia Fund. The important criterion is that commissioning is genuinely joined between health and social care. This should be compulsory.

**Recommendation:** The Government should insist that the Dementia Fund is jointly commissioned between health and social care. It could be set up as a protected Fund and channelled through the Better Care Fund (as with the Disabilities Facilities Grant), and this could be one of the terms of the revised BCF. Or it could be channelled through other local joint commissioning approaches.

**Recommendation:** As with the Pupil Premium, funding should be distributed on a regular basis (monthly or quarterly) so that any changes in the predicted level of take-up are reflected in the funding available locally.

**Objective 3: Flexibility so that individuals can use funding allocation in different ways that best match their needs**

*Why this matters in a Dementia Fund*

People living with dementia receive care and support in very different ways. For instance, around six in ten live independently, whilst the remainder live in residential care or nursing homes. The support needed can depend on the severity of their disease, the availability of family or unpaid carers, the suitability of their home, and the availability and affordability of care services in the local level. Their needs often stretch across health and social care as they often have other long-term conditions.

Although there has been a general tendency to promote the benefits of independent living, policymakers should as far as possible remain neutral in terms of the mode of support chosen by the individual. The danger otherwise is that people with dementia would have an incentive to receive care in a specific setting that may not be optimal for them. Given that the needs of people living with dementia also change over time, as may their preferences, individuals will need to be able to alter who receives the funding.
As described in the Table below there are multiple options which could be pursued. Trade-offs to be considered include factors such as set-up costs, transaction costs, the extent to which an individual can make personal choices.

**How this could be achieved**

<table>
<thead>
<tr>
<th><strong>Strengths</strong></th>
<th><strong>Weaknesses</strong></th>
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<tbody>
<tr>
<td>PBs already in place in social care.</td>
<td>Some evidence that Personal Budgets are not appropriate for all people living with dementia.</td>
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<tr>
<td>Personal Health Budgets (PHBs) are being rolled out, with people living with dementia seen as a priority group and hence set up costs would be lower than if PHBs had to be set up specially for the Dementia Fund.</td>
<td>Potentially high transaction costs if PBs were given to individuals solely on the basis of this policy and were not being rolled out in any case.</td>
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<td>Support structures already in place to help individuals to make decisions.</td>
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<tr>
<td>Putting funding in the hands of people with dementia may help drive quality improvements as they will have an incentive to seek out high quality care.</td>
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<tr>
<td>Could potentially accelerate the wider roll out of Personal Health Budgets.</td>
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<td>Integrated personal budgets would allow a person to spend their aggregated health and social care budget to meet their needs.</td>
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<tr>
<td>Would give supplier the discretion to spend the funding on the most helpful aspect of care.</td>
<td>Individuals would not have a choice over how they used their funding.</td>
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<tr>
<td>Lower transaction costs than PBs.</td>
<td>Even in public sector markets, such as schools, funding may leak away and be used for other purposes (see Pupil Premium case study below).</td>
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<tr>
<td>An example is ‘NHS-Funded Nursing Care’ which is a fixed-rate payment made by the local CCG directly to the nursing home to support the provision of nursing care for eligible residents.</td>
<td>Would be administratively efficient in cases where an individual stayed with a specific provider for a long time, but would not function well if a person changes their care provider or uses more than one provider for support.</td>
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<tr>
<td>Simple and easy for central government to administer.</td>
<td>There is a risk that there is low awareness of any supply side subsidy among individuals and therefore that they may not apply for the funding.</td>
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<tr>
<td>Low transaction costs because each council would likely only commission a small range of services (rather than passing money to all individuals or suppliers).</td>
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<tr>
<td>Individuals would not have a choice over how they used their funding.</td>
<td>The money would be unlikely to reach all (or potentially even most) individuals living with dementia. Therefore, it only partially addresses the ‘fairness’ dimension.</td>
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<tr>
<td>Risk that the funding leaks into other programmes.</td>
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Would give local authorities flexibility to link funding into other services (e.g. growing enthusiasm for Total Place and community budgets).

| A competitive fund open to bids from CCGs | Competitive element could incentivise innovation. Transaction costs probably lower than PBs but pushed up by bidding process. | Individuals would not have a choice over how they used their funding. The money would be unlikely to reach all (or potentially even most) individuals living with dementia. Therefore, it only addresses the ‘fairness’ dimension partially. The bidding mechanism might be more effective for preventative measures or programmes to increase diagnosis rates where there is more scope for innovation. |
| Distribute through cash transfers such as Attendance Allowance | Administratively efficient as transfer mechanism already exists. Individual could spend the money on the support they want. | Incomplete coverage of those who would be eligible for the Dementia Fund: • Only covers those aged over state pension age: 5% of those living with dementia are aged under 65. • Not paid to those in care homes receiving local authority support. Cash payments may be less appropriate for many individuals living with dementia than notional budgets that come with support through a PB (see below). We know that 156,000 individuals who received AA reported dementia as their main disability. However, many other individuals who receive AA may have dementia as a secondary condition. |

Based on these trade-offs, our view is that, in a context where personalisation is being rolled out under the NHS Long-term Plan, personal health budgets (PHBs) offer the preferred option. Personal budgets may come with higher transaction costs than some other options, although this would partly depend on how far PBs have, in any case, been rolled out to individuals living with dementia as part of the NHS Long-term Plan. PBs hand control and choice to individuals their families, allowing them to consider how their health and social care needs are met drawing on public support, unpaid care and private resources.

While this is our preferred option, other approaches could be cheaper to administer although less targeted at addressing the dementia penalty and are likely to come with their own downsides. Other potential options include allocating funding to local authorities or distributing money through Attendance Allowance. Such options could also potentially be quicker to implement.

Note: when we refer to ‘personal budgets’ we mean budgets that could be a repository for health or social care funding.
Box 1 describes what Personal Budgets are; below we then discuss in more depth some practical challenges and opportunities.

**Box 1: Personal Budgets and Personal Health Budgets**

Personal budgets are currently available in social care and are means tested.

‘Personal Health Budgets’ cover an individual’s needs in healthcare and are available to some specific patient groups. They are not means tested because they are meeting a healthcare need.

‘Integrated Personal Budgets’ consolidate funding available across health and social care. Integrated personal health budgets can be either 100% NHS-funded (for instance from NHSCHC), or joint-funded.

Thus far, evidence suggests that Personal Health Budgets can lead to improvements in well-being and help people live more independently.\(^{18}\) Costs may also fall – although this is more contested.

PBs can be managed in three ways: a notional budget (held by the commissioner), a third party budget (held by an independent organisation on behalf of the individual); or a direct payment (the money is transferred to the bank account of the individual).\(^{19}\)

There is significant momentum behind the roll out of integrated Personal Budgets covering health and social care needs.

