

# National Mental Capacity Forum

## Annual Report 2022-2023

### Preface

In 2023, individuals who are subject to the provisions of the Act, their relatives and professionals are witnessing the MCA's networked systems facing potential collapse.

Without prioritising investment in (i) life-long, supported decision-making and (ii) the primacy of care and support in our homes, the default option of long-term care in acute hospitals, specialist hospitals and care homes is real.

During April 2023, the Department of Health and Social Care stated that *"the Government had taken the difficult decision to delay the implementation of the Liberty Protection Safeguards beyond the life of this Parliament..."* Nine years after Liberty Protection Safeguards were recommended by the House of Lords Select Committee this delay has significant implications for people's right to liberty. It impacts on service systems and those who are working on improvements. It means that all involved are required to operate a system already deemed unfit for purpose.

For example, Richard Charlton, a solicitor specialising in mental health and deprivation of liberty cases, gave evidence to the Joint Committee on Human Rights:

*"No case that we take on ( ... ) does not include periods of unlawful detention ( ... ) Sometimes we see the paperwork and a person has been unlawfully detained for years ( ... ) What is so tragic on a human level is you see in that time that the person concerned has been objecting but has not reached or engaged in the process at all and, in that time, they have become much more disabled"*(p18).<sup>1</sup>

The Joint Committee put this into perspective:

*"We know that an estimated 270,650 applications for DoLS [Deprivation of Liberty Safeguards] were received in 2021 to 2022. The number of cases has increased very significantly since 2013–14 when there were only 13,500. There was a sharp increase to 137,540 in 2014–15 following the Cheshire West judgement and in subsequent years there has been average year on year increase of 12%. We also know that an estimated 124,145 cases were not completed in 2021–22, and that only 20% of standard applications were completed within the statutory timeframe of 21 days...Prior to the implementation of LPS,*

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<sup>1</sup> House of Commons House of Lords Joint Committee on Human Rights *Protecting Human Rights in Care Settings*, Fourth Report of Session 2022-23, 13 July 2022

*[Liberty Protection Safeguards] we will continue to work with local authorities to assess the nature of delays in the system and will continue to encourage local authorities to fulfil their legal duties under these vital safeguards.” (p11)<sup>2</sup>*

In addition, the DoLS annual data collection for the year 2021-2022, reveals that there were 140,800 applications for authorisation that could not be granted. Of these, 41,365 people had died in care homes or hospitals waiting for their applications to be processed by local authorities and, as a result, were deprived of their liberty.<sup>3</sup>

The delayed LPS implementation stalls training, preparations and progress and risks undermining the significance of the Mental Capacity Act itself.

This Annual Report sets out the challenges facing the MCA and it gives coverage to the hopeful and constructive ideas of Forum members and practitioners. It applies a “legacy mindset” to ensure that the Forum is a good ancestor.<sup>4</sup>

In terms of structure, the Report begins with a personal message from the Chair. Then, the Forum’s work is outlined. This includes the preparation of brief and vivid case studies spanning the life course. These are accompanied by commentaries which underline the complexity and necessity of creativity in addressing the dynamics of contention and “altruistic deviance” surrounding the application of the MCA. Priorities and emergent themes for the longer term are identified. Since much has happened in the 18 years since the Act came into being, it is important that the Forum and its Friends are proactive in thinking ahead.

There are four Annexes.

Annex A presents the Forum’s revised Terms of Reference

Annex B lists the members of the NMCF 2022-2023.

Annex C provides a timeline and summary of the Chair’s work programme.

Annex D presents the answers to questions arising from webinars.

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<sup>2</sup> House of Commons House of Lords Joint Committee on Human Rights *Protecting Human Rights in Care Settings: Government Response to the Committee’s Fourth Report*, Third Special Report of 2022-23, 14 December 2022

<sup>3</sup> [Mental Capacity Act 2005, Deprivation of Liberty Safeguards, 2021-22 - NDRS \(digital.nhs.uk\)](#) (accessed 14 June 2023)

<sup>4</sup> Krzsnaric, R. (2020) *The Good Ancestor: How to Think Long-Term in a Short-Term World*, London: WH Allen

## Message from Margaret Flynn: Chair of the National Mental Capacity Forum (NMCF)

I was appointed as the Chair of the NMCF during April 2022. The experience of attending some of the Forum's rapid response webinars during the pandemic reminded me of the Law Commission's project on mental capacity. As Lady Hale<sup>5</sup> recalled:

*We started this in 1990, encouraged by the Law Society, by parents with mentally incapacitated adult children, by adult children with mentally incapacitated parents, and by healthcare professionals. What to do when serious or sensitive decisions had to be made, like whether to resuscitate a desperately ill patient or whether to sterilize a seriously mentally disabled young woman? Or even when there were disagreements about more mundane matters, such as whether an elderly person with dementia should go into a care home? ...in 2005, the Mental Capacity Act was passed, only ten years after the Law Commission's report (Pages 116-117).*

Having contributed to the Law Commission's consultations with social workers, health care professionals and lawyers, we understood that the MCA was pioneering legislation. The presumption of capacity was groundbreaking and so reassuring for my family and others with relatives with different kinds of support needs. It was encouraging that "all or nothing" assumptions concerning capacity were set aside and capacity became time and decision-specific. The Act heralded a viable means of making decisions in advance by the person concerned and by those to whom the person had given a lasting power of attorney. It mattered to me that it was no longer a "them and us" scenario of those assessed as having, or not having mental capacity because all of us are vulnerable to losing our capacity on a temporary, progressive or permanent basis. Crucially, the best interests' requirement confirmed our obligation to further the legitimate interests and insights of people with compromised capacity.

In the much changed climate since the MCA was enacted, I have charted some pivotal events and controversies since these are relevant to policy and practice. A broader ambition is that they bring into focus the urgency of attention to contexts - including the fragility of social care; the processes and roles generated by the Act; and crucially, the acknowledgement that things change and that there is always room for optimism, reflection and renewal:

- The 2014 House of Lords Select Committee's post-legislative scrutiny report concerning the Act concluded that it was failing those it was designed to protect and empower and that too many people were being deprived of their liberty without the protection of the law or the safeguards intended. It proposed that there should be an independent body to oversee, monitor and drive forward the Act's implementation and provide a "focus for enhanced activity;" in addition, it determined that the 2009 Deprivation of Liberty Safeguards (DoLS) should be replaced with legislation that is more aligned with the language and ethos of the MCA;

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<sup>5</sup> Lady Hale (2022) *Spider Woman: A Life*, London: Vintage

- HM Government's 2014 response to the Committee's report<sup>6</sup> disagreed with the proposal to create an independent body but acknowledged the necessity of maintaining oversight and identifying priorities;
- since 2010, it has become much harder to secure social care support. Unless people are in a position to pay for social care themselves, they are dependent on rationing in a fragmented and volatile market;
- there are 165,000 vacancies in the social care workforce, "a new care workforce pathway" is to be backed by £250m;<sup>7</sup>
- safeguarding inquiries in England and Wales consistently highlight undue influence and harms prevailing in unaccountable services;
- the Child Trust Funds of 18 year olds who do not have capacity to manage their money require their families to access these via Court of Protection processes;
- very poor practice concerning Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) Notices achieved particular prominence during the pandemic;
- the plans to "overhaul" the Human Rights Act 1998 are relevant to DoLS and the provision of care. That is, they have the potential to impact on persons with mental health challenges who currently receive the protection of Article 5 (ECHR)<sup>8</sup> via the DoLS if a person's behaviour is not considered to meet the, as yet unspecified, standards of personal responsibility;
- the concept of Deprivation of Liberty has been expanded far beyond that which was envisaged in 2007;
- the Mental Capacity (Amendment) Act 2019 was introduced to "fix" the problems with DoLS and replace it with the Liberty Protection Safeguards;
- there are tens of thousands of people outside the scope of DoLS whose right to liberty may only be protected by making applications to the Court of Protection;
- since professionals must "have regard" to out of date Codes of Practice, in February 2022, 39 Essex Chambers prepared an "entirely unofficial" guide to the Codes concerning the main body of the Act and to the DoLS because neither has been updated since their publication in 2007 and 2009 respectively;
- the DoLS regime has heralded soaring numbers of authorisations each year;
- the health and welfare and the property and affairs Lasting Powers of Attorney relied on cumbersome, paper-based processes and the Office of the Public Guardian's Modernisation Programme began during 2021. Its backlog led to lengthy waiting times;
- there is disquieting anecdotal evidence that colleges and universities are short-changing students. That is, the teaching of mental capacity law and practice to prospective NHS and social care employees is variable in terms of content and depth;

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<sup>6</sup> "Valuing every voice, respecting every right: Making the case for the Mental Capacity Act 2005 [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/318730/cm8884-valuing-every-voice.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/318730/cm8884-valuing-every-voice.pdf) (accessed 16 April 2023)

