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The impact of the coronavirus (Covid-19) on people who work as social care Personal Assistants

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Acknowledgement and disclaimer

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Summary

1. Working and not working

- From our initial sample of 105 Personal Assistants (PAs) who participated in an earlier study, in April 2020 we found many of them had either decided to stop working or had been asked by their employer to stop. Most employers and a small number of PAs had decided to 'shield' – the latter because of their own long-term health problems or those of a close family member.
- PAs were often asked to stop working by their employer as many were often engaged in helping their employers to get outside the home and take part in activities in the community, which increased the risks of virus transmission. However, some employers, with other care workers from home care agencies were, by contrast, retained or replaced by family members. This was because personal care needs had to be met (and were not the responsibility of these PAs). However, care needs were not always met by the same agency worker, and agency care workers also worked for many more clients. This may therefore have put a PA's employer at greater risk of infection and had to be balanced with their need for personal care. One PA suggested that some care agencies may have insisted that only their workers visited a client's home, (to minimise risk to their client and to their staff) and that they would withdraw support if not.
- Many PAs had started detailed pre-lock-down preparations to best support 'vulnerable' clients and minimise risk of infection, including considering what would happen in the event of their employer becoming ill with Covid-19.
- PAs generally displayed a considerable sense of responsibility toward their employers and employer's families. The majority gave accounts of immense dedication and bravery, saying they would continue to look after their clients if they became sick with Covid-19 and needed help, even if this meant putting themselves (and sometimes vulnerable family members) at risk, and they had to self-isolate either in their employer's accommodation or their own. One PA reported their spouse having also stopped work in order to prevent risk of infection spreading to them and then inadvertently to the PA employer.
- Interviews highlighted the precariousness of many PA contracts and their lack of employment protections:
 - Some PAs were not eligible for furlough or self-employment payments.
 - Only one PA said they had insurance against sickness (all had personal indemnity insurance).
 - Many relied on a partner/spouse to maintain family income therefore were less affected by not working. However, one PA acknowledged that worry about loss

of income could result in PA discounting how unwell they felt and thereby spreading infection.

- Local authorities varied in their level of support to PAs. Some had told employers to use their Direct Payments to continue to pay PAs even if the PA had been asked not to work; but others had made no contact with the employer.
- Those PAs who were in touch with a brokerage service managed by a 3rd sector organisation seemed better placed because the organisation was able to support group applications for furlough for these self-employed PAs.
- Some self-employed PAs did not receive any pay if they were not working.
- Though most PAs said they wanted to continue working as a PA in a post-Covid-19 context, a small number of PAs who had second jobs in different employment settings stated that better employment conditions there had led them to reconsider whether to continue working as a PA.

2. Changes to working role due to Coronavirus

- Regardless of whether they were paid, unless they were themselves 'shielding' to protect themselves or a family member, nearly all PAs were helping others in some way on a voluntary basis. For those still working, though taking their employer out was no longer possible, other, sometimes new tasks, continued, including:
 - Shopping and additional work outside the house if they had been asked not to provide in-house care.
 - Staying/working longer shifts so client had less exposure to risk with multiple care workers.
 - Extra shopping trips to obtain scarce provisions.
 - Telephoning regularly to provide emotional/social support from a distance.
 - Supporting some employers to use information technology – for example, internet/online shopping but also social media to encourage employers to interact with friends and family.

3. Sources of information for PAs

- Other than limited, general guidance from the government which was not always thought useful by PAs, there were few other reliable sources of information about the virus, or about practical arrangements such as when and where to get tested, to obtain Personal Protective Equipment (PPE), and to learn safe practices. Other sources of information that were used included
 - Mainstream media, (newspapers, television and local and national radio).
 - Daily televised government briefings from Downing Street that started in response to the pandemic.

-
- Local authority bulletins (only a small number of PAs received these on a regular basis - East Sussex County Council sent daily emails, and then later twice a week which were widely praised). PAs working in other local authority areas either received no information or found the bulletins that were sent too long and not clearly written.
 - Many PAs used their own initiative in seeking out information, signing up for updates from reputable sources of information (one PA, for example, received regular information from the World Health Organisation).
 - PA employers and their family members also received and passed on information to their PA.
 - PAs and employers were generally 'on the same page' in respect of their understanding of the virus, the level of risk it posed, and how best to stay safe.
 - Most PAs were 'savvy' about sources of information and seemed able to discriminate between accurate information and 'fake' news and misinformation.
 - Some PAs expressed disillusionment and a lack of trust in government guidance, and the media generally.
 - Many did not know whether they were keyworkers or how this status was conferred. This meant it was more difficult for them when shopping for their employer, and some expressed concern about whether they might be fined if stopped by the police during 'lock-down'.

4. Personal protective equipment (PPE) and PAs

- Most PAs wore masks, gloves, aprons and said it was likely to become routine practice for them now, and many said they would now continue to use most PPE even in a 'post-Covid' setting.
- It was often difficult for PAs to obtain PPE. Some obtained PPE through personal contacts, some bought it online. Regional PPE 'hubs' (where care workers could obtain supplies) were generally not used by PAs because they did not have appropriate registration. A handful of PAs had managed to secure some PPE through this source, and felt that what they had been provided with was grossly inadequate in terms of quantity.
- Self-employed PAs usually paid for PPE themselves: for most directly employed PAs the employer paid for it. The costs of PPE had escalated – both because prices had risen due to scarcity, and also because more was being used. This caused some resentment.

5. Impact of change in status of PAs in society

- Though some PAs were optimistic that the virus may have permanently raised the status of health and care workers, the majority were either pessimistic or equivocal that changed attitudes towards key workers and their improved status within society would be sustained.
- Some were concerned that the impact of the virus on the economy would mean that funding for improvements in training, pay and conditions would not be available.
- None of the PAs made any comments about the need for unionisation, increased regulation and so on.

6. Attitude towards neighbourhood schemes

- There was some concern about safety of these schemes, and many felt that although most of those working as volunteers would be well-meaning, there might be a few who may take advantage because DBS checks or other forms of screening were not being carried out.

7. Attitudes to flu vaccine

- Attitudes to annual flu vaccinations were mixed. Many PAs had not 'got around to it', with some preferring not to have a vaccination – either because of concerns that it would make them ill, because they said they had a 'needle phobia' or because when they had asked to be vaccinated they had been told they were not eligible. A few PAs mentioned the possibility of a coronavirus vaccine being a solution to longer term challenges, but there appeared to be more faith in tracking, tracing and testing approaches.

8. Role of 'brokerage' agencies

- The absence of other sources of information meant that several PAs relied on advice and support received from 3rd sector brokerage agencies. Many of these agencies will not have been funded to support PAs, but just to offer guidance to employers.

9. Things PAs felt would help or have helped

- PAs were asked about what would be most helpful to them in responding and adapting to the Covid virus. Several suggestions were made, including

-
- Ready access to sufficient quantities of good quality PPE. This was the single most mentioned thing that PAs said would help.
 - The implementation of easily accessible, reliable testing – both for the presence of the virus, and antibodies; and a recognition that tests would need to be done repeatedly.
 - Effective mechanisms for contact tracing to help prevent the spread of the virus.
 - A single source of contact for support and reliable and accurate advice.
 - Better pay, contracts and less precarious working conditions.
 - Financial support to people who were unable to work, but were not being paid by the employer, and did not qualify for the government’s furlough scheme.

Policy Options

The PAs felt ‘unknown’ to health and care services, despite their payments coming from public money in the main (via local authority Direct Payments made to people in need of care and support). Their status as key workers could not be acknowledged and access to information and PPE was patchy. There is room to explore if the names and contact details of local authority indirectly funded PAs could be collected by local authorities in their setting up, review and monitoring of care plans which detail the agreed care arrangements under Direct Payments. This could be piloted to see if it would be practicable.

If a local authority had a record of PAs then it would be able to send information to them in any further Covid outbreak locally or nationally and would also have this information for any future emergency. It would be able to provide ‘proof’ of their status and engage with them in the supply of PPE.

Third sector agencies that support PA employers could be consulted about what support they could provide to PAs, not simply information but also support, and what would enable them to provide this.

The loss of PAs to this part of the care sector through decisions that other work is more remunerative and secure, suggests that poor terms and conditions are not sustainable. Contracts and fair pay are not a matter of ‘choice’. Local authority contact with PAs should set out their rights and those advising Direct Payment recipients in local authorities should be able to refer potential PA employers to standard contracts and employment information, or refer them to organisations such as Skills for Care. Reviews of an individual’s wellbeing and outcomes when in receipt of Direct Payments - the responsibility of the local authority or a delegated body - should cover employment terms and conditions to protect the interests of both employers and PAs, and the care sector.

In the short-term, details of PPE access for PAs should be sent to Direct Payment recipients and other local groups that may have contacts with PAs. Estimates of which Direct Payment recipients will need PAs to have PPE coverage should be collated by local authorities.

All Direct Payment recipients with PAs should have support in developing a contingency plan for infections and other related emergencies that should be developed with support from the local authority as part of its agreement of care plans and their reviews. These plans should also be lodged with the local authority and be reviewed as necessary.

The views of PAs, and their clients, about vaccines are important to consider if a vaccine is developed. This suggests wider public health messaging about vaccines for people who are at substantial harm from Covid-19 and those working for them.

Background

The novel coronavirus, Covid-19, is creating unprecedented challenges for health and social care systems globally. Within the UK, to prevent NHS Intensive Care Units (ICUs) being overwhelmed, Public Health Services have offered advice to the public about how to minimise risk of infection, with specific advice to people living with a range of health conditions and other characteristics which may put them at particular risk. As well as slowing demand for scarce NHS resources, concerns have been expressed at the lack of personal protective equipment (PPE) for NHS staff and the absence of testing facilities, making cross-contamination more likely.

Though care services have been less vocal in expressing concerns about the risks they also run, or pose, the nature of social care (often involving personal care) means practitioners need to follow strict hygiene protocols to protect themselves and those they care for or support. Both are vital: if care workers are unable to protect themselves or those they care for, more people will require NHS treatment, and the care sector will be unable to meet the needs of all of those who depend on it.

To date (early July 2020) there are few studies of the impact of Covid-19 on care work. Reports have suggested that many older people living in care homes have been exposed to the Coronavirus; in part because a decision by the Government to abandon attempts to track and trace people for the virus meant older people admitted to hospital for other reasons from care homes or the community acquired the virus whilst there, and were discharged whilst infected. Care homes were also reported to be ill-equipped to cope because of shortages, in the early weeks of the pandemic, of personal protective equipment (PPE), and the design of buildings and needs of residents meant quarantining of infected residents created especial challenges.

Even less is known about the impact of the virus on people giving and receiving care in community settings, though calculations made of 'excess deaths' made since the virus arrived in the UK suggests that many people may have died of the virus without receiving a diagnosis or even showing symptoms.

Social care Personal Assistants

Amongst the social care workforce, social care Personal Assistants (PAs) are a small but growing segment of that workforce. An estimated 75,000 people in England with needs for support in activities of daily living are employing around 145,000 PAs, to support them in work and leisure, or more often with personal care (Skills for Care, 2019). This number has been steady for the past three years with the proportion of Direct Payments recipients employing their own staff estimated to be nearly a third (31%, Skills for Care 2019, p.21). Proportionally, younger adults in receipt of community based local authority social care funding to meet their care and support needs are more likely to receive Direct Payments than older people: 71,000, (29%) and 39,000 (12%) respectively (Idriss et al., 2020 p.12).

This study draws on our earlier, and larger, study of Personal Assistants (sometime also referred to as directly employed care workers (Woolham et al. 2019). PAs are a popular alternative to more orthodox care services for some disabled people. This previous study aligned with other smaller studies, in finding that because PAs are directly employed (or directly hired, if the PA is self-employed) they offer genuine opportunities for relationship-based care, which can lead to far greater levels of person-centred care/support than are possible in more traditional care roles, and care/support relationships that could be mutually satisfying. However, our 2019 study also found that aspects of the PA role were very problematic. PAs are unregulated (they are believed to be the only group of care practitioners that are not regulated and inspected, despite providing personal care). They are also, largely, unsupported, having no professional association to represent their interests; and in our previous study, none belonged to a Trades Union. Their working environment is also usually a very isolated one, unless part of a team providing 24 hour cover for a disabled employer. Many did not have contracts, or contracts that did not accurately reflect the nature of the work. Most were expected to work flexible hours to suit their employer: effectively, a zero-hours working relationship; and if there was a problem with their employment relationship, though support was often available for their employer, PAs had no access to independent advice. Access to training was also limited for PAs paid for by Direct Payments: as no 'ring fencing' of funds for training is made, employers tended to use their Direct Payment to pay for PAs to work for them rather than attend training. Though PPE was usually provided by the employer, in our first study, some PAs chose not to use it (this was earlier generally referred to as health and safety related equipment) as they felt it 'medicalised' their relationship with their employer, and self-employed PAs were generally expected to provide their own work-related clothes or items (e.g. gloves).

