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Irrelevant & Sensitive

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Laura Taylor
Module Lead Solicitor
Via email: solicitors@covid19.public-inquiry.uk

04 January 2023

Reference for Request – M2/R9R/CARERSNI

Dear Laura

Further to your letter on 24 November 2022, and the request for information relating to the COVID-19 pandemic under Rule 9 of the Inquiry Rules 2006, please find attached our response to the questionnaire.

We would be happy to discuss any aspect of our responses or provide further information as needed.

Yours sincerely

Personal Data

Richard Meade
Director
Carers NI

Questionnaire

UK COVID-19 Inquiry: Module 2 - Rule 9 Request to Carers Northern Ireland

1. A brief overview of the history, legal status and aims of the organisation or body. Please explain whether the work of the organisation or body is UK wide, or is instead confined to Northern Ireland only.

Carers NI is Northern Ireland's membership charity for unpaid carers, with over 1,000 registered members. We work to represent and support the over 290,000 people in Northern Ireland who provide unpaid care for ill, older or disabled family members or friends – fighting for increased recognition and support for all carers and to ensure they have a voice in policymaking.

Carers NI is the Northern Ireland arm of Carers UK, the leading UK charity for anyone looking after family or friends who are unwell, disabled or need support in later life. With over 40,000 members and over 1,000 volunteers, our vision is of a society that recognises, values and supports carers for the huge contribution they make to families and communities. As well as delivering public policy campaigns and training, we provide specialist information and support including a unique UK Helpline, which last year answered over 38,000 enquiries from over 25,000 carers across the UK.

2. A brief description of the group(s) which the organisation or body supports or represents.

Carers NI represents and advocates for unpaid carers in Northern Ireland. These are unpaid family members, partners or friends who help a person with daily activities who wouldn't be able to manage if they didn't have help. This could be someone who is seriously ill, disabled or who needs extra help as they grow older. We estimate that there are over 290,000 adults in Northern Ireland providing some form of unpaid care.

3. A brief overview of the work of the organisation or body in supporting or representing the relevant group(s) between January 2020 and May 2022 as it relates to the response to Covid-19 of (i) the UK Government; and/or (ii) the Government in Northern Ireland.

Carers NI undertook extensive work to represent and support unpaid carers throughout the pandemic, with much of this activity seeking to ensure unpaid carers were properly supported by the NI Executive, Assembly, health service and other public bodies. This included the following:

- Providing information and sign-posting in response to queries from carers regarding Covid regulations, access to vaccinations and a wide range of other themes. This included setting up a referral process between Carers NI and the Covid-19 Community Helpline.
- Running an extended Advice Line, which was later partially funded by the Department of Health, to respond to carers' queries about the pandemic, the

support available to them and information on the likes of vaccination, access to PPE, Covid restrictions and more. In the 2020-21 financial year, the Advice Line received over 3,300 queries, a near 50% increase on the previous year.

- Advocating to the NI Executive, Assembly, Health Trusts and others on the needs of carers, particularly around health and social care services, financial support and access to other public services such as special educational needs (SEN) support (see below).
- Responsive listening activities with carers to take note of the most pressing pandemic-related issues they were facing and ensuring the NI Executive was aware of those issues. This was across our information and advice services, social media channels and wider contact with carers.
- Conducting and publishing research on the impact of the pandemic on unpaid carers and carers' experiences during the pandemic. The findings from this research were used to platform carers' concerns and advocate for greater services and supports.
- Carers UK's Director of Policy and Public Affairs was involved in close consultation on the Coronavirus Act and the drafting of related guidance. They also worked closely with the Department of Health and Social Care in England to create information and advice for carers on government websites, including relating to infection control.

4. A list of any articles or reports the organisation or body has published or contributed to, and/or evidence it has given (for example to UK Parliament or the Northern Ireland Executive) regarding the impact on the group(s) which the organisation or body supports or represents of the response to Covid-19 by (i) the UK Government; and/or (ii) the Government in Northern Ireland. Please include links to those documents where possible.

Carers NI and Carers Trust Northern Ireland joint statement on Covid-19, published 12.03.20.