- The Care Act (2014) gave people a legal right to access a Personal Budget for their social care needs.
- Personal Budgets may be particularly relevant to people living with dementia. NHS England argues that the benefits of PBs are likely to be greatest where the patient has a complex long-term condition and where a coordinated approach could be beneficial.\(^{20}\) In fact, NHS England noted that for ‘conditions, most notably Alzheimer’s disease, other forms of dementia and long-term neurological conditions, the proportion who could benefit from personal health budgets or IPC is relatively high due to the types and intensity of NHS and other services and support they commonly receive’. The Government consulted earlier this year on extending the right to have an integrated Personal Budget to other groups including people with ongoing social care needs, who also make regular and ongoing use of relevant NHS services and those with mental health needs.\(^{21}\)
- Those eligible for NHSCHC funding already have a legal right to have a personal health budget. By April 2019, NHS England expects that everyone living in their own home who is in receipt of NHSCHC funding will have a personal health budget, apart from in exceptional circumstances.\(^{22}\)
- In the NHS Plan, the Government commits to accelerating the roll out of Personal Health Budgets, with up to 200,000 people benefiting from a PHB by 2023/24.\(^{23}\) As of March 2018, there were 28,040 PHBs.\(^{24}\) This is part of a broader ambition in which the NHS commits to rolling out the ‘NHS Personalised Care model’, ‘reaching 2.5 million people by 2023/24 and then aiming to double that again within a decade.’\(^{25}\)
- The NHS Plan commits to applying the ‘Comprehensive Personalised Care Model’ approach for people living with dementia.\(^{26}\) This approach includes personalised
care and support planning after diagnosis, personal health budgets and integrated Personal Budgets.  

- We note that direct payments cannot be used to fund permanent residential care, but we envisage that the funding could be held in a notional or third party budget. In such cases, this may bring a risk that the additional funding made available through the Dementia Fund leads to higher prices charged by the provider and goes into general running costs. One potential step could be to require providers that receive such additional money to explain how it is using these funds to provide additional services or higher quality care for individuals living with dementia.

While such initiatives indicate wider take-up of PBs in the future, it remains unclear how prevalent PBs will be for individuals living with dementia in five years’ time. We argue that they represent the best mechanism for distributing the Dementia Fund, and that the fund could be used as a catalyst for ensuring full roll out over the next five years. We believe that the Dementia Fund could help widen access and best practice in use of PBs among people living with dementia.

Evidence also suggests that specific challenges would have to be overcome and addressed in the use of PBs:

- Past studies have suggested that PBs can be confusing and difficult to acquire for people living with dementia.
- There can be a reluctance to give PBs to people living with dementia, and there are concerns about the suitability of Personal Budgets for some.
- Anecdotal evidence suggests that policymakers should give more thought to when individuals are offered PBs. Moments of crisis when people living with dementia or their family seek out professional assistance may not be the best time to consider moving onto a PB.
- We should also guard against them being tokenistic – and greater attention should be put on the care and support plan and updating it.
- Research by Alzheimer’s Society identified issues to resolve if PBs are to be made more accessible to people living with dementia, including: poor communication, slow and opaque processes, and improved understanding among councils of dementia and the personalisation agenda.

Even when funding is put in the hands of individuals through PBs, as with any increase to social care funding, there is a risk that providers respond to increased funding levels by increasing prices without commensurate improvements in quality. Measures may be necessary to ensure that the additional funding delivers improvements in care and or cost reductions for self-funders. This is partly being addressed by efforts to improve competitive pressure on providers by ensuring that individuals are empowered to make informed decisions.

Alternatively, if local authorities were to negotiate lower prices with care providers than they currently pay, providers would receive the same amount of funding as currently and councils would capture the difference for use on other social care services. Therefore, it will be very important to monitor the impact of additional funding on the quality of placements across different providers.
**Recommendation**: Funding should be allocated to each person living with dementia into a Personal Budget. This could be done either by ensuring that individuals have a social care personal budget set up or by establishing a personal health budget / integrated personal budget. These accounts could be managed by the individual, a professional or a third party.

**Recommendation**: Policymakers should monitor the impact that the Dementia Fund has on the quality and cost of care.

**Recommendation**: Further work is needed to ensure that Personal Budgets are made available to people living with dementia and in appropriate formats. The Dementia Fund could be used as a catalyst to promote better access to Personal Budgets.

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**Resilience and sustainability of the Fund**

*Why this matters in a Dementia Fund*

The case studies indicate that there is a significant risk that money in the Dementia Fund could leak out into other parts of the health and social care system and that the purpose of the Dementia Fund may be diluted or lost. Although the Dementia Fund may eventually be made irrelevant were a government to adopt a free-at-the-point-of-use taxpayer-funded health and social care system, it needs to be sustainable as a concept until this point arises.

*How this could be achieved*

The case studies and other analysis suggests that the following mechanisms may be useful for establishing the Dementia Fund as a sustainable source of support for people living with dementia:

- **Clarity of purpose**: Successful Funds have a very clear purpose which can be communicated straightforwardly (e.g. Pupil Premium). For instance, analysis by the King’s Fund of transformation funds taken forward in other countries, found that those where the objective was clearest (e.g. hospital transformation rather than just ‘transformation’) were more effective.34

- **Salience of purpose and label**: Labelling may also matter (as in, for instance the Cancer Drugs Fund). It may be important to test how the public react to different titles for the fund. For instance, polling carried out by Alzheimer’s Society found that 49% of UK adults agreed that people with dementia inevitably experience worse care and support than people with other long-term conditions like cancer or heart disease.35

We also believe that emphasis should be put on establishing a level playing field between people living with dementia and other social care users, as the concept of ‘fairness’ can be powerful.
**Independence and transparency:** Independence may help Funds remain resilient to meddling from politicians or other commissioners. Analysis by the King’s Fund of how a transformation fund could be set up to achieve sustainable reform of the NHS recommended that any such fund should be independent of NHS management so that the funding could not be used for short-term purposes and to fund day-to-day activities. The King’s Fund also recommended that any such fund should be transparent and made publicly accountable.

Measures that should be considered to enhance the independence of the Dementia Fund include:

- Transparency of reporting of funding and outcomes specific to the Dementia Fund (e.g. improvements it has driven).
- Separate legal status.
- Oversight of the Dementia Fund given to a neutral independent body such as the Care Quality Commission. The OBR should be asked to report annually on how the money has been spent.

**National or local scheme:** As described in Chapter 2, there may be good reasons to vary the level of funding that an individual receives according to the base cost of social care that they face in their region. This will help ensure that people are not penalised for living in areas where wages are higher. However, there is a strong case for a national scheme rather than a local scheme to ensure consistency.