These problematic aspects of the PA role mean that poor working practices and health and safety issues could be ignored or disregarded, and their isolated and unsupported and 'hard-to-reach' status for researchers also make it more likely that they might be overlooked in attempts to understand the impact of the virus on this part of the care sector.

This present study therefore explores the impact of Covid-19 on the working relationship of PAs with their employers; for example, what steps PAs are taking to protect themselves and their employers, or how this virus has impacted more generally on their employment relationship.

Objectives

This study aimed to:

1. Explore the personal impact of Covid-19 on PAs and their families, and on attitudes to working as a PA
2. Identify the ways in which PAs have had to adjust and adapt their work to enable them to do their job safely
3. Describe the impact of Covid-10 on PAs paid for by Personal Health Budgets
4. Find out more about the information and support needs of PAs specifically in relation to Covid-19
5. Describe the impact of Covid-19 on PA relationships with other community based professionals.

Design and methods

The study utilized the prospective sample obtained for our earlier study of PAs. In that study, 105 PAs were interviewed and most indicated that they would be willing to take part in further studies, should these occur. Before the present study took place, a favourable ethical opinion was sought, and obtained, from King's College London's Research Ethics Service before the study commenced (ref. HR-19/20-18212).

Data for this present report came mostly from PAs identified in this earlier study. Additionally, two PAs who had not been part of the original study were identified and invited to take part. A total of 105 PAs were contacted by email and asked if they would like to take part. Information sheets and consent forms were attached to the email, and PAs were invited to reply, and return the completed consent form if they were happy to take part. Two reminders were sent.

One incidental but telling finding from this part of the study was that amongst those who replied, many who had been working as PAs in the first study were no longer doing so.

Did not respond to request to take part in study	48
No longer working as a PA	16
Specified reasons:	
<i>Maternity leave</i>	
<i>Recovering from serious illness</i>	2
<i>Retired</i>	2
<i>Started a family</i>	2
<i>Bereavement</i>	1
<i>Shielding vulnerable family member</i>	1
<i>Studying for PhD</i>	1
	1
Invalid email address/uncontactable	2
Interviewed	41

Table 1. Respondents no longer working as a PA amongst those who replied.

The total number of ex-PAs was 16 – or 15% of the original sample who had stopped working as a PA at some point over the previous 36 months. This seems likely to be an under-estimate, as we do not know how many of those who did not respond to our request to take part in this study had ceased to work as a PA.

Some of those contacted had been directly affected by the virus. One PA's husband had died of Covid-19 infection two weeks before being contacted, another had stopped working voluntarily to 'shield' a vulnerable family member and another PA (who did take part) was still recovering after being seriously ill with the virus.

All interviews were conducted by telephone at a time convenient to the participant. One member of the team (JW) carried out all interviews. The interview questionnaire was semi-

structured; 27 questions were included, each of which focused on the impact of Covid-19 on their work as PAs. The questionnaire was designed by one member of the research team (JW) and agreed by the full team. All the interviews were audio recorded with the consent of the PA. The average length of the interview was around 45 minutes: the shortest about 20 minutes, the longest well over one hour. Each audio recording was fully transcribed. All interviews took place between 16th April and 21st May. All participants were sent a £20 High Street gift voucher or equivalent to thank them for their time.

Transcribed data were pseudo anonymised before being entered into NVIVO qualitative software to help manage analysis. Framework analysis was used for this purpose. The analysis was conducted by two team members (KS and CN), and full team discussions (KS, CN, JW and JM) were held to check and validate emerging themes. The report was written by three team members (JW, KS and JM).

Findings

1. Demographic profile of respondents *(For full data, please see appendix 1)*

A total of 41 respondents participated. Respondents were overwhelmingly female (95%) and White (83%). 93% were of British nationality. Their mean age was 48.5 years. Nearly half (49%) were caring for another family member, and a similar proportion was caring for children within their family. Participants came from all parts of England.

2. The impact of the coronavirus on work as a PA

Many PAs had been asked not to work by their employer, or had themselves decided to temporarily stop working as a PA. Amongst those who were continuing to work for their employer, the impact of the virus on the working lives of many of the PAs cannot be understated.

a. Changes to occupational role. PAs who continued to work faced marked changes to their role. Younger adults and their PAs were particularly affected by the introduction of 'lock-down' as it was suddenly not possible to visit a day centre, mix with others, or do everyday activities such as shopping. This meant new responsibilities and marked changes to the PA's role:

I feel I have more responsibility in terms of making sure my clients are safe, and doing everything I possibly can to make sure things stay that way, and so in terms of myself, I'm self-isolating at home alone and I just go to work and the only thing that I do is get petrol; that's the only place I go where I might come across someone else. I'm doing everything else online; shopping, so I've retreated a lot myself in order to trying and keep myself well and to keep my clients well.

DM550285

Providing social and emotional support to their employer(s) was the most frequently mentioned impact of the virus, with PAs describing many of their employers being bewildered, anxious and frightened by the pandemic:

We have to do lots of reassuring now. Some of our clients are very scared about us coming into their house.

DM550314

This is the time of year when he would normally be able to go out and socialise and go to pubs and clubs because it's too cold the rest of the year and he can't leave the flat. Those are the main changes. And, to be fair it's probably not what you asked, but his mood, particularly in the first month of lock-down was really, really affected by the fear, literally abject fear, of this virus that was going to kill him, basically. I think he's relaxed a little bit with it now, but honestly, trying to jolly him along, not that... that wasn't really my role, but to try and make things a bit lighter sometimes...

DM550326

PA views about the attitude of employers toward the virus are explored more fully in a subsequent section.

Lock-down and shielding also meant a dramatic reduction in social contact, which led some employers to become both lonely and bored. Some PAs who were not visiting their employer maintained social contact by telephone:

... with one client, instead of visiting her, I actually phone her up and talk to her on the telephone, to see how she's doing with regard to her medication and other

things that are going on with her, and allow her space to talk about her mental health, so I do still kind of work, it's a bit of a grey area because I don't want to charge them a lot of money for phoning up...

DM550288

Some PAs spoke of advising their employers to reduce the time they spent watching or listening to news reports on television or radio, and visiting social media sites, because of the fear and anxiety this created.

The need for most employers to 'shield' because of their vulnerability was also reported to contribute to problems with mental health – both their employer's and their own.

The virus led to some dramatic changes in working practices, to keep employers and PAs safe. In our previous study of PAs, PPE (in the form of gloves or an apron, for example) were usually available but often not used because of concerns that they 'medicalised' the relationship of the PA and their employer. This had completely changed, and all PAs in the present study wore PPE and most said they would continue to do even when the threat from the virus had ended. However, wearing PPE – especially surgical masks – sometimes created serious communication and other barriers between the PA and employers who were deaf, or had dementia:

... so I turned up in gloves and masks and all those aids, and tried to carry on as normal, but there were things we didn't consider because this lady with dementia, also the hearing is bad, so when I put the mask on it was almost impossible for her to hear me, so I kept moving the mask so she can hear me, or speak up and it wasn't really working, she was struggling to understand me with the mask on, so we decided that's not really working because it made her more agitated, more unsettled.

DM550306

Hand washing and ensuring cleanliness within the employer's home were also frequently mentioned. One PA described the elaborate steps she and other members of a team of PAs took daily to protect their employer:

Well, we have to be very careful, we basically had to transfer everything we do into a safe environment, so we had to come down with a lot of restrictions in our workplace about things like, for example, when we enter the house, leave the shoes by the door, we have to wash hands straightaway and we wash hands in a way that nurses do in the hospital, so it's like almost before surgery, washing hands.

DM550302

b. Shopping. Many PAs continued to help their employer with shopping. Shopping was particularly problematic, especially immediately before and after the Government introduced lock-down measures in March 2020. Panic buying meant that it was sometimes impossible to obtain everyday household items. The absence of hand sanitisers, but also of toilet rolls and some food items that were in particularly short supply were widely reported,

but PAs also described difficulties in obtaining specific (usually branded) items of foodstuff preferred by their employer, describing queuing for long periods to enter a shop only to find certain items unavailable. Some PAs persisted by queuing outside several shops to obtain specific items. Because they were shielding, employers were often reported to have had little understanding of the additional burden this placed on their PA, who were effectively unpaid for much of the time they spent trying to obtain items. PAs also said that on-line shopping had often been impossible because of various problems: the unavailability of home computers and the limited IT skills of employers, because of the difficulty of obtaining delivery 'slots' because of high demand, and situations where many items were unavailable and substitutions sent considered inadequate:

They probably could have been shopping online anyway, but quite often people like to be taken to a supermarket and do their own shopping. But as soon as the lock-down appeared, I tried very hard to organise online shopping for one person, but I couldn't even get through to the customer service desk, it was a real no-go. It might be okay now, perhaps, but I just was totally unsuccessful in trying to get through to anybody. Apparently, all the slots were taken as well.

DM550288

Physically visiting shops also enabled PAs to make judgements about alternatives to non-available items.

c. Key-worker status. Many PAs did not have key-worker status. There was some uncertainty among them about what constituted having this status; but where it was conferred this usually took the form of a letter from an employer, or a brokerage company/organisation, which was carried with them in case they were stopped by the police and challenged about the purpose of their journey during 'lock-down':

I'm thinking, if I was at work now, I ain't got any ID to prove I'm a carer because we don't get given it; we're employed direct by the client and not to an organisation, we don't get any ID that that's what we're doing and I could be anybody claiming to be a carer and I understand why they do it because people could lie about it and claim it, but those who genuinely are, we don't get any way of proving it.

DM550294

However, the 'currency' of letters from employers may have been of little worth unless it came from an NHS England source; one PA, who also worked as a part-time social worker for the local adult social care department, recalled:

...so I'm a social worker as well, so I went to skip the queue because the queue was massive and I'd been at work all day, I needed to do my parents' shopping, and I showed them my badge and they wouldn't accept it; they said it's not the NHS, but then I had my key worker letter which has the NHS logo on, even though I don't work for the NHS, I showed them that and they let me in.

DM550304

d. PAs and support with healthcare needs. PAs were attentive to the healthcare needs of their employer in the pandemic. Though most reported that deliveries of prescriptions and medical supplies were unaffected, occasional problems were reported:

...sometimes prescriptions are late, sometimes pads are late, sometimes the wrong pads they send, the wrong sizes are sent, and she didn't used to cope very well at all with that at one time, but I got her to a stage where at first I was calling them in front of her and saying, you know, what you have to say, and we're in this position and this is not good enough, etc., etc., and can we please have more consistent service, because she couldn't do that and she wouldn't do that, but now she can do that. So if ever they send the wrong pads out, there's always a stock, we made sure there was a stock by ordering when we didn't need any, so they've got a stock, she then knows that she's got the time to call and say, look, you sent the wrong pads, the wrong size pads or whatever, can someone please come and fetch them back and send us the right ones, and that is usually sorted out within a short time.

DM550289

A handful of PAs also found it difficult to obtain health services for their employer when needed:

.... getting in touch has been okay, but it's all been over the phone. It's been very difficult... one of my clients has got a funny mole on her back and we've been trying to get someone to come out, and that's proving quite difficult; we've put on the back burner for a couple of weeks again. I keep sending in pictures, I email them a photo, at least they can see these changes, but actually getting anyone to come out or to get in on an appointment is quite difficult.

DM550297

Unhelpful and time consuming bureaucratic obstacles were also sometimes reported:

So it's a lady with MS who became totally unable to move anything, she can't move her legs or anything, so when she could, which was up to very recently, she was on single-handed visits; now we all say she needs two carers to help for everything to do with her personal care, and two weeks ago I asked for them to review it. Because the social worker can't come out to do a review, I've had to actually do the review on paper and they've asked for a five-day minute-by-minute account of what we do for this lady, just to prove that we need the extra carer.