<sup>7</sup> This is half the sum that was promised in 2021

<sup>8</sup> This protects us from having our freedom arbitrarily taken away

- there are 16 supported and substitute decision frameworks in England and Wales;<sup>9</sup>
- the consultation *Changes to the MCA Code of Practice and implementation of the LPS* was published during March 2022;
- on 5 April 2023, the Department of Health and Social Care stated that “the Government had taken the difficult decision to delay the implementation of the Liberty Protection Safeguards beyond the life of this Parliament...”<sup>10</sup>
- There is uncertainty concerning the training of Best Interests Assessors (BIAs). Although BIAs are to be replaced by Approved Mental Capacity Professionals there is no certainty when this will happen.

Discussions with Forum members and Friends of the Forum about this trajectory confirm that a master plan is required. It is important to promote the ideas, work and expertise of Forum colleagues to enable the delivery of a future which fully reflects:

- (i) feedback from those who are subject to the Act,
- (ii) the experience of professionals and families who are applying the Act in their day to day and working lives, and
- (iii) ambitious planning and policy implementation.

A personal thanks to all Forum members, Friends of the Forum and colleagues in the Department of Health and Social Care, the Ministry of Justice, the Essex Autonomy Project and the Social Care Institute for Excellence – all of whom are focused on the promotion of supported decision-making throughout our lives. Particular thanks are extended to Neil Allen, Sophie Borrett, Lorraine Currie, Georgina Edwards, Chelle Farnan, Mark Jayes, Kirsty Keywood, Betsey Lau-Robinson, Wayne Martin, Alex Ruck Keene, Anna Volkmer, Louise Warren and Claire Webster for their contributions to this report.

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<sup>9</sup> That is, unpaid support; Best Interests decisions; General defence; Lasting Power of Attorneyx2; Deputyx2; Advance Decisions; Independent Mental Capacity Advocate; Enduring Power of Attorney; Consultee; Relevant Person’s Representative; Appropriate Person (Care Act); Advocate (Care Act and Social Services and Well-being (Wales) Act); Appropriate Person (LPS); and Appointee. See Barnes, R (2022) *Supporting Everyday Legal Capacity: Navigating the complexities of putting rights into practice*. In Mary Donnelly, Rosie Harding and Ezgi Taşcioğlu (Editors) *Supporting Legal Capacity in Socio-Legal Context* (2022) Oñati International Series in Law and Society, Oxford: Hart Publishing

<sup>10</sup> <https://committees.parliament.uk/committee/93/human-rights-joint-committee> (accessed 14 June 2023)  
See “Correspondence from the Minister of State for Social Care in the UK relating to LPS implementation dated 14 June 2023

## The NMCF's Work

### The Terms of Reference

Before 2022, the NMC Forum had a Leadership Group and an Implementation Group with separate Terms of Reference. Since the rationale for this was lost during the pandemic, a line has been drawn. It made sense to have a single Forum. Virtual contact with Forum members confirmed that the distinction was unnecessary and discussions gave rise to the merit of updating the Forum's terms of reference. The result features in Annex A.

### Learning from the Webinar Series

The Forum has co-produced four free, one hour webinars with the Essex Autonomy Project<sup>11</sup> during 2022-2023. The webinars bring together experts to address specific challenges relating to the MCA and provide opportunities for participants to ask questions and shape the agenda for future webinars. They provide practical learning prompts for novice and experienced practitioners, professional associations and networks.

Initiated during the pandemic, the Forum's lunchtime webinars provide a unique means of gathering information and feedback from frontline professionals and others involved in applying the MCA. In 2022-23, the average registration at the NMCF webinars was 1175, with registration ranging from 1084 to 1258. Actual attendance ranged from 675 to 975 per webinar with an average actual attendance of 845. The feedback confirms that the webinars continue to be highly valued.

As part of the registration process for the NMCF webinars, delegates are invited to answer a series of questions that relate to the application of the MCA in professional practice. Responses to these registration questions are analysed and summarised by members of the Autonomy Project research team and have provided an important source of data about the knowledge base, training needs and professional concerns of members of the workforce involved in applying the MCA in practice. Zoom polling conducted by the Autonomy Project team during the webinars themselves has provided a useful tool for probing and assessing participants' understanding of the webinars' subject matter. Post-webinar questions provide a stimulus for identifying future webinar topics. The webinars' audience is largely made up of health and social care staff, with social workers, and in one instance nurses, being the most represented group.