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**Recommendation:** The purpose of the Dementia Fund should be very concise and clear. This could be addressing the additional costs faced in social care by those living with dementia.

**Recommendation:** The Dementia Fund should be constituted as an independent body with oversight from a neutral body.

**Recommendation:** The status of the Dementia Fund should be enshrined in law if possible.

**Recommendation:** Expenditure through the Dementia Fund should be reported on annually by the OBR and associated outcomes reported on by the regulator.
Overview of commissioning process

Step 1
NHS clinician diagnoses dementia at a given level or updates diagnosis
AND / OR
Local authority assesses social care needs with dementia component

Step 2
Individuals have a personal budget established if they don't have one and a Care Plan is drawn up / reviewed

Step 3
Dementia Fund support available through NHS and local authority joint commissioning arrangements and placed into Personal Budget.
This penalty will be calculated as the average additional costs faced by individuals living with dementia in England (as a proportion of the costs of social care clients without dementia in a similar setting). This percentage figure will then be applied to the base cost of service in that local authority area.

Step 4
Individual living with dementia (or their agent) uses Dementia Fund to help purchase services
CHAPTER 3: ESTIMATING THE COST OF THE DEMENTIA FUND

This Chapter estimates the costs of the Dementia Fund now and into the future. It estimates:

- How many people have dementia and the prevalence of the disease by severity.
- How much it would cost to provide support to those in residential care with or without nursing facilities, based on regional dementia penalties and the numbers within residential care. We apply different penalties for self-funders and local authority places.
- How much it would cost to provide funding to those in domiciliary care based on the numbers with dementia in England and average penalties across the country.
- How the cost of the Dementia Fund would change into the future.

The estimates do not include the potential administration costs associated with creating and running the Dementia Fund.

How many people have dementia

The cost of receiving care depends upon a range of criteria including, but not limited to, the stage of dementia, the setting in which the individual is receiving care and the region. There is a strong regional and even local authority element to dementia care. Because of differing population demographics there is significant variation in the number of individuals living with dementia across England.

New provisional research from MODEM suggests that in 2015 there were approximately 690,000 people with dementia in England. The raw number of people with dementia varies significantly between the regions within England. Analysis suggests there are approximately 40,000 people living with dementia in the North East compared to 123,000 in the South East.

Of the 690,000 people with dementia in England, just over half (55%) of individuals have mild dementia but a considerable proportion (45%) have moderate or severe dementia and are likely to have complex health and social care needs. Individuals with dementia either live within a residential care home or in the community.

While not all individuals with dementia have a diagnosis, within our modelling we assume the NHS target of having two-thirds of those living with dementia diagnosed is achieved throughout England. The current rate of diagnosis within England is very close to the target.

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\(^{ii}\) Here we assume each region has an equal dementia diagnosis rate. We use the proportion of those with a diagnosis within each region to create regional dementia figures.
Approximately 4 in 10 of those with dementia live in residential care. This is either a standard care home or a residential care home with nursing facilities. Just over half (58%) of individuals with dementia who are in a care home are in a standard residential home, the remaining individuals are in homes with nursing facilities.

The stage of dementia and setting of residential care affects the cost of care due to the specific needs of the individual at that time. However, it is not possible to obtain information on the cost of dementia care by severity and setting. Due to the large penalty associated with nursing care, our cost modelling assumes that the cost of care varies only by setting and not by severity of dementia. We assume the proportion of individuals within residential care is 58% regardless of whether the individual is a self-funder or local authority funded.

Source: SMF analysis based on a range of assumptions from literature references throughout the paper

[iii] A nursing home has registered nurses on duty at all times of day, allowing the home to take individuals with more complex medical needs.
Local authority funded places

More than half (59%) of those within residential care are funded by their local authority. In most situations, local authorities do not pay the same rate for residential care as self-funders. The Competition and Markets Authority found that on average self-funding fees are 41% higher than those paid by the local authority. These differences need to be accounted for when calculating the cost of the Dementia Fund. Our evidence suggests the level of underpayment from local authorities for residential care is consistent regardless of whether the individual has dementia and therefore the extent to which a local authority is underpaying for social care more generally is not considered within the modelling. To do otherwise would be to address the overall funding shortfall in social care rather than the specific focus of the penalty faced by those with dementia.

The Dementia Penalty in a local authority funded context is therefore the difference between what the local authority pays for the care of an individual with dementia compared to somebody without dementia.

We estimate that just over 106,000 of those in care homes with dementia are funded by their local authority. Whilst the largest proportion of local authority funded individuals are in the North East, the North West has the largest number of people in care homes with dementia who receive local authority funding, as is shown in Figure 5.

Figure 4: Number of individuals with dementia in a care home who receive local authority funding by region

Source: SMF calculations based on self-funding figures from LaingBuisson and dementia estimations.

The Family and Childcare Trust’s older people care survey 2017 has figures on the average amount of funding that local authorities pay for older people’s social care in the regions of England. Based on these figures we can estimate the average amount each region’s local authority is willing to pay for residential care. This varies by the setting of care and whether the individual has dementia. We are able therefore to compare the average amount paid for care for someone with dementia with the average costs paid for someone without dementia to establish the penalty. (There are regions within this data that are, on average, willing to pay less for dementia care than care for those with other conditions.)
We are unclear on why this may be taking place and whether these are simply data anomalies or relate to the conditions of those without dementia in specific areas.

The figures show that the average dementia penalty in England is 7.1% for those in standard residential care and 4.3% for those in homes with nursing care.

**Figure 5: Average penalty faced by local authorities in England by care setting**

![Figure 5](image-url)

*Source: SMF calculations based on Family and Childcare Trust’s older people care survey 2017*

When applying the average dementia penalty in England to the costs of standard residential care in each region, we can see that the smallest monetary penalty per annum is in Yorkshire and Humber at £1,591, whilst the largest penalty is in London at £2,262. The dementia penalty in nursing homes for local authority funded places ranges from £1,125 in the North West to £1,652 in London.

**Figure 6: Average dementia penalty per annum for local authorities by region and setting, based on the average English penalty for the regions**

![Figure 6](image-url)

*Source: SMF calculations based on figures from Family and Childcare Trust (2017)*

The average dementia penalty for local authorities across England is £1,820 for residential care and £1,300 for nursing care, this equates to £35 and £25 per week respectively.
Establishing a Dementia Fund that covers the cost of the average dementia penalty associated with being in residential care in England and paid by local authorities, with the penalty determined by setting of care, would cost £170 million in 2018.