DM550314

Concerns were expressed about the potential impact of hospital lock-downs and the inability of employers to receive visits from non-hospital based staff:

He wouldn't survive without somebody who knows his needs, so nobody would be able to know what he's saying, nobody would be able to provide oxygen for him, so I can't see it myself, that he'd actually even survive without a family member or a PA with him. Even just... literally on his way in, he wouldn't make... he wouldn't even be

able to get in, but as soon as his oxygen pipe isn't achievable with his tongue, that would be it; he'd be dead. So, yeah, it's a huge concern. One of us would have to force our way in there, or they'd realise pretty quickly that they've killed somebody who needed some extra support.

DM550326

e. *Impact on relationships.* As well as changes to the role of PAs and the tasks they undertook, the coronavirus also led to changes to relationships; not only between PAs and their employers and their employer's family, as indicated earlier, but also to the relationship between PAs and their family, and circle of friends. This could involve potentially big sacrifices:

...because we are from Poland and all my family is back in Poland, so we only have really friends here in England. So we haven't seen any friends since all of it started and it's all... my family is taking all of the precautions because of me working for a vulnerable person, so we're all very careful and my husband was considering going temporarily to do other works because there are works available, but I said it's way too risky for the person I work for, for my employer, because you never know who you will be in contact with. We try to absolutely minimise the risk, so we are fine at the moment with me working full time for my employer and just living off the wages I get, so we say we don't want to take this risk because obviously due to my employer's condition, this virus can be fatal.

DM550302

Other PAs spoke of being in relationships with other key workers, and their concerns not only about infecting their employer, but partners and their contacts, and vulnerable relatives. Part of the risk calculations made by some PAs therefore involved not only thinking about their employer's welfare, but a much wider circle of contacts. A small number of PAs had, themselves, decided not to continue working for a period of time to protect a relative. Others, in relationships with other key workers, expressed concerns about the financial implications of both having to self-isolate for 14 days, in accordance with government guidance, if either came into contact with someone with the virus.

Many PAs were acutely aware of the impact of the virus on their employer, and what they were missing through having to 'shield':

We are actually his only company at the moment. He has his parents living very close by, ten minutes by car, but they are not coming over because they are elderly as well, they could be in a risk of coming over, they don't leave the house as well, so basically it's only us really. He is using Skype because of his sister and his niece, he's using all the media stuff. He's 37 years old, so he's very good with any social media, any equipment, computer equipment, to use, so at least he can use those to have contact with his friends.

DM550302

3. The impact of the coronavirus on PA pay

As well as radically changing the role of the PA and the tasks they did, the virus also had a big impact on pay. A very small number of PAs found that they were picking up more work than prior to the pandemic, but for most, the impact was negative.

a. Furlough, or suspension of work. To shield effectively, many employers took the decision to furlough their PA, suspend their work, or reduce their hours of work. The financial impact of this on PAs varied. Some PAs had more than one employer, and retained work from one or some of these, but most PAs experienced a sudden, and drastic, loss of income:

I've basically gone from 12 clients down to two, and a lot of my clients obviously are self-isolating because of their age and basically I've lost a lot of clients because of that really.

DM550320

Others worked part-time in another job entirely, which was an alternative source of income. Some PAs said that within their local authority their employer's Direct Payment continued, and was passed on to retain the PA even though they were not working. This was not true of all local authorities at the time the interviews took place:

It is difficult to discuss it because I don't like discussing money when I've become so close to the family. So I did discuss it; the council haven't issued any guidance to families around it, they haven't provided any information, so the family that I'm working with are a bit confused around what to do. They've said that they think they might pay me maybe half of my wage for 12 weeks, so pay me for six weeks, rather than 12, but they're not quite sure yet.... So I actually work for (X) Council as well, separately from my PA job, and I work in short breaks team and in (X) we are paying the PAs, but in (nearby town) where the family receive their budget from, they haven't issued any guidance at all.

DM550304

Some local authorities were continuing to pay employers their Direct Payments, and leaving it to the discretion of the employer as to whether to pass this money on to the PA:

...and I was like, what do you mean, we're not entitled to the furlough, then I rang the brokerage company that pairs us with clients, what does this mean... and they said, don't panic, panic over... I'm like, oh, my God... I've literally just signed the lease on a new car, I'm like, I can't pay my rent, I can't pay my car.... panicking. He was like, don't panic, it's entirely up to your client, your client can choose to still pay you, which was a huge relief.

DM550301

Some PAs were in contact with an intermediary agency such as a user-led organisation or brokerage service. These third sector organisations played an important role in advising PAs and interceded in making applications on behalf of PAs for the furlough scheme.

Some self-employed PAs who had not been working as a PA for very long said they did not qualify for the Government furlough scheme. Although many PAs found themselves in a much more precarious financial situation as a result of the virus, they were managing – just – to get by, often by drawing on savings. In a small number of cases, though, the financial impact of sudden loss of income was much more serious:

So I'm in my overdraft. I don't want a grant, I don't want to have to put myself into that situation where I'm paying something back, so yeah, and in fact our son who has recently got a management trainee position with (XX), he's the only one with income, so if we need to, we'll have to rely on him because he's been furloughed.

DM550310

The decision of employers to shield and suspend many PAs was also stated to affect the employer. Some PAs who had been furloughed or suspended said that they had been working alongside care workers (from local care agencies) and visits by care workers – who in contrast to PAs may have been required to visit the homes of many more clients - had continued. One possible explanation is that the care worker role in meeting personal care needs was deemed essential by the family or employer – necessary to sustain life - and therefore retained; whereas the PA role, which enriched the employer's quality of life and reduced family carer burden – making life worth living - was not. Another, for which limited evidence emerged, was that care agencies may have imposed 'lock-down' on their clients by insisting that only their staff visited their clients. The study was unable to verify the extent that this occurred. There were concerns expressed by one or two PAs that some staff working for care agencies did not always wear PPE even if available:

...so they've got carers going in from an agency, and that is another reason why I didn't want to go in because I don't know where they've been... and they don't always wear masks. I've had a few clients tell me that they've had one girl come in and she'll be masked, gloved, and then later on in the day another carer will come in and she hasn't even got gloves or mask on and they're from the same company....and that is why I'm not going in.

DM550320

Several PAs also commented that the role they had performed which might well include personal care was now carried out by family members, but that this was unlikely to be sustainable for a long period of time.

b. Insurance, sick pay, and other benefits. Though all PAs had professional indemnity insurance, almost none had insured themselves against ill-health, and/or income protection and most said that they thought they would not be paid in the event of falling ill and being unable to work, and would have to claim statutory sick pay:

Have you taken out any insurance yourself for sickness?

No. I haven't got any sickness insurance; I've got a liability insurance.

So if you infect other people you're covered, but if you get infected, you're not?

Well, I think that's the way it runs, isn't it?

DM550298

As self, or directly employed workers, too, the only form of sick pay available was statutory sick pay. This was seen by those who had investigated the circumstances in which they might be eligible to claim as insufficient as compensation for lost income:

If I wasn't being paid by the families, I would have to go on statutory sick pay, and for me, that wouldn't pay the bills.

DM550301

A few PAs – those who had lost all their work, and believed they were not entitled to furlough money, were claiming universal credit. This was reported to be a very stressful process with uncertain outcomes:

I'm having a nightmare with the universal credit because I got the statement because obviously we were told that we could make a claim for it and my husband was furloughed and I'm self-employed, and we made a claim and the statement came the other day and I don't understand what it means, I don't know things that... I had to ring them up and ask them how it works because I don't understand and they haven't paid us anything.

DM550320

4. Self-isolation and shielding

One of the most significant impacts of the Coronavirus has been on social contact and relationships with others, which changed suddenly and dramatically with 'lock-down' but affected PA employers, and therefore PAs, to an even greater extent. The health status of many employers and their vulnerability to the virus meant that they had to 'shield' rather than self-isolate. Some PAs had also stopped work and were shielding because they, or family members had long-standing health conditions that put them high risk. Interviews explored the impact of these changes on both employers as well as PAs and family members.

a. Impact on employers. PAs had different kinds of contingency plans if they were unable to work – if they had come into contact with an infected person and had to shield, or if they themselves became ill. If the PA was part of a wider team, this involved adjusting rotas. If the PA worked alone, the contingency was usually that immediate family members would step in. In only one or two cases was an employer so socially isolated that there was no-one else who could take over. In these circumstances, PAs said they would contact the local authority adult social care services in their area and ask them to help, and one said that her employer had moved into respite care as a precaution:

Fortunately, most do (have someone who can step in), which is why (name of employer) that's gone into the respite: it's to prevent that scenario from occurring, because she wouldn't have any more help. She has a massive family and there's only one, maybe two members of the family that are prepared to help and that's not full-time, which is why I go in. So they would be absolutely caught short as well if I weren't there.

DM550313

For employers, shielding often also meant a decision either by themselves or their family to ask PAs not to visit. The nature of the duties that some PAs often carried out meant that essential personal care tasks were carried out by care workers, whilst relatives and family members took over PA responsibilities

...he has two daughters, so it's not as if... neither of them are necessarily relying on one of their children, they both have more than one child, so one of their children would take over and see to any needs, whether it was having to go into a care home or whatever, really.

DM550288

These arrangements worked reasonably well for some people. However, many PAs felt that in the medium term, these arrangements were not likely to be sustainable because of the stress this was likely to impose on family members:

So the family that I work with, there's Mum, there's five children, including the child that I support, well, he's not a child any more, sorry, but I've looked after him since

he were little, and also a step-father, so the family... Mum does have some support but she is the primary carer, so she's doing everything at the moment in terms of personal care, medication, etc., but the other family member is doing the shopping so Mum... she's getting by because she has to do, but I think it's a struggle for her.

DM550304

A few PAs expressed concern about the physical wellbeing of their employer since their work had stopped:

Their personal hygiene; when I see these people on a regular basis, I can see what sort of week they've had, how they present themselves, if they're wearing dirty clothes. One gentleman in particular, I cook all his meals for him in a week and batch freeze them for him; he can do beans on toast and things like that, but I go in and specifically cook him meals for a whole week... so that's having an effect on him, and to help him, or prompt him to tidy his own house. It's just the little things, and he really doesn't see anyone else and, because we've built up a good relationship, we have a very good social communication as well. That is all lost, really.

DM550JH2

However, more were concerned about the psychological impact of self-isolation under lock-down:

... obviously what she's missing out on is going out and being away from the household, so in terms of her social and wellbeing needs being met, yes, that is affected because she's quite intense, and when the four of them are in the house together, that's Mum, Dad and the two of them with learning disabilities, and she's in her 40s, and so is he, it can be quite fractious because she is quite intense, and what she started to do is to write to me three or four times a day and call me, so I had to block her and only make it one day a week, which she's not happy about so I get bombarded with the longest letter you've ever seen on Thursday. So in terms of her... not her physical needs, but certainly her wellbeing needs, definitely, and also that of her family because, because she is... she rules the roost because of her behaviour, they're not able to get respite from it, and that was my... I would take her out so they can just have some breathing space...

So that family will be under quite a bit of stress at the moment, then?

Oh, a lot of stress.

DM550309

A few PAs kept in touch with their employer even after they had been asked to stop working.

b. Impact of the PA and their family. Several PAs had chosen to stop working during the pandemic because they themselves had long term health problems that put them at risk or whose age made them more vulnerable.

One PA had considered moving in temporarily with her employer to reduce his overall level of risk, but had then decided against it:

Because I've got my husband, who also had a heart attack a few years back, and we don't have anyone else living with us, I was a bit concerned about leaving him, so decided not to move in with them, but stay away, and I told the husband, who is the carer, if he needs any support in terms of picking up medication or shopping or anything I can provide from the outside, to give me a call and I'm happy to do that, and we done that. We done shopping and all the support I could provide remotely, so to say, and he took over my role, that six hours support which I was providing.

DM550306

Other PAs had also chosen to stop working to protect a family member whose underlying health put them at risk, or decided to self-isolate for a period of time to ensure they were virus free before continuing to work for their employer. One PA was related to the person she supported and employed by a member of her own family, and also had to take steps to protect her mother:

Yeah, so my Mum, who lives with (name of person cared for), so not within my household, but with (his); she's over 70 and she had diabetes. She has high blood pressure and she's not very well in all sorts of ways. I suppose I'm not self-isolating, but I have, from almost the beginning of March, had no contact with anybody except my household, so my partner and my daughter and I haven't been going to the supermarket and I don't go for (name of person care for) shopping either, which is something I used to do before, because I don't want to have any contact with the outside world. I don't go anywhere apart from here and to (cared for person's home). I just wanted to have that sort of seal of... I didn't want to have to worry... but... yeah, and I think the danger of me becoming ill was another factor in thinking very early on that I would take the relatively extreme at that point, so we hadn't been advised to be in lock-down at that point, but we as a family decided that we were going to do that beforehand.

