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We used a broad range of terminology in our searches to ensure that any potentially

The spread across types of literature is included below:

Type of literature	Number
Primary research - survey, mixed or qualitative	17
Policy / Guidance / Consultation	

2. Theme one: National policy and regulation relating to using direct payments and PHBs to engage PAs

2.1 Overview of relevant literature

There were seven documents that addressed this research theme. Three of these were national policies on direct payments published by the DHSC, two were guidance on PHBs by NHS England and NHS Improvement, one was national legislation on direct payments in the NHS and one was guidance on PA working by Skills for Care. Sub-sections 2.2 to 2.7 summarise what we found.

2.2 Local authorities should provide information, advice and support for those employing PAs

2.3 Local authorities need to be involved in contingency planning and provide access to training opportunities for PAs

The Care and Support statutory guidance (2022a) also highlighted the responsibility and role of local authorities in relation to **contingency planning** if a PA is sick or absent:

> *Where a direct payment recipient is using their payment to employ a personal assistant (PA) or other staff, the local authority should ensure that there are clear plans in place of how needs will be met in the event of the PA being absent, for example due to sickness, maternity or holiday. Local authorities still have **a duty to ensure needs are being met**, even if the person makes their own arrangements via the direct payment, so contingencies may be needed. Where appropriate, these should be detailed in the care and support plan, or support plan.*

There is also mention of the fact that local authorities should ensure that PAs are able to access **training opportunities**:

> *Training should take place at all levels in an organisation and be updated regularly to reflect current best practice. To ensure that practice is consistent – no staff group should be excluded. Training should include issues relating to staff safety within a Health and Safety framework and also include volunteers. In a context of personalisation, boards should seek assurances that directly employed staff (for example, **Personal Assistants) have access to training and advice on safeguarding**.*

2.4

2.5 Local authorities and Clinical Commissioning Groups (CCGs)[3] need to be more flexible with regards to how direct payments are used

Two pieces of guidance were published by the DHSC (2022b, 2022c) during Covid 19 - one related to people receiving direct payments and PAs, and the other to local authorities and CCGs. These emphasised the importance of taking a flexible approach towards the care and support people receiving all forms of direct payments to maintain their wellbeing. Both were withdrawn on 1 April 2022, when the government published its plan for living with Covid-19[4], but as mentioned above can be interpreted as the beginning of a shift in attitudes towards direct payments and PAs by policy makers:

> *The fundamental approach to payments should reflect the trust needed between providers and receivers of payments that the money will be used as intended to meet agreed outcomes for care, support and improved wellbeing. Payments should continue to be used flexibly and innovatively with no unreasonable restrictions placed on the use of the payment, so long as it is being used to meet eligible care and support needs.*

With regards to **flexibility in how PAs are engaged**, a number of scenarios we

2.6 PHBs can be spent on any services agreed in the care plan that help meet needs

Legislation on PHBs by Gov UK (2013) and guidance associated with this legislation (NHS England, 2014) said that in principle:

> *A direct payment can be spent on a **broad range of things** that will enable the person to meet their health and wellbeing needs. A direct payment may only be spent on services agreed in the care plan. The term 'services'…. refers to anything that can be bought and which will meet someone's health needs. The care plan must be agreed by both the CCG and the person receiving care, or their representative. Before signing off the care plan, the CCG must be reasonably satisfied that the health needs of the patient can be met by the services specified in the care plan.*

However, the legislation also provided **barredôservices** which include:

> ***A direct payment cannot be used to purchase** primary med676.18 TB12 Tf1 0 0 1 265.25 53*

2.7 Clinical Commissioning Groups (CCGs)[5] need to provide a range of advice, information and support that people may need as employers

3. Theme two: Trends and preferences for accessing care and support at home

3.1 Overview of relevant literature

There were seven documents that addressed findings related to this research theme. Three of these were national statistics published by governmental bodies or other organisations, such as the Kings Fund. A further three were findings from primary research, surveys in particular and the final one also reported survey findings from a public consultation on the extension of PHBs and integrated personal budgets. Sub-sections 3.2 to 3.5 summarise what we found.

3.2 The uptake of Direct Payments and the employment of PAs

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This increase in uptake was in line with the findings of a public consultation run by the DHSC and the NHS (2019) on the potential extension of PHBs and integrated care budgets to a broader group of people. The findings demonstrated broad support for all proposals with an average of 83.5% of respondents agreeing with each proposal. The consultation also sought views on whether, when extending the right to a PHB, an additional right should be created to include an explicit right to have this budget managed through a direct payment. The questions on extending rights to direct payments were on average supported by 86% of respondents, demonstrating strong levels of support.

