Law for Dementia Carers (L4DC) Covid-19 Report
Impact of the Coronavirus Act 2020 and legal issues on Carers of People with Dementia

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Introduction and Background

Introduction

With Covid-19 changing the world, carers of people with dementia have been particularly affected by the pandemic. The Alzheimer's Society have published a report "Worst hit: dementia during coronavirus" which states that:

> "More than a quarter of those who died in England and Wales had dementia which means it is the most common pre-existing condition for coronavirus deaths. The biggest spike in excess deaths was also in people with dementia." [1]

And it finds that:

> "92 million extra hours have been spent by family and friends caring for loved ones with dementia"[2]

An understanding of the law, what it means for carers and their legal rights has become even more important.

A new Act of Parliament was passed on the 25 March called the *Coronavirus Act 2020*. Fast tracked through parliament in four days, the Act contained 'emergency powers' to enable public bodies to respond to the Covid-19 pandemic.

The *Coronavirus Act 2020* was accompanied by supporting documents including the *Coronavirus Action Plan*, *Care Act easements guidance for local authorities*, and *Responding to Covid-19: the ethical framework for adult social care*. The Ethical Framework outlines the values and principles which should guide practice.

The Care Act easements guidance for local authorities states that

> *"*Local authorities will be expected to observe *the Ethical Framework for Adult Social Care*…..Alongside the framework local authorities should continue to respect the principles of personalization and co-production.*"*[3]

The Ethical Framework lists a set of 8 principles which it expects local authorities to consider and apply alongside professional codes of conduct and official guidance and legislation. There is a caveat saying that

> "…it may not be feasible to consider all the principles ….each principle must be considered to the extent possible in the context of each

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[1] p 4 Worst hit: dementia during coronavirus, Alzheimer's Society, September 2020

[2] Ibid, p 6

[3] Department of Health and Social Care

> circumstance with appropriate risk management and considerations of individual wellbeing, overall public good and available information and resources."[4]

Making It Real, the Think Local, Act Personnel (TLAP) framework for personalised care and support is also referenced on the Department of Health and Social Care website. This includes a statement by Think Local, Act Personal (TLAP) which reinforces the

> "…fundamental principles of personalization and co-production" [5]

and an expectation that local authorities will

> *"…*view those of us in receipt of support or carers providing support, as equal partners. We continue to be experts in our own care and support whatever the circumstance*."*[6]

These two documents were effectively being referenced to act as the test of good practice to ensure that the Coronavirus Act was being implemented in an ethical and personalised way.

While there was an acceptance that emergency legalisation was needed at this unprecedented time, there were concerns about how the health and social care aspects were to be implemented across the four nations of the UK. A key concern of L4DC was to understand what impact the Coronavirus Act 2020 was having on the day to day lives of carers of people with dementia including their access to assessment and support, and whether any other legal issues that affect carers were also of particular relevance during this crisis.

This report outlines the approach taken by L4DC to Covid-19, its key activities, findings and recommendations for supporting carers of people with dementia during the Covid-19 pandemic.

Background

L4DC is a 2 year project funded by The Legal Education Foundation. It is a partnership between Life Story Network/tide (together in dementia everyday) and Making Space, with support from the Justice Hub which is run by the University of Manchester's Law School. L4DC has a rights based agenda and aims to raise awareness and inform carers of people with dementia of their legal including human rights which can support them in their role. It planned to do this via the co-creation of training for carers as part of tide's carer development programme, and to also create training for front line health and social care staff to raise awareness of legal issues as a critical health outcome for carers via a social prescribing model. The project was originally geographically focused on Greater Manchester given its Dementia United programme and aspirations for people with dementia and their carers.

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[4] ibid
[5] ibid
[6] ibid

The onset of the Covid-19 pandemic and accompanying emergency legislation that applied across the UK, prompted a temporary pivot of the L4DC project to focus on the impact of Covid-19 on legal issues for carers of people with dementia. The objectives were to:

- Raise awareness of legal issues with carers of people with dementia, including the health and social care aspects of the Coronavirus Act 2020 and specifically the potential use of Care Act easements
- Provide an opportunity for carers to have increased contact with other carers potentially leading to reduced feeling of isolation
- Increase the confidence of carers of people with dementia to articulate their rights and make more informed decisions about care and support
- Increase access to timely support via appropriate signposting
- Gather feedback and give a voice to carers about their experiences of the legislation and legal issues during Covid-19
- Extend the geographic scope of the Covid-19 focus to consider the experiences of legal issues across the UK
- Understand how the health and social care aspects and specifically the potential use of Care Act easements in the Coronavirus Act legislation was strategically implemented in Greater Manchester by the Greater Manchester Health and Social Care Partnership
- Collate the information and any findings and recommendations to inform the 6 months review of the Coronavirus Act

Project Activities

There have been a number of studies and research about Covid-19 and the impact it is having on carers. While many of the surveys and research conducted on carers is consistent with the findings of L4DC, what makes this study different from is its focus on legal issues. The activities of L4DC have not sought to be academic (and do not conform to academic requirements) and cannot claim to be representative of the experiences of all carers of people with dementia. However what the activities do provide is an insight into the lived experience of carers of people with dementia across the UK from a legal perspective during Covid-19. They identify the lack of knowledge and awareness of legal issues that many carers have, the difficulty in accessing information, and even when legal provisions are in place, the difficulties in exercising some of these. They also voice some of the challenges, dilemmas and tensions that carers have been dealing with over recent months, shining a light to Government and policy makers, both nationally and locally on the impact that Covid requirements can have as they are implemented locally.

L4DC has engaged in a number of activities to meet the overall Covid focused objectives. They include the following:

- Launched the pivot of L4DC on tide and Making Space websites
- The Justice Hub at The University of Manchester produced ‘Easing the Care Act’, an easy read guide to potential changes to the Care Act 2014, which was made available to carers via tide and Making Space
- Hosting a L4DC Webinar for carers providing legal information about issues at different stages of dementia together with information about the Coronavirus Act, Care Act easements and other legal issues furing the pandemic
- Conducted a carers survey of legal issues
- Follow-up interviews with a sample of respondents to the survey
- Survey of Greater Manchester’s Health and Social Care Partnership’s strategic approach to the implementation of the Coronavirus Act
- Created alliances and networks across carer, dementia and legal rights organisations and contributed to webinars hosted by NDCAN (National Dementia Carers Action Network) and LTC Responses to Covid-19 (International Long-term Care Policy Network)
- Press publicity of carers stories arranged in local newspapers in Yorkshire, Northwich and Warrington.

Approaches and Methodologies

This section will focus on the 2 key activities where L4DC engaged directly with carers: the legal webinar and the Carers Survey, and will also outline the approach taken to the GMH&SCP survey.

L4DC Webinars

A legal webinar was arranged as a follow on activity to the production of the ‘easy read guide’ to the Coronavirus Act and the Care Act easements. It was considered to be a way of communicating with and providing information for carers of people with dementia about legal issues affecting them during the Coronavirus pandemic.

The webinar took place on 23 June from 4.00 – 5.30 p.m. This was hosted by tide and Making Space and featured a presentation by Neil Allen, Barrister, Senior Lecturer and Clinical Lead at The University of Manchester Law School together with contributions from law students on specific areas of the law. The webinar provided the facility for carers to comment and ask questions via the chat function and also verbally at points throughout the presentation. The webinar ran over the planned time due to the high level of interest generated and the willingness of the presenter to respond to questions.

Linking with the original objectives of the L4DC project, the presentation was structured around 4 headings that are used in national guidance - Dementia Care Pathways. These pathways represent key stages in the journey for a person with dementia and have been adopted as a structure to consider relevant legal issues for the L4DC project as a whole:

- Diagnosing Well
- Supporting Well
- Living Well
- Dying Well

In advance of the webinar, law students from The University of Manchester considered legal questions (under supervision) that had emerged from a previous L4DC carers survey on legal issues together with other questions linked to the introduction of the Coronavirus Act 2020. Carers who registered to attend the webinar were also invited to send in questions ahead of the event. While some of the questions raised and questions covered were specific to the Coronavirus Act, other issues that were of enhanced relevance to this period but have broader application beyond the pandemic were also of interest to carers. Information from these areas will be incorporated into the development of the future carer training modules.

Promotion of the event was via tide and Making Space and via wider carer and health and social care networks. Over 220 people registered for the event of which 149 attended from across the UK. Live feedback from carers at the event via the 'chat' function was very positive and included comments such as:

> "*Thanks for a great webinar… Fabulous style and top quality information in an easy to understand format."*
>
> "*Really helpful to have joined the meeting. Determined to fight for my lovely parent's wellbeing and rights necessary, but great to do this together through Tide"*
>
> *"…it was good to hear from other carers"*

A webinar feedback form was distributed to those who registered after the event but the feedback response rate was relatively low (*Appendix 1).* This is likely to be due a time lag between the webinar being held and the availability of the feedback form which was delayed in order that post webinar communications could be combined in one mailing. Although the responses that were received were helpful, this is a learning point for future events. The webinar was recorded and was sent to all those who registered for the event. The webinar has also been made available on the tide website for other carers who may be interested.

A L4DC webinar was also held in Scotland on 14 August which was attended by 71 people. This webinar from a Scottish legal perspective, similarly aimed to raise awareness and inform carers of legal issues, their rights as carers and the support available. This webinar was intended to be the first in a series to support carers.

Carers Survey and Interviews

A L4DC Covid-19 Carers Survey gathered feedback from carers across the UK regarding their experiences of legal issues including the implementation of the Coronavirus Act. Given the prominence of *Making It Real* amongst the guidance for implementation of the Coronavirus Act, the survey was structured using key themes from the framework using ‘I statements’. This approach had already been successfully used by Making Space (a partner in L4DC) to seek feedback from people on its services. The draft survey was tested with tide carers prior to being publically launched. The survey included both quantitative information and the option for additional qualitative information to be provided.

The survey was promoted via tide, Making Space and linked networks. L4DC also gained publicity and survey promotion via newspaper articles featuring carer stories in the Yorkshire Post and local papers in Northwich and Warrington. The survey ran from 17 July – 5 August 2020 but was extended to try to attract a more diverse demographic response. 191 people responded to the survey from across the UK. Of these, 94% identified themselves as either current or former carers, with the vast majority of other respondents identifying themselves as relatives of people with dementia. 74% lived in England, 10% from Scotland and 10% from Wales, and 5% from Northern Ireland. Within these countries there was a broad geographical spread across the regions. 94% described themselves as White, with less than 1% identifying as Caribbean or African or Indian. These figures are disappointing with L4DC clearly finding it harder to reach and engage with a more diverse and representative population. 83% of respondents were women and 17% were men. While the survey was open to all age groups the largest age group were carers aged 55-64 years (37%), followed by carers aged 65-74 years (30%). While some carers provided solely quantitative information, very many carers shared their personal experience and challenges during the pandemic. *(Appendix 2)*

Respondents were asked whether they would be interested in taking part an interview linked to the survey. There was a very positive response to this request with 58% of respondents leaving their contact details for potential follow up. Purposive semi-structured interviews were intended to explore some of the questions in more detail to provide a richer understanding of carers experiences. Timescale and resource constraints led to a small sample of respondents being selected for interview. Selections were based on the range of issues raised together with a geographic distribution across countries. Interviews were harder to arrange than anticipated but could be the result of carer’s change in circumstances or change of mind in relation to the actual request to being interviewed. 9 interviews took place and these provided valuable detailed information to compliment the survey findings.

Greater Manchester Health & Social Care Partnership (GMH&SCP) Survey

The original focus of L4DC was located in Greater Manchester. There were existing links with Greater Manchester and tide was already involved in the ambitious Dementia United programme which formed part of the Greater Manchester Health and Social Care Partnership. It incorporates a Dementia Carers Expert Reference Group so that cares lived experience can be actively included in its planning and implementation activities. While the pivoted project had extended its brief to include the whole of the UK, the GMH&SCP provided an opportunity to understand how a strategic partnership approached meeting the needs of its local population and specifically, carers of people with dementia.

The response from GMH&SCP details how the Partnership operating across 10 local authorities and the health system has facilitated strategic planning, collaboration between organisations and an integrated approach. It is worth noting that while the North-West which includes Greater Manchester has had one of the highest incidences of cases of Coronavirus across the UK, none of the Greater Manchester local authorities have considered it necessary to invoke the Care Act easements in order to respond to the challenges faced. Their response is available in *Appendix 3*.

Findings, Good Practice and Areas for Improvement

L4DC's focus on the experiences of carers of people with dementia, has produced these findings, examples of good practice and areas for improvement outlined below following the application of the Ethical Framework and specifically the "I Statements" during the course of its activities between March and August 2020. The primary source of feedback has come via the Carers Survey and interviews but also includes information gleaned from the webinars and carer and legal networks.

At the start of focus of the pandemic, it was anticipated that much of the information related to the Coronavirus Act would be about the use of Care Act easements that were introduced as an option for local authorities in order to prioritise and manage resources effectively. In the event only 8 local authorities in England invoked the easements, and for many these easements were very short lived. Solihull Borough Council was one of the first and last local authorities to invoke the easements and arguably the process that they adopted made their thinking and approach much more transparent to the public. Although a requirement of the easements was to make information publically available about their use and to inform people who use their services, it was very hard, if not impossible to access information generally from local authorities who used this provision. The Care Quality Commission (CQC) which was given the responsibility for oversight of the easements, listed government guidance about their use on their websites and the current local authorities who had invoked the easements, but there was no publically available information found that tracked the use of the easements, the decision making processes exercised, and the impact on people with needs and their carers. Anecdotal information has suggested that while most local authorities did not invoke the Care Act easements, changes in practice did occur some of which resulted in not maintaining their full duties during this period.

The Government overview of the Coronavirus Act has included 2 monthly reports which are publically available. However while understandably the focus has been on reducing the number of cases and deaths and the deployment of resources to do this, the impact analyses have failed to focus on impact that the measures have been having on people with needs including dementia and their carers.

Carers have been left on the one hand, feeling isolated and marginalized, and on the other, having to take on far greater responsibility for the people they care about, often at high personal cost.

58%

of carers of people with dementia reported that there had been a lot of changes to their caring responsibilities since the beginning of lockdown

58%

of carers told us that they were not able to continue as a carer in the way they wanted to; for those not living in the same household as the person with dementia, this rose to 72%.

50%

of carers did not have a carer's assessment at the time lockdown commenced in March

Not all carers are aware of their right to an assessment and only 32% of carers said they knew their legal rights and had access to information.

Carers have a legal right to be involved in decision-making, for example, when they are acting under a Lasting Power of Attorney.