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<sup>11</sup> The EAP is a research and public policy initiative based at the University of Essex and directed by Professor Wayne Martin. It is associated with the School of Philosophy and Art History and with the Essex Human Rights Centre. The EAP provided the technical support to the webinars. It hosts recordings of these, plus the slide-decks, on its website, along with the Social Care Institute for Excellence <https://autonomy.essex.ac.uk/>

The four NMCF webinars conducted in 2022-23 focused on the following topics:

1. 20 October, 2022: *CPR Decisions and the MCA*
2. 7 December, 2022: *Families and the MCA*
3. 19 January, 2023: *Practical Steps for People with Communication Difficulties*
4. 25 April, 2023: *Executive Dysfunction and the MCA*

The data generated through these webinars confirm that the landscape of public professional education requires attention. Key challenges and priorities include:

- the content of the professional MCA curricula;
- the time dedicated to the MCA in pre-professional qualification training;
- the supervision of new professionals by managers whose own training pre-dated the implementation of the MCA;
- the inattention of professionals' regulatory bodies to the MCA in annual appraisals and continuing professional development;
- knowledge of the relevant case law, most particularly that which supersedes the two Codes of Practice; and
- inattention to bringing the MCA to life over the life course.

An area of particular concern pertains to the high-pressure clinical and ethical dilemmas of "Do Not Attempt Cardio Pulmonary Resuscitation" (DNACPR recommendations are sometimes inaccurately referred to as "DNR Orders"). Data from the NMCF webinar on this topic demonstrate the need for a collaborative exercise in consensus building as well as improved guidance and training.<sup>12</sup> The work of the Essex Autonomy Project has laid important groundwork for such an initiative, but it is clear that further training and policy-development in this area are matters of importance.

For a summary of data arising from the 2022-23 NMCF Webinar Series, see Annex D.

## Nurturing Partnerships and Networks

Identifying and cultivating partnerships has resulted in productive contacts with safeguarding boards' national networks, the Office of the Public Guardian (OPG), the Care Quality Commission, Care Inspectorate Wales and Health Education and Improvement Wales; the Five Nations spanning the UK and the Republic of Ireland; Norfolk County Council; charities; and academic researchers. Such important relationships yield different types of innovations. For example, Safeguarding Boards' Chairs are keen to collectively address the misunderstandings which prevail in the use of the MCA; the OPG's Modernisation work in terms of making and registering Lasting Powers of Attorney is addressing the inefficient and

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<sup>12</sup> See <https://autonomy.essex.ac.uk/wp-content/uploads/2022/09/Social-Care-and-Human-Rights2608223.pdf> (accessed 14 June 2023)

complex processes required of a paper-based system whilst ensuring that donors are protected; the inspectorates are making judgements about the application of the Act and are challenged by, *inter alia*, DNACPR recommendations and the use of restraint; there is scope for abstracting emergent lessons from the development in terms of mental health in Scotland and the Republic of Ireland's Decision-Support Service; Norfolk County Council's MCA workshops to take stock and identify better ways of supporting practitioners has led to routine pan-disciplinary meetings to discuss particular cases; Anheddau, a north Wales charity supporting adults with learning disabilities is returning to "the basics" of setting out what is known about the decision-making skills of the people it works with and assisting its staff to make connection between good support and the MCA; and academic researchers in England and Wales continue to explore ways of improving the implementation of the Act.

## Case Studies over the Life Course

Case studies feature in this annual report – and on the webpage - because the Forum acknowledges that they provide compelling insights into the use of the Mental Capacity Act and the many contexts in which it applies. The following accounts might be seen as (i) prompts to those engaged in updating the Act's Code of Practice whilst we wait for that vitally important task to be completed and (ii) reminders of the necessity of ensuring expertise in invoking and using the Act.

Forum members responded to the invitation to draw the case studies from their education, nursing and social care practice and records. They are anonymised to protect people's identities. A life course is a helpful way of considering changes in our decision-making. Another way may be to consider decision-scenarios as a result of expected transitions and unexpected events, such as discontinuities and changes in relationships over time. This sample combines both approaches. In addition, it signals the Forum's investment in compiling readable, real world experience accounts of working with people from 16 years to the end of life. Additional case studies feature on the Forum's webpage.

Not everything about these people's circumstances is set out since the authors of each made decisions about what to include. Some cases are typical in terms of the authors' day to day practice and others capture memorable cases. They acknowledge that the circumstances described are situational and that people's lives and histories are only fleetingly captured. We know that people's whole stories exceed anyone's knowing.