Finally, many responses to the consultation referenced the independence and freedom that people are able to achieve through adopting a more personalised approach. In particular, direct payments were identified as a mechanism that can really enable individuals to take the responsibility they want when managing their own care. This individual approach was thought to contribute toward recovery, as people feel invested in their treatment and care. A short case study, highlighting the employment of PAs was included:

"Darren is in his 40s with tetraplegia. His 24-hour care package enabling him to live at home was provided by a single agency, but he wanted more independence. He

respondents were asked to what extent they agreed or disagreed with five statements:

60%

Other results indicated that in later life, the most preferred option for over a third of respondents was to live independently (37%). This was followed by supported living (17%), extra care housing (13%), retirement villages (12% and, nursing/care homes (9%), with the least preferred option being sheltered housing (5%). This is depicted in Figure 3 below which compares current living situations with current preferred options and preferences for later life.

Figure 3: Preference for housing setting

Image copied from Mulliner E., et al (2020)

The findings also indicated that people place significant importance on adaptations and support that will enable them to **stay independent and at home as long as possible**. For example, the 65 74 and 75+ age groups both placed a significantly higher level of

comparison to the youngest age group (55 64). The authors *this is not surprising given that there is extensive research indicating that most older people prefer to continue living in their own home for as long as possible'* (Mulliner et al., 2020; pp. 13).

3.5

4. Theme three: Attitudes towards and support for using SEPAs

4.1 Overview of relevant literature

There were eight documents that addressed findings related to this research theme. Six documents consisted of findings drawn from primary research, either surveys or a mix of surveys and qualitative research. Four of these studies were primary research conducted with PAs and other stakeholders including local authorities and other organisations that support and/or work with PAs. However, only one of these focused specifically on SEPAs. The others included a mix of directly employed and SEPAs, with the latter usually accounting for a small part of the sample. The other two studies focused on the experiences of community m

Many of these views were also echoed in studies conducted with community micro-enterprise schemes by the New Economics Foundation (Boyle and Needham 2008) and Needham and Glasby (2021). Those working as sole-traders, with a close approximation to PA roles, identified two important advantages of moving away from more traditional jobs in social care.

The first was **autonomy** - the participants very much appreciated being able to choose who they support and how they support them. Many described having had bad

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them to rush from one client to another, thereby providing inadequate support. Operating as sole-traders or small micro-enterprises

is devolved to the lowest possible level: that of the people engaged in the activity of giving and receiving care. They develop the support together. One sole-trader described an example of how she has gone in to provide a meals service, and then went further than that because of the perceived need:

"Took this new man on. Dementia. It was a, like, holiday cover. His sister's gone away. Says, 'Will just go and, you know, do his dinner for me? Just put the vac round?' He's got a dog. Cause he's got dementia, every time the dog barks, he feeds him. So he's just barking all the while, so he's just giving the dog food. And [his sister] says, 'Just do his dinner and go.' So now, what I do, put his dinner in when I get there, wash up, wipe the sides down, put it on the plate, put the vac round, and when that's cooled down, give him his dinner and take the dog for a walk. Stops the dog barking and he can eat his dinner in peace. And he's ate at least three-quarters of his dinner every day."
(Needham and Glasby, 2021; pp.9)

4.3 Issues and risks associated with working with SEPAs

In the limited literature on this topic there were a few key but important themes that emerged. Firstly, Woolham et al (2019) in their semi-structured interviews with PAs and other stakeholders drew attention to the risks employers ran by working with people who may claim to be self-employed but were in fact **not registered with HMRC**. For example, some stakeholders worked in organisations that managed PA registers where

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verified and no background checks are made. Instead, potential employers were advised to verify all information and conduct checks themselves. This **responsibility of verification** was also highlighted in the Low Income Tax Reform Group (LITRG) guidance (2022) on ascertaining whether PAs are self-employed or not. The authors state that:

"It is very important to understand that it is your responsibility to correctly decide the 'status' of your PA (that is, whether they are employed or, less commonly, self-employed) based on the specific working arrangements between you, so that you can operate PAYE if you need to. You cannot just pick a status because it is either better for you or because the PA wants to be self-employed or because the PA states they are self-employed for the work they do for others."
(LITRG, 2022; pp.2)

Another risk is that while PAs may have registered with the HMRC they **did not actually meet the criteria for being self-employed**. In both these cases **tax liabilities and national insurance contributions** can be transferred to people engaging SEPAs as the former can in fact be deemed to be employers. With respect to this the LITRG state:

"Tax law can override what either you or your PA intended. This means that even if you have a contract with your PA that says they are self-employed, if the facts indicate otherwise, HMRC can decide that they must be treated as your employee. Be aware that employment status is not a choice. There have been cases where a court has ruled that a carer who was previously considered 'self-employed' is in fact legally]^{T} /