Even when carers know their rights, these can be ignored or overruled by health and social care staff

Law 4
Dementia Carers

"I statements" *Making it Real* and the Ethical Framework	What carers of people with dementia have told us – findings, good practice examples and areas for improvement
Have there been changes in your caring responsibilities since March?	**Findings** **58% said there had been a lot of change** **25% said there had been a little change** **Only 18% said there had been no change** Changes included: • Deterioration in the health and well-being of the person with dementia – frequently reported concerns about significant changes and deterioration in the person's physical and psychological well-being. Examples of loss of mobility, continence, falls leading to hospital admissions, confusion, agitation, depression, mood changes, memory loss which led to additional needs for support which in some cases, led to the need for hospital or care home admissions. "Major changes to circumstances The lack of been able to take the person you care for out even just for a small walk has had a major effect on the person I careful health has deteriorated drastically plus my own health and well-being has drastically taken a downward turn" • Health and social care services unavailable or much reduced "I have taken in the role of day to day care of my mother since March as the care package was put on hold. Other services including OT was put on hold, even though my mother left hospital just before lock down with hip replacement. I have needed to escalate as emergency for any additional services." • Community services e.g. dementia clubs, suspended – many examples where community support had previously been the central form of support for carers and people with dementia. "The person I care for has had no social support mechanisms so more has fallen to me. I don't mind me doing more but the effect on her has been devastating." • Absence of usual forms of support leading to an overwhelming sense of isolation for both the carer and the person with dementia; seen as being integrally linked to the person with

“I statements” ***Making it Real*** **and the Ethical Framework**	**What carers of people with dementia have told us – findings, good practice examples and areas for improvement**
	dementia’s deterioration “it has meant I am alone in my caring role If i don’t encourage conversation the situation becomes worse but every conversation is instantly forgotten and repetition is hard on my own mental health I’ve used music and online activities but I have to initiate everything He has definitely deteriorated in the last few months” • Services cancelled or reduced by the person and/or carer as a result of trying to safeguard people with dementia from the virus • Carers changing from being part-time carers to 24/7 carers – when services were either no longer available e.g. day centres, respite care, or when services were reduced or stopped (home care) • Deterioration in the health and well-being of carers as a result of increased caring responsibilities • Some carers who had previously had a very active role in caring were unable to continue to provide care at all; this was the when the person with dementia lived in care homes. Unpaid carers frequently had a very active role in visiting, supporting the person, interpreting their needs and connecting them with their wider world but the closure of care homes to relatives halted their involvement. • Financial impact on carers who are sometimes having to juggle caring with working “I’m a working carer on a minimal wage I’m not entitled to carer allowance as I earn 130 a week which is just a little over the entitlement for the cares allowance This is so unfair as I pay for my own experience to care for my mother who has Dementia I need financial help to support me as a carer for my mum” • Some positive experiences of caring in a pandemic “More relaxed. Much more time as no appointments, no visitors. Good weather much of the

"I statements" *Making it Real* and the Ethical Framework	**What carers of people with dementia have told us – findings, good practice examples and areas for improvement**
	time too."
Carer Assessments: **Carers who had a carers assessment in March** **Carers who requested an assessment during the pandemic**	All 4 nations in the UK have the right to carers assessments enshrined in legislation. Carers Assessments became a statutory right for carers as part of the Care Act 2014 in England. "The duty to carry out a carer's assessment applies regardless of the authority's view of a) The level of carers needs for support, or b) The level of the carer's financial resources or those of the adult needing care" *legislation.gov.uk* This enables carers to have their needs assessed ad potentially to access support in their own right as carers. There is an equivalent Act – the Social Services and Well-being (Wales) Act 2014. In Scotland, the Carers (Scotland) Act, carers have the right to an adult carer support plan, and the right to support to meet their eligible needs. In Northern Ireland, carers rights to a care assessment comes from the Carers and Direct Payments Act (Northern Ireland) 2002. **Findings:** **In March** **38% of carers had a carers assessment** **50% of carers didn't have a carers assessment** **12% carers said it was not applicable**

"I statements" *Making it Real* and the Ethical Framework	What carers of people with dementia have told us – findings, good practice examples and areas for improvement
	During the pandemic **7% of carers requested a carers assessment but were denied** **59% hadn't requested a carers assessment** **34% said it was not applicable** • Information received prior to the survey, in preparation for the legal webinar, indicated that not all carers were aware of, or familiar with their right to a carer assessment. • Carers assessments are not being made available to some carers when they have been requested. Coronavirus and the pandemic measures has been cited as the reason why these are not being done; this example quoted in a local authority which had enacted Care Act easements. • Carers assessments are not always considered to be of value "my carers assessment amounts to nothing in terms of support: **Best Practice** Carers assessments can offer the opportunity for carers needs to recognised separately from the needs of the person that they care for, and for support including signposting to be made available. The availability of information as part of this 'offer' and the value of community based services such as carers centres and groups is frequently mentioned. These forms of support have been less available during the pandemic but there are innovative examples where existing support networks have adapted including going on-line to enable carers to remain connected, informed and to maintain well-being. **Areas for Improvement** • Ensuring that carer assessments are provided alongside the provision of assessments for people with care and support needs. • The Health and social care system recognising carers as 'equal partners' in providing support

“I statements” *Making it Real* and the Ethical Framework	What carers of people with dementia have told us – findings, good practice examples and areas for improvement
	for people with needs, and having needs in their own right.
Care and support: **Were you or the person you care for receiving care and support in March?** **Were you or the person that you care for receiving care and support at the time of the survey?** **Changes in care and support**	**Findings** **In March, people with dementia and their carers were receiving care and support from the following sources:** **32% from local authorities** **18% from NHS** **26% privately arranged** **17% from the community** **28% - none** **At the time of the survey this had changed to:** **30% from local authorities** **17% from the NHS** **18% privately arranged** **11% from the community** **36% - none** These figures demonstrate the shift from care and support being provided by paid for care to unpaid care by families and friends. However what these figures do not highlight is the substantial reduction in the amount of paid care that in many cases is now being provided; the closure of day care and substantial reduction in the use of respite being key examples of this change. This has again placed

“I statements” *Making it Real* and the Ethical Framework	What carers of people with dementia have told us – findings, good practice examples and areas for improvement
	greater reliance on informal carers as critical in meeting the needs of people with dementia. “The day centre for Sikh Elders with Dementia was a good for both of my parents, but this has gone online recently, but is not the same as physically attending etc.” “No day centre support. No access to Live at Home Scheme. No local charity support. All changed to telephone contact or zoom meetings. Lack of socialising caused problems for my husband as there was no definite structure to the week anymore.” “I work in the NHS but have had to maintain my role as a hands on carer for an elderly vulnerable parent with dementia, whilst doing my best to maintain her safety as I continue to work with and alongside Covid patients” Carers have frequently recognised the need to keep the people that they care for, safe, which may have led to consciously reducing or removing services but have also been concerned that by doing so, in the future they may be seen by the health and social care system as no longer having eligible needs. Alternative options should be considered if the usual support is not available, and while this is challenging during the pandemic, there are not many examples where these seem to be have been considered. Direct Payments is a possible mechanism to continue to provide support but in a different way. “My wife has a severe form of FT Dementia and also has been living with PS Palsy, so requires 24 hour care at home. 3 days at the local day centre on a weekly basis withdrawn at the beginning of lockdown. 1 weeks respite every 7 weeks withdrawn. This has resulted in £600 a month costs just to provide some basic help during the day! No alternative help provided until I cited to the Local Authority 2 weeks ago that they had a duty of care to provide an equivalent level of support. They have come up with 10 hours a week extra support” People who are not eligible for financial support from the local authority can also face challenges.

“I statements” ***Making it Real*** **and the Ethical Framework**	**What carers of people with dementia have told us – findings, good practice examples and areas for improvement**
	Eligibility for financial support and needs assessments have suffered from confusion in the legislation in the past, however the Care Act made clear that needs eligibility should be considered first and separately from financial eligibility. An example where this hasn’t happened in practice: “The person that I care for has not had a needs assessment. I have now requested one and been told that there are definitely 'eligible needs' but as we are not entitled to any financial help I have been told that we would be 'low priority' and we are waiting for a social worker to be allocated.”
I have been able to continue as a carer in the way that I wanted to during the Coronavirus pandemic **If the person that you provide care and support for does not live with you, have you been able to continue to provide care and support in the way that you wanted to?**	**Findings** **26% agreed or strongly agreed** **58% disagreed or strongly disagreed** “I was able to continue caring, which was the important thing. We just had to get creative in how we did it.” **When the person with dementia does not live with the carer, these figures are even more stark** **28% agreed** **72% disagreed** Not living in the same household has created challenges for carers and when there is also a distance involved this becomes even more challenging. This has left people even more isolated and has exacerbated the situation further. “Have to be with my parents 24 hours a day only been home 3 times” “As I live 70 miles away I have been unable to travel to either of relatives with dementia. One is in a care home and one in extra care sheltered. Neither establishment has been proactive in supporting my

“I statements” *Making it Real* and the Ethical Framework	What carers of people with dementia have told us – findings, good practice examples and areas for improvement
	relatives to keep in touch despite us providing iPads” People with dementia living in care homes (the majority of care home residents), was a very frequent and recurrent theme from the respondents to the survey. Carers were particularly affected by the restrictions on carers visiting care homes and they felt that this was having a detrimental effect on the person with dementia. These are just a few of many comments made by carers in the survey: “Not allowed to visit My husband wasn't eating and drinking He has lost a lot of weight I feel he was pining for family I feel I could have coaxed him to eat and drink” “Since my husband was admitted to the care home in April 2019,I was allowed to assist with his care, each day for about 7-8 hours. I was affectively his keyworker. Since covid 19, in March 2020 the home closed its doors to all visitors, until recently when visits by appointments were allowed for 30 minuets every 2- 3 weeks.” “I am recognised only as my husband’s wife and no longer as the person who previously provided personal and emotional support. My visits are intermittent and at a distance. I am unable to comfort or touch husband during these visits. There is a chaperone present, always to ensure the visiting guideline are not broken.” **Best Practice** This comment summarises some of the experiences of carers as seen by a former carer who now works for a care support organisation and gives an example of how organisations are finding ways of adapting to meet local need. “I work on a Dementia Helpline and have regular contact with third sector providers of Dementia Services …... We are aware that there has been an enormous increase in carers' caring responsibilities since March. Many cancelled care calls from home care providers, because they feared infection. Carers then took on additional personal care responsibilities. Family members could not visit and support went to phone support, this put additional burdens on many carers who lost out on much needed respite. For most carers, they are relieved to be safe with the person they care for, but their social circle stopped, no more social groups, dementia cafes, tea/coffee shops. Only approximately

“I statements” *Making it Real* and the Ethical Framework	What carers of people with dementia have told us – findings, good practice examples and areas for improvement
	30% of (the town) carers have access to the internet. These kept in contact virtually with family and staff and other carers, but for the majority they relied on phone contact and support with shopping and prescription deliveries. Over time most carers became jaded and some really struggled to cope. We set a freephone helpline up each evening for these carers in May and this is still going strong.”
Knowing my legal rights as a carer and access to information	**Findings** **Only 32% of carers agreed that they knew their legal rights and had access to information** Both the legal webinars and the carers survey have highlighted how little carers generally feel they know about their legal position and how the law can support them in their role. Carers are frequently confused about how the health and care systems work and how to access care and support. Staff working in health and social care systems themselves are often unclear about how it all fits together. There is also confusion from carers about sources of financial assistance and the rules around this. Some carers consider that they are knowledgeable about their rights. “It would be dangerous for me to think I know everything. I think I am reasonably well informed about our rights.” However carers are often uncertain about their rights and don’t know what they don’t know. Carers are also often unclear about where they can go to get accurate information that is relevant for them. “The information in the media, and largely what I have found online relates only to typical working families and essential workers. Anyone outside that seems to have been overlooked.” “I thought I had no rights because he is placed in a state funded home and that my power of attorney was worthless too.” “Very little information or access to legal information I work in the NHS; so have an understanding from that in terms of LPA and MCA but nothing has been advised to us as a family/ carer”

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	The way in which carers can feel undervalued by a lack of information and legal agency is summed up in this quote “But do my rights matter at all?” Even when carers are more knowledgeable about the law and their rights, it can still be difficult to exercise these when in contact with health and social care services as this quote confirms “I am sure many legal rights are being ignored. There was a situation at ….. Hospital over my husband’s care where I was told that POWER of ATTORNEY just simply didn't matter. They took him off asked him thousands of questions which he couldn't answer so he began to make up the answers and this affected ..influenced the care they gave him .. or in this case DIDN'T give him. He was discharged with severe concussion, couldn't walk out of A and E, and was being sick ... and not making any sense to me. I had to take him back next morning because he was bleeding from his eye to find out that they had recorded the rubbish he had spoke even though he had dementia and recorded it as FACT. The second time they did allow me to stay with him as his representative. I know my legal rights and those of my husband were breached but did not know enough to stand my ground.” **Best Practice** There are examples of best practice where people have had their concerns listened to and have received timely and appropriate signposting. The Justice Hub at The University of Manchester runs a Dementia Law Clinic. This provides free legal information to people and their carers. Their involvement in the Legal Webinar was greatly appreciated by many participants in the event. “I do not know my legal rights or neither am I up to date with information but I have become more involved with Forward Carers since my breakdown who, already in the space of 2 weeks, have assessed me and referred me to relevant agencies but most importantly listened to me so I feel the

"I statements" *Making it Real* and the Ethical Framework	What carers of people with dementia have told us – findings, good practice examples and areas for improvement
	information I may need will be available when required" "The carers centre was helpful in keeping us aware of our rights - info was not given as dementia specific." **Areas for Improvement** • Carers having greater access to timely, clear and accurate information including in non-digital form • Health and social care professionals having a greater understanding of carers rights and the power that these rights confer • Carers rights being respected and valued

“I statements” *Making it Real* and the Ethical Framework	What carers of people with dementia have told us – findings, good practice examples and areas for improvement
I have been treated with respect and have been included in decisions that have affected both me as a carer and the person that I am caring for **I am supported by people who listen to me. They support me to live the life I want**	**Findings** **Only 42% of carers felt that they had been treated with respect** There were positive comments made by carers but the picture is very mixed: “People have been as helpful as possible in the circumstances. Aware of limitations on everyone and resources are very stretched.” “Social worker and district nurses and (once - after mum fell) paramedics have been superb” “I have always been treated respectfully, but I feel I need to make clear that certain details of my husband's care need to be addressed, as detailed in his care plan.” “Despite having Power of Attorney, the social workers only take into account what they are being told by the cared for. As they have/had dementia, they don't/didn't have capacity to make informed choices about what they do. For example, he refuses to eat his meals for the carers, so they just leave it there and say "he didn't want it", noting down in the book that he refused food. Clearly, this is not an option as he has to eat to stay alive but, as it's his choice, they don't push it. We always manage to encourage him to eat, even if he says he doesn't want it initially.” “This is a two sided answer .. The Community health care team and some GPS have treated us with great respect. Some GP's and NHS staff certainly haven't Their behaviour has been extraordinary and disinterested and verging on negligent” “Decisions seem to happen and I am informed later.” In the area of Advance Planning and DNAR’s, some feedback from carers is particularly distressing: “I have had no discussions or input with the Community Nurse Team regarding their decision for 'Refusal to Treat'/'Withdrawal to Care'. I cannot explain how devastated I was when they informed, constantly bursting into tears since yesterday because I believed, they made me believe and prior to

“I statements” *Making it Real* and the Ethical Framework	What carers of people with dementia have told us – findings, good practice examples and areas for improvement
	COVID-19, we were a team. It has affected the way I interact/feel towards them as I no longer trust them at all. That therapeutic bond has gone.” **Best Practice** There are clearly examples of the health and social care system working as ‘equal’ partners with carers to best support the person with dementia. These examples have been very much appreciated by carers and their families and should become the norm for how people and systems work together. **Areas for Improvement** There are also clearly areas where actions are being taken and decisions made without adequate reference to and involvement of carers even when they have legal authority via Powers of Attorney. Actions are needed to address these concerns and to ensure active and appropriate involvement of carers.