Self-funders

In England 4 in 10 of those within any form of residential care are self-funding. As a result, we estimate there to be 74,000 self-funders with diagnosed dementia in care homes. Again, there is substantial regional difference in the proportion of self-funders, only 18% of those in the North East are self-funding compared to 54% in the South East.44

It is not possible to obtain figures on the specific dementia penalty faced by self-funders due to a lack of available data. However, evidence from Paying for Care based on UK averages obtained by LaingBuisson in the Care of Older People UK Market Report, suggests that individuals in standard residential care face a dementia penalty of 2.11% and those receiving care within a nursing home the penalty is 3.4%.45 This is an average figure for all individuals within residential care and does not control for whether they self-fund their care. These averages are likely to hide the significant variation in the dementia penalty faced by self-funders within specific care homes across the country. We know the dementia penalty across England for local authorities is considerable higher than the average.

Figure 7: Average penalty faced by those in residential care in England by care setting

Due to the lack of data on self-funders care costs, it has not been possible to obtain regional figures on the cost of care for these individuals. There is strong evidence to suggest that self-funders pay an additional 41% for their care compared to the local authority rates.46 Therefore, to best approximate the rates paid by self-funders for care we have uprated the regional local authority rates by 41% to establish the cost of care for self-funders in residential and nursing homes.

Once these base figures for social have been established, the average dementia penalty of 2.1% and 3.4% was applied for the regions of England to create the dementia penalty for self-funders in monetary terms.
For self-funders receiving standard residential care in Yorkshire and Humber the dementia penalty is on average £665 per annum, whereas for those in London it is equivalent to £946. The dementia penalty is higher proportionally and in monetary terms for those receiving care in a home with nursing facilities. Those in the North West pay the smallest penalty at £1,227 per annum compared to London where the penalty is £1,876.

The average dementia penalty for self-funders across England is £761 per annum within residential care and £1,477 in nursing care, this equates to £14.63 and £28.39 per week respectively.

Creating a Dementia fund that covers the cost of the dementia penalty associated with being in residential care for self-funders, with the penalty determined by setting of care, would cost £79 million in 2018.\(^\text{iv}\)

**The cost of the Dementia Fund for residential care**

When combining the cost of self-funders and local authorities this takes the total cost of funding the dementia penalty for those in any form of residential care to £249 million in 2018.

**Table 1: Cost of covering the dementia penalty faced by individuals in residential care in England, 2018/19**

<table>
<thead>
<tr>
<th>Coverage of Dementia Fund</th>
<th>Cost in 2018</th>
</tr>
</thead>
<tbody>
<tr>
<td>Self-funders in residential care</td>
<td>£79 million</td>
</tr>
<tr>
<td>Local authority places in residential care</td>
<td>£170 million</td>
</tr>
<tr>
<td>Total</td>
<td>£249 million</td>
</tr>
</tbody>
</table>

The penalty used within this analysis is based on the best available evidence, however the data is incomplete. Research by Alzheimer’s Society suggests that in some places the dementia penalty may be as high as 40%.\(^\text{47}\) For illustrative purposes, Table 2

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\(^{\text{iv}}\) This is based on applying the regional dementia penalty by setting to our estimates of the number of individuals within each region in each type of care home.
demonstrates how the cost of the Dementia Fund associated with residential care would change based on different scenarios for the penalty.

Table 2: Cost of covering the dementia penalty for individuals within residential care in England by dementia penalty scenario, 2018/19

<table>
<thead>
<tr>
<th>Dementia Penalty</th>
<th>Cost of the Dementia Fund</th>
</tr>
</thead>
<tbody>
<tr>
<td>5%</td>
<td>£291 million</td>
</tr>
<tr>
<td>10%</td>
<td>£582 million</td>
</tr>
<tr>
<td>15%</td>
<td>£873 million</td>
</tr>
<tr>
<td>20%</td>
<td>£1.2 billion</td>
</tr>
<tr>
<td>25%</td>
<td>£1.4 billion</td>
</tr>
</tbody>
</table>

The value of the Dementia Fund support received by individuals or local authorities varies substantially under these scenarios. If the penalty was assumed to be 5% regardless of the payer and care settings, the average English weekly funding support would range from £24.60 for local authority funded places within residential care to £41.31 for self-funders in nursing care. If the penalty was found to be 25% for all payers and settings the weekly funding support would range from £123 for local authority funded places in residential care and £206.57 for self-funders in nursing care.

Receiving care within the community / living independently

Around 60% of those with dementia are living within the community, this is approximately 417,000 people. These individuals may be living independently or with family.

Almost three-quarters of the costs associated with dementia care in the community fall onto unpaid carers. Almost three-quarters of the costs associated with dementia care in the community fall onto unpaid carers. It is estimated that within the UK 670,000 people are acting as primary unpaid carers for people with dementia. The costs of unpaid care are not in scope for the Dementia Fund due to the difficulty in monetising their care costs and the fact that it would open a much wider debate about the role of family carers.

Figure 9: Number of individuals living with dementia in the community by severity, In England, rounded to the nearest 1,000 and assuming 66% diagnosis rate

Source: SMF analysis based on a range of assumptions from literature referenced throughout the paper
**The cost of the Dementia Fund for domiciliary care**

There is very little evidence on the cost of domiciliary care borne by self-funders or local authorities, regardless of their dementia status. Therefore, it is not possible to calculate a unique dementia penalty for domiciliary care.

In order to provide a rough estimate of the potential costs, we assume that those with mild or moderate dementia who live within the community face the average dementia penalty faced by self-funders in standard residential care. These individuals face a dementia penalty of £761 per annum. By assuming those with severe dementia in the community face the average penalty of self-funders in residential care with nursing, the dementia penalty is £1,477 per annum. Individuals with mild or moderate dementia would receive £14.63 per week and those with severe dementia would receive £28.39.

Under these assumptions the covering the domiciliary dementia penalty would mean the Dementia Fund would cost £219 million in 2018. The value of the Dementia Fund within domiciliary care is based on the severity of dementia and is not a percentage of the current cost of care borne by the individual or local authority for any specific individual. This is to ensure that the Dementia Fund does not differentiate between those who receive support from their family and those who do not.

**Table 3: Cost of the Dementia Fund for individuals in the community in England**

<table>
<thead>
<tr>
<th>Coverage of the Dementia Fund</th>
<th>Cost of Dementia Fund in 2018</th>
</tr>
</thead>
<tbody>
<tr>
<td>Moderate and Severe</td>
<td>£46 million</td>
</tr>
<tr>
<td>Mild, Moderate and Severe</td>
<td>£219 million</td>
</tr>
</tbody>
</table>

Table 4 shows the cost of the DF for community-based care based on a range of penalty scenarios.