DM550312

In ensuring that the employer was protected as far as possible, other members of a PA's family sometimes also agreed to make considerable sacrifices.

The financial consequences of not working were weighed, by some PAs, with the financial and other costs of becoming infected with the virus. For example, in one PA's family, all family members were key workers and therefore thought not entitled to furlough money as they were expected to continue working. If all members of the household had to self-isolate because one person became infected, there would fears of no household income:

... if I was to come down with the virus and tested positive, then that would impact my family because they're all nurses and health care workers.

DM550319

c. *Sources of advice.* If a PA was unable to work because they had been in contact with an infected person, or had themselves become ill, it might be necessary to inform not just an employer's family, but others: to minimise the risk of further infection, to ensure the needs of the employer were met, and to establish if they had actually been infected. Many PAs felt that this might be important, but had little idea of who they should contact, other than the health advice line 111.

5. Reflections about the impact of Covid-19

Interviews covered several questions that enabled PAs to talk about the attitude of their employers towards the virus, and what had happened since the pandemic started.

a. *Deciding to suspend the PA.* This report has already reported that most PAs had lost work as their employers took the decision to ‘shield’ from the virus. The decision was usually taken swiftly, with minimal notice for the PA, though in some cases, there were discussions between the PA, the employer or the employer’s family about the best course of action to take:

I raised my concerns... about (client) not really understanding the guidelines that had been put in place and could people make sure that they remind her about washing her hands when she went back in the house and all those sort of things, so that was the week leading up to when the lock-down came into place. I then had a conversation with her Mum, before the decision was made and we all knew that it was perhaps going to happen, I had quite a lengthy discussion with her Mum on the night before, saying what... we were really basically talking to each other about what we felt would be best for (client) if the lock-down were to happen, and it was during that conversation that I think we both agreed that (she) would be safest moving back into the family home for whatever period of time it took.

DM550316

Despite the loss of income, all PAs understood and were sympathetic toward those who had decided to shield. Essential tasks the PAs had formerly carried out were either now carried out by family members, a smaller number of other PAs (where a team of PAs were employed) or by care workers who had been previously working alongside PAs. Decisions to suspend the PA were often taken by family members rather than the - nominal – employer. As one might expect, PAs felt that the decision was driven – whether taken by the direct employer, their family, or both – by a desire to remain healthy and safe. PAs felt that over time, as the lock-down period continued, all employers experienced some degree of mental distress. Loneliness was commonly reported, and many PAs, aware of the potential consequences of social isolation, remained in telephone contact with their employer. Loneliness appeared to affect all age groups, but older people more than some younger adults, who were more able to keep in touch with friends through social media. Younger adults with physical and learning disabilities appeared to have been more affected than older employers by being unable to visit familiar places such as parks, cafes, and day centres through which social contacts were maintained. PAs shared a keen sense of what was being taken away from their employer:

I fluctuate between thinking, yeah, this is dead serious and I must wash my hands to within an inch of the blood coming out of all the cracks in them, etc., and sometimes I think, oh, for crying out’s sake, we’ve survived everything else and it’s just another virus and most people have had it with losing their sense of smell, and why is the

whole of society shut down because of that? And I did have an outburst at him the other day, not a nasty one, but I said I feel very upset that you're stuck in losing one year of your already restricted lifespan just for what; to wait while government mismanages it? I thought, he hasn't even seen a flower or a blossom or whatever this year and I just thought it's really quite sad, a sad exchange, but... maybe that's because I am out and about on my bike going to work and getting exercise and stuff, and I can see the wider world.

DM550326

b. *Feeling/not feeling safe.* PAs also said that many employers were extremely fearful of acquiring the virus:

I think some of them are overwhelmed by it, and I've encouraged them if they're able to and they want to watch the news, then they try and limit what they watch and how often they watch it, because a lot of my clients have the television on all day long because it's company for them, and so there's a regular, as I'm sure you know, the Coronavirus is on the television a lot of the time and some of them are overwhelmed and they don't always understand, and so I have asked them to limit how they view and keep themselves updated. I think in the main they're accepting the situation as it is, but I do think they're a little bit frightened by it too...

DM550285

... he was scaring himself, to be honest, he was sat there every day watching what the latest thing was and his Mum's telling him, don't watch it, just watch something else on YouTube, ignore it, and he was that worried constantly as soon as they ever mentioned that they had a case confirmed over here...

DM550294

Some employers had taken steps to minimise risk to themselves before the government decision to 'lock-down' by insisting that people coming in and out of their home should take precautions to protect them.

c. *Lack of understanding.* PAs working for people with dementia, learning disabilities, autism or brain injury said that their clients either had little comprehension of the magnitude of events that were unfolding, and/or could not retain information about this when told:

...because she's wondering why I'm not coming any more, every time we explain it to her, every time I explain about the social distancing she understands, but even in an hour or the next day, she needs to be explained again.

So she can't retain the information?

Yes. She understands, she accepts it in the moment, but it could be as little as in an hour and she asks why I'm not coming, and you keep explaining it over and over again.

DM550306

This reportedly created considerable challenges for PAs: for example, people with autism could not understand why they could not go out; some people with dementia became agitated when their PA approached wearing PPE, and people with acquired brain injury might lash out in frustration at being confined to keep them safe.

d. Disregard/fatalism. By contrast, a third category of attitudes toward the virus were people who disregarded it or took a fatalistic attitude towards the prospect of being infected:

... it was quite difficult because I had to get her to understand that according to the rules I had to leave and not be there, and she can be very aggressive, and she aggressively accused me of not wanting to go round, and I tried to explain to her that she needs to self-isolate and needs to keep the sink like this and this type of thing and gloves and... but as I say, she wouldn't listen to me, but she did listen to... when her son phoned up and I happened to be there and I could hear... this particular son, she listened to him. She listened to everything he was saying I'd already said, but although she wouldn't take it from me, she took it from him, she just listened to him, so took it from him.

DM550288

A few PAs had decided to withdraw their support completely because the behaviour of their employer put the PA, and therefore the PA's other clients, at risk:

One of my clients, I've had to change... it's been my choice to change the service that I give to him because he's refusing to follow guidance and he's actually going out more than he ever did before he was told not to go out.

Oh, dear.

So I had to withdraw my direct service from him and put in place telephone support. So we'll have the same amount of time, but only on the phone because I couldn't allow his actions to put me at risk and the people... my family and the people that I'm supporting who are doing all the right things.

DM550297

This group also included relatives of employers, and several PAs expressed concerns that their own scrupulousness in maintaining good hygiene was undermined by their behaviour:

I wear my mask and my apron, but the family goes in and does lunch and they don't wear any of it. So I suppose that's a sort of a double standard, even though they bought it all for all the carers. I suppose they don't do her personal care, but they are in very close contact with their Mum.

DM550307

(One employer's) partner is very blasé about the whole thing. Luckily he can't go to work, so he's building an extension on his house, which he was going to do anyway, but he does have the builders in, and I've said all along they're not allowed in the house, but I've got an idea that as soon as I'm gone they might be in the house.

There was no electricity the other day and obviously, someone had been in and turned it off that they could do something outside in the extension, and he's a guy who... I suppose on week three of shut down, had some friends round in the garden for a drink, and I didn't feel it was my place, but I felt I had to talk to him about it and ask him not to do that again while we're caring for his partner.

DM550314

I do personal care, so yes, I'm all geared up for it and masked up, but you're dealing with quite irrational individuals sometimes that might pull your mask off, so yeah, there's a vulnerability there, but what do you do; you can't go in a space suit.

DM550310

d. Health concerns of PAs. As well as evident concern for the welfare of their employers, PAs also expressed concerns about becoming infected themselves and were also acutely aware of unwittingly transmitting the virus to other employers, but also family members and friends. A small number of PAs had decided to self-isolate/shield themselves because they themselves suffered from a long-term health condition that put them at greater risk.

A decision to act to try to protect themselves and others from infection occasionally had bad consequences. One PA worked for an employer whose relative came back to the family home from a part of the world in which the pandemic was at its peak at that time. The PA felt that if she had continued to visit this family, her risk of contracting the disease was such that she would be unable to visit her other employer. This led to her immediate dismissal:

...the government hasn't said (then) that people coming back from (X) had to self-isolate, he didn't see why he should have to self-isolate and I said that I couldn't work without informing my other clients, that I would then give them the choice because obviously losing 44 percent of my work, sometimes I would be better off working for them at this time, this is how I was thinking at the time, I would be better off keeping that job and not seeing someone I was only doing for two or three hours a week, but I needed to give everybody the option first. So they... I wasn't the only care worker went in there, so I don't know what they're doing; they basically have not contacted me in any way since, and I worked for them for eight years.

DM55030

Another PA explained how she had narrowly avoided contracting the virus from one of her employers, who had previously been admitted to hospital suffering from sepsis:

...the day before he was going to come out of hospital she (employer's daughter) messaged me and said can you come back in, and I said, oh, yeah, that's fine; but it was playing on my mind, he's been in hospital, he's been in hospital, who's he been near, you know, with this Covid thing, and I was worried and I said to my husband, I really don't feel comfortable going in to him and he's just coming straight out of hospital, and my husband said, just say you can't come in then, until he's been at home and there's no symptoms or anything, and I said okay, so I messaged her and

said I'm really sorry but I'm not going to be able to come in, I'm going to give it seven days after he's been in hospital and she messaged me back and said, it's alright, my Dad's really poorly again. He come out on the Friday, this was the Saturday, and then that morning when I messaged her she said don't worry, my Dad's really, really ill again. I thought, oh, okay, so she said don't worry about coming in, we'll let you know, and he went back into hospital and he had Covid.

DM550320

Despite the risks, several PAs also said that they would be prepared to continue to provide care or support for their employer if they became infected, providing they had proper PPE.

e. Safety at work. Most PAs said that they felt safe, or safe enough, when working for their employer, and some employers reportedly went out their way to ensure that cleaning products were available:

...the lady who we support, her Mum said if we need any extra money, if we need to order things online, and our families know the job that we do; our friends know the job that we do. My Mum, she's also a PA and she had a neighbour drop off two bottles of hand wash on her doorstep, and said, take that into work; she really has been amazing, I can't fault her...I do feel like everybody's pulled together.

DM550296

However, many other PAs reported problems in obtaining hand sanitiser, anti-bacterial wipes and other household products; though some also felt that hot soapy water was an effective alternative. A very small number of PAs felt that the home of the person they were visiting was so unclean that everyday cleaning products were insufficient to make the environment safe for them:

...she's a hoarder, and you would be horrified if you walked into her accommodation, absolutely horrified. It's filthy dirty, she's even got mice, and I'm onto the council, I'm onto her social workers all the time. It's terrible that she's allowed to live like it, but there's not much I can do about that... One of my son in laws said to me I don't know whether you should be going to her with all this going on; I said, I'm not going to get Covid-19, I'm more likely to go down with the bubonic plague.

DM55029

Some PAs were highly resourceful in obtaining cleaning products:

...one of my friends who is now a PA...she got a massive, 50 litre thing of medical-grade sanitizer and what she's done is she's bought individual bottles from a well-known store online and we each have bought individual bottles from her to help pay for that chunk, because it was about £150 she had to pay for it.

DM550310

Sourcing PPE was difficult for some, but not all PAs, and those PAs affected were concerned at the cost of what was available. Self-employed PAs generally accepted that they were responsible for providing their own PPE, but it was not always clear to those who were directly employed whose responsibility it was to provide it.

Maintaining social distancing in an employer's home was not always possible:

Dad might be in the kitchen cooking tea for the rest of the family and I need to go in there to access meds or... I don't know, make a cup of tea, whatever, and it's a lot closer than six foot. It is almost impossible to do, but we try, we try as much as we can.

DM550313

f. Responses and opinions about flu vaccine. Though there is no vaccine available for the coronavirus at the present time, there are many who, for various reasons, may not have been given an annual flu vaccination, available to all UK citizens over 65, people with long term conditions that put them more at risk, and front-line health and social care staff. PAs were asked if they and their employer had received a flu vaccination.