Themes and Recommendations

A number of themes have emerged from the L4DC focus on carers' experiences of the pandemic and the legal issues and legislative measures that have taken place.

Carer Assessments – the right of carers to have their needs as carers assessed has been incorporated in all contemporary social care legislation across the UK. This right was long fought for and seeks to acknowledge the immense contribution that unpaid carers make to the people that they care for including people with dementia, and is recognition that carers have needs in their own right which require support.

Recommendation:

1. Legislation and guidance should reinforce that the right to a carer's assessment has not changed as a result of the Covid-19 global pandemic. Systems should be in place to monitor that legislation and guidance are being implemented by social care authorities.

Care Homes – the concerns about the consequences of care homes being isolated from the wider community and unpaid carers and families have been well reported. People with dementia form the majority of care home residents (c70%). While there is unequivocal support for ensuring that residents and paid carers are kept as safe as possible, the detrimental affect of isolation is having a profound effect on people with dementia and causing great distress to carers.

Recommendation:

2. Unpaid carers form the biggest dementia workforce and save the health and social care economy about £13.9bn per annum, even before any impact of the pandemic is taken into account. The care home sector needs clear guidance about how to work with unpaid carers and include them in the care of residents safely. The proposal to government from One Dementia Voice to enable unpaid carers to be recognized as keyworkers should be supported; this would enable carers to have contact with residents in a care home in a safe and managed way and give them access to Covid testing and PPE. The care home sector needs clarity about how to include unpaid carers. It is encouraging to hear that Care Minister, Helen Whately has announced that a pilot to enable carers to be keyworkers in care homes in England is due to take place.

Decision-making: evidence from carers suggests that legal and ethical rights of carers are commonly being over-ruled during the pandemic. This affects people with dementia by excluding the carers who know the person best and understand their needs and wishes.

Recommendation:

3. Health and social care should automatically include carers as equal partners in key decision-making that affects the person with dementia's health and well-being. This should be accompanied by clear guidance to staff with monitoring arrangements in place to ensure decision making conforms to this standard. Staff should be reminded that carers have a legal right to be involved, for example, when they are acting under a Lasting Power of Attorney.

Carers Allowance: the benefits system includes the payment of Carers Allowance for carers needing to spend at least 35 hours per week caring for someone. Many carers are having to juggle both increased levels of caring, and employment. The current earnings level means that carers who are both caring for over 35 hours per week and working above the maximum number of hours or pay, are ineligible for the Carers Allowance.

Recommendation:

4. The rules around eligibility for the Carers Allowance should be revised on a temporary basis to reflect the current situation and the potential for further waves of the virus.

Information and the exercise of legal rights – carers found accessing information, and understanding and exercising their legal rights problematic. The lack of knowledge of carers rights within the health and social care system was already acknowledged prior to Covid with the importance of information and legal information being recognized as a key health outcome. This has been exacerbated by the pandemic. There also appears to be a potential chasm between strategic leaders and day to day implementation by front line staff in health and social care which can lead to misinformation and inappropriate messaging or use of the law.

Recommendation:

5. Information should be publicly accessible and transparent, for example concerning Care Act easements. Front line health and social care staff need to have an awareness of legal issues in relation to their role and those of carers and people with dementia.

Supporting people in their own home – this has proved to be very challenging for many carers as other services and support are reduced or paused. This has resulted in an increased reliance of unpaid carers to provide critical support. While some services and support have been able to make some adaptations that have been creative and welcome, many carers feel very isolated and unsupported. Community services have been a lifeline for carers previously and continue to try to adapt. Options for formal support are not always being considered creatively leaving carers with inadequate support. The rules around the financial support usually available to carers in the form of the Carers Allowance, have continued and do not recognise the exceptional contributions that carers are having to make.

Recommendations:

6. Local authorities and their front line staff should exercise creativity about meeting needs in partnership with carers and the person with dementia to provide alternative options for care and support where possible.
7. The crucial role of community support activities and their ability to diversify to provide a range of approaches in a changing environment should be recognized and supported by health and social care commissioners.

Appendix 1: Law for Dementia Carers webinar feedback

Number of responses: 14

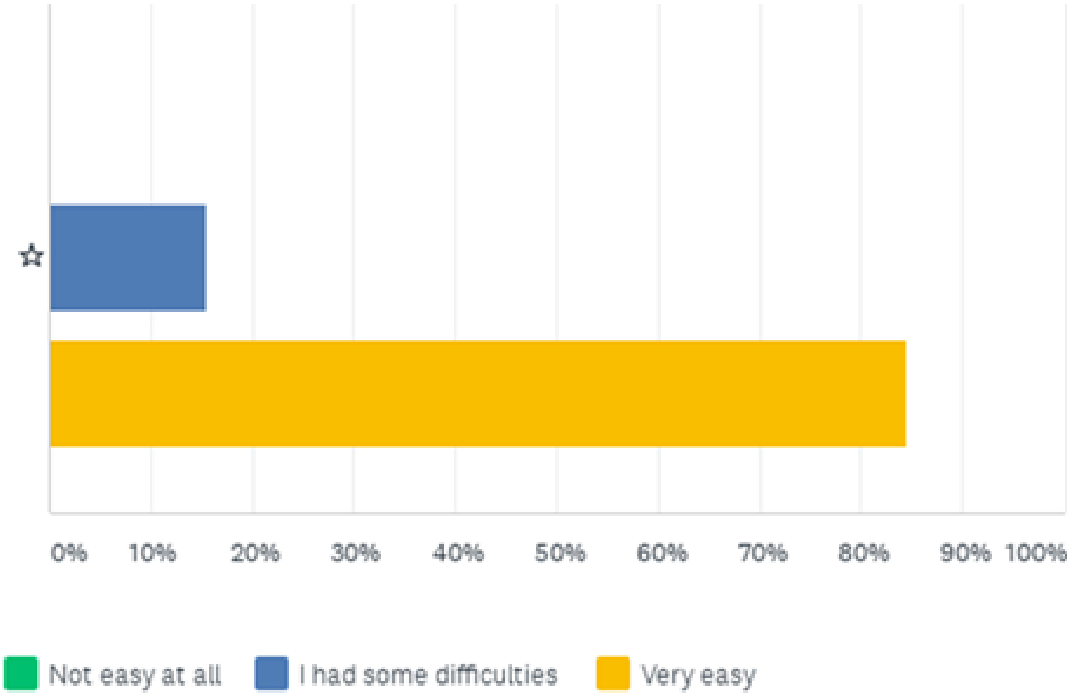
Q1 How did you hear about the Law for Dementia Carers webinar?

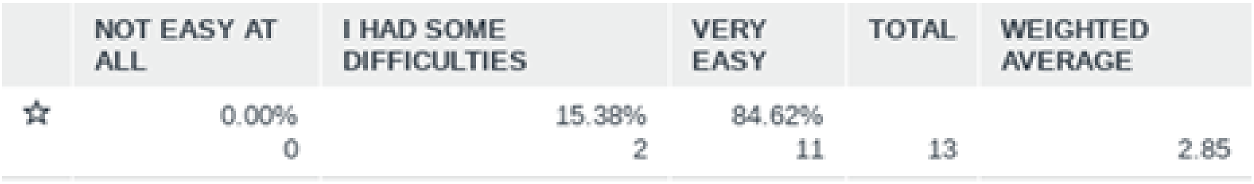
Number	Responses
1	Through Making Space
2	Email from carers hub
3	Support for Carers
4	I am a member of Tide
5	From TIDE
6	From TIDE.
7	The information was emailed to me by a local district council team I work in partnership with.
8	Email
9	Forwarded to me by the manager of my husband's Day Centre
10	Recently joined tide
11	From an Email sent by Tide.
12	6 degrees carers support
13	Through tide
14	Email from The carers center Leicester

Q 2 Please tell us the name of your Local Authority:

Number	Responses
1	Derby City Council
2	Dudley
3	Leicester County council
4	Knowsley
5	LONDON BOROUGH OF CROYDON
6	Wiltshire
7	Waverley Borough Council/Surrey County Council
8	Cheshire west
9	Essex
10	Oxfordshire
11	City of Bradford Metropolitan District Council.
12	Salford
13	Liverpool
14	Leicestershire County Council

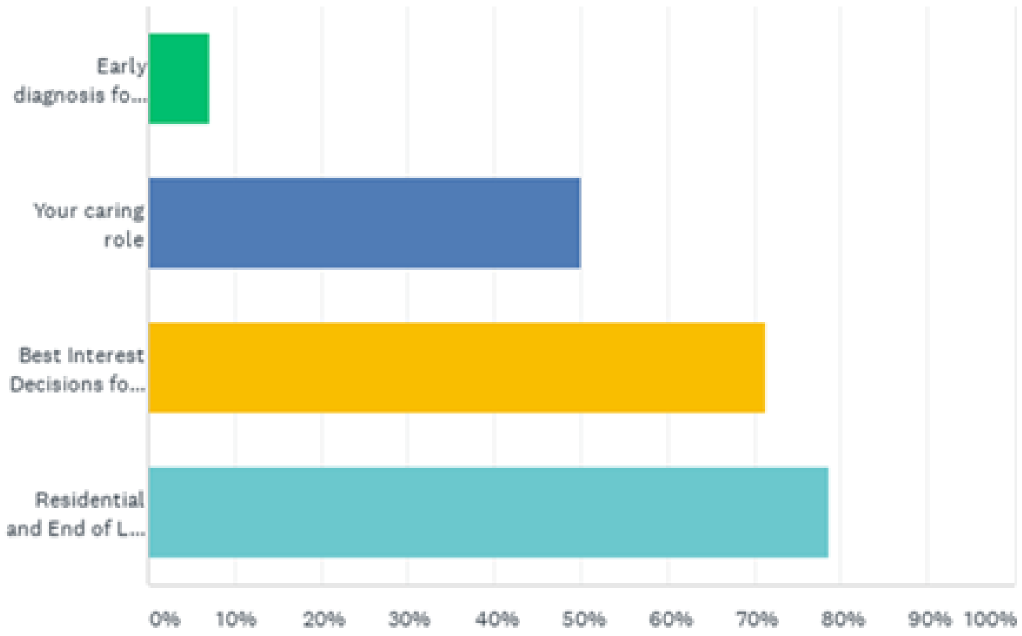
Q3 How easy was it for you to book your place and access the webinar?





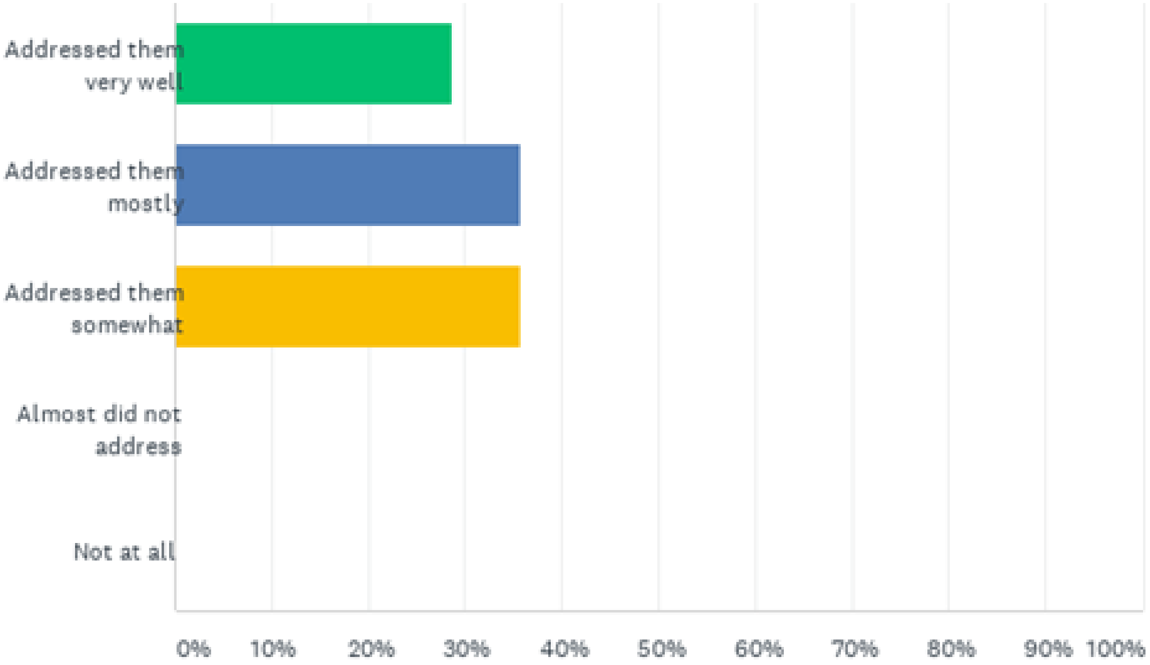
	NOT EASY AT ALL	I HAD SOME DIFFICULTIES	VERY EASY	TOTAL	WEIGHTED AVERAGE
☆	0.00% 0	15.38% 2	84.62% 11	13	2.85

Q4: The webinar covered 4 key areas: Your caring role, Best Interest Decisions for the cared-for person, and Residential and End of Life Care. Which of these key areas were you most interested in?



ANSWER CHOICES	RESPONSES	
Early diagnosis for the cared-for person	7.14%	1
Your caring role	50.00%	7
Best Interest Decisions for the cared-for person	71.43%	10
Residential and End of Life Care	78.57%	11
Total Respondents: 14		

Q5 How well did the contents of the webinar address your preferred key areas?