**Table 4: Cost of covering the dementia penalty for those living with dementia in the community in England, to the nearest million (£) 2018/19**

<table>
<thead>
<tr>
<th>Dementia Penalty</th>
<th>Cost of the Dementia Fund</th>
</tr>
</thead>
<tbody>
<tr>
<td>5%</td>
<td>£501 million</td>
</tr>
<tr>
<td>10%</td>
<td>£1 billion</td>
</tr>
<tr>
<td>15%</td>
<td>£1.5 billion</td>
</tr>
<tr>
<td>20%</td>
<td>£2 billion</td>
</tr>
<tr>
<td>25%</td>
<td>£2.5 billion</td>
</tr>
</tbody>
</table>

The average weekly funding support for those with mild or moderate dementia would range from £34.69 if the dementia penalty was 5% to £173.43 if the penalty was 25%. For those with severe dementia under the same assumptions the weekly funding ranges from £41.31 to £206.57.

**The cost of the Dementia Fund in 2018**

The cost of the Dementia Fund in 2018 is an estimated £468 million. This would cover the dementia penalty faced by all individuals with dementia regardless of whether they were living in the community or residential care and irrespective of whether they paid for their own care or received local authority funding.
The table below shows how the overall cost of the fund would vary depending upon the penalty faced by those with dementia and the diagnosis rate achieved within England. The previous analysis has assumed a diagnosis rate of 66%, however table 5 shows how the cost of the fund may change if the diagnosis rate increased to either 75% or 100%.

**Table 5: Cost of the Dementia Fund in 2018/19, based on a range of penalty scenarios and diagnosis rates**

<table>
<thead>
<tr>
<th>Dementia Penalty</th>
<th>Cost of the Dementia Fund (66% diagnosis rate)</th>
<th>Cost of the Dementia Fund (75% diagnosis rate)</th>
<th>Cost of the Dementia Fund (100% diagnosis rate)</th>
</tr>
</thead>
<tbody>
<tr>
<td>5%</td>
<td>£792 million</td>
<td>£900 million</td>
<td>£1.2 billion</td>
</tr>
<tr>
<td>10%</td>
<td>£1.6 billion</td>
<td>£1.8 billion</td>
<td>£2.4 billion</td>
</tr>
<tr>
<td>15%</td>
<td>£2.4 billion</td>
<td>£2.7 billion</td>
<td>£3.6 billion</td>
</tr>
<tr>
<td>20%</td>
<td>£3.2 billion</td>
<td>£3.6 billion</td>
<td>£4.8 billion</td>
</tr>
<tr>
<td>25%</td>
<td>£4 billion</td>
<td>£4.5 billion</td>
<td>£6 billion</td>
</tr>
</tbody>
</table>

**The cost of the Dementia Fund in the future**

The number of people with dementia in England is expected to increase to 1.4 million in 2040.\(^v\)

There are several scenarios for how social care may have changed by 2040, including increased productivity, a reduction in the proportion of individuals moving into care homes and changes to the means test system and therefore the proportion who are self-funding. The current funding model assumes that the severity of dementia within the population remains the same. Keeping all other assumptions equal, funding the dementia penalty for those in residential care will cost £487 million in 2040. Covering the dementia penalty faced by those within the community will cost £428 million. This brings the total cost of the Dementia Fund to £915 million in 2040.

\(^v\) Based on provisional figures from MODEM for England and LSE.
Figure 11: The cost of the Dementia Fund in England from 2018 to 2040, in £’s million 2017/18 prices, based on a 66% diagnosis rate

Source: SMF calculations based on current costings and dementia predictions from MODEM & Alzheimer’s society

If we assume the number of individuals with dementia increases by the same percentage each year, we are able to estimate how the cost of the Dementia Fund will evolve overtime. Figure 11 assumes the average dementia penalty applies, however, as previously stated reliable figures on the value of the dementia penalty are not available. See appendix for cost forecasts based on differing penalty scenarios and diagnosis rates.
CHAPTER 4: WIDER BENEFITS AND IMPACTS OF THE DEMENTIA FUND

This Chapter describes the wider impact on the health and social care system from adopting a Dementia Fund.

**Improved quality of care**

Quality of care is important for individuals across the social care system, and evidence suggests quality shortfalls particularly for those with more complex needs, such as those with dementia. Research has shown that 23% of dementia care services in England are failing compared to 19% of all services.\(^{50}\)

The dementia penalty in domiciliary care may in part act to address quality challenges. Research by Alzheimer's society highlighted that 38% of homecare workers have not received any dementia training and only 2% of those affected by dementia say that homecare workers have enough dementia training.\(^{51}\)

The Dementia Fund could enable self-funders who receive domiciliary care to increase the amount they pay their carers, improve their training or increase the time of visits. This could have positive knock-on implications for those with dementia who live independently and enable them to continue to live within their own home for longer, which is an ambition of the NHS.

For those in residential care, increased funding by local authorities into care homes could be matched by improvements in quality.

**Impact on cross-subsidy**

Our analysis has highlighted the significant differences in the rates paid by self-funders and local authorities for care. There are many reasons why this may occur, such as self-funders requesting better quality care and local authorities benefitting from buying places in bulk and reducing their unit cost.

In some cases, local authorities pay less than the going rate for care homes places and self-funders are left to pay a cross-subsidy. In this situation self-funders are paying additional fees to cover the gaps left by local authorities. By implementing the Dementia Fund local authority-funded residents in care homes could use their increased personal health budget to increase the funding going into their care home. By increasing the amount local authority residents pay there could be less cross subsidy within the market, which would benefit self-funders. Self-funders would also benefit directly by having part of their costs met by the state. The overall impact on cross subsidy would depend on factors such as how local authorities re-negotiate prices.

**Benefits to family and unpaid carers**

The creation of the Dementia Fund could help family members and unpaid carers. For those with mild dementia living in the community there is scope to use the Dementia Fund to increase the use of personal social prescribing. The Government is already looking at ways to increase the use of social prescribing in combating some of the needs of those with a variety of health conditions, such as dementia and loneliness. This could allow
those who care for a loved one with dementia to reduce the amount of time they spend caring and provide some respite. If the quality of domiciliary care increased through greater training or length of visits this may reduce the current reliance on family carers who may feel unable to rely on the system to provide care for their family.

**Impact on diagnosis**

Giving someone with dementia a timely diagnosis is key to ensuring they and their families can make the right decisions for their future based on their care needs. Prompt diagnosis may also reduce the number of people receiving a diagnosis, being admitted to hospital or moving into care homes during crisis points.

The potential impact of the Dementia Fund on diagnosis rates is difficult to appraise.