Responses varied markedly. Most PAs said their employers had them routinely every year, citing reasons such as them being vulnerable or having other health conditions that made them susceptible to serious illness. Three said they were not sure as they had never really discussed this with their employer:

Yes, I do know that the lady that I support on a Tuesday, she has it, and I would imagine the other gentlemen that I support, they're quite... they're under the doctors for everything else, so it wouldn't surprise me that they don't have it as well. That's not a question I generally ask them because I see them probably... one for six hours on a Monday and one for another four hours on a Tuesday, it's not any longer than that, and because I'm not doing any personal complex care, it's not really anything that I've discussed with them in detail because... I suppose if you're doing more personal care with them, obviously I've got all my jabs up to date, which I have anyway, but I would know that information about them a little bit more maybe.

DM550JH2

Nine PAs said their employers had decided not to have a flu vaccination for different reasons; including a lack of belief in their value, and a preference for herbal remedies, suspicion of vaccinations and needle phobia:

Do you know if your clients/employers have all had flu vaccinations this year?

Yes. I think all the PAs that I know, and my clients because of their maybe immune systems or whatever, had the flu vaccine, all except one, and this is the [person] with learning disabilities because I believe [their] learning disability came from a vaccine; it gave [them] brain damage. And [their sibling], so what that means obviously is I think that the family are reluctant for jabs, but I don't know, I can't say for sure.

So they believe that the vaccine was responsible for the learning disability?

It was, because they had a pay-out.

Oh, right, okay.

It's many, many years ago. So I don't know what the vaccine was. So obviously there's an issue there, but otherwise I know all the staff I work with, we all have it done.

DM550310

Though there appears to be some evidence that vaccinations for some illnesses – not flu (particularly Pertussis, or whooping cough), it is also the case that people with learning disabilities are less likely than others to have a vaccination even if entitled to one.

Many PAs also appeared not to have received a vaccination. Reasons for this ranged from not being offered one, not feeling like they were in the vulnerable category or needed one, to being cautious, or even rejecting vaccination if a previous vaccination had made them unwell:

I did have a reaction once and I said, never again.

Okay. So it made you poorly?

I was poorly for two weeks and it's the only time in my life I've ever had two weeks off work sick.

DM550314

However, the most frequently reported reason was that they had simply just not 'got around to it'.

There were mixed reasons about eligibility; where one PA was offered one as a care worker, while another said that despite offering to pay for it, her local doctors had not been able to arrange it for her as care workers were not seen as eligible:

So I made an appointment to go to the doctor's because I was told because I was a carer I could get one, and then when I got there they wouldn't do it.

Did they tell you why?

[Doctor] just said I couldn't have it done because I wasn't... I think she said I wasn't a member of the family looking after the person, I was like a private carer and I should have to pay for it; I said, I'll pay for it then, I don't mind paying for it, but the family I worked for said, if you've got to pay for it we'll pay for it for you, and then when I got there she said, you can't have it done here anyway, you'd have to go somewhere else, and then I just never got it done.

DM550305

Government guidance on eligibility, however, seems clear:

Frontline health and social care workers are also eligible to receive the flu vaccine.

It's your employer's responsibility to arrange and pay for this vaccine.

<https://www.nhs.uk/conditions/vaccinations/who-should-have-flu-vaccine/>

[accessed 02.07.20]

Three PAs described themselves as not being the type who got ill often and therefore did not routinely prioritise taking the flu vaccine. One PA who did not feel particularly vulnerable compared themselves to older parents and did not feel they were at the stage of life:

I don't feel I'm a particular risk. I've never... I got poorly in January, coming back from [holiday destination], but other than that I've not had the flu. I've got a friend and she had the flu jab and she ended up in hospital with pneumonia and it put me off, but I don't feel that I need it at the moment. I just feel it should be for more... the vulnerable. My Mum's diabetic, I always make sure she has it; my Dad has COPD, I make sure he has it, I make sure my clients have it. I don't have it.

DM550296

g. Personal protective equipment (PPE). Most PAs said there was little support offered to them from the government or local authorities in helping them to obtain PPE. Some PAs took the lead in obtaining PPE, obtaining support from their employer and their employer's family. One or two had made significant preparations in advance:

...before any of this happened I was watching it from the outbreaks in China, and then watched America, watched all over, so I started collecting and thinking, what will we need and so it's been mainly down to me, it hasn't... but it was my idea and I gone and managed to get clear masks and hand sanitizer and put a care package together and handed that out well before the government started issuing things and said, this is there, this is a contingency, what do you think, and they've gone, yeah, yeah, that's great. I said right, so we know you've got anti-bacteria, you've got hand sanitizer, you've a box of gloves to start your off with, there's this, that and the other and basically dropped them off and said, keep them, just in case you need them for you, I've got stuff for me, but if you need to do anything or access any services, you've got the equipment because they might not have it. That was given out from me from the start.

DM550303

Though self-employed PAs generally saw it as their responsibility to provide PPE, for those who were directly employed, many PAs saw this as the responsibility of the employer. Some employers had been very efficient in providing necessary equipment and clothing and PAs felt that they had all that they needed:

...her daughter was very, very... I think because of her own ME, she was very hot on sort of the germ aspect of things.

So she's very hygienic?

Yes. It was... she changed hand washing, things that we hand washed with and she provided aprons, gloves, overshoes that she wanted us to wear, and masks.

DM550317

Others were not, and this meant PAs had to obtain their own supplies. Some PAs in this situation accepted the situation as it was and took it upon themselves to source PPE:

... to be honest, to perhaps expect people that perhaps have disabilities and things like that to be able to organise getting PPE isn't perhaps the best idea, especially some people might have learning disabilities and things and be supported with their family, but families are just ordinary people, and trying to source government supplies from an ordinary person when even the frontline staff haven't got enough supplies is obviously a major issue.

DM550295

However, it was also a source of resentment for others, since it was difficult to procure, and expensive (particularly given the low pay many PAs received):

I just make sure to wear my protective clothing, like, gloves and masks when necessary, and that's it. On the bus I do wear it, but when I get to the client's house I don't, I have to take it off.

So you don't wear protective clothing when you visit your client's house, but you do on the journey?

On the journey, and in the client's house I wear gloves and an apron, but for the masks, I don't wear the mask there.

Is that because she doesn't like the mask, or you prefer not to wear it?

I prefer not to wear it because I have to buy it. I buy two pairs of masks for £3.50.

That's expensive, isn't it?

By the time I wear it on the street, I have to throw that one when I get there....

And you have protective clothing; I think you mentioned that you've got gloves and mask and...

I have gloves, apron and masks, yeah. I think she needs to provide it, and when told her...

At them moment you're buying it yourself?

I told her I bought two face masks for £3.50, she said that's not fair, and yet still she's not providing it.

Okay, so she's not providing it and you're having to pay for it out of your own money?

Yeah, I buy it myself.

DM550321

Some PAs reported being given information about regional distribution centres where PPE was being made available, but self-employed PAs who knew about these centres were unable to access this because they had no CQC registration number:

When you actually do apply for the gloves you ring up the companies and they're like, oh we need your QC number, and we're like, I haven't got a QC number, we're self-employed. Oh, well, we can't give them to you then, because you're not a home or anything... we fall between (the cracks) because I'm self-employed and when I spoke to this girl on the phone she's like, have you got one, and I said no, I'm self-

employed, and she's like, oh, oh, right, how come you're ringing us then? I said because we've been given an email with all the numbers that we can ring to get gloves before we go onto the NHS ones, because they said you have to try all these avenues before you go onto the NHS, because obviously NHS need them for their hospitals, and she's like, oh, I'm sorry, I can't help you.

DM550320

I have no PPE. I have actually ordered online my own masks and glasses just in case to keep in my car, or whatever, but they haven't come yet, there's a three-week delay. I got in touch with the supply distribution service, run by the national supply distribution response team, I sent two emails and for about three weeks I had no reply, so I sent an email again and then I had a reply just saying... thank you for your email, my apologies you've not had a response, we are unable to provide PPE to personal assistants, I would recommend getting in contact with adult social care department with your local authority who may be able to provide you with PPE. That's all very well, but the local authority doesn't necessarily have PPE.

DM550295

Others were more successful but found that volume of supplies of PPE provided was grossly inadequate. There was also concern expressed that guidance on PPE during the early stages of the pandemic reflected the need to conserve limited supplies nationally, rather than scientific advice:

So do you think the guidance is wrong?

Yes.

Okay.

And I think it's that because they know that they wouldn't be able to supply... or we wouldn't be able to get supplies for everyone, would we?

DM550314

One or two PAs were also concerned that PPE might offer false reassurance and there were concerns about the quality of what was provided, with some reporting that masks were uncomfortable and sometimes disintegrated when worn:

...because we have to change masks every person that we see – that particular pack, the ear things kept snapping, which... it wasn't a big deal for me because I aren't showing any symptoms, but yeah, some of them aren't great either, and they hurt your ears.

DM550322

In the absence of properly organised supplies of PPE and long delays in securing items ordered online, some PAs drew on local contacts and informal networks:

Gloves and masks you have to buy; they're very difficult to get hold of. I've just ordered some cloth ones, somebody I know makes them and they're actually

washable, so I'm going to try these out as well because when you've got the one-time ones which you put on and then you've got to chuck them away, it's just a waste of money. I think they're about £40 for... when you get them online I think there's about twenty-something masks; it's ridiculous, £40. This woman who's making them, a friend of a friend who's a carer, and they're £4 each and they're patterned so they look alright as well and they're £4 each but I can wash them, so I'm not wasting money that I ain't got. I can actually put it on, take it off, wash – put it into a bag, take it home – wash it and put another one on.

DM550320

h. Testing and tracing. Most PAs felt that contact tracing and testing – at the time the interviews took place this was not generally available to PAs – would be extremely helpful in enabling them to protect themselves, and their employers/clients. However, many attached caveats to this because of the limitations of testing: false results, the long-term value of testing for live infection (because even if a test produced a negative result it would be possible for someone to become infected in the days that followed) and because it was unclear if antibodies (in an anti-body test) meant that someone had future immunity:

It depends on the test, really, doesn't it? Because you could be tested one day and not have it. It depends on which test we're talking about. The one that... there's two tests, isn't there; there's one that says that you've had it and so you're maybe immune, and the other one's you've got it, I believe.

DM550288

I don't know, talking about this. The thing is they say that it's, what, 14 days incubation, so if you were tested and it was negative on that particular day, it doesn't mean to say that it'll be negative a few days down the line, does it, really?

DM550290

Some PAs felt that to be effective tests needed to be re-done regularly, not as a 'one-off':

So if there was some sort of regular testing set up in the future, that would be a good idea, so that you could say, I have been symptomless for two weeks and I have a test every three weeks or something like that, then it's almost like a prophylactic sort of thing.

DM550295

Many PAs also felt that the government's response in organising testing had been very poorly organised. Some reported that they had been advised to make very long journeys (100 miles +) to get to a testing station.

There was also concern that because of government decisions to underfund public services over the previous decade, the infrastructure to support regular, and rigorously conducted testing had been compromised:

...testing would make all the difference, it would make a huge difference, but I think

they're going to have to reverse decades of cutting back on local amenities, local resources and so on if they're going to get testing done in GP surgeries, or town halls or whatever it might be. There's not the infrastructure anymore; it's been destroyed, it's been... it's all lacking. So I can't see how they're going to be able to do it, which is negative, I know, very pessimistic, but that would be the ideal, it would be wonderful if you could go down to your doctor's surgery having made an appointment and be tested on the spot. That would be perfect; then at least you would know, before you showed signs or symptoms, whether you were asymptomatic or perfectly alright or had the virus. That would be ideal, but they have been so intent on chopping everything that worked in the past. It's a bit like saying, before Beecham's cuts to the railways, you could get from village A to village B, and now, how do you? Well, you can't; unless you have a car. And the analogy really holds because we just don't have the facilities anymore.

DM550JH1

i. Specialist training. Part of a Direct Payment made to direct employers is intended to pay for training, but it is not ring-fenced. In some areas, self-employed PAs can attend training courses arranged by organisations that offer support to employers and PAs.