ANSWER CHOICES	RESPONSES	
Addressed them very well	28.57%	4
Addressed them mostly	35.71%	5
Addressed them somewhat	35.71%	5
Almost did not address	0.00%	0
Not at all	0.00%	0
TOTAL		14

#	PLEASE PROVIDE YOUR COMMENTS
1	I have experience in all areas discussed. It's very important that any updates or change of policies relating to health and social care are communicated.
2	Following the event I had emailed Neil regarding the free legal advice to which he had alluded and still await his response.
3	In the flyer, there was mention of the Coronavirus Act 2020 and how services for carers could be withdrawn if an LA triggers easement. I was hoping for much information about this - esp as the flyer also said that our comments would be put fwd when the Act is reviewed in the coming months.
4	Although some of the content I was already familiar with, I have not had such clear and practical information about deprivation of assets and mental capacity. I also found the personal experiences of carers and their questions very useful.
5	Very interesting webinar and although time was long enough for it, a follow on would be great
6	More info on funding and finances would be much appreciated and an explanation of the financial assessment and how it is calculated
7	As everyone's situation is different it is hard to address things in this type of setting. Our situation is that we are self-funding but would like to access professional help from health service and/or social services. Local memory clinic service has 'discharged' mum to GP so we now have no access to any specialised medical or social care support. Also waiting for a social worker but of course we are not high priority. We are not in crisis but there could well be a crisis point before we are anywhere on anyone's priority list. Is dementia a disability or a physical health condition? If so, why can't we access help from NHS?
8	It is difficult to cover everything, the meeting ran over and I had to leave at the planned finishing time.
9	I was a little confused about how these key areas were being covered at the beginning of the webinar. I think my real problem was that I had no information about the easements and hoe these may relate to me.
10	I had to leave the seminar earlier than I wanted to, so missed some of the content that would have been most useful. one of the reasons for leaving early was because some of the questions and content brought forward by other participants seem to be taking over the session

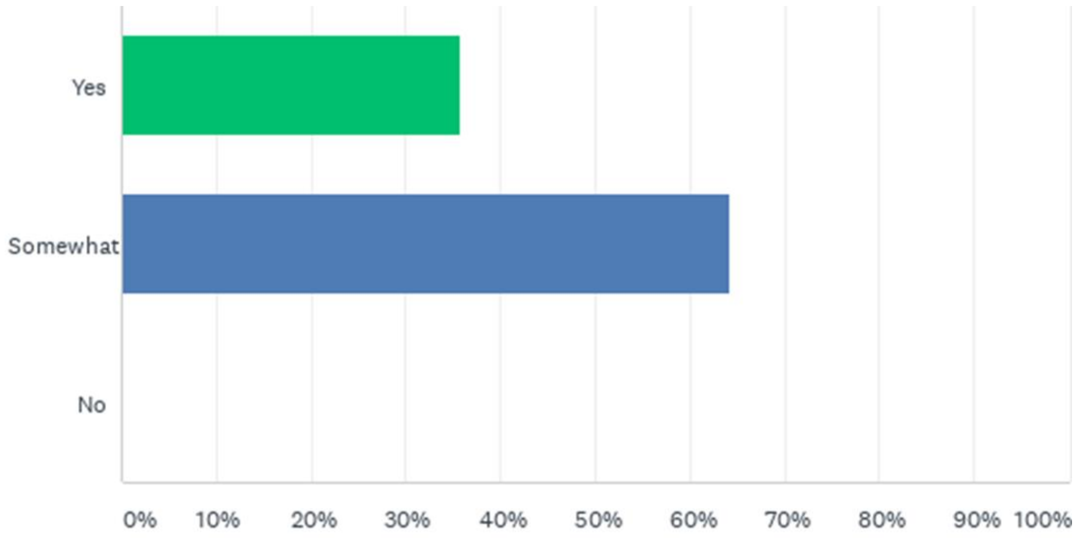
Q6 What other topics would you have liked the webinar to have addressed?

#	RESPONSES
1	Continuing care
2	The lack of the correct community facilities support for carers especially when the cared for require 24 hour care.
3	Would having Advance Directive need to be registered and is there a fee payable?
4	The Coronavirus Act 2020. Care homes charging residents for PPE (this affects the unpaid carer).
5	Other law relevant to people with dementia and their carers that is less well known/harder to find information on. Relevant case law.
6	Financial help
7	What happens if self-funded and money runs out?
8	As above!
9	All the major areas had been addressed. It was not intended to provide legal advice.
10	Legal implications of not having power of attorney or court of protection. Advice In respect of assets/property rights of person suffering with dementia and carers left with the responsibility

Q7 Please tell us if you have taken action or done anything differently as a result of attending the webinar.

#	RESPONSES
1	I have discussed tide with my brother who shares Power of Attorney with me for my mother
2	I have re-visited the care act and decided that I need to plan quality study time relating to Dementia.
3	I plan to set up a Lasting Power of Attorney myself.
4	I have already been supporting a carer with LPA for his wife who is at the stage of needing paid care. I was able to more confidently advise him of the implications of the council perceiving deprivation of assets and what he should do if there was a dispute.
5	Have contacted social services and got more funded hours
6	No.
7	No

Q8 Has attending the webinar improved your understanding of legal issues faced by carers of people with dementia?



ANSWER CHOICES	RESPONSES	
Yes	35.71%	5
Somewhat	64.29%	9
No	0.00%	0
TOTAL		14

#	PLEASE PROVIDE FURTHER DETAILS BELOW
1	I personally was aware of all the issues discussed because of personal circumstances relating to a family member LWD who I cared for. It was vital I knew and understood legislation. This was vital as during that period, I had to fight/ advocate on behalf of my family member especially for CHC funding.
2	When the two attorneys appointed need to agree on a course of action and they are each determined to disagree, the matter gets referred to court. Resulting expenses can deplete the individual's assets the longer it takes for the matter to be resolved.
3	Free legal aid available in a DoLs situation.
4	The question time where carers could ask about their own circumstances really helped me to see how the law can be applied in real scenarios, which I often find difficult to understand when advising carers.
5	I still have questions
6	I would like to understand more. I want to use my experience to help others and to be able to learn from what others have experienced or studied as well.
7	It cleared up my understanding of some issues.

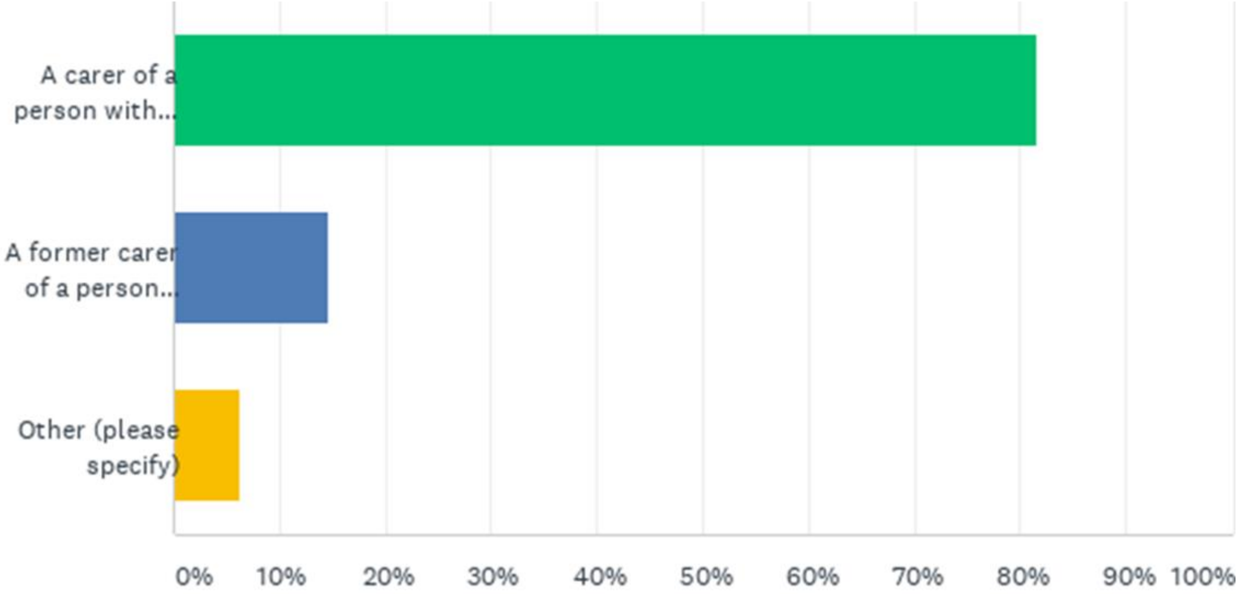
Q9 Other comments or suggestions

#	RESPONSES
1	Interesting to share similar experience with others
2	I'd like to say thank you to all involved and looking forward to more of these events in the future.
3	The Law Professor was excellent and so patient. It was great the way some of his students were given the chance to present also. However, for me, too many questions were taken from carers and then often subsidiaries allowed. This was very time-consuming - no wonder the event over ran. Given the fact that we all have the opportunity to make a private appointment with the legal project should we wish, it would have been more useful to have had fewer questions and more golden nuggets from the Professor.
4	Although I have been to other information events about some of these issues, this was the most useful and covered some areas I hadn't had much information about before. A really informative webinar.
5	It was good to hear from other carers
6	A number of the attendees were at pains to stress how important it was to keep their loved one at home perhaps making some of us who feel our family member would be much better placed and happier in a Care home feel a little guilty. Could we look at how to address this other option i.e. how to Convince the local authority this would be the right thing to do both from the family members point of view and that of the Carer?
7	Thank you for putting ion webinar and taking feedback. It was very well presented and easily accessible and inclusive. See question 3 above which wasn't easy to answer - due to format of question? I hope to take part in more events like this if possible so as to understand more and feel more connected to others and hopefully then be more confident and empowered in my role as a carer.
8	Try to stop some of the delegates in a polite way to stop "going on".
9	I have not completed LPAs for my husband, although we do at least have EPAs and this has prompted me to do so.
10	perhaps participants questions could be submitted prior to the seminar so they can be covered by the 'presenters' within the content, rather than the participant taking over the session

Appendix 2: Carers Covid-19 Survey

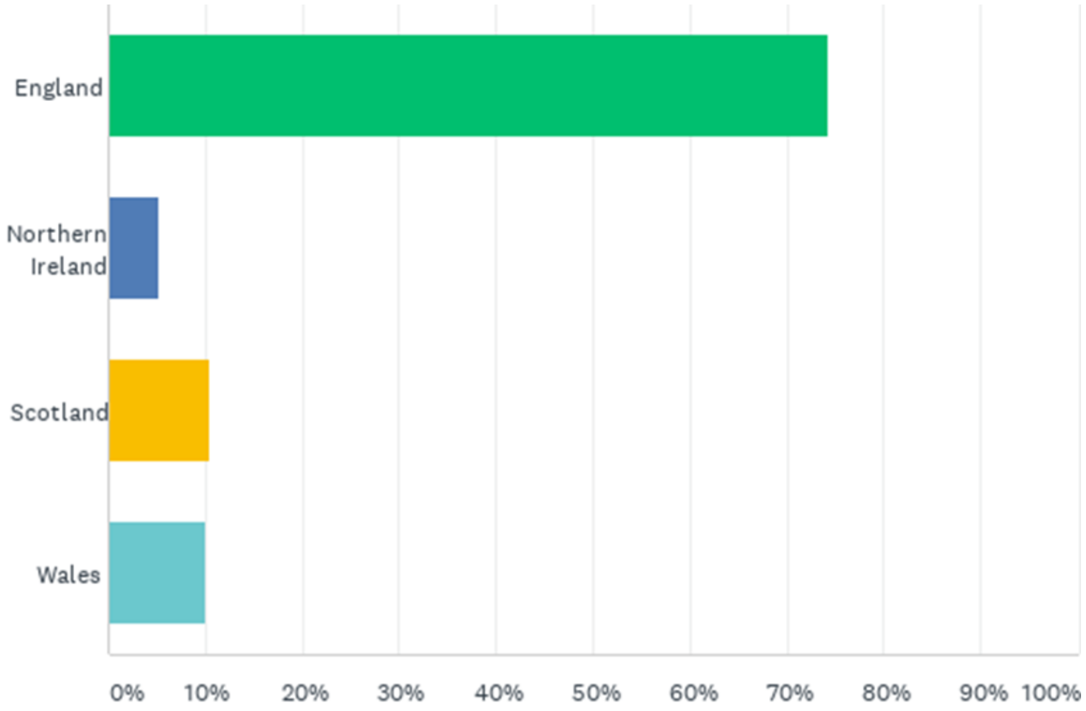
Total responses: 191

Q1 Are you:



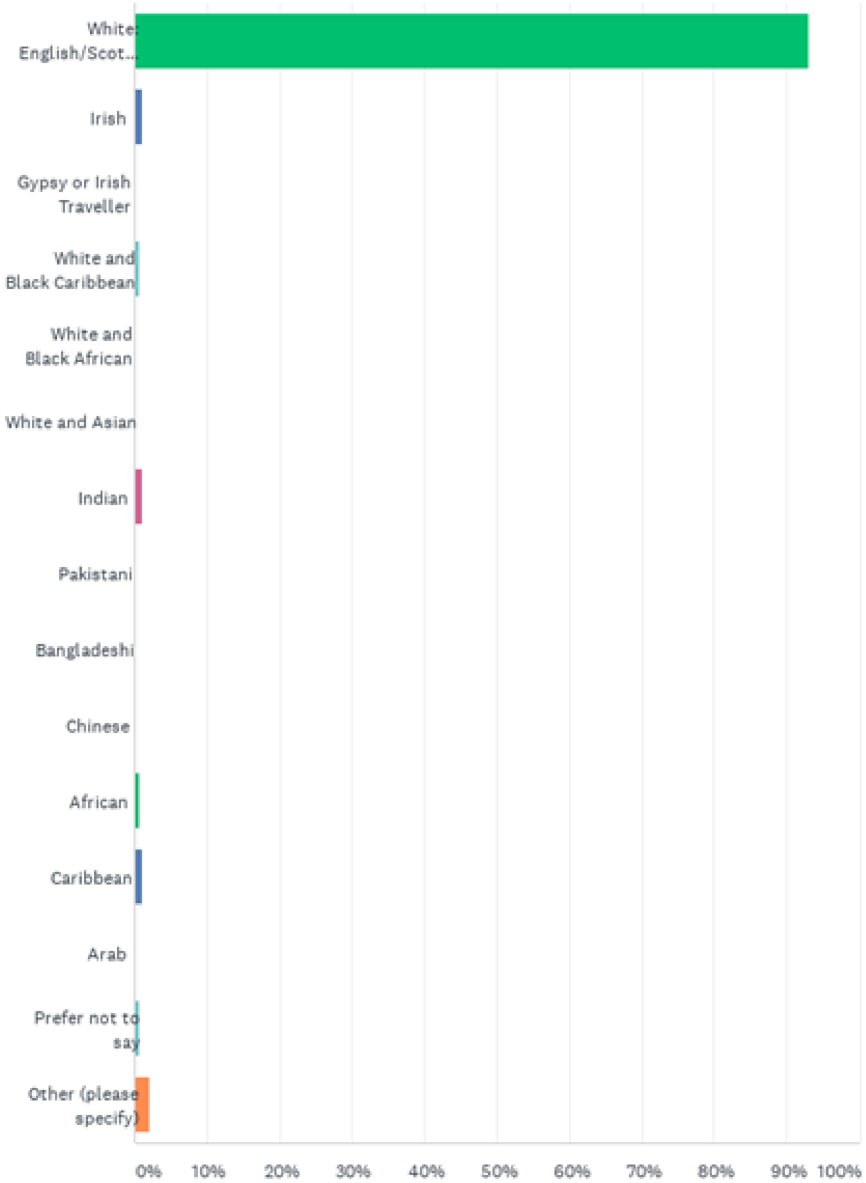
ANSWER CHOICES	RESPONSES	
A carer of a person with dementia	81.68%	156
A former carer of a person with dementia	14.66%	28
Other (please specify)	6.28%	12
Total Respondents: 191		