<https://www.carersuk.org/briefings/carers-ni-and-carers-trust-northern-ireland-joint-statement-on-covid-19-coronavirus/>

Carers UK briefing: The Coronavirus Bill and what it means for unpaid carers, published 24.03.20.

<https://www.carersuk.org/briefings/carers-uk-briefing-the-coronavirus-bill-and-what-it-means-for-unpaid-carers/>

Caring behind closed doors: Forgotten families in the Coronavirus outbreak, published 23.04.20.

<https://www.carersuk.org/reports/caring-behind-closed-doors-forgotten-families-in-the-coronavirus-outbreak/>

Carers Week 2020 research report, published 08.06.20.

<https://www.carersuk.org/reports/carers-week-2020-research-report/>

Caring behind closed doors six months on: The continued impact of the Coronavirus (Covid-19) pandemic on unpaid carers, published 20.10.20.

<https://www.carersuk.org/reports/caring-behind-closed-doors-six-months-on/>

Coalition of Carers Organisations oral evidence to Assembly Committee for Health re: Covid-19 disease response, 12.11.20.
<http://aims.niassembly.gov.uk/officialreport/minutesofevidencereport.aspx?&AgendaId=24169&eventId=12404>

Unseen and undervalued: The value of unpaid care provided to date during the Covid-19 pandemic, published 26.11.20
<https://www.carersuk.org/reports/unseen-and-undervalued-the-value-of-unpaid-care-provided-to-date-during-the-covid-19-pandemic/>

Breaks or breakdown: Carers Week 2021 report, published 07.06.21.
<https://www.carersuk.org/reports/breaks-or-breakdown-carers-week-2021-report/>

State of Caring 2021: A snapshot of unpaid caring in Northern Ireland, published 03.11.21.
<https://www.carersuk.org/reports/state-of-caring-in-northern-ireland/>

During the pandemic period, Carers UK published a number of briefings related to Covid-19 vaccination, including the following:

- Unpaid carers and Covid-19 vaccination: Policy briefing, published 12.01.21
<https://www.carersuk.org/briefings/unpaid-carers-and-covid-19-vaccination-policy-briefing/>
- Briefing on Covid-19 vaccinations for unpaid carers, published 07.10.21,
<https://www.carersuk.org/briefings/carers-uk-briefing-on-covid-19-vaccinations-for-unpaid-carers-7-october-2021/>

5. The view of the organisation or body as to whether the group(s) it supports or represents was adequately considered when decisions about the response to Covid-19 were made by (i) the UK Government; and/or (ii) the Government in Northern Ireland. Please also explain the reasons for the view expressed by the organisation or body in this respect.

It is the view of Carers NI that, while the NI Executive was facing an unprecedented pandemic situation for which most governments around the world were ill-prepared, the needs of unpaid carers were not always adequately considered when decisions were taken in response to Covid-19 in Northern Ireland. We believe this was evident across a number of themes, as detailed below.

Reduced access to services and supports

The closure, reduction and barriers to accessing health and social care services in Northern Ireland from March 2020 has, and continues to have, a profound impact on unpaid carers here. Many vital services – including social care, day centres, short breaks and respite provision – stopped almost overnight when the pandemic began, with little-to-no warning or consultation, and have been heavily disrupted, reduced or closed ever since; creating significant care gaps which, in many cases, were/continue to be met by unpaid carers. In October 2020, 85% of carers told a Carers NI survey that they were providing more unpaid care than before the

pandemic began, nearly half (45%) because of the reduction or closure of local health and social care services. ^[1] The situation scarcely improved over time, with 48% of carers reporting toward the end of 2021 that they still faced reduced day services; 29% still had reduced support from paid care workers; and 36% had reduced short break services. ^[2] At the end of May 2022 – the period to which this inquiry covers – the average proportion of adults with learning disabilities receiving their full day care entitlement compared to the pre-Covid baseline was less than 45% across Northern Ireland’s five Health Trusts. ^[3]