The current system often fails to diagnose people with mild dementia. The current NHS target is for at least two-thirds of those with dementia to be diagnosed. At present there is significant local variation in the rate of dementia diagnosis. As noted above, the CCGIAF assesses CCGs on their dementia diagnosis rate as well as their use of care plan reviews.

The Dementia Fund could apply incentives on clinicians to increase the diagnosis rate of dementia, particularly during the early stages. Health professionals may be readier to diagnose dementia if they know that there is some support available. In addition, it may encourage commissioners to establish more trigger points at which dementia diagnosis would be considered. This could, for instance, include when individuals are admitted to hospital, with evidence suggesting that, despite significant improvements, many people living with dementia are discharged without it being recognised that they have dementia. This can lead to repeat readmissions. However, there are also potentially countervailing forces. For instance, linking diagnosis to access to funded care could deter diagnosis and diagnosis initiatives if clinicians, commissioners or policymakers are worried about costs.

**Savings to the NHS and improvements to the care experience**

Research by Alzheimer’s Society covering 65 NHS trusts found that, in 2016/17, more than 50,000 admissions for people with dementia that could have been avoided. Recent reductions in social care funding for those over 65 has led to increased admissions into A&E. Improving the quality and coverage (through earlier diagnosis) of dementia care has the potential to reduce the occurrence of unnecessary hospital admission for those with dementia and hence saving the NHS money and resources. More appropriate placements may also help reduce delayed transfers of care.

The impact of prompter diagnosis and better dementia care is likely to be felt as much in better care and health outcomes as in straightforward cash savings downstream. Many factors affect the ability of commissioners and providers to unlock cashable savings. Cost savings can be lumpy (e.g. reducing the number of patients so as to withdraw a member of staff or close a hospital ward).
Benefits beyond dementia care

Of those with dementia, 92% have another health condition.\textsuperscript{57} Four of the five most common comorbidities people living with dementia are admitted to hospital for in the UK are preventable.\textsuperscript{58} Individuals with dementia can suffer from depression, and the lack of treatment for depression amongst those with dementia costs the health and care system an additional £502 million.\textsuperscript{59} Through increased Personal Budgets and better quality care there is potential for individuals to use their Dementia Fund to treat other conditions they are faced with, such as working on their depression through social prescribing tools.

Given the extent of comorbidities in those with dementia it is possible that by enabling individuals to drive up the quality of their care through the Dementia Fund the quality of care they receive in relation to their other conditions will also increase. If the overall quality of care within the system improves as a result of additional funding this could have an impact on all individuals using the social care system and not just those with dementia.
Summary lessons from case studies

Lessons from NHS Continuing Healthcare:

- Excessively complex assessments. There is a real risk that assessment processes become excessively complex and time-consuming leading to problems of access, inefficiency and unfairness. Assessment processes can lead to false expectations if the qualifying criteria are complex.
- Risk that a fund could promote or be perceived as contributing to cost shunting between health and social care. The structure of the NHSCHC as a health and social care service commissioned and funded by the NHS appears to contribute to perceptions of cost shunting between health and social care.
- Potential risk of unfairness. Some patients can have all their social care support payments for under NHSCHC leading to perceptions of unfairness.

Lessons from the Pupil Premium

- Funding can be structured to increase access. Schools receive funding for each pupil registered on the Pupil Premium, and this incentivises them to ensure that eligible pupils are registered. This is particularly relevant to dementia given low levels of diagnosis.
- How funding is distributed matters. Providing payments to suppliers may lead to leakage with money spent on other purposes.
- The resilience of a policy may partly depend on its simplicity and salience. The salience and simplicity of the Pupil Premium’s purpose and structure appears to make it resilient as a programme.
- Funding adjustments can be made in year. Regular (quarterly) funding adjustments are made to help schools cope with changes in their school population.

Lessons from the Cancer Drugs Fund:

- Labelling matters. Framing the Fund around the targeted ‘disease’ may improve the salience of the policy.
- Reasonable cost estimates may reduce criticism. The CDF has seen large underspends and overspends, undermining its credibility.

Lessons from the NHS Sustainability and Transformation Fund:

- Clarity of purpose may avert leakage. Critics have highlighted the fact that much money in the STF was used for filling NHS provider deficits rather than transformation. This suggests the importance of clarity of purpose when a Fund is set up.
- Establishing the Fund as an independent entity may reduce the risks of leakage. It is likely that the STF suffered from a lack of independence from NHS leaders who had short-term priorities to address.
Lessons from the Better Care Fund:

- Creating an additional commissioning channel to promote integrated care for people living with dementia may be viewed as overlapping and counterproductive.
- The BCF has had a mixed impact on the integration of health and social care with some concerns that it has been used to cover council core funding.

**NHS Continuing Healthcare**

Some people with long-term complex health needs qualify for free social care arranged and funded solely by the NHS, through NHS Continuing Healthcare (NHSCCHC). CCGs are responsible for assessing whether someone qualifies for NHSCCHC and for funding the services.61

Eligibility for NHS continuing healthcare depends on a person’s assessed needs being primarily for healthcare as opposed to social care support, and not on any particular diagnosis or condition. Candidates have an initial screening before going through a full assessment carried out by a multi-disciplinary team.62 Individuals are assessed based on having a primary healthcare need that is more than incidental or ancillary to their social care needs. Across a range of needs, if an individual receives at least one priority need, or severe needs in at least 2 areas, then they ‘usually’ qualify for NHSCCHC. In that event, a care package for health and social care support is arranged and support is directed through a Personal Health Budget.63 The total cumulative number of cases eligible year to date for NHSCCHC was 131,258 up to the end of Q3 2018-19.64

<table>
<thead>
<tr>
<th>Eligibility and assessment</th>
<th>Delays in assessments and approvals. In most cases eligibility decisions should be made within 28 days but in 2015-16, about one-third of full assessments (24,901 assessments) took longer than 28 days.65</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>A patient’s likelihood of receiving support is partly dependent on geography. Analysis suggests that there is wide regional variation in terms of who qualifies for funding, suggesting a lack of consistency in terms of access to the scheme in different CCG areas.66</td>
</tr>
<tr>
<td></td>
<td>Raises false expectations and creates uncertainty for patients.67 For instance, NHS England estimates that 62% of people who were screened using the checklist went on to have a full assessment in 2015-16. Of these only 29% were deemed eligible.68</td>
</tr>
<tr>
<td></td>
<td>The NAO has expressed concerns about the consistency of assessment processes.69 The uncertainty of the assessment process leads to bureaucracy and appeals.70</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Collaborative System</th>
<th>Creates unfairness in terms of social care support. NHSCCHC has been described as an ‘all or nothing’ assessment because if you pass then all your care and accommodation costs are free.71 This means such individuals are then better placed than other individuals with other conditions.</th>
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<td></td>
<td>Causes friction between NHS and local authority commissioners: A King’s Fund review found that it ‘creates much friction between the NHS and local authorities over who should pay’.72 The NHS may feel that it is spending its money on a social care problem.</td>
</tr>
</tbody>
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**Pupil Premium**