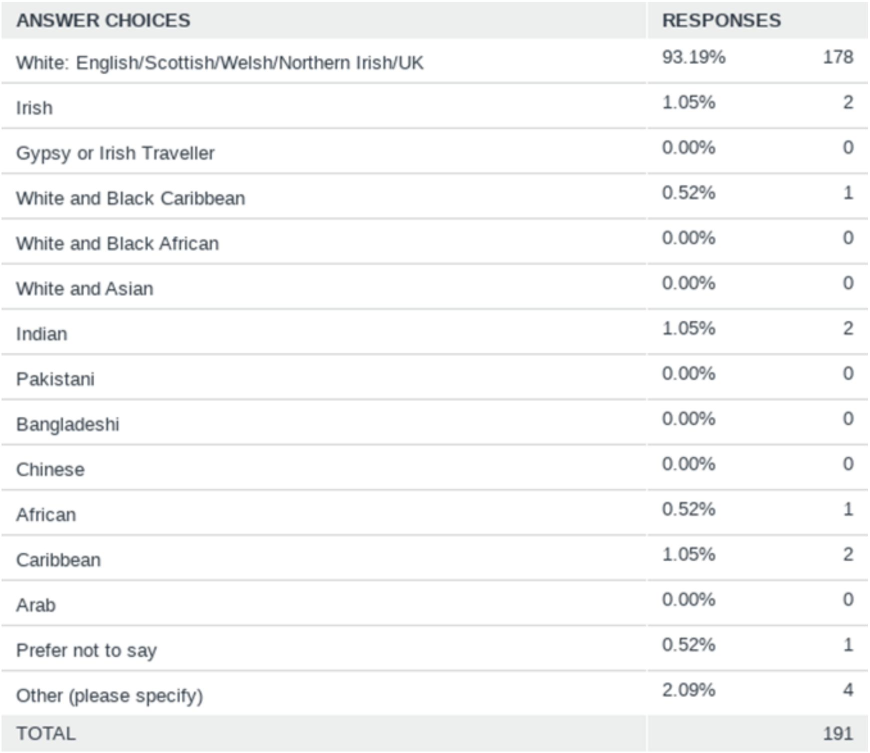
Q2: Where do you live in the UK?



ANSWER CHOICES	RESPONSES	
England	74.35%	142
Northern Ireland	5.24%	10
Scotland	10.47%	20
Wales	9.95%	19
TOTAL		191

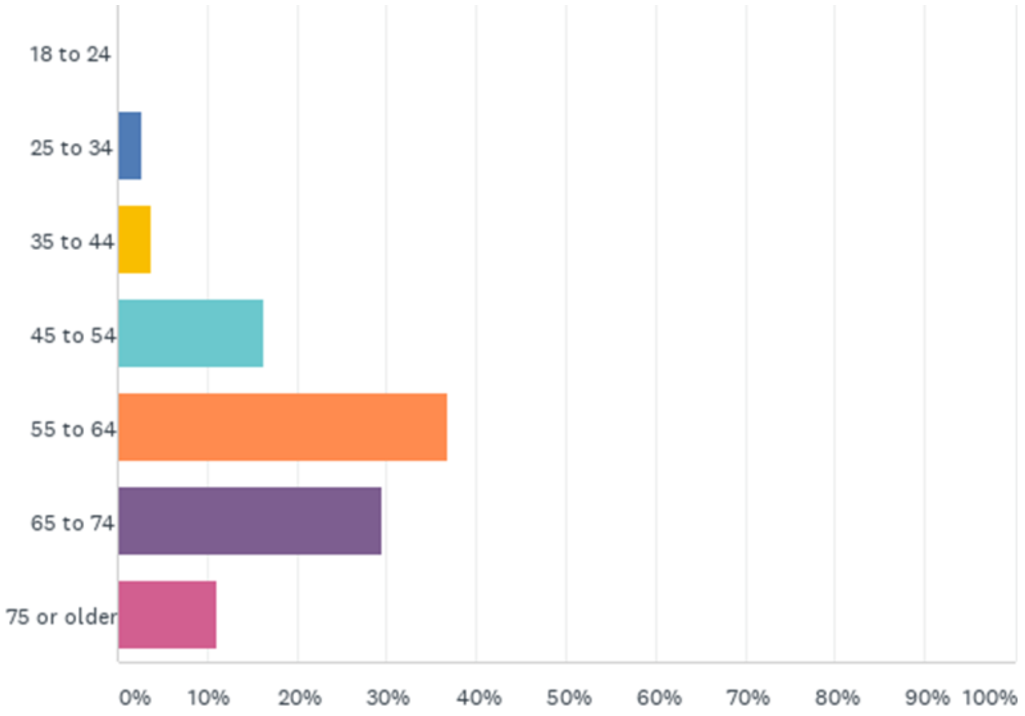
Q3: Which ethnicity best describes you? Please choose only one:

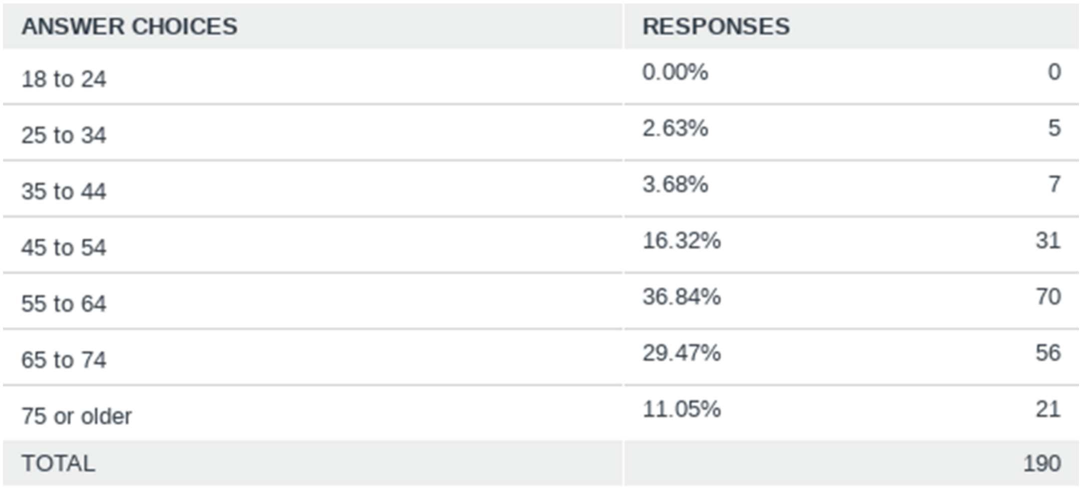




ANSWER CHOICES	RESPONSES	
White: English/Scottish/Welsh/Northern Irish/UK	93.19%	178
Irish	1.05%	2
Gypsy or Irish Traveller	0.00%	0
White and Black Caribbean	0.52%	1
White and Black African	0.00%	0
White and Asian	0.00%	0
Indian	1.05%	2
Pakistani	0.00%	0
Bangladeshi	0.00%	0
Chinese	0.00%	0
African	0.52%	1
Caribbean	1.05%	2
Arab	0.00%	0
Prefer not to say	0.52%	1
Other (please specify)	2.09%	4
TOTAL		191

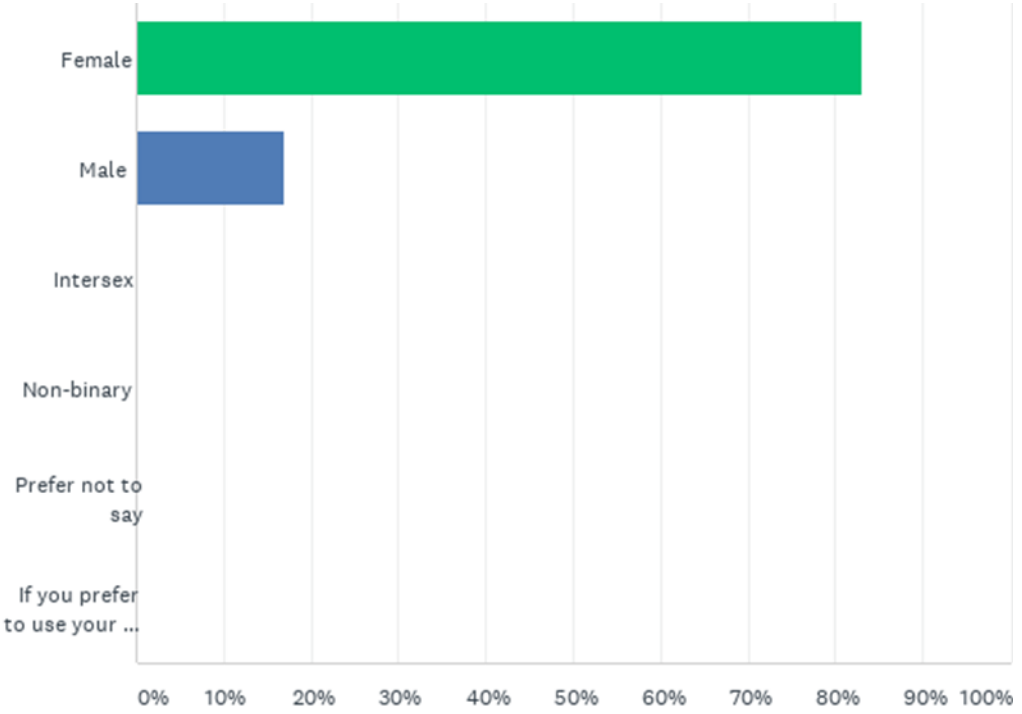
Q4: What is your age?





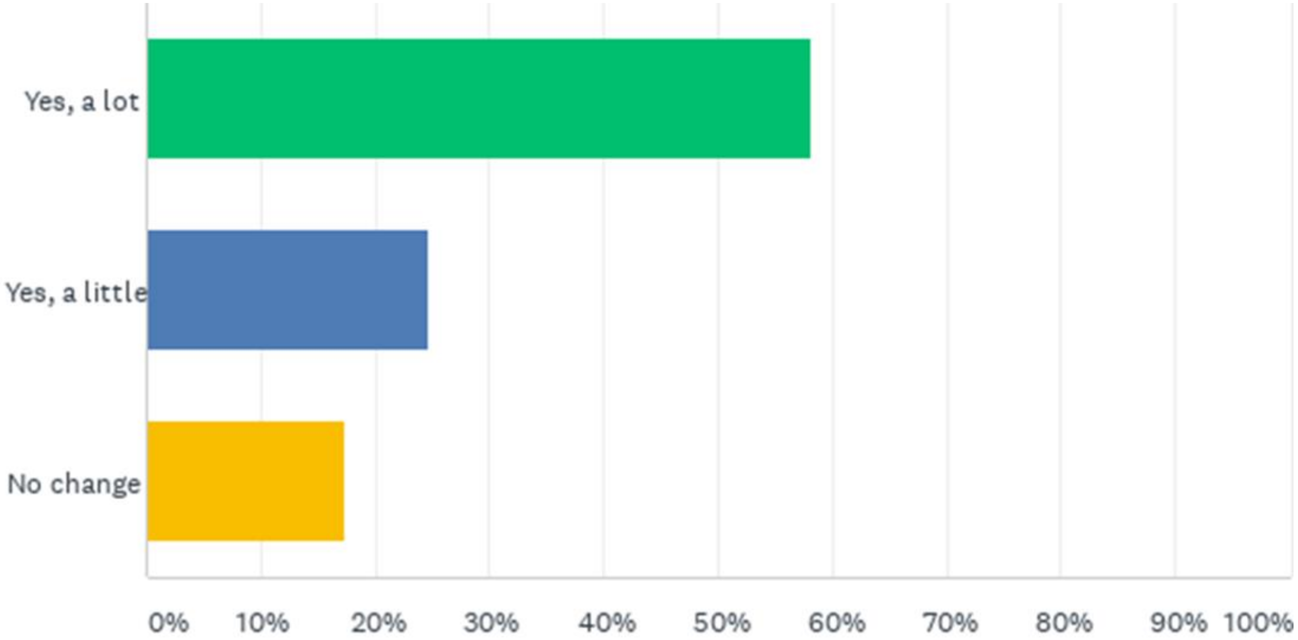
ANSWER CHOICES	RESPONSES	
18 to 24	0.00%	0
25 to 34	2.63%	5
35 to 44	3.68%	7
45 to 54	16.32%	31
55 to 64	36.84%	70
65 to 74	29.47%	56
75 or older	11.05%	21
TOTAL		190

Q5: What is your gender?