Stakeholders in the study conducted by Woolham et al (2019)

people at particular risk of **colluding with illegal activities** such as benefit fraud or employing people without the right to work in the UK. One stakeholder described one such experience:

'I've had a case where the tax man has come after someone because the PA – self employed PA, been their PA for 20 odd years, client dies, PA claims redundancy, "No, you can't do that, you're self-employed". Talk to the insurers, "Oh yes, they can, they actually can". So, he claims redundancy and the widow is distraught because that's a lot of money. Then, when the redundancy is paid, lo and behold HMRC go, "Hang on a minute, where's the NI (National Insurance) contributions for the last 20 years?" and it's been cash in hand, self-employed, they haven't kept records, so HMRC thinks, "Okay, he's been doing 30 hours a week for the last 20 years". Even though he might not, they take the last snapshot and they come after the client for unpaid National Insurance, any – if the PA hasn't been paying their tax and the employer has no way of knowing that they are doing, they'll come after them for that as well'.
(Woolham et al., 2019; pp.55)

Some stakeholders felt that **PA registers could be used as a form of a PA óaccreditationô** system, in which there were conditions attached to registration. One worked for an organisation that required compulsory basic training, checks on HMRC registration and insurance (because all those who registered were regarded as self-employed) and DBS checks.

Not all those who applied to join this register as a PA were successful. This participant argued that this kind of approach offered both safeguards and quality standards and was also an effective way for PAs to secure employment.

These findings were also echoed in a survey of and focus groups with PAs and gatekeeper organisations conducted by the Scottish Centre for Employment Research (2018). In addition to the risk of employers being faced with large HMRC bills for unpaid

In another survey of local authorities and NHS organisations conducted by Skills for Care (2016) respondents reported a mixed number of employment models where local

All the necessary **quality assurance and safeguarding checks** are also conducted by these ULOs, including DBS checks, ensuring the correct insurance is in place, checking references and the right to work in the UK. Finally, both organisations also recognise the importance of their continuing involvement in the relationship between service users and PAs, through some type of **supervision and oversight**. For example:

> ibk initiatives believes that supervision is key and is one of the reasons this model of employment works so well. They offer supervision services and they feel it really

6. Theme five: Support and guidance needed by SEPAs

Helping the employer with medical tasks (medications, dressings) One PA

mentioned using an Epi-Pen. Another PA had given injections
Checking and looking after/cleaning equipment essential for the employer
Providing massage/helping with exercises to improve mobility and comfort

6.5 Access to PA registers and or introductory / brokerage agencies

The Self-Directed Support Scotland survey (2021) reported that all seven SEPA respondents stated that they would voluntarily register to be on a PA register as they felt that this would support them in their role. **Training and development**

7. Theme six: Issues faced by, and views of,

People also felt that the caps and limits on pay for PAs is partly a reflection of the fact that the **role is not socially valued** and often held in **low esteem**, despite the skills, specialist experience, and knowledge and training needed by many to work as a PA often alone and meeting complex and diverse needs. The **ótime and taskô model** adopted by funders also makes it harder to find PAs to work the hours needed and is very much in direct conflict with the ethos of direct payments and PHBs which is about outcomes and enabling people to use their budgets flexibly and in a way that meets their needs. Respondents felt that all these factors - low pay, the low esteem in which the role is held, poor terms and conditions - worked together to discourage people with the right skills, experience, values and training from taking up work as a PA. In fact, many respondents reported experiences of how some people who came for interviews were totally unsuitable for the role (Skills for Care, 2016; TLAP, 2022a).

Some respondents in the survey conducted by TLAP (2022a) were also concerned that **introductory agencies** were affecting supply by taking affordable PA capacity out of the local market by offering better rates of pay. Additionally, more than a third of respondents said they have found fewer people are available for PA work **following Brexit or immigration restrictions**. This was also echoed by Graby and Homayoun (2019) in their article on direct payments and how well they are working for people with disabilities. They report that PAs employed by people tend to be citizens of other EU countries, who are often more likely than British citizens to apply for, and to put up with, poorly-paid work.

This issue of **insufficient ósupplyô** of PAs is also felt to be a reflection of unrealistic and ill-informed funders and commissioners - one example given of this was how people were prevented from using a SEPA, significantly limiting the pool of PAs available to them and created inequalities in the market as self-funders can contract with whomever they choose (TLAP, 2022a). Another study conducted by Skills for Care (2016) with local authorities and NHS organisations found that when asked if a good supply of PAs existed locally, three-fifths of both local authority respondents and NHS respondents

of respondents reported that a good supply of
PAs existed. This disconnect between actual and potential supply was attributed to a range of reasons. For example, the fact that the PA role is not socially valued and can

make recruiting PAs to smaller packages of care very difficult. Additionally, respondents also reported that it can be difficult to recruit PAs for more complex care and health tasks.