The Pupil Premium scheme was set up in 2011 with the purpose of reducing the attainment gap experienced by children from disadvantaged backgrounds. Grants are paid out by the Department of Education and Education and Skills Funding Agency to schools for each
pupil who is on Free School Meals or is (or has been) in local authority care. Schools have discretion over how they spend the money, although they must report on how they have used the money and are subsequently assessed by Ofsted. In 2017-18, £2.4 billion of Pupil Premium funding was allocated in respect of around 2 million pupils. Eligibility for FSMs is determined being in receipt of a qualifying benefit or an income threshold.73

| Eligibility and assessment | The Pupil Premium makes use of FSM as a proxy for disadvantage, which has advantages and disadvantages. On the positive side, it means there is no expensive or time-consuming assessment process. On the other hand, in 2015, the NAO reported that 11% of eligible pupils do not currently receive free school meals because their parents do not claim the entitlement.74
|                            | Paying the premium to the school has the positive effect of reducing the incentive for schools to tacitly dissuade applications and admissions from pupils from more disadvantaged backgrounds.
|                            | Attaching the premium to eligibility to FSM may also encourage schools to make parents aware of the FSM status, which could benefit pupils and their parents.

| Purchasing                 | Quarterly payments mean that changes in the composition of schools are reflected in changes in funding.75
|                            | There is consensus that the PP has increased focus on improving outcomes for disadvantaged children. Of school leaders, 57% said they targeted support at disadvantaged pupils before the creation of the Pupil Premium, compared with 94% now.76 However, concerns have also been raised about leakage to other general initiatives as well as use of inefficient methods to improve outcomes for FSM pupils.

| Resilience and sustainability | The PP is highly politically salient and appears resilient as a programme. There is no indication that a Labour Government would remove it (in fact they called for an additional Arts Premium). It is supported by the Conservative and Liberal Democrat parties. Its clear focus along with its transparent and simple funding mechanism are advantages.
|                            | Accountability shortfall: the biggest problem identified by NAO is that there is insufficient accountability for how money is being spent and whether it is the most cost-effective spending.77

Cancer Drugs Fund

The Cancer Drugs Fund (CDF) was set up in 2011. Its purpose is to offer an alternative track for cancer medicines to be approved for funding other than through NICE, so that patients can gain early access to medicines where the effectiveness of medicines are ‘uncertain’. From 2016 the CDF became a ‘managed access’ fund – which enabled access to drugs for an initial period before a definitive view was made on whether the NHS would fund them.78 A significant number of medicines have been made available through the scheme.79 The total annual budget for the CDF is £340m.80

| Resilience and sustainability | Criticisms of whether the money could be spent more cost-effectively on other treatments and diseases. Academics have criticised the initial version of the CDF as poor value for money in terms of the predicted cost-effectiveness of drugs funded.81 Others have criticised the scheme for only focusing on cancer - i.e. the funding could pay for more Quality Adjusted Life Years if spent on other diseases.82
|                            | Framing matters: The CDF offers interesting parallels as a disease-specific Fund. Although it has come under significant criticism, it fulfils a purpose that is a political and public priority. The Labour Party proposed that the Fund should also cover surgery and radiotherapy, rather than that the Fund should be abolished
**Funding structure:** The CDF has an allocated funding pot, but expenditure is affected by the availability of new medicines and demand for those medicines. This has made it difficult to predict and ration spending, because the costs of treatments and availability of new treatments are hard to predict and ration. This approach has led to overspends and underspends. The Budget was increased from £200m in 2011/12 to £340m in 2015/16. Despite this, the CDF has exceeded its allocated budget each year since 2013/14. The final outturn position for 2015/16 was £466m - an overspend of £126m (37%). The NAO concluded in 2015 that the fund was not sustainable in its current form. Spending appears to be more controlled under the reformed scheme. At the end of 2017-18, there had been an underspend of £38m against the £340m budget allocation. The Dementia Fund is unlikely to experience such significant problems of funding predictability in the short-term, but it suggests that this is important.

### Sustainability and Transformation Fund

The Sustainability and Transformation Fund (STF) was announced in 2015 to 'give the NHS the time and space it needs to put transformation plans in place'. It had a twin purpose ‘to help trusts reduce their deficits and allow them to focus on transforming services to deliver excellent care for patients every day of the week.’ This was part of the front-loading of NHS funding to help the NHS reform and transform its services as part of the Five Year Forward View.

**Resilience and sustainability**

The STF appears to have predominantly been used to manage short-term financial problems rather than assist in ensuring the on-going sustainability of the NHS. The NAO noted in its 2018 review of the financial sustainability of the NHS, that in 2016-17, the NHS used ‘measures to rebalance its finances, some of which have restricted the money available for longer-term transformation’. Chris Ham, Chief Executive of the Kings Fund, criticised the use of the money, which had been ‘spent on addressing acute hospital deficits rather than being invested in new service models, which is holding back progress’. The NAO has noted elsewhere that this transfer of funds to reduce short-term deficits meant there was insufficient funding for Vanguards to take forward reforms.

### Better Care Fund

The Better Care Fund (BCF) was established in the Care Act 2014 and is the only mandatory policy to facilitate the integration of health and social budgets and commissioning. The BCF brings together health and social care funding into pooled budgets for commissioning at the local level. In 2018-19, the BCF totals £5.6bn, including: a minimum £3.7bn contribution of CCGs, £0.5bn from the Disabled Facilities Grant; and £1.5bn from the adult social care grant. Monies must be: jointly commissioned, contribute to investment in NHS out-of-hospital services and towards managing transfer of care between settings and services. Local areas can contribute additional funds to joint commissioning, and they can also ‘graduate’ out of some of the national conditions set. The BCF is seen as a facilitating tool to enable joint commissioning and ‘Integrated Personal Commissioning’, whereby individuals receive personalised care and support planning with a Personal Budget across health and social care.

**Collaborative System**

The BCF has had a mixed impact on integration. An evaluation by QORA found that the spending through the BCF had reduced delayed transfers of care. A 2018 review by the NAO reached the same conclusion. An NAO review of the BCF found that it has not achieved its principal financial or service targets (savings of £0.5bn and
reduction of demand for hospital services). However, it has led to improvements including: a reduction in permanent admissions of older people to residential and nursing care homes and in incentivising local areas to work together.\textsuperscript{93}

However, the NHS Plan announced a review of the BCF due to its complexity, lack of clarity on return from investment and because the money has at times been used to replace council core funding.\textsuperscript{94}

The BCF contains general funds as well as specific protected funds. The Disabilities Facility Grant (DFG) is a protected section of the BCF. The DFG provides capital grants to eligible individuals to support people into more suitable accommodation and adapt existing housing stock.\textsuperscript{95} There may be potential to mirror this approach for the Dementia Fund.