Carers told us repeatedly throughout the pandemic that they felt abandoned by the services they previously relied on and were in the dark as to when they may return. These significant extra caring responsibilities and lack of support drove unpaid carers to breaking point and made it challenging, in some cases impossible, for them to take meaningful breaks from their caring roles – with severe consequences for their health and wellbeing. In June 2021, 79% of carers in Northern Ireland reported not being able to take a break from caring during the pandemic, with 72% saying this had made their mental health worse. A further 78% reported feeling exhausted and worn out as a result of caring during the pandemic. ^[4] Services like day centres and respite provided a lifeline for many carers and the only opportunity they had to take breaks and lead lives of their own outside of caring. The significant and ongoing challenges that many have faced to accessing these services since the pandemic began has been a source of considerable pressure on Northern Ireland’s unpaid carer population, which was already facing exhaustion, burnout and high levels of mental and physical ill-health.

While it was inevitable that Northern Ireland’s health system would be disrupted by the pandemic – particularly during its early months – Carers NI believes that unpaid carers were put under additional strain by the lack of a universal strategic approach to remobilising vital services, from the Department of Health and Health Trusts, when the rest of society was continuing to open up again. Health Trusts have adopted differing approaches to, and timelines for, reopening and remobilising the services outlined above, creating a postcode lottery across Northern Ireland. The Department of Health’s Pathway for remobilising adult social care services, ^[5] which was approved in January 2022, does not seem to have been implemented in a coordinated fashion across Trusts and the legal status of the document has been unclear from its publication. While targets have been set for each Trust to restore services to full pre-pandemic capacity, these targets have been missed and, according to the latest information available to Carers NI, are under review again, with no tangible end date in sight at the time of writing. ^[6] The Department of Health has acknowledged the challenges this has caused, recently issuing a public apology that *“there is a cohort of service users still not receiving adult day care or receiving a*

¹ Carers UK (2020). Caring behind closed doors six months on: The continued impact of the Coronavirus (Covid-19) pandemic on unpaid carers.

² Carers NI (2021). State of Caring 2021: A snapshot of unpaid caring in Northern Ireland.

³ See: <https://www.health-ni.gov.uk/publications/remobilisation-learning-disability-services-documents>.

⁴ Breaks or breakdown: Carers Week 2021 report.

⁵ <https://www.health-ni.gov.uk/sites/default/files/publications/health/doh-services-remobilising-pathway-full.PDF>.

⁶ See attached minutes of the joint meeting of the APG on Carers and APG on Learning Disability, 25.10.22.

partial service."^[7] The extent to which the Department of Health has held Trusts to account for these delays is unclear based on the information available to us.

We would also argue that Health Trusts have adopted an inflexible approach to remobilising services which did not always strike the right balance between Covid-19 infection control and the need to deliver as much support as possible to service users and their unpaid carers. This has been the case with asymptotic testing and isolation requirements for day services – which, carers told us, often presented insurmountable barriers to accessing services, particularly in the learning disability category of care. It was also especially evident in regard to Health Trust transportation services to-and-from day services, which for large parts of the pandemic period maintained one metre physical distancing requirements – significantly reducing capacity – even after that requirement was dropped in most other parts of society.

Overall, we believe that unpaid carers have suffered significantly from a prolonged lack of access to vital services and supports, which were removed almost overnight, with very little warning, and which have been unacceptably slow to return across Health Trust areas. While some service disruption was unavoidable when the pandemic began, we believe a more strategic and coordinated approach from the Department of Health and Health Trusts could have delivered better outcomes for Northern Ireland's unpaid carer population and resulted in the full return of these vital services much more quickly.

Carers Assessments

Data published by the Department of Health highlights that Health Trusts failed in their statutory duty to offer and carry out Carers Assessments during parts of the pandemic period in Northern Ireland. The Carers and Direct Payments Act 2002 gives anyone over the age of 16 who provides 'substantial and regular care' the right to a Carers Assessment. These are carried out by a health or social care professional and examine a person's situation to see if they are entitled to any services that would make their caring role easier. A Carers Assessment should cover a range of topics including the carers' health and wellbeing, access to breaks, finances, housing situation and more.

The Department's data shows that, during the quarter ending June 2020, the number of Carers Assessments offered across Northern Ireland declined by 32% compared to the quarter ending March 2020. The Department explained that this was caused by the impact of Covid-19 and stated, as a mitigating factor, that assessments continued to be offered and completed (virtually) when requested.^[8] This would seem to represent a misunderstanding of the legislation, however, as the Carers and Direct Payments Act imposes a duty on Trusts to inform carers of their right to an assessment – it is not the responsibility of carers to ask for one.