Most of the PAs who took part in this study said they had not received any formal training that would have been directly useful in enabling them to respond to the changes in their role required because of the virus:

No, I haven't had any training. He's (employer) sent out bits on... we've got a WhatsApp group for covering staff and for giving out information, so when bits of information that are science-based have come out, he's posted it up there, so... like how to disinfect your phone was a biggie for him, but things about the length of time and how to hand wash correctly. I know all this already, but that's gone out on there just to... it kind of becomes a thing that you know your employer's expecting that of you and you know you're being observed to do that, basically it just becomes the norm, doesn't it? The length of time the virus lasts on different surfaces, that kind of information, yeah, that's what we've put out, or he's put out, and nothing much else. I'm not exactly a nurse, but I have done stuff before, so I am health trained.

DM550326

Training, where provided, was organised by a few employers, and information provided from some third sector organisations was praised by PAs who had received and used it:

Yes., we've all had to complete a Covid-19 test, so we had a booklet going over laundry issues as well, the stuff we've done already with our yearly courses, but this has extra things about hand-washing, the areas that are often missed out and about the Covid virus, and we all had to do it, fill in our answers and hand it in to our manager.

Presumably this is something that Support with Confidence organised.

No, that's the individual setting.

...But the Support with Confidence, like I say, every day they have sent guidelines, charts, flow charts, information, it's been absolutely fantastic, the emails from Support with Confidence Eastbourne, the East Sussex County Council, amazing. Anything I want, they just say, look, any problems, call this number. It's brilliant, absolutely brilliant.

DM550310

Information was available online which informed changes to working practices for some PAs. Some of this came in the form of regular bulletins from local authorities, or third sector organisations and visits to government and NHS websites.

No, it's just... we've got the link for the NHS website. Most of the stuff... I don't think I've ever had formal training as a carer, it is just pick it up as you go, kind of thing, as long as your client's happy or your customer, whatever, as long as they're happy you just carry on. With the Covid-19, it's just a case of reading what I'm allowed to do and what I'm not supposed to do, but I also sign up to the emails, so when they're releasing the updated procedures and stuff, I'm having a little scan through that when I'm eating my breakfast or whatever, checking that I'm up to date... it's from the gov.uk, you can just sign up to... everybody can... you can just sign up to the updates, so every time they update the Covid-19 Act or if they update a policy or guidance, mainly guidance, when they update it, it gives you in the care settings, home care settings, it gives you the information that they've got, which is stuff like double-bagging; it's obviously better than just putting it in with the normal waste, but that, I suppose, is just self-taught, there's nobody to tell you any different, the clients don't know any different, so you're just guessing.

DM550315

Some local authority bulletins were criticised for being too long and taking up too much time to read.

In one or two areas, PAs had formed closed social media groups using WhatsApp apps or similar, to share information about the virus, updates on government guidance and on where to obtain PPE and to get tested. However, two PAs raised concerns that track and tracing apps then being developed for mobile phones could erode privacy and civil liberties and seemed less inclined to accept such initiatives.

6. Information and support for PAs

A striking trend in all participant transcripts was the initiative they had all taken to acquire information and advice during the pandemic for themselves. Even though a high proportion of them were looking after vulnerable clients, the precautions PAs undertook against spreading infections to the clients or carrying infections home with them were purely self-driven, self-motivated and self-initiated. They had received very little and mainly no information, training, support or advice coming to them as self-employed care workers.

a. Sources of information and support. There was no central or formal arrangement from where all PAs regularly received information, or indeed felt they had access to it. Many reported finding their own sources of information and needing to decide for themselves which sources were more factual or credible than others. Most referred to BBC updates, daily government briefings and updates, and the news as sources of information. As government guidance seemed to be constantly changing, the need to be keep updated was also seen as important. Most participants sought this out on their own initiative and responsibility:

So every day I look at www.gov.uk and update myself, every day.

Because the guidance is changing, isn't it?

Yeah, so just to make sure that I'm up to date with everything, I check it every day before I go out.

DM550285

The high emotions and anxiety provoked by news reports were also raised. Some PAs felt that watching news briefings from the government were distressing and provoked anxiety with rising numbers of deaths being reported daily, and therefore some avoided these:

Where are you getting information about the Coronavirus from at the moment?

I have decided to minimise my social media, television, radio and I mainly look at gov.uk because that is going to be factual, that is giving me the right information and up-to-date information and I think that's the best source for me. I do watch the news, but I'm limiting to once a day because I get overwhelmed with it and I get very emotional.

DM550285

A small minority of participants said they got updates on a regular basis from their Local Authorities (two such examples were East Sussex County Council). These updates had been sent daily by email at the start of the pandemic, but had subsequently gone down to twice a week. Those who received them said they found this invaluable, as they also offered advice and support for things they may need, such as PPE, or more information about protocols:

... but certainly East Sussex County Council and their team, I just feel... because as a PA you're very solitary, you make your own decisions, you haven't got a boss, you don't answer to anybody really, except yourself, and so at times like this you want to

say, help, you know, where do I get that glove, or what's the protocol for this, and you've got this little invisible body, if I want to pick up the phone, I can phone them, but it's there and that's a valuable resource and they've really stepped up to the mark, so I feel fully supported, if I need it.

DM550310

In two other areas, local organisations had also been supportive with sending out regular information (e.g. Support with Confidence in East Sussex and Oxfordshire Association of Care Providers):

We haven't had training as such, but yeah, all the information; we get emails every day from OACP, updating us about different things, about testing and everything like that, yeah, we get so much information.

Sorry, what was the organisation? You mentioned...

Oh, OACP, it's part of the PA group that... if I can find it, hold on; it is Oxfordshire Association of Care Providers, and they've emailed me nearly every day. This one was Monday's and it gives you an update of what's going on, where to get your PPE, testing centres, it's giving you the 24/7 mental health helpline; so much information.

So is it useful?

Yes.

Good.

Definitely useful, because we didn't know that we could get PPE from the day centre down the road; we thought we was going to have to go out and buy it, but we found that out off of there. They're saying about testing and they'll keep us... yeah, it's really helpful. It's quite long, but it's definitely worth... and it's all bullet-pointed as well, so you can pick up the bits that you need to read.

DM550296

One PA had signed up to email alerts from the government website for updates and changes in guidance, so they would have ready access to new information:

it's from the gov.uk, you can just sign up to... everybody can... you can just sign up to the updates, so every time they update the Covid-19 Act or if they update a policy or guidance, mainly guidance, when they update it, it gives you in the care settings, home care settings, it gives you the information that they've got, which is stuff like double-bagging; it's obviously better than just putting it in with the normal waste, but that, I suppose, is just self-taught, there's nobody to tell you any different, the clients don't know any different, so you're just guessing.

DM550315

b. Digestibility and trustworthiness of information. Not everyone found the format of the daily updates from Local Authorities in the form of long emails appealing or accessible. For instance, one participant said that they struggled to find the time to sift through long emails for details that were relevant to them. Instead, it was quicker to read a text from a colleague who had read the email and passed on relevant content:

You know, I started reading them at the beginning because I think you're more scared at the beginning than we are now, even though it's serious now, but I kind of find things out from colleagues rather than there because someone might sit and read it one night and said... I found out today that I didn't have to pay for parking in my area in town if I put my badge on the dashboard, I didn't have to pay for parking, but apparently it's in one of these long emails; I wouldn't have known that unless my colleague told me.

DM550314

Whether or not a source was trustworthy was also discussed in the context of where information was obtained. There was awareness of fake news and misinformation circulating, and that individuals needed to be responsible in accessing reliable information for themselves. Over half of all participants disparaged social media as incredibly unreliable, subjective and sensationalist. Two participants specifically highlighted newspapers that sensationalised headlines as sources of information to avoid.

Many felt government reports and briefings could be counted upon. However, one participant revealed that they took government briefings with a pinch of salt too, after having watched a Panorama programme that described some of the early decisions taken by the government with regards to PPE and deaths in care homes:

After watching Panorama the other night when it was about a company that's desperate to supply England with PPE, and they're having no reply from the government, so it's gone to America. That was on Panorama. ... Well, I'm concerned now as well with the deaths in care homes. That hasn't been very up-front, I don't think.

DM550314

c. Specific advice. There appeared no or limited sources where advice could be sought for specific challenges or queries. One participant said they thought there was a "Covid-19 advice line" but they did not know the telephone number, but felt they could find it if they needed to. Three participants said they would rely on their own social networks of friends, family who worked in a relevant health or social care sector and whose advice and opinion they generally trusted:

I'd phone my friend, X, who's a scientist and I asked them if there was any sense in ordering a litre of disinfectant, the hand wash stuff and they said, no, just use soap, ordinary soap, so that's what I did. So when everybody else was spending a fortune in Tesco's I bought the cheapest soap possible and I still trust that that was the right advice.

DM550312

The reliance on social networks also extended to existing informal networks of PA colleagues:

We had a lot of emails and videos and we're sending each other links, government links to inform each other on a daily basis and there was a lot of information that would touch on internet reading, all different information, sending straightaway. We have a WhatsApp group which we use to contact each other, or any messages are directly sent to everyone and we can check it on a regular basis. So yes, we do try to keep each other informed. Anything that comes up, we try to inform each other anything related to Covid.

DM550302

d. Specialist training. No specific Covid-19 training was offered to any of the participants interviewed. Most participants were trained (often from previous work) and confident in infection control procedures, but nothing specifically related to Covid-19 had been discussed or offered.

Not any particular training, apart from... which was... no, I'm not aware of any training, apart from the obvious infection, which you would have anyway, I've had that training.

So basic training.

Yes, the basic training, not actually for Covid, but all infection control.

DM550306

Most used their own learning and information-seeking to guide them with regards to what was the best thing to do in looking after their clients. One PA mentioned that their employer's daughter had been forthcoming with wanting to encourage the PA to access any specific training, but they had not been able to find anything. The daughter therefore did her own research about what was necessary, and worked with the PA regarding what would be appropriate guidelines going forward in keeping with Covid-19 restrictions:

The elderly lady's daughter, she was on the internet looking at things and she was very hot on it and talked to me about it quite a lot, and asked me as well if there was anything I would want, anything I could think of that would help, and things like that.

DM550317

7. The role of 'brokerage' agencies

a. Different models of support. Though some PAs worked completely independently, others – both people who were self-employed and others who were directly employed by a person or their family – used third sector organisations; typically, Independent Living Centres or other user-led organisations to find employers. These brokerage organisations enabled employers to describe their needs and the skills of the PA they were hoping to recruit, and PAs could contact the employer, via the brokerage agency, if they were interested in applying for a position.

Our previous study (Woolham et al., 2019) found that though these organisations were usually funded only to support employers and not PAs, some did offer 'pro-bono' guidance if PAs encountered difficulties in their working relationship with their employer.

In the present study, equivalent levels of support seemed to be offered by some of these organisations, which offered advice to PAs about how to keep themselves and their employers safe. Importantly, too, many were able to offer practical assistance with the furloughing process – advising on whether PAs were likely to qualify, but also organising the process of obtaining furlough monies available from the government. This was possible where Direct Payments were paid to the brokerage organisation by the local authority from which employers drew down. Though this may have compromised the direct employment relationship, it made organising payroll easier, paid for insurance, did not appear to affect the control employers had over their PA, and it mitigated the financial problems some PAs may otherwise have faced.

So presumably, your pay is being affected by Coronavirus.

Yes, it's 80 percent...So you get... you know the government have decided that you can have 80 percent of your earnings...My boss had to apply for that, my employer. Because I work for the Derbyshire Centre for Independent Living, they get a budget, don't they, and so it has to be done through them. They have to do it with the people that provide the wages, I can't think what they're called, I can't remember the name of them, but that's where the wages come from, anyway.

Right. Are you actually employed by an independent living centre, or are you self-employed?

Yes, it's... no, it's not self-employment. What it is, is Derbyshire Centre for Independent Living, which is under Derbyshire County Council, they pay a budget...That budget then goes into their bank account or into wherever and then what they do is, what my particular employers do anyway, is they recruit a proper person that does wages, I don't know what they're called, I can't remember now...
Payroll.

... and what they do is they draw down from that budget and they pay me. So then the parents of the children have to get liability insurance and that all comes out of the budget, you see?

DM550289

This may have been a different arrangement to those described in the earlier study and locally determined: we did not collect detailed information on this but it would be interesting to compare local practices.