Further work remains to promote cross working: According to the NAO in 2017, ‘the Better Care Fund is widely regarded as an initiative that primarily benefits local government, and consequently health bodies can become disengaged’. A recent evaluation of the BCF found that overlapping policy initiatives aimed at promoting integrated care were unhelpful and in competition with each other.\textsuperscript{96}

**Diabetes Transformation Fund**

From 2017-18, £44 million of funding has been set aside to improve treatment and care for the 2.8 million adults and children diagnosed with Type 1 or Type 2 diabetes. This includes: increasing uptake of structured education; improving achievement of the NICR treatments targets (e.g. blood pressure and cholesterol for adults); improving access to multi-disciplinary foot care teams (to reduce the number of amputations); improving access to specialist inpatient support to reduce lengths of hospital stays.\textsuperscript{97} CCGs can bid for a share of this funding.

We are not aware of any evaluation of the programme.

**Attendance Allowance**

Attendance Allowance is paid to individuals aged 65 and over who require a disability severe enough that they need someone to help look after you.\textsuperscript{98}

**NHS-Funded Nursing Care**

NHS-Funded Nursing Care is a payment made directly to nursing homes by the local CCG. Its purpose is to support the provision of nursing care by registered nurses for eligible individuals in nursing care homes. The fixed-rate payments are only available to individuals in nursing care homes.\textsuperscript{99} As of the end of 2018, 77,741 were eligible for the payments.\textsuperscript{100}
ANNEX 2:

**Figure 12:** Cost of the Dementia Fund between 2018 and 2040 based on a range of scenarios for the penalty, in billion (£) assuming diagnosis rate of 66%

Source: SMF calculations based on current costings and dementia predictions from MODEM & Alzheimer’s society

**Figure 13:** Cost of the Dementia Fund between 2018 and 2040 based on a range of scenarios for the penalty, in billion (£) assuming diagnosis rate of 75%

Source: SMF calculations based on current costings and dementia predictions from MODEM & Alzheimer’s society
Figure 14: Cost of the Dementia Fund between 2018 and 2040 based on a range of scenarios for the penalty, in billion (£) assuming diagnosis rate of 100%

Source: SMF calculations based on current costings and dementia predictions from MODEM & Alzheimer’s society
ENDNOTES

2 https://www.dementiastatistics.org/statistics-about-dementia/prevalence/
3 Alzheimer’s Society, Dementia – the true cost: fixing the care crisis (2018)
4 Alzheimer’s Society, Dementia – the true cost: fixing the care crisis (2018)
5 The Health Foundation & The King’s Fund, Approaches to social care funding (2018)
6 https://www.alz.org/alzheimers-dementia/stages
7 Nigel Keohane et al, A Future State of Mind (SMF, 2013)
9 NAO, Health and social care integration (2017)
10 NAO, Health and social care integration (2017)
12 DH and DCLG, 2017-19 Integration and Better Care Fund – policy framework (2017)
13 DHSC and MHCLG, The Integration and Better Care Fund: Operating Guidance for 2017-19 (July 2018)
17 DWP, Stat Explorer, August 2018.
21 A consultation on extending legal rights to have for personal health budgets and integrated personal budgets, Prepared by the Department of Health and Social Care, and NNS England (2018)
30 https://www.thinklocalactpersonal.org.uk/News/Local-Authorities-urged-to-make-personal-budgets-dementia-friendly/
31 https://www.thinklocalactpersonal.org.uk/_assets/Resources/CareAct/GatheringTheEvidence.pdf
32 Alzheimer’s Society, Making personal budgets dementia friendly: A guide for local authorities. The Social Care Institute for Excellence also raised many of the same issues and others including poor data on PBs for people living with dementia. SCIE, Improving personal budgets for older people: A research overview (2013)
35 Alzheimer’s Society, Dementia – the true cost: fixing the care crisis (2018)
38 MODEM project, project summary (2018)
39 Kings College & London School of Economics, Dementia UK: second edition (2014)
40 SMF calculation based on data in Kings College & London School of Economics, Dementia UK: second edition (2014)
41 Kings College & London School of Economics, Dementia UK: second edition (2014)
42 Competition & Markets Authority, Care homes market study: final report (2017)
For the data please see Family and Childcare Trust, _Older people’s care survey 2017_ (2017).


Alzheimer’s Society, _Dementia – the true cost: fixing the care crisis_ (2018).


Alzheimer’s Society, _Dementia – the true cost: fixing the care crisis_ (2018).


Browne J et al, _Association of comorbidity and health service usage among patients with dementia in the UK; a population-based study_ (2017).

International Longevity Centre, _Dementia and comorbidities; Ensuring parity of care_ (2016).


[https://www.kingsfund.org.uk/sites/default/files/field/field_publication_file/Commission%20Final%20%20Interactive.pdf](https://www.kingsfund.org.uk/sites/default/files/field/field_publication_file/Commission%20Final%20%20Interactive.pdf)

[https://www.kingsfund.org.uk/sites/default/files/field/field_publication_file/Commission%20Final%20%20Interactive.pdf](https://www.kingsfund.org.uk/sites/default/files/field/field_publication_file/Commission%20Final%20%20Interactive.pdf)


House of Commons Briefing, _The Pupil Premium_, 2018.


House of Commons Briefing, _The Pupil Premium_, 2018.


[https://www.york.ac.uk/media/che/documents/policybriefing/Drug_prices.pdf](https://www.york.ac.uk/media/che/documents/policybriefing/Drug_prices.pdf)
83 NAO, Investigation into the Cancer Drugs Fund (2015)
85 NAO, Sustainability and transformation in the NHS (2018)
88 DH and DCLG, 2017-19 Integration and Better Care Fund – policy framework (2017)
89 DH and DCLG, 2017-19 Integration and Better Care Fund – policy framework (2017)
90 DH and DCLG, 2017-19 Integration and Better Care Fund – policy framework (2017)
91 https://www.pssru.ac.uk/pub/5424.pdf
93 NAO, Health and social care integration (2017)
94 NHS Plan.
95 DH and DCLG, 2017-19 Integration and Better Care Fund – policy framework (2017)
96 https://www.pssru.ac.uk/pub/5424.pdf
98 https://www.gov.uk/attendance-allowance