⁷ See Assembly Written Question AQW 4546/22-27 to Minister for Health, 24.10.22.

<http://aims.niassembly.gov.uk/questions/printquestionssummary.aspx?docid=383991>.

⁸ Department of Health (2020). Quarterly carers' statistics for Northern Ireland: April-June 2020.

While the number of assessments rose by 21% in the following quarter – quarter ending September 2020 – this still represented an 18% decrease in the number during the same quarter in 2019, prior to Covid-19. ^[9] Similarly, the number offered during the quarter ending December 2020 was down 11% on the same quarter in 2019. ^[10]

Carers Assessments are often a vital first step in identifying carers' needs and connecting them to sources of support – which they arguably needed more than ever during the pandemic. Our research has consistently shown that many carers are unaware of what a Carers Assessment is, ^[2] and this situation is likely to have been compounded during the pandemic by the decline in Trusts proactively informing carers of their right to an assessment.

Financial support

Carers NI would argue that unpaid carers in Northern Ireland were not provided with adequate financial support during the Covid-19 pandemic. Even with all else being equal, many unpaid carers face financial hardship due to a complex mix of above-average household bills for the energy, food and travel required by the person they're caring for; barriers to paid employment, and inadequate support from the social security system. This was exacerbated during the pandemic, with 35% of carers telling a Carers NI survey in 2021 that their financial situation had worsened since the onset of Covid-19. In that survey, 70% of carers said they were spending more on household bills, shopping and everyday items, while almost one in four (23%) were spending more on equipment or products for the person they care for. ^[2] Many unpaid carers juggle caring with paid employment, and some experienced a drop in salary due to being furloughed or having to take unpaid or sick leave from work due to reduced childcare or social care support.

In this context, it was warmly welcomed when the Department of Health announced its intention to provide unpaid carers with a £500 Covid recognition payment in January 2021. This was never delivered, however, after the Department received advice that it had no legal basis for establishing such a scheme for unpaid carers; was unable to form a robust list of unpaid carers who would qualify for the payment that complied with good governance principles; and was unsuccessful in escalating delivery of the payment to other departments in the Executive. ^[11] The situation has been deeply frustrating for unpaid carers who struggled to get by financially during the Covid-19 pandemic, particularly when a similar scheme was successfully rolled out for unpaid carers in Wales.

Elsewhere, Carers NI worked with our colleagues across the UK to advocate for an increase in social security benefits for unpaid carers during the pandemic. While a £20 weekly uplift to Universal Credit was delivered during the period March 2020-September 2021, unpaid carers on legacy benefits or Carers Allowance did not receive any uplift. This, combined with the failure to deliver any form of lump sum payment to unpaid carers, as set out above, entrenched carers' financial struggles

⁹ Department of Health (2020). Quarterly carers' statistics for Northern Ireland: July-September 2020.

¹⁰ Department of Health (2020). Quarterly carers' statistics for Northern Ireland: October-December 2020.

¹¹ See attached letter from Minister for Health re: carer Covid payment, day services and other matters, Oct 21.

and continues to have an impact today; with many carers insufficiently equipped to manage the cost living crisis.

6. Whether the organisation or body raised any concerns about the consideration being given to the group(s) which it supports or represents with (i) the UK Government; and/or (ii) the Government in Northern Ireland, when those governments were making decisions about their response to Covid-19. Please provide a list of any such correspondence or meetings with (i) the UK Government; and/or (ii) the Government in Northern Ireland, including the dates on which the body or organisation wrote or such meetings were held, to whom the correspondence was addressed or with whom the meeting was held, and any response received from the UK Government or the Government in Northern Ireland addressing such concerns.

Throughout the pandemic period Carers NI engaged extensively with the NI Executive, Health Trusts and other public bodies on the impact of the pandemic on unpaid carers and the consideration being given to the carer population in Covid decision-making.

This included raising concerns and engaging with the Department of Health, NI Assembly, Health and Social Care bodies and other stakeholders on the following themes.