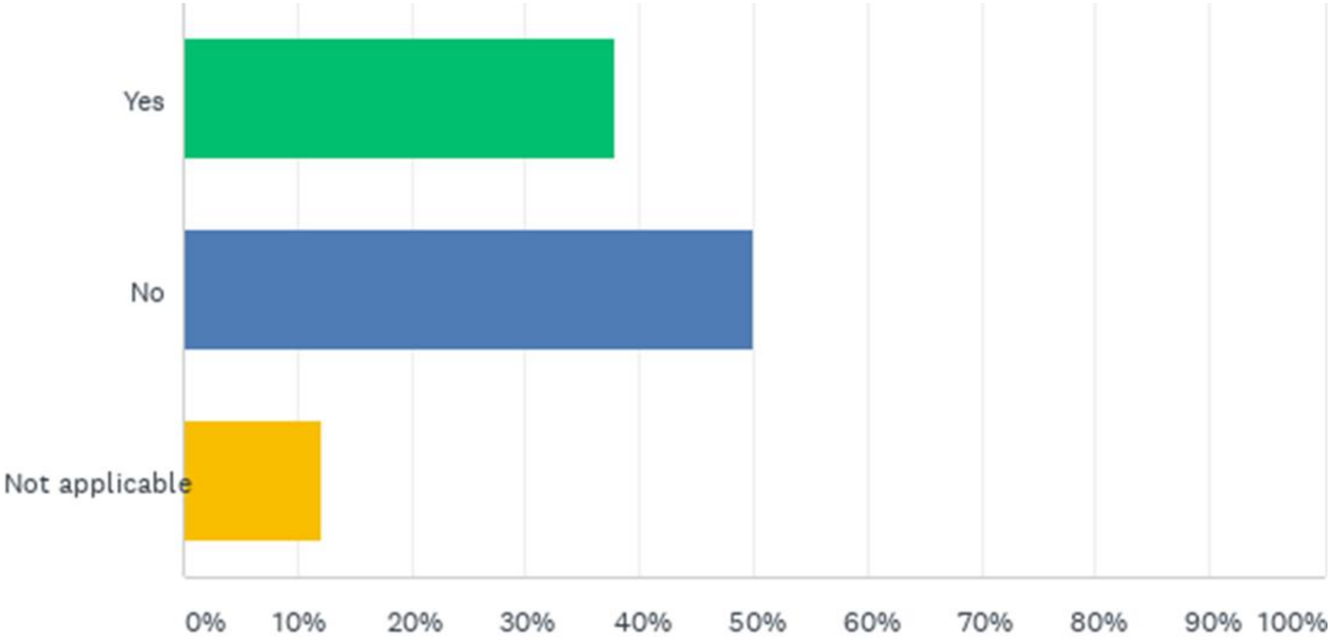
ANSWER CHOICES	RESPONSES	
Female	83.16%	158
Male	16.84%	32
Intersex	0.00%	0
Non-binary	0.00%	0
Prefer not to say	0.00%	0
If you prefer to use your own term, please specify here	0.00%	0
TOTAL		190

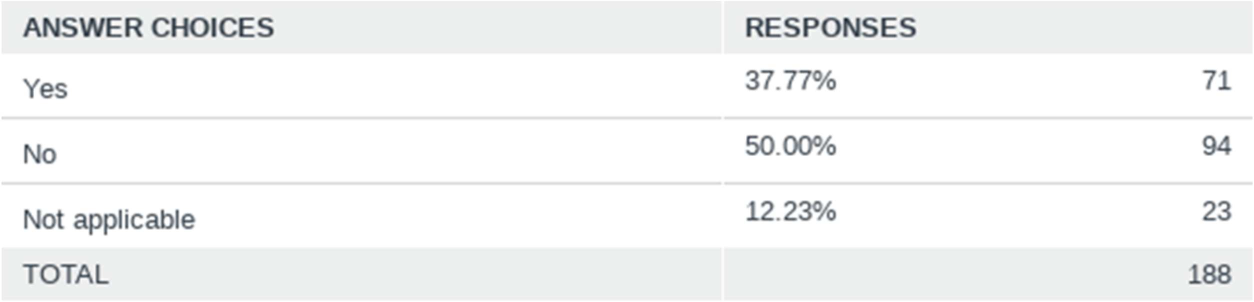
Q6: Have there been any changes in your caring responsibilities since March?



ANSWER CHOICES	RESPONSES	
Yes, a lot	58.12%	111
Yes, a little	24.61%	47
No change	17.28%	33
TOTAL		191

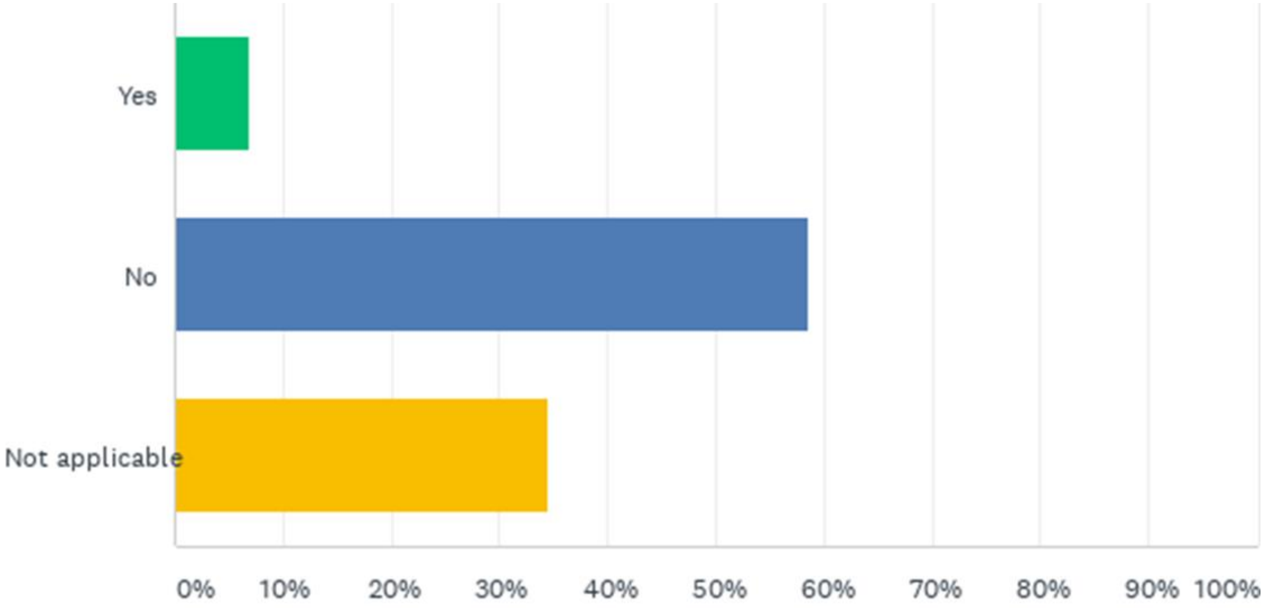
Q7: Did you have a carer’s assessment in place in March?





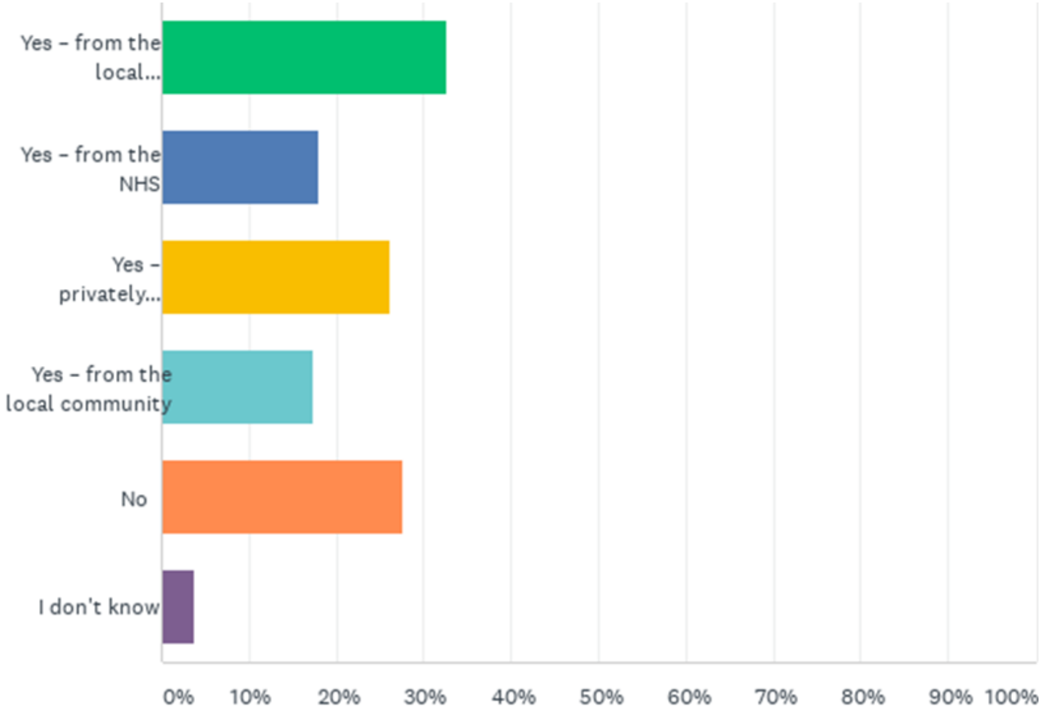
ANSWER CHOICES	RESPONSES	
Yes	37.77%	71
No	50.00%	94
Not applicable	12.23%	23
TOTAL		188

Q8: Since March, have you requested but been denied a carer’s assessment?



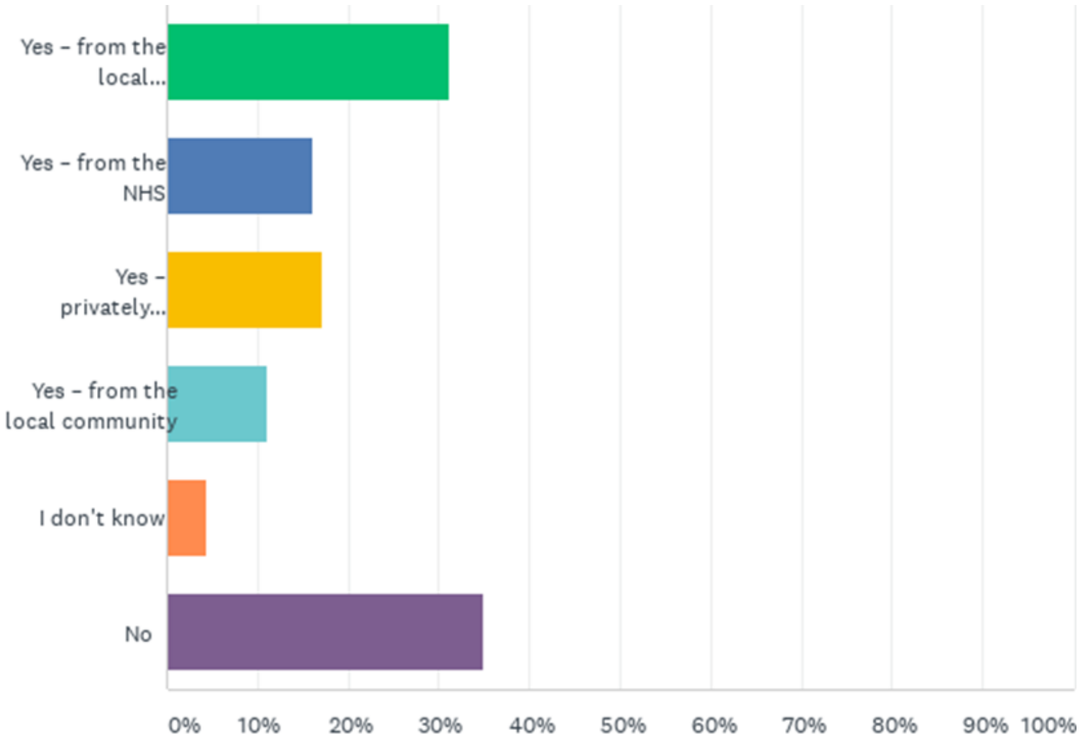
ANSWER CHOICES	RESPONSES	
Yes	6.91%	13
No	58.51%	110
Not applicable	34.57%	65
TOTAL		188

Q9: Were you or the person that you were caring for receiving care and support in March? (You can tick more than one box)



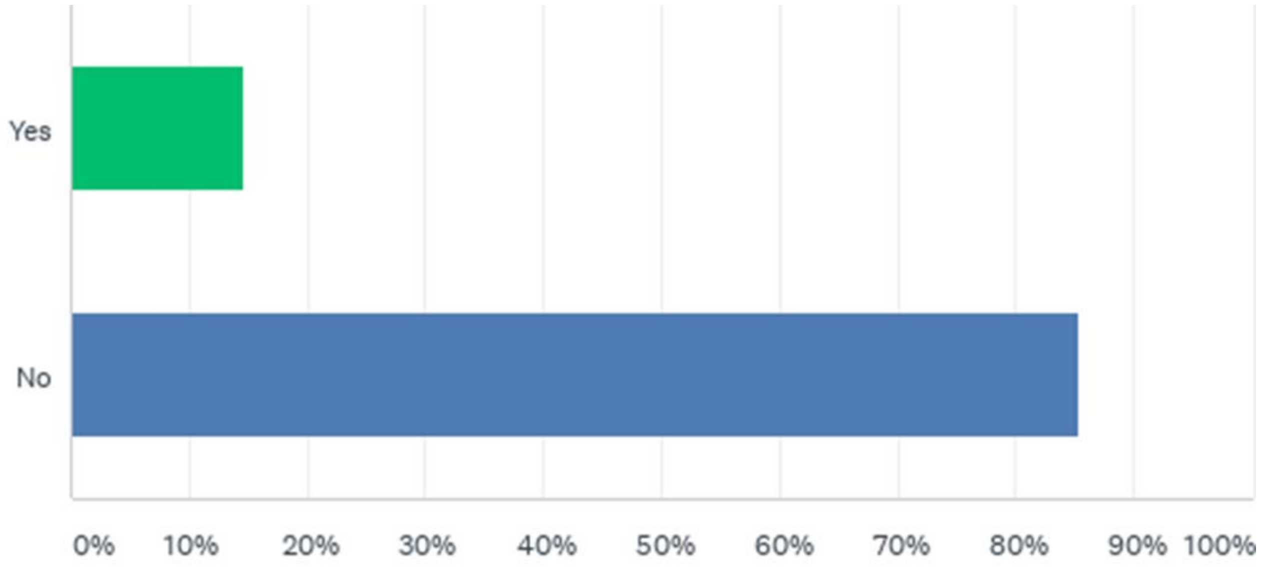
ANSWER CHOICES	RESPONSES	
Yes – from the local authority/ Health and Social Care Trust in Northern Ireland	32.61%	60
Yes – from the NHS	17.93%	33
Yes – privately funded	26.09%	48
Yes – from the local community	17.39%	32
No	27.72%	51
I don't know	3.80%	7
Total Respondents: 184		

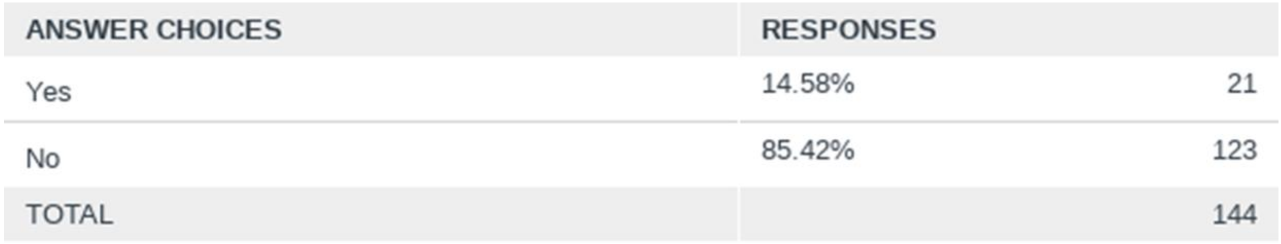
Q10: Are you or the person that you were caring for still receiving care and support? (You can tick more than one box)