In other local authorities, Direct Payments were made directly to the employer to enable them to continue to pay their PA if they decided to 'shield'. One PA noted that though most of her employers complied with this arrangement, one was less willing to continue to pay because they were also making a contribution to the cost of the PA though an 'assessed contribution' (in accordance with the means tested element of adult social care):

Well, I do have a client that was a bit iffy because they have to contribute to their care, so they have to pay money out of their own pocket, and I was like, okay, I completely understand if you decide not to... there's going to be no hard feelings when it's all over, I'm not going to decide not to work for you, because at the end of the day they shouldn't be paying money out for literally nothing.

DM550301

b. Decline in the level of support available. Support from brokerage agencies and other local organisation was not universal, and one PA had experienced a decline over time:

I also was a PA years and years ago, and then, hate to harp on about the olden days, but when I was a PA before, I was in a really supportive network of other PAs and social services and stuff, who really looked out for us as well. They were doing it for a number of reasons, obviously, to safeguard the individual we're working with, etc., etc., but it became quite a powerful support network, or at least that's how it felt as a PA. So I'm really crucially aware, and in some ways I quite like it, that I'm absolutely alone in this role at the moment. So if there's one thing that could potentially change, then that would be to be at least supported by somebody in the role, not just your employer, who I happen to get on with very well, but just the feeling of a network of some description that's to do with that role.

DM550326

8. Relationships with other organisations

Interviews also explored PA experiences and opinions of neighbourhood help schemes, access to sheltered housing and care homes.

a. Neighbourhood help schemes. One consequence of the pandemic has been the proliferation of local 'good neighbour' schemes in different parts of England, encouraged by the government as a way to prevent the groups of people most at risk of the virus from going without basic provisions. Participants were asked about whether their employers had signed up to local neighbourhood help schemes, such as Covid Mutual Aid groups, and what their opinions of these were.

A small proportion of participants said they were not aware these groups existed. Most participants had heard of these groups; only two had employers who had used one of their local schemes as a source of support for shopping and medication. More relied instead on family networks to support them with shopping and other essentials they may need, and another said they would turn instead to a local charity that had been helpful in the past.

Many PAs felt that safeguarding was a concern. They expressed a need for caution about letting a stranger go into the home of their employer, and to hand over bank details or cash for any shopping to be done. This concern stemmed from a lack of monitoring of Disclosure and Barring Service (DBS) protections and checks among volunteers. Even though there is no requirement for PAs to be checked by the DBS, many PAs felt this was very important:

Yes. We've got quite a stringent DBS check, don't we, to go into someone's house or even to get medication I have to show ID sometimes and I did think a random guy turning up on a bicycle with someone's medication, is anyone checking up it's been delivered if someone's got dementia, or... I know it's... everyone's saying it's hard times and we've got to relax things a bit, but there is a bit of a worry, isn't there?

DM550314

Another PA referred to a volunteer team to which she belonged, but which did insist on checks:

I've always belonged to a neighbourhood care group, it's a voluntary job that I do, but we are all vetted with CRB (the former term for DBS) and I know that that is really important. So even one person amongst many slipping through the net like that could be a potential problem for people. So all of these people who haven't volunteered, they haven't been CRB checked, as far as I know, and obviously that could lead to problems.

DM550318

Some PAs went to some trouble to set up online shopping for their employer to ensure they did not need to rely on these local networks:

No, and they wouldn't do and that's the reason why I've gone to the extremes of talking them through shopping online, getting them to a place where they can shop online and shopping locally because they've got a local shop which they use all the time, which I encourage them to use, and the staff know them and know their situation and they're accommodating, so therefore they would not use anyone they do not know.

DM550289

However, some PAs also expressed concern about the greater potential for frauds and scams to occur though a move to online banking. One of these participants felt her clients were "savvy" for the most part, but she was unsure whether they would necessarily spot a subtle scam straightaway:

The only thing that worries me at the moment with some of them are on the internet is some of these scams and things that are coming up. There was a scam about buying self-testing things, you put your details in and they take your money and extra money and all that sort of thing, and they're not even real tests, so some of those things which are topical in today's situation, I just think, I'm not sure they would always spot things.

DM550292

Some PAs weighed the risks of using 'pop-up' neighbourhood organizations with their potential benefits. This was particularly so in smaller rural communities where people were much more likely to know one another:

...our volunteer group, I think... you can only vet as far as you can, can't you, and it's run through Facebook, so anybody can have access to it. I don't know, I would just like to think maybe the majority are doing it for the right reasons, but there are always going to be those... I don't quite know how you would safeguard against that happening.

I guess in a village situation people are much more likely to know...

Yeah, we know each other, exactly, and word would get out, I think, if there was any issues, but in a larger setting I really don't know how that would work.

DM55029

b. Access to sheltered housing and care homes. There were varied responses to the question regarding whether participants had access to employers living in sheltered accommodation, and what might happen were the sheltered scheme to go into lock-down due to an infection.

Five PAs had employers currently living in sheltered accommodation, four of whom had not faced any problems, so far, in relation to access. One PA said access to their employer had been easy because they had care worker status:

I've actually got a case; it's the building, [name of housing scheme], for independent living, so they don't have carers (care workers) on board but they're looked after

quite well food-wise and there's a manager there. They're on what you'd probably class as lock-down, there's no family allowed to visit and deliveries left at the door, but there was no questions asked about myself going in.

DM550314

There was a widely held view among PAs that should a sheltered housing or care home go into lock-down, they would have to consider whether to move in with a specific employer: something that some PAs said might be challenging:

If [the sheltered home] goes into lock-down, I think it would be very difficult because, if X showed symptoms she'd understand why you were there, you're there for a reason, but if [sheltered housing scheme] went into lock-down just because, it would be quite hard on our staff, having to stay there that long when you've got the whole day and you cannot get outside; the closest you can get outside to is opening a window so far, and you're with somebody who is non-verbal.

DM550296

Another PA was also part of a team of PAs providing 24 hour care to an employer living in sheltered accommodation. They had already discussed how they would work it out within the PA team if lock-down occurred:

We have spoken about this, if this lady is locked down, what we said was what we were going to do was whoever... if she had it, at that point whoever was with her would stay and we would lock those people down and then, depending how long it took we would then pay each other back for the time. So that's the way we worked it.

DM550298

One participant said they had contacted a scheme manager on behalf of their employer and having explained the situation to them, was allowed to continue to visit:

I phoned the manager of the sheltered housing to see what policies they had in place and asked whether I was allowed to go on site, so I... yes, I've had that contact with him.

So the sheltered housing person, they've also locked you out, as it were, for the time being?

No, no, I explained the circumstances and they're quite happy if I was only going to that one person on site, then that was fine.

DM550308

Another PA, however, was concerned that they might struggle to gain access if they had no ID to prove they were a care worker. This was an issue that also concerned them in relation to needing to shop on behalf of their employer at a certain time or if they were stopped by police and asked why they were not at home:

I can see how it would be difficult because obviously the thing is we don't have ID. It's things like, I was thinking this the other day, it's like, we go out, and let's say we're PAs and let's say the police, because they do a lot of patrols round this area at the minute, and I get, where you going? Work. Prove it. I can't, whereas somebody else going and they ask somebody for example, that have NHS ID, that's where I'm going, and we've got no way of doing that, especially in a PA role with no uniform, no nothing, just turn up in our regular every day whatever you want to wear clothes, and I can see it getting difficult getting stopped by the police. Let's say I go shopping, I was saying earlier on, I'm going to work now but not dressed for work, haven't got any ID, and I can see how problems would develop, yeah.

DM550294

Concern was also expressed that the closeness of the relationship between PA and employer might lead others to mistake the nature of their role:

I think we're almost seen as friends, I suppose, we're not seen as professionals. So yeah, I think you're probably right; somebody going in with a uniform with... I don't carry a card that says what job I do or... so I don't feel like a professional, therefore if I don't feel like a professional I'm not going to be treated like a professional.

DM550316

A small number of PAs supported employers who were living in a care home (and were paid for privately), but because the nature of their role was focused on activity, stimulation and companionship, they had been seen as non-essential and had been locked out:

... at home I used to support them with personal care, they've now got carers (care workers) doing that, but I support them just with activity and companionship and stimulation, help them to eat. So those kinds of things, those things, other than the help to eat will have gone, because these are things they just don't have time to do in care homes, even in ordinary situations, that kind of one-to-one intense support that I was offering for two and three hours at a time; everything else, the care staff will do.

DM550297

9. Future status of PAs and care workers

There was a wide spectrum of response to a question about whether PAs felt that the coronavirus might lead to permanent changes in the esteem with which health and care workers were held by the general public. Some were hopeful that the positive attitudes demonstrated by society during the pandemic would be sustained long after it had gone; whereas others were more sanguine, and believed that memories were short-lived and care workers' sacrifices and contributions would soon be forgotten. Most PAs were ambivalent about the prospect of change in societal attitudes being long-lasting.

There was a strong sense that despite PAs and care workers sometimes being seen by society as potential 'virus spreaders', the pandemic had shone a light on the great contribution, and sacrifices, health and care workers had made. This made some PAs hopeful that they might be 'as a bit more of a priority in future' as one PA put it. Another described the two opinions succinctly using examples they had read about in local newspapers:

I think it splits the camp. I think the majority of people think we're amazing, like I do with the NHS. I get quite emotional just looking at these nurses and doctors putting their lives on the line, and that's like I said to you, I felt guilty not going in to work. In terms of how people view me, I think some people are going to think, great, well done you, I couldn't do it. A lot of people say that anyway; I couldn't do your job, which I think is ridiculous because most people have been a parent or an aunt or a sister, and I think all you're doing is you're providing... you become family for these people, so I think it's ridiculous; we can all do this job. And so I think there's going to be an awful lot of respect for those that put themselves out there. Then you've got this tiny minority that see us as disease spreaders. Now, I haven't had that myself, but I know there have been local stories of people being spat at or having their tyres slashed or whatever, and you just think that's got to be somebody that's got a very low IQ or you have to think positively that they don't understand the situation. Or do they really believe that?

Do you actually know anybody that's been treated like that?

Not personally, no, but I've read lots of stories, little news feeds about it, because I do like to see how things are going with support workers and care. So yeah, you've got that. I think, I hope that the majority of society are going to think; good on you, and be proud of what we all provide; I still don't think I do enough. I'm not a nurse, but I am providing my form of care to my ability, and I just hope that people would see that as a real positive and see you as a good person, but I'm not sure everyone will. Some people don't want to come near you just in case you've got something. It's like being a leper, isn't it?

DM55030

Most PAs spoke of their contributions now being recognised as society finally saw their job roles of keeping people independent and looking after vulnerable people as valuable:

I think because they're probably seen more as like this army of people that can keep people out of care homes and stuff, and help people to stay independent in their homes, I think it'll probably be the former, to be honest, but yeah, it's always hard to know how things will go. I think people forget things very quickly; today's news is very often just dead in no time.

DM550288

Pessimism was also evident among PAs. Many felt that society's memories were short-lived and although care workers were being valued during the pandemic, they still struggled to obtain basic PPE to keep safe while they did their work:

No, I think we'll be cast by the wayside as soon as it's done. It's kind of put a value, how people value us, into perspective, really. I know they're doing clap for carers and all that lot, but we are actually the unsung carers, because we're in people's homes and I'm not wanting to be taking away from the nurses, gosh, what they're doing is unbelievable, but we're doing our bit as well. And I'm not saying I want people to clap for us, I don't mean it that way, but we need looking after, we need the proper PPE, it's the PPE more than anything, but so do the nurses, don't they, so do the doctors.

DM550313

Most PAs were ambivalent, and phrases such as 'I hope so', 'who knows', 'I'd like to think so', commonly stated. Many hoped that the current esteem with which health and care workers were held would last, but were not sure it would, and if it did, for how long:

I'm hoping they'll appreciate them more. I think before, people working in old people's homes and things like that, they weren't considered a key worker, were they? But now all of a sudden, because everyone needs them, the people appreciating them more...

Do you think that will last, once the virus is over?

I don't know. I hope so. I hope they get valued more for the work they do. I don't think a lot of people realise what it takes to be a carer. A lot of them think it's an easy job and it's easy money and everything, but it's not.

DM550305

Some PAs reflected that the contributions of care workers had been overlooked with the overwhelming support that had been shown to the NHS and healthcare frontline workers. As described earlier in the report, one PA described their experiences of their care status not being recognised when they went shopping during times allocated to 'NHS staff and keyworkers', and one having to produce separate, seemingly NHS ID to be allowed in:

Yeah, I think so. I think this clapping at eight o'clock, I feel that it has its positive and it has its negative impact as well. I think it is very much focused on the NHS, which I think is a shame because there's a lot of us that don't work for the NHS. We might work for councils or we might be self-employed or work in the private sector, and I feel like all these things around shopping and things, getting priority in the queue and things I think it's very directed at the NHS, and that's great, the NHS are doing a great job, but there's a lot of us in other services that are doing just as much an important job, if that makes sense.