- The effect on carers of closing and reducing health and social care services.
- Access to PPE for unpaid carers.
- Reduced availability of breaks for unpaid carers in the context of service closure and/or reduction.
- The impact on unpaid carers of Covid-19 guidance concerning issues including care contingency planning, infection control in social care settings and HSC discharge.
- The financial pressures facing unpaid carers and their need for greater financial support, including through cash grants, Discretionary Support payments and more.
- The additional pressure facing carers of/with children as a result of the closure of educational/special educational settings.
- The need for greater support for carers to access essential daily services like pharmacies and grocery shopping.
- Access to testing and vaccination for unpaid carers.
- Carer wellbeing in the context of lockdowns and the wider pandemic effects, including access to mental health support and emotional/psychological services.
- Health and Social Care recovery/'post-lockdown' plans and the impact of these on the services and supports available to unpaid carers.

More information on some of this activity is available via the attached correspondence and meeting information listed below.

List of relevant correspondence

June 2021

- Letter from the All Party Group (APG) on Carers (for which Carers NI is the secretariat) to Minister for Health on carer Covid payment, day services and other matters, 29.06.21 [attached]
- Minister for Health response to above letter [attached]
- Paper from Health and Social Care Board to APG on Carers on Health and Social Care Trust services and supports for unpaid carers during the pandemic [attached]

May 2022

- Carers NI letter to Minister for Health on Unpaid carers and the Covid-19 autumn vaccination booster programme, 24.05.22 [attached]
- Minister for Health response to above letter [attached]

List of relevant meetings with NI Executive officials

Throughout the pandemic, Carers NI engaged regularly with Executive departments, Health and Social Care bodies and other stakeholders. In the initial months after the outbreak in Northern Ireland, this occurred on a daily or weekly basis, including via email, telephone and face-to-face (virtual) meetings. The information below provides an overview of the key meetings we held, the themes discussed and any relevant outcomes (where applicable).

16.03.20

- Teleconference organised by the Department of Health and including a range of community groups. The call discussed pending Covid-19 guidance for care homes, specifically care arrangements and infection control for staff. Carers NI highlighted the importance of access to PPE for unpaid carers. The call also discussed new hospital discharge guidance, where medically fit patients would be discharged promptly and unpaid carers would be asked to cover any gaps or delays in implementing care packages in the community. Carers NI argued that this would put greater pressure on unpaid carers, many of whom were already facing burnout.

18.03.20

- Meeting with official from the Department of Health Elderly and Community Care team to advocate for formal Covid-19 guidance for unpaid carers. This marked the beginning of the process of developing such guidance, which was added to over time based on – among a wide range of other things – the issues being raised with Carers NI through our Advice Line.
- Engagement with the Department of Health Elderly and Community Care team to highlight the pressure on unpaid carers as a result of the closure of special educational needs settings. DoH subsequently liaised with the Department for Education and confirmed that SEN children would receive occupational and speech and language therapy following their school closures, with a timeline to be confirmed.

April 2020

- Meeting with the Regional Carers Strategy Group – coordinated/convened by the Health and Social Care Board – to begin developing a carers ID card to facilitate priority access to supermarkets and other essential shops during the pandemic. The ID card was later launched in June 2020.

06.07.20

- Meeting with the Regional Carers Strategy Group to discuss a wide range of issues, including Trust service reset and recovery plans and community support for unpaid carers.

10.07.20

- Meeting with official from the Department of Health Elderly and Community Care team to discuss scoping for a carer Covid-19 award/recognition payment, with DoH committing to investigate the idea further. This was discussed again at a meeting of the Regional Carers Strategy Group on 03.08.20, where DoH confirmed that discussions about such a payment were taking place with the Department for Communities. Subsequent meetings about this payment were held with and/or including DoH on 19.08.20, 07.12.20, 06.01.21, 21.01.21, 28.01.21, 01.02.21, 02.02.21, 23.04.21, 18.05.21 and 25.05.21. As is noted above, this was ultimately without success, however, and the payment was not delivered.