ANSWER CHOICES	RESPONSES	
Yes – from the local authority/ Health and Social Care Trust in Northern Ireland	31.11%	56
Yes – from the NHS	16.11%	29
Yes – privately funded by the person who receives care	17.22%	31
Yes – from the local community	11.11%	20
I don't know	4.44%	8
No	35.00%	63
Total Respondents: 180		

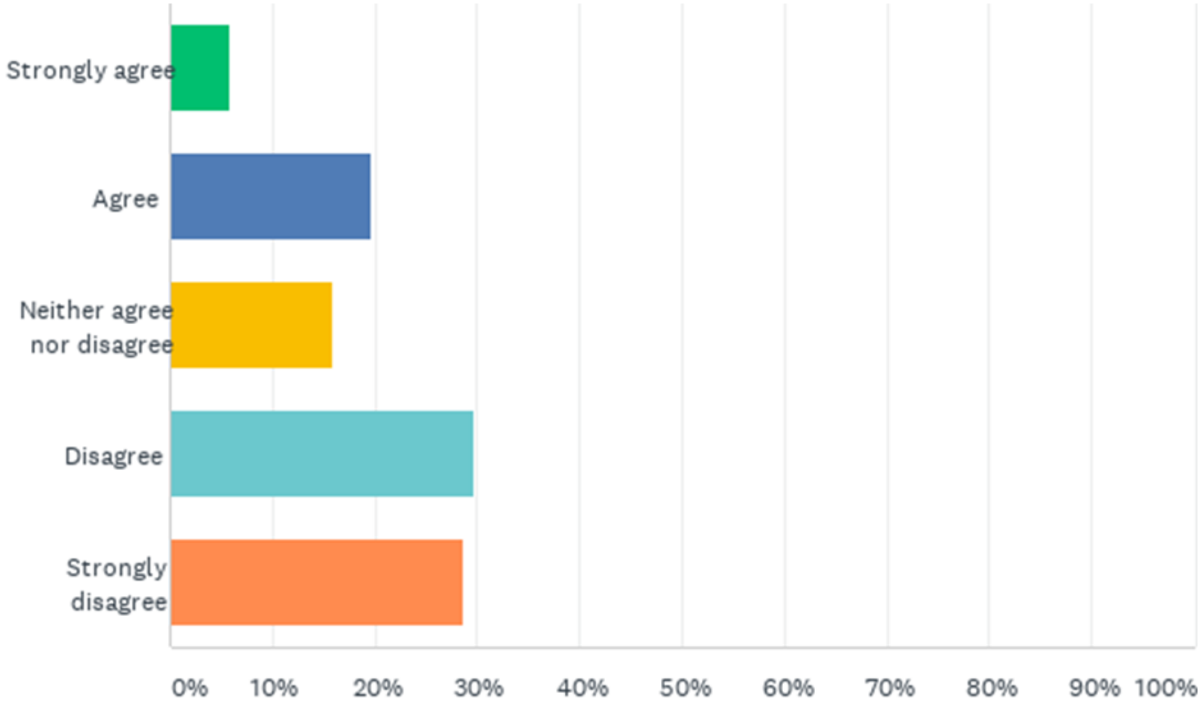
Q11: If the care and support has changed because of Covid-19 e.g. respite no longer being available, has an alternative option been offered to you?

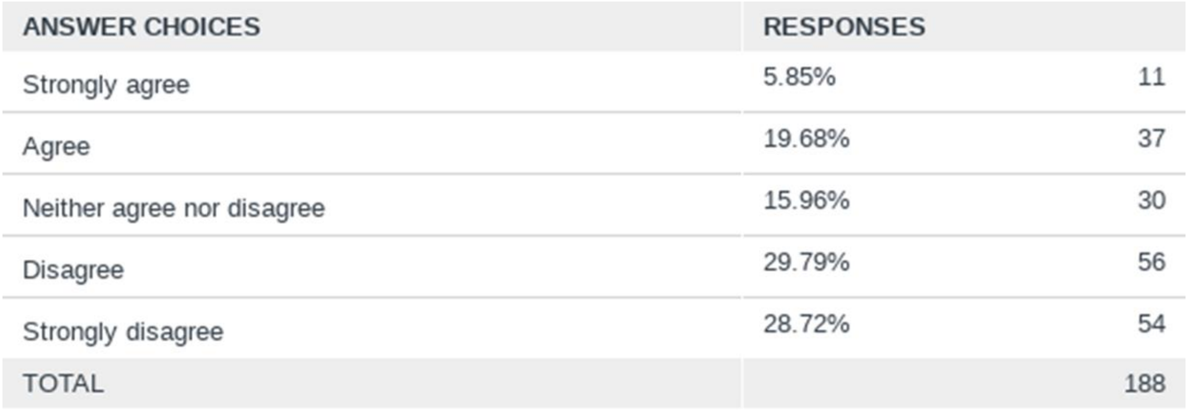




ANSWER CHOICES	RESPONSES	
Yes	14.58%	21
No	85.42%	123
TOTAL		144

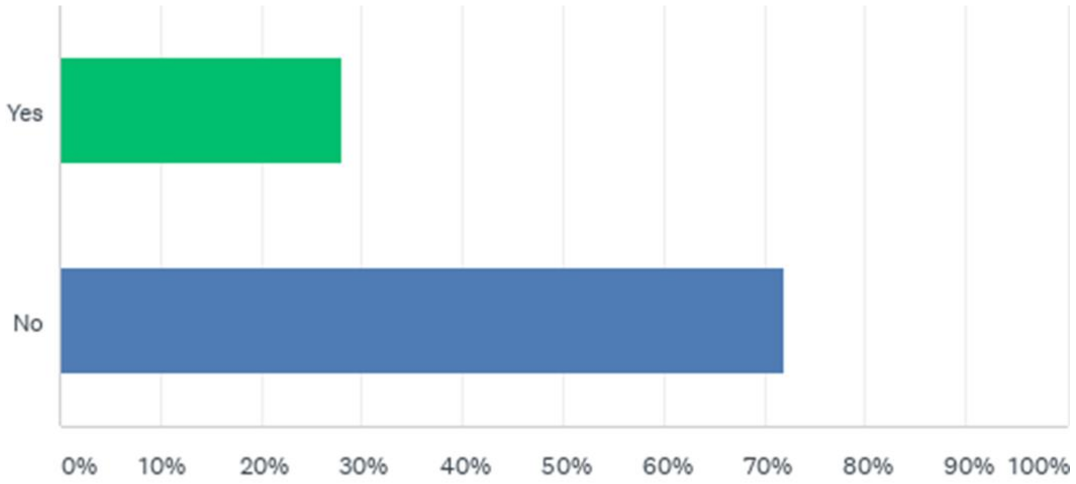
Q12: I have been able to continue as a carer in the way that I wanted to during the Coronavirus pandemic

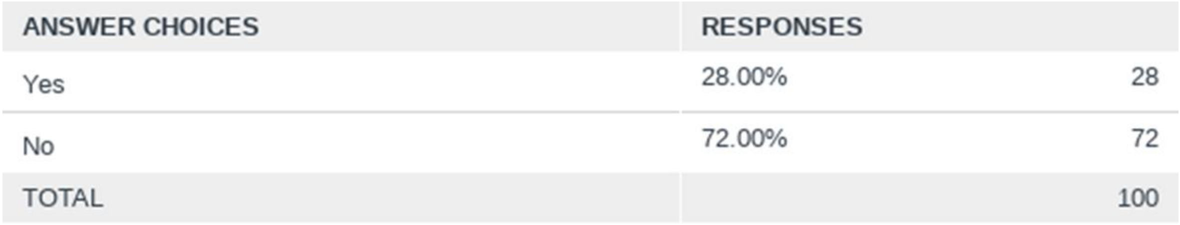




ANSWER CHOICES	RESPONSES	
Strongly agree	5.85%	11
Agree	19.68%	37
Neither agree nor disagree	15.96%	30
Disagree	29.79%	56
Strongly disagree	28.72%	54
TOTAL		188

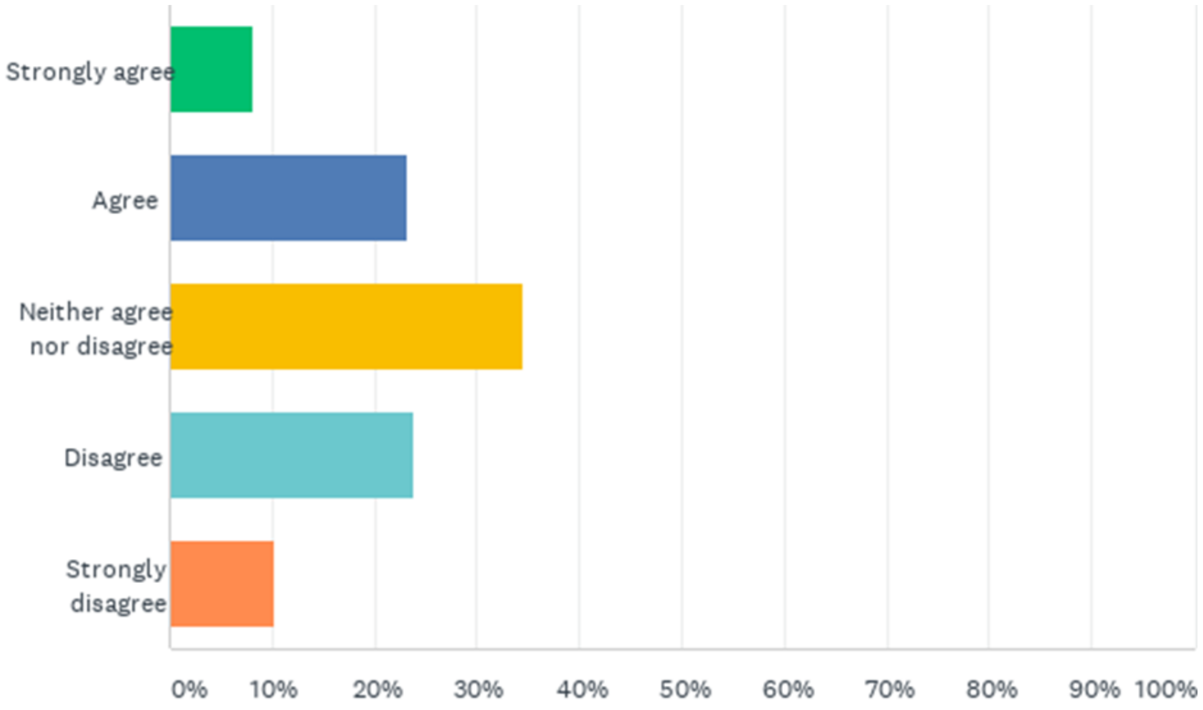
Q13: If the person that you provide care and support for does not live with you, have you been able to continue to provide care and support in the way that you wanted to?





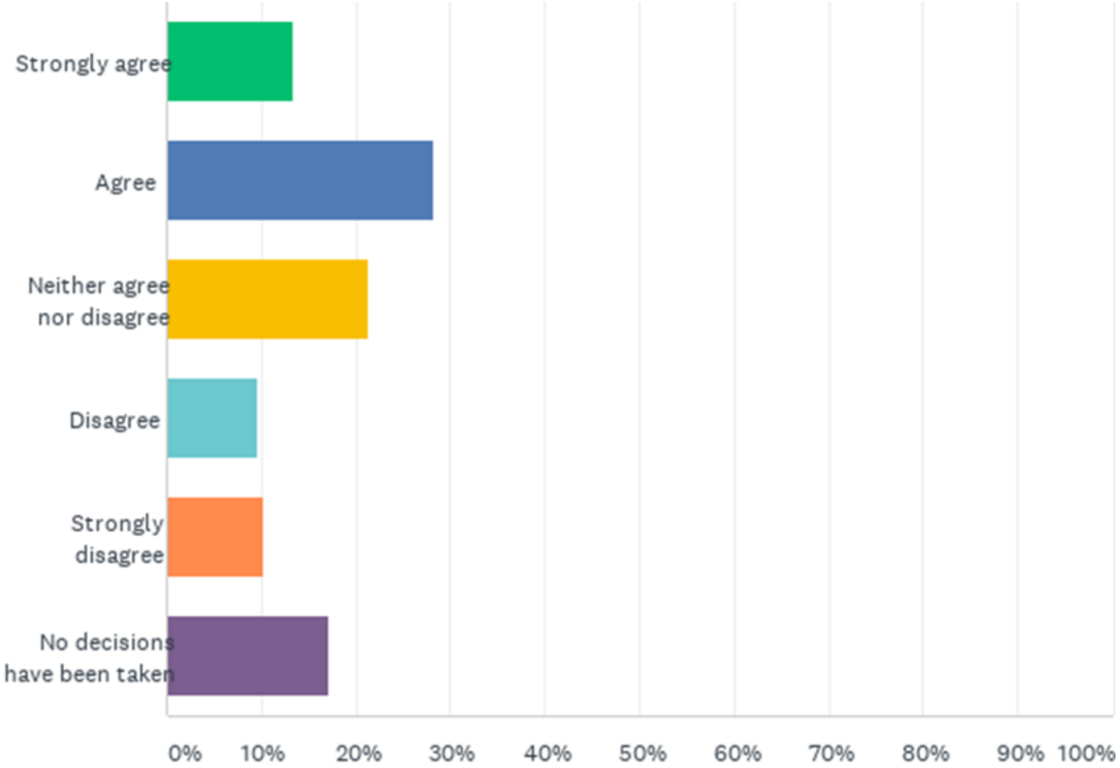
ANSWER CHOICES	RESPONSES	
Yes	28.00%	28
No	72.00%	72
TOTAL		100

Q14: I know my legal rights and have access to the information I need for myself as a carer and for the person I am caring for. The information has been accurate and up-to-date.