There is also evidence across the literature that the recruitment of PAs is difficult because of a **lack of support from local authorities and NHS funders**

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Some people said that they had found PAs through word of mouth or adverts in shop

Another key reason for leaving was that PAs found that the **job was not right for them**. PAs who left because the nature of the work was not right for them used this to highlight how the role and demands of PA work is not well understood or defined. Some PAs told their employers that they were leaving because of **mental health issues**, often mentioning stress, anxiety or depression in particular. Some people reported that during the pandemic they had been able to recruit people furloughed from their jobs, and therefore **returning to these old jobs** was also often a reason given for leaving.

The respondents also described how although they tried to make the role interesting and rewarding, the **low pay**, **no reward for length of service**, **little opportunity for career progression and/or training** often limited the length of time that a PA would stay in the role. Finally, people described the negative impact of the **turnover of staff**, particularly for people with complex needs or challenging behaviours:

Finally, in an article written by Which? (2021) on employing private carers the authors also emphasise that direct employment, rather than going through an agency can come with the absence of other key support. For example, an employer can be left without a replacement if the carer is absent from work, whereas an agency will usually find cover. Additionally, agencies provide employers with the added protection of staff training and vetting as well as an established complaints procedure to resolve any issues that may arise.

7.7 Disadvantages and advantages of engaging with SEPAs

Self-Directed Support Scotland (SDSS, 2021) carried out a small-scale survey where eleven of a total sample of 39 respondents were in fact people who engage with SEPAs. When asked about the disadvantages of contracting with them a number of key themes emerged. Many were concerned with **staff turnover** and how a SEPA can resign without being held to a **notice period**, and the length of time it can take to recruit a new one. Others mentioned the **difficulty getting cover** if a SEPA is sick or has an emergency.

> *"Difficult to get cover. Holidays can usually be covered by existing team, if we get enough notice, but sickness and other emergency leave is very problematic and I (daughter) often end up covering shifts myself, and my health isn't so good."*
> *(SDSS, 2021; pp.5)*

Another key theme was that of the **lack of clarity and guidance** from local authorities. As one respondent commented:

> *"The difficulty is not with the PAs themselves. The difficulty has been in convincing, cajoling, and myth-busting with local authorities. The barriers and hurdles that already stressed people are having to deal with in order to get even four hours of care from their chosen SE PA, is not acceptable."*
> *(SDSS, 2021; pp.3)*

Other disadvantages mentioned included the risk that SEPAs may not have the **required training**, that they are not bound by employment law, and as discussed earlier the fact that people who engage them can still be **found liable by the HMRC** for taxes and penalties even if the PA is registered as self-employed. However, the authors report that it was interesting to hear from one respondent who said there is *'no more risk than when contracting the services of any self-employed professional. Most self-employed people will do the extra mile as its their name, reputation and future business that will be harmed if they do not perform as per the agreed contract. When both parties*

When asked about the benefits of doing so **flexibility** was identified as a key theme, but not discussed further by the authors. Other benefits mentioned included not having to deal with **employment related processes** (payroll, paperwork) and costs (sick leave, maternity leave) and **more control** over the PAs they engage.

8. Conclusions

A key finding of this review is that there is a dearth of published literature about the experiences and needs of SEPAs and the people that engage them. Similarly, there is also little research evidence about how the market for SEPAs operates both locally and nationally. At the same time, we know anecdotally that the market for SEPAs is growing as they are seen by some as a possible solution to fill the gap in available PAs.

Given the lack of an established market for or consistent policies towards SEPAs they also face challenges and identify a need for support and advice. For example, they struggle to access training and development opportunities and access job opportunities via PA registers or introductory agencies. They also have no organisation or body to turn to for advice and support in the case of a serious dispute with a client or if they face any abuse or exploitation. Additionally, challenges faced by those engaging SEPAs can include difficulty finding cover if a PA is sick, the lack of a need for a notice period and the lack of clarity and guidance from local authorities about how to engage with SEPAs.

Whilst SEPAs can clearly be seen as one of the options for individuals that require support to live an independent life, it is clear from this review that there is a need for better support, advice and guidance for SEPAs, individuals who engage them as well as the as organisations involved in funding direct payments across health and social care. The dearth of relevant literature highlighted in this review also means that further research is needed to understand how the market for SEPAs operates on a local level as well as a need to better understand the experiences of, and support and guidance needed by all stakeholders involved.

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NHS England (2017) Options for managing the money Personal Health Budgets ao

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