October-November 2020

- Regular meetings of the Regional Carers Strategy Group to discuss Health Trust reset and recovery plans, specifically breaks, mental health and emotional/psychological support for unpaid carers. Updates were sought from each Trust on how they were fulfilling their obligations to/supporting unpaid carers.

20.11.20

- Meeting with Department for Communities to discuss the sources of financial, welfare and wellbeing support for unpaid carers. Carers NI and the Department agreed to awareness-raising actions to promote all open schemes and sources of community support among unpaid carers.

07.12.20

- Meeting with the Minister for Health to discuss remobilising day services and respite, financial support for carers, vaccinations for carers and other issues. The Minister committed to: writing to each Trust to ask for assurances that they were supporting carers as far as possible; developing a paper on options for financial support for carers; and to discussing with the JCVI the importance of prioritising carers in the vaccination rollout.

20.01.21

- APG on Carers meeting with the Department of Health Chief Social Worker, Name Redacted. Items discussed included further Covid-19 guidance for unpaid carers and improving access to Direct Payments/Self-Directed Support during the pandemic.

19.05.21

- APG on Carers meeting with officials from Department for Communities on the carer Covid payment, temporary uplift to Universal Credit for carers and other matters [minutes attached].

25.02.21

- Meeting with the head of the Department of Health's Vaccination Taskforce, **Name Redacted**, to receive an update on the rollout for carers and seek clarity on how carers were being identified for priority access to vaccinations.

7. A brief summary of the views of the organisation or body as to any lessons, if any, that can be learned from any consideration which was given to the group(s) that the organisation or body supports or represents by (i) the UK Government; and/or (ii) the Government in Northern Ireland when they were making decisions about their response to Covid-19.

Carers NI believes the pandemic experience in Northern Ireland has highlighted and reinforced the importance of the following key learnings.

Supports for unpaid carers need to be prioritised during emergency health situations

Northern Ireland's pandemic experience – from the onset in March 2020 to the present day – has underlined what many unpaid carers here already believed: that they, and the services and support they need, are not a priority for decision-makers. The failure to remobilise vital social care and day services – lifelines that many carers have now been missing for more than two-and-a-half years – reinforces the view of many carers that the health service is prepared to rely on their good will and sense of obligation toward those they're caring for, in order to prioritise attention and resources elsewhere.

The opposite should be true. Unpaid carers are estimated to have saved Northern Ireland's public purse £19m in care costs per day during the Covid-19 pandemic.^[12] Restoring the services they need to support them in their caring role, take breaks from caring and look after their own health and wellbeing should be an urgent priority for the Department of Health and Health Trusts. The reliance on, and lack of support for, unpaid carers in Northern Ireland is having profoundly negative consequences on the health, wellbeing and quality of life of many.

Unpaid carers should be treated as strategic partners in the HSC system

In the context of the enormous contribution carers in Northern Ireland make to society and public services, they should be recognised and treated as strategic partners in the health and social care system – with robust consultation on decisions that will impact their lives. This could have resulted in unpaid carers receiving proper communication and engagement when the like of day services and respite provision were removed at the beginning of the pandemic. It is unacceptable that, at the time

¹² Carers UK (2020). Unseen and undervalued: The value of unpaid care provided to date during the Covid-19 pandemic.

of writing, some carers are still unaware as to when or if the services they used to rely on will return to full pre-pandemic capacity.

Unpaid carers need greater legal protections in the health and social care system

The decline in the number of Carers Assessments offered during the pandemic period is just one example among many which underlines the need for greater legal protections for carers in the health and social care system. Not only do carers have no legal guarantee to receive support after having needs identified in a Carers Assessment, but there seems to be essentially no consequences if their Trust fails to inform them of their right to an assessment in the first place. The Power to People report – a landmark review into the future of the social care system in Northern Ireland – recommended that the rights of unpaid carers be put on a more robust legal footing.^[13] Northern Ireland's pandemic experience illustrates why that proposal is so important.

Carers NI believes that this should form part of wider reform to make unpaid caring a protected characteristic under equality legislation – enshrining carers' legal protections, rights and entitlements to the support and services they need.

¹³ Expert Advisory Panel on Adult Care and Support (2017). Power to people: Proposals to reboot adult care and support in Northern Ireland.