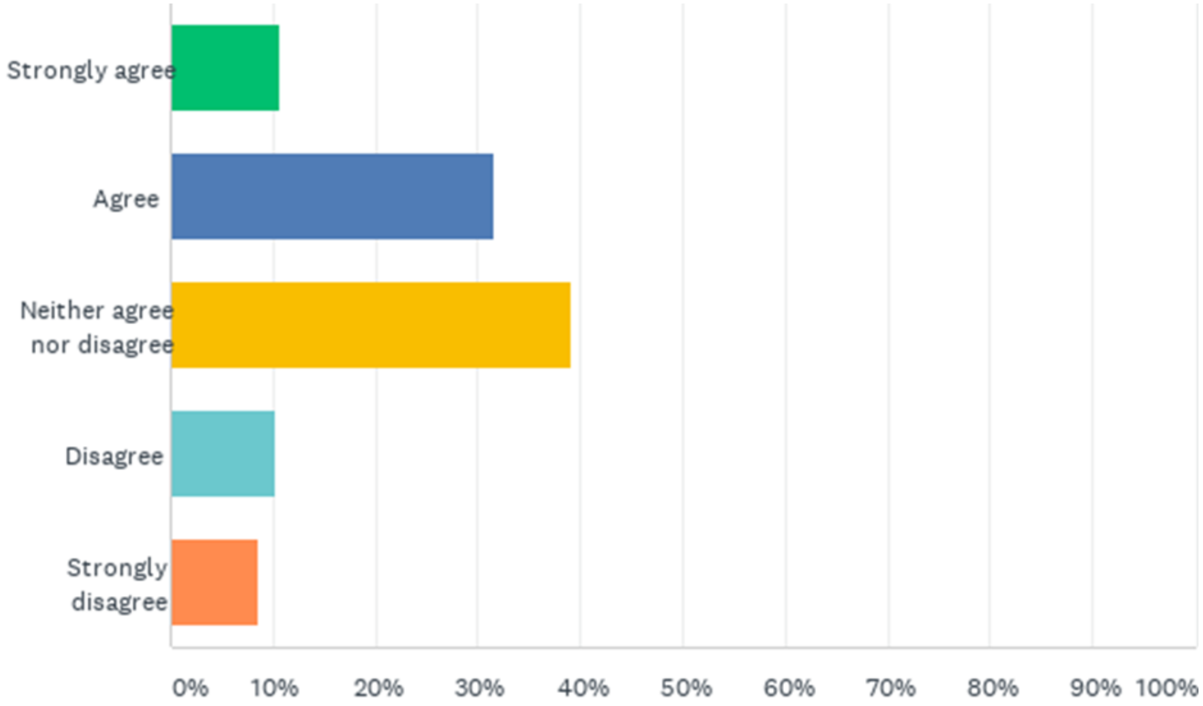
ANSWER CHOICES	RESPONSES	
Strongly agree	8.11%	15
Agree	23.24%	43
Neither agree nor disagree	34.59%	64
Disagree	23.78%	44
Strongly disagree	10.27%	19
TOTAL		185

Q15: I have been treated with respect and have been included in decisions that have affected both me as a carer and the person that I am caring for.



ANSWER CHOICES	RESPONSES	
Strongly agree	13.37%	25
Agree	28.34%	53
Neither agree nor disagree	21.39%	40
Disagree	9.63%	18
Strongly disagree	10.16%	19
No decisions have been taken	17.11%	32
TOTAL		187

Q16: I am supported by people who listen to me. They support me to live the life I want.



ANSWER CHOICES	RESPONSES	
Strongly agree	10.70%	20
Agree	31.55%	59
Neither agree nor disagree	39.04%	73
Disagree	10.16%	19
Strongly disagree	8.56%	16
TOTAL		187

Appendix 3

Greater Manchester Health and Social Care Partnership - Covid-19 Response Introduction and Background

L4DC (Law for Dementia Carers) is a 2 year project which is funded by The Legal Education Foundation which started in November 2019. It is a partnership project between tide and Making Space working together with the University of Manchester's Justice Hub. It aims to raise awareness and knowledge of legal issues that affect carers of people with dementia, among carers themselves and for front line health and social care staff via a social prescribing model. The project is the first in the country and is being piloted in the Greater Manchester area linked to the Greater Manchester Health and Social Partnership and Dementia United.

With the onset of Covid-19 and the introduction of the Coronavirus Act 2020, L4DC has temporarily pivoted its focus to the legal issues raised by Covid-19 that affect carers of people with dementia across the UK. It has produced information for carers on the Care Act easements, and held a legal webinar on 23 June which was well attended and received excellent feedback. A carers survey is being launched across the UK in July to seek feedback from carers about their experience of the first wave of the pandemic. While there have been many surveys conducted during this period, this survey is different in that it focuses specifically on the legal issues that carers have faced including the Care Act easements as a result of Covid-19.

Given the core geographic focus of this project, the links with the Greater Manchester Health and Social Care Partnership and Dementia United, a particular focus is also being given to Greater Manchester. The pivoted project wants to understand from a strategic organisational perspective, what this has meant for carers of people with dementia. This information, along with feedback from carers over this period will be used to influence the statutory 6 month review of the Coronavirus Act which is due in the Autumn.

Thank you very much for your time in completing this survey. Please can this be returned to Karen Greenhalgh, Project Manager – L4DC Karen@lifestorynetwork.org.uk by Friday 7 August.

Survey Questions

Completed on: 6 August 2020 Completed by: Gill Walters & Zoe Aldcroft Role: Dementia United.

Greater Manchester Health and Social Care Partnership is uniquely positioned in England to provide joined up health and social care for the 2.8 million people who live in the area. What have been the benefits of having a partnership during the pandemic?

In Greater Manchester, we have a whole public service approach to commissioning. In health and social care, each of the 10 localities has formed an integrated commissioning function between CCG and local authority – and several localities have a single chief officer for both organisations. This has led to the creation of significant pooled budgets at place level. These commissioning arrangements facilitate a whole system population health perspective on spend and deployment of models of care and support. ***As such, they have proved to be a vital enabler of an integrated, place-based response to COVID-19****. Social Care is an integral part of governance at local and GM level and this has allowed a fully joined up approach within the city region*

Health & Social Care is an integral part of the GM Unified Model of Public Services. This is based on public services working together principally at the neighbourhood level (30,000 to 50,000 population). This has enabled a place-based response to the pandemic.

For example, in the 10 districts in GM, health and social care partners have worked with wider public service partners and the VCSE, to support vulnerable people through the locality hubs. Each locality was able to stand up a co-ordinated response rapidly based on a culture of collaboration and system working. All 10 localities have a Local Care Organisation (LCO) which brings together a range of community-based services including primary care, NHS community services, mental health and social care.

There was significant mutual aid provided across GM's localities and across GM's hospitals, which have operated as a single system under the auspices of the Hospital Cell. Professional networks operating at GM level have also made important contributions to the response.

Mental Health trusts in GM have taken important steps to reduce demand from mental health service users on A&E during this crisis. The trusts have established 24/7 telephone access alongside significant mobilisation of telephone and online support and therapy. They have set up a new model where that provides access to the Mental Health system for known service users (via a single number) and unknown service users through the existing Clinical Assessment Service Model in GM.

Localities in GM have also set up facilities for mental health urgent care provision away from A&E units – again relieving the pressure on the system as a whole.

Partners in Greater Manchester are also working to expand the GM Resilience Hub – which was set up after the Arena bombing in 2017. This is to help address the mental well being impact of COVID- 19 and will initially focus on front-line staff affected.

Primary Care in GM (including General Practice, Pharmacy and Dentistry) has come together in a primary care operational cell – reporting to the Out of Hospital (Community-based Coordination Cell). This has allowed primary care to share best practice (for example, on becoming a ‘digital first’ service) and collaborate: a new GP staffing bank was set up covering all of GM and primary care adopted a common approach to death certification.

What have been the challenges?

Health & Social Care partners have played an important role in the GM Humanitarian Assistance Group, which has focused on the needs of vulnerable groups. One key issue we have recognised is that localities are experiencing **large numbers of people who typically would have presented in primary care accessing the system through the locality hubs**. We are co-ordinating our approach to this with wider public services through the **Humanitarian Assistance Group**. Each locality in GM has undertaken an equalities impact assessment to understand the impact and reach of its COVID Hub response arrangements, given the **disproportionate impact the pandemic is known to have on more deprived communities and individuals**.

This has not only been about the impact on groups vulnerable to the COVID infection, such as the shielded population, but also about understanding the potential need of people in the community that will suffer increased isolation, vulnerability and need and fall outside the official shielded list. The Health and Social Care Partnership has continued its support (including through financial investment) during COVID-19, for the A Bed Every Night programme. This provides key accommodation and support for people who are experiencing rough sleeping, or at imminent risk, in Greater Manchester.

What role has the Greater Manchester Health & Social Care Partnership had in leading and co- ordinating the response to Covid-19 across Greater Manchester?

From a health and social care perspective, the Partnership played a full role in the national emergency arrangements put in place via NHS England. The Partnership speedily established a Hospital and Out of Hospital cell as per the national arrangements – with a Core Leadership Group to co-ordinate between the two cells at Greater Manchester level. The two cells report into the NHS command structure and liaise with the NHS at national and regional level on key issues such as testing, shielding vulnerable patients and PPE. GM is also connected to the national NHS response through the North West region Incident Command Centre. The Core Leadership Group has played a key role in connection to the broader, city region LRF approach in Greater Manchester ensuring a co- ordinated and aligned response.

What Regulations and Guidance have directed Greater Manchester Health & Social Care Partnership's approach to the pandemic?

GMHSCP has worked in accordance with all national regulations and guidance throughout the pandemic, using a strong communications team to ensure that all partners and staff are fully aware of all emerging guidance with regular updates, websites, newsletters and briefings both for internal staff and external partners. Regular briefings from the Mayor have re-inforced continued public messages to the public to maintain full awareness of the legal and regulatory context to the pandemic.

Has the Greater Manchester Health &Social Care Partnership provided any additional instructions or guidance to health and social care organisations within Greater Manchester?

Working fully within the regulatory context as outlined above, several new ways of working have resulted from the response to the pandemic, In our planning for recovery we will aim to capture the learning from these in a systematic way so that they can be deployed most effectively within the system. *Examples of the new ways of working include:*

A rapid acceleration of a digital-first model in primary care – online triage; telephone and video consultations with patients;
Rapid progress in the implementation of integrated care records;
A move to a digital outpatient model;
The creation of live, Sit Rep reports across primary care, mental health, community services and social care.
A deepening of mutual aid between localities and within the hospital sector;
Standardised discharge arrangements for care homes;
The extension of our Clinical Assessment Service (CAS) for Urgent Care to include mental health and paediatrics;
A significant increase in digital mental health consultations.

Has the Greater Manchester Health and Social Care Partnership taken an overview and/or monitoring approach to health and social care organisations response to the pandemic?

As noted in Question 3, GMHSCP has played a key role in connection to the broader, city region LRF approach in Greater Manchester ensuring a co-ordinated and aligned response. The Core Group is chaired by the Health & Social Care Portfolio Holder in the Combined Authority (Sir Richard Leese) and there are regular updates provided from key LRF forums into the Core Group.

To support crisis response, we established a series of Sit Rep reports on Primary Care, Social Care and Mental Health. This included an OPEL alert system (similar to the one used in hospitals) to flag immediately where a local area was facing difficulties and facilitating rapid mutual aid across GM. We believe we are one of the first areas in the country to introduce these reports community-based services. They include status updates on staffing levels, PPE, the number of GP practices open and the availability of beds in care homes.

The Coronavirus Act 2020 gave local authorities the ability to enact Care Act easements. While the Greater Manchester area has had a relatively high incidence of Covid cases, the easements have not been enacted in this area.

What has enabled local authorities to continue to operate without enacting the easements?

As noted above, Care Act easements have not been enacted to date in any of the Greater Manchester areas. The Directors of Adult Social Care across the 10 areas have worked together on issues such as PPE; support to care homes; and integrated discharge arrangements. The GM Directors of Public Health have collaborated on testing arrangements and infection and prevention control to care homes. The maturity of the neighbourhood operating model, and integrated working between CCGs and local authorities in each area of Greater Manchester have all contributed to this.

At local level in GM, we have seen organisations show flexibility in adapting their governance arrangements in order to implement new schemes safely, with high quality and at pace. This has given teams across the whole health system the confidence to establish and embed new models of care and seen a real willingness for collaborative working, bringing together the out of hospital and in hospital priorities as a one goal. The VCSE has led the coordination of volunteers across the system, both in terms of recruitment of local volunteers into volunteer centres and other established VCSE organisations, but also linking with mutual aid groups that have formed in response to COVID-19.

Across GM, the VCSE has:

Provided Frontline Services - food supply, advice and advocacy, physical tasks, support with mental health; Supported People and Communities in the Most Vulnerable Situations - communities of identity and experience, people on low incomes, those not in contact with statutory services; assisted Sector wide Collaboration - coordination and leadership, volunteer coordination, accessing funding, communication, data and insight, practical support for smaller organisations, redeployment, leadership and strategy for VCSE sector. The localities have involved the VCSE in their emergency response arrangement and the sector has supported with the coordination of volunteers across the system.

The Greater Manchester Health and Social Care Partnership has had an ambitious plan to make Greater Manchester the best place to live with dementia. Has there been any specific consideration given to the needs and impact on carers of people with dementia during this pandemic? What actions have been taken and what impact has there been on carers of people with dementia?

Prevention is a core theme of all GM strategies, including our health and social care strategy Taking Charge. It is central to our service operating model in neighbourhoods and Local Care Organisations. We have a Population Health Plan in place to support people to start, live and age well. The approach to prevention is system wide, crosses the public services and embraces the VCSE. As such, it has provided an important foundation for our integrated, place-based response. The maturity of our neighbourhood model has facilitated the deployment of mutual aid across GM and has acted as a platform for humanitarian assistance. Within this context, the response of the GM Dementia Programme has included the following;

Stakeholder Engagement, including the voice of people living with dementia & carers, and engagement with localities

Quarterly locality meetings – all GM locality Dementia leads in attendance
Full GM Mapping exercise of Post Diagnostic Support services (pre and post covid-19)
Greater Moments prototype ready for testing
Identifying common issues and challenges. Raising appropriately across the system to help facilitate change

Development of specialist resources, toolkits or advice

Acceleration of Delirium toolkit
GP Resource paper developed in partnership with GP clinical lead
Best Practice digest developed
Advice to the Nightingale Hospital NW regarding how to be dementia friendly
Care Home resource paper
Memory Assessment Service Summit being organised to support restarting of services

Communication & awareness raising
Website refresh with covid-19 section (reviewed weekly)
Living well in lockdown blog produced during May 2020 action week
Monthly DU bulletins

Have there been any lessons learnt in relation to carers of people with dementia as a result of the first wave of Coronavirus? If there are further waves over the coming months, should carers expect to see anything different in the way they or the people they care for are supported?

Both locally and nationally, the Crisis has helped highlight the vital role of carers of people living with dementia, and the VCSE sector. VCSE has played an important role in neighbourhood responses to COVID-19. The existing engagement of the VCSE within LCO models in GM is a key foundation for this. The sector has played a vital role in the operation of the Community Hubs in each of the 10 localities.

The VCSE will play an increasingly important role in addressing the health inequalities linked to COVID-19. A Greater Manchester VCSE intelligence stream is being developed and this will be reflected in the Dementia United Programme, putting more emphasis on issues such as Deconditioning, recovery and helping to link Carers through Primary Care, for example, to opportunities for Social Prescribing.

Throughout this, the Dementia programme across GM will continue to seek to capture the voices and perspectives of at-risk groups and ensure that these perspectives are used to inform future decision making in the system as we move to a locality based model, strengthening its connections across localities & feeding into key GM programmes on inequalities, prevention, living well at home, housing & health, healthy ageing and mental health.