DM550304

Many PAs used their incomes and pay as an indicator of whether their role was and would be valued by society:

Well, I think the standard of living, that's the wrong the word, but... goes up every year, but when people are on PIP (disability benefit), that doesn't go up by the same percentage as your... what do you call it, your living... the percentage...?

The cost of living increase?

... the cost of living increase, their personal... I think some of them have never gone up since their first time, so there's no way that we can ever ask for any more money without either them dropping hours or... so we're in a bit of a catch 22, so I don't think after this Covid thing that they're suddenly going... well, increase all their personal budgets. If they were linked to the living wage, or whatever, going up, things went up every year, it would be fine, but I think... yeah, so working conditions and money and things are not... I've done this for eight years now and I've put very, very little increase in any of my wages from when first started to now.

DM550307

One PA compared their role and pay to traditionally more well-paid jobs such as bankers and used it as a gauge to reflect on what was valued by society:

...we're the ones that are taking care of people that are vulnerable, day in, day out. One would hope that people realise that actually bankers don't need to be paid – and celebrities – all that money; it should be going to... but you know, we can't change the world, can we?

DM550301

Underlying all of the responses was a general sense of it being difficult to predict what the future would look like with future waves of the pandemic, and a potentially shrinking economy after lock-down had been eased, with several PAs remarking that it was a 'wait and see' situation:

I think it will, possibly, to the public, but I'm not so sure about people who employ them, especially when there's economics, money involved. It may stay the same, but maybe it might force things to change, so getting a more positive job structure for

PAs. I'm not being flippant, but I guess it's just one of those things we're going to have to wait and see, really. It could take time, but I hope that it does bring something positive so far as for the workers and the workforce.

DM550309

Discussion

This study is the first to address the impact of the Covid-19 pandemic on the work of social care Personal Assistants supporting people in need of care and support. Drawing from a sample of 105 PAs, we were able to interview 41. This may reflect the turnover of PAs; likely to be high during this present period but also reflecting high turnover rates in social care more generally. There will be interest in seeing if social care recruitment improves in the current context but attention is also needed to retention.

Our sample of interview participants reflected what is generally known about PAs in that they are predominantly female, middle aged and work part-time. As our data suggest this suggests the PA workforce generally works locally and is likely to have family responsibilities for children and young people as well as other relatives. These had their implications for the present period; notably that many PAs were not the main or sole income source for their household. However, despite working part-time, many do have more than one employer and their hours of employment are not substantial. Living locally, many undertook tasks such as shopping in areas with which they are familiar; not all had their own transport or use of family transport.

The finding that PAs felt overlooked in relation to access to PPE was not unexpected but the impacts of this are clearly articulated in this report. PAs realised that their lack of access could affect their employers and that it could put others at risk too, including their own families. The data show that apart from a very small number who happened to live in areas where the local authority was funding an agency to support PAs and their employers, PAs were not known to local authorities who therefore did not include them in communications or acknowledgement. This did not only apply to PPE but affected their ability to 'prove' their care work status. For possible localised situations of lock-down this may be relevant to PAs in certain areas. Being and being known as a 'key worker' could be an aspiration for this part of the care workforce. It would be possible to devise systems to address this in our view.

PAs have the right to be treated as other employees: they are not a different type of worker despite working in people's homes and providing care and support. As with other employees they are protected in law from summary dismissal but this data show how their lack of proper contracts and enforcement of employment rights are not routine and PAs do not regard themselves as potential litigants. In other workforce debates they would be regarded as taking on the risks of their work and the gendered nature of this work would be seen as highly relevant. Our previous report pointed to this as an area of deep inequalities and Covid-19 has amplified this situation. There would appear room to address this subject as part of the social recovery from Covid-19.

We found that few sources of local information were used; rather that PAs, like the rest of the population were keeping up to date through the mainstream media. There is clearly room to explore LAs' role in providing local information to supplement national information in rapidly changing times. But if LAs do not know who has a PA or is the PA then they

cannot provide information or signpost PAs to it. LAs who fund care plans that include provision for a PA and then monitor the care plan are in a prime position to access the PA's details.

More broadly there was some lack of trust by some PAs in 'official' information, but no evidence of 'fake' information being used or accepted as credible. There may be room to build on this finding when talking of the possibility of extending vaccines to PAs, for Covid-19 or otherwise. However, while we do not have substantial data in respect of health beliefs or medical consumerism among PAs, these are important topics for health and safety, infection control and relationship-focused care. The lack of PA training which is specific to their roles remains a telling gap.

Our study has its limits; none of those interviewed was being paid from a Personal Health Budget or Continuing Health Care. This misses a very small section of the PA workforce that is under, theoretically, the auspices of community-based health professionals. We noted that PAs in the previous study were interested in doing this work (Norrie et al., 2019). This may suggest that they have a rightful place in the 'recovery' of individuals, such as rebuilding confidence and accessing the community, and could be better engaged in care co-ordination. The strength of our study lies in its contemporaneous data collection and the wide spread of participants from across England. Our sample and the previous sample (in case some had returned to PA work) would also be a possible source of data in the months ahead to see how the 'new normal' or post Covid-19 situation was affecting their work and lives.

At the end of this report it is important that we thank those who participated in this research. Our interviews took place at anxious times and we are grateful to participants for their time and trouble, we hope this report reflects their feelings and experiences fairly.

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Appendix 1. Demographic profile of PAs

	No.	%
White	34	83
Multiple/dual heritage	3	7
Asian	2	5
Black	1	2
Total	41	100

1. Ethnic background

	Yrs.
Minimum	21
Maximum	71
Mean	48.5

2. Age

	No.	%
Male	2	5
Female	39	95
Total	41	100

3. Gender

	No.	%
Yes	19	49
No	20	51
Total	39	100
Missing	2	
	41	

4. Caring for member of own family

	No.	%
Yes	15	49
No	20	51
Total	39	100
Missing	2	
	41	

5. Caring for children/ students in own family

	No.	%
British	38	93
Polish	1	2
Hungarian	1	2
Jamaican	1	2
Total	41	100

6. Nationality

Appendix 2. Questionnaire used in this study

Follow up interviews with PAs: the impact of Coronavirus on working as a social care Personal Assistant

These questions are designed to find out about the impact of Coronavirus at the present time on the way you work with your employers - or those who hire you if you are self-employed, and whether it has had any impact on your life.

1. Is the Coronavirus affecting your work?

(e.g., more hours, you would leave etc. to protect other people you work for/family, they went to hospital, etc. If this has happened – how and when were you told/did you suspect? Any new demands? Do you still do things that you'd now prefer not to do - because of health concerns - anyway? If so why? – What's new etc., are families more or less in contact than before? What's the story?)

2. Is your pay being affected by the Coronavirus?

(Have you asked for more money or some other financial arrangement as a result of the risks you may run of getting Coronavirus e.g., pay rise, sick pay, guaranteed income, agreement to work for only one employer)

3. Do your clients know who to contact at the council or CCG if they need more support due to being ill with the Coronavirus and how soon can they pass on that money to you?

4. Have you taken out any insurance about sickness etc., or did you have it already?

5. Do you have children and if so, are they allowed to attend school?

(Is that due to you being allocated key worker status?)

6. Are you currently self-isolating?

(In what circumstances e.g. pregnancy, family member symptomatic, long standing health problems, age personal choice?)

-
7. If you are/were or were to be self-isolating, to look after yourself or your children, or care for a family member:
- a. Do you have a source of income?
(e.g., sick pay or insurance, benefits? If not, how are you managing?)
 - b. What impact would it have on your family?
(e.g., are you the sole breadwinner, are any family members vulnerable to the virus because of health problems or age?)
 - c. What would happen to anyone who employs you if you aren't able to visit them to provide care or support: does your employer have a contingency plan of any kind?
 - d. If you were unable to work because of this virus, would you go back to PA work, and your same employers *(or would they make other arrangements?)*
 - e. Do you know anyone at the local council or GP who you would tell if you were no longer able to do your job? Would that be something you would like to have?
 - f. Are there any arrangements in place so you could tell others (like your local council, GP, Disabled Living Centre etc.,) if you couldn't work, so they could arrange care or support for your employer?

Doing your job

8. What are the main changes that you or your employer(s) have had to make in response to the coronavirus?
9. If you help your employer with shopping, are there any problems with obtaining any items?
(e.g., such as hand sanitiser or toilet rolls?)
- a. Do you have to spend a long time queueing?
 - b. Have you had any problems in obtaining basic food items?
 - c. How much additional pressure does this put on you?
 - d. Have you helped your employer do this online?
 - e. Does your employer make use of any volunteer/good neighbour local schemes?
10. Have there been any problems with medications/aids and equipment (e.g. pads) or with talking with NHS professionals?
-

-
11. Social gathering spaces that you may have taken your employer to – day centres, coffee mornings, cafes, etc., are closing because of the virus. Is this having an impact on you, and those who employ/hire you? *(e.g., employers more reliant on you for company?)*
 12. Are you and your employer 'on the same page' regarding health guidance around the coronavirus?

Personal Health Budgets

13. Are any of your employers funded by PHBs and does this change anything in relation to dealing with Coronavirus?
14. Not just for PHB - Are there medical-related tasks you would like to carry out for your employer that you cannot do but would like to?
15. Are there any circumstances in which you would consider continuing to care for an employer if they got the coronavirus?
(Would you be prepared to help with oxygen or ventilators at home if this became necessary? Are you aware of this happening already or have direct experience already?)

Safety at work and safety concerns

16. Do you feel that your working environment is safe (as far as possible) in respect of coronavirus *(Raise any discrepancies in approach between them and their employer)*
 - a. Do you have any protective clothing?
(e.g., gloves, aprons, masks etc., who provided it, is it what's really needed, is it disposable, who disposes of it, etc.)
 - b. Are there any items of protective clothing you need/would like but don't have?
(Who buys it – do you get it paid for?)
 - c. In our first study, many PAs said they preferred not to wear protective clothing because it seemed to 'medicalise' the relationship they had with those who employed/hired them. Do you now wear protective clothing when before you didn't? If so, has it had any impact on your relationship with your employer?
 - d. Do you have what you need to help keep your working environment/employer's home clean?
-

(e.g., disinfectant & bleach).

- e. Have you had any training/information to help you protect yourself and others from coronavirus?

(e.g., what was it, when was it provided, who provided it & was it useful?)

17. Would testing for coronavirus (either for you or your employer) make you feel any safer?

18. Do you think your employer feels safe (in respect of Coronavirus) at the moment?

(e.g., what are they telling you about their views of risks?)

19. Do you know if your employer has had a flu vaccination? And what about you?

Information and support needs

20. Where are you getting information about Coronavirus from?

(e.g., internet/Facebook/twitter, etc., friends, TV, - who do you trust?)

21. Do you have any access to advice or support to help you at this time?

(If yes, who provides it, and is it helpful?)

22. Do you feel that coronavirus has/or will made people think differently of social care workers and Personal Assistants?

(e.g., more likely to be valued and seen as valuable, skilled, dedicated, committed etc., or seen negatively as potential virus 'transmitters'.)

Relationships with other organisations and professionals

23. Do you think it might be difficult to continue going into some settings (e.g. sheltered housing/extra care) if these get 'locked down'?

(e.g., 'credentials' and ambiguity about the PA role made working relationships with other professionals uncomfortable for some PAs in the previous study).

24. People you work for may need to call on newly established neighbourhood networks or community organisations to fill in gaps in care. How do you feel about this?

(e.g., in what situations would this be appropriate? Are you part of any yourself? Do you see any safeguarding risks?)

25. If NHS professionals have been in touch with your employer, did they talk to you or leave communications for you?

Impact on the future

26. Have you thought about doing a different job as a result of coronavirus?

27. In your opinion, does coronavirus make any difference to your opinions about pay and conditions, status, unionisation, regulation or Disclosure and Barring Service checking of PAs?

28. Thinking specifically about Coronavirus, what would be the two best ways to support you in your work as a PA at this time?

29. Do you think coronavirus is changing PAs as a professional group? *(e.g., regulation, DBS checking, recruitment, unionisation?)*

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