It will be seen that professionals from different backgrounds, and a person's relatives, sometimes struggle to do the right thing and that conflicts and dilemmas may result. Each case study is followed by a commentary. The commentaries reflect on the Mental Capacity Act – they have been drafted by Lorraine Currie, Chelle Farnan, Kirsty Keywood, Betsey Lau Robinson, Alex Ruck Keene and Claire Webster. They draw out how exacting, difficult – and potentially life enhancing - it can be to support a person's decision making.



**Lucas reminds us that families' adjustments to the challenges a young person experiences are affected by economic strains and the availability of appropriate help and support. Although he came to be deprived of his liberty, no true picture of Lucas' wishes or aspirations was sought.**

Lucas is 16. He has young siblings. His diagnoses include autism, Attention Deficit Hyperactivity Disorder and, potentially, foetal alcohol syndrome. His mother works part time and his father works away from home for long periods during the week. Lucas' parents were experiencing difficulties in managing his missing episodes from home and school as well as his agitation and self-harm. Since Lucas was found in some high-risk situations and he was removed to a place of safety, including a local police station. He was assessed as being at risk of death by misadventure.

Lucas' parents agreed to him being placed at a short-term residential unit under S.20 Children Act 1989. He settled well and returned home when the placement ended. However, he went missing and when the police found him he had self-harmed which resulted in an emergency hospital admission. The Mental Health Liaison Team assessed Lucas as ineligible for detention or treatment under the provisions of the Mental Health Act. It was agreed that a prolonged stay in a paediatric ward was inappropriate.

Despite daily searches for a more suitable placement, Lucas remained in a paediatric ward for over three months. Then, due to the national shortage of regulated secure children's homes, the local authority had no option but to place Lucas at an unregulated service. However, although the placement was arranged with the consent of Lucas' parents it was a significant distance from the family home and from the professionals who knew Lucas. The parents specifically consented to Lucas' being restrained. Due to the risk of him going missing and self-harming, 3:1 supervision was initiated. In addition, the locks were changed and the doors secured.

During a multi-agency review, health staff queried the legal framework concerning Lucas' 3:1 supervision, restraint, and the practice of locking him in the property - measures which equate to confinement. There were no recorded attempts to ascertain whether Lucas had the mental capacity to consent to the arrangements, or about his wishes and feelings. The local authority's legal advice was that there was no requirement to seek court authorisation for Lucas' deprivation of liberty because he was subject to s.20 Children Act 1989 and his parents had consented to the care plan which cited these restrictions.

#### **Commentary**

Unfortunately, the legal advice received by the local authority was entirely wrong. Parents cannot authorise the confinement of their child when they turn 16, irrespective of their child's decision-making ability. It is irrelevant that they have entered into a s.20 Children Act agreement with the local authority, or even that they have specifically sought to consent to the specific arrangements that confine Lucas. It would only be if Lucas could, himself, consent to the arrangements that they would not give rise to a situation requiring court authorisation: and in circumstances such as Lucas,' investigating this would not just be a question of whether he had the mental capacity to do so, but also whether any consent was voluntarily given. It

is almost impossible to imagine circumstances such as Lucas' where court authorisation would not be required, providing both external scrutiny and a vitally important point at which – belatedly – to identify Lucas' own wishes and feelings, both about the arrangements at the placement and more broadly.

***It is essential that practitioners question a young person's life changing circumstances. However, compliance with the MCA and other relevant legislation is an enduring challenge for practitioners and sometimes for those advising practitioners.***

**Although David's early life was troubled, as a young adult he settled into the routines of a care home. His shyness profoundly affected his contact with others. A delay in reviewing his circumstances led to a belated assessment of his mental capacity, using pictures as engaging "practicable steps." He was given the time and means to decide where and how he wanted to live. His circumstances highlight the tensions which may prevail in deciding who should participate in discussions concerning an individual's best interests.**

David is 26 and has lived in a care home since he was 18. Records suggested he had a diagnosis of learning disabilities, with autistic tendencies and a 'borderline' IQ score. Some years ago he had set fire to a bin. In addition, it was alleged that he had sexually assaulted a woman. This charge was dropped suggesting that there was no evidence to support the allegation.

David's room suggests that he has settled at the care home. He has a fish tank and he is proud that he looks after his fish without assistance. He has a huge selection of DVDs and CDs. He was very shy and noted to "hide behind pillows" during visits.

Once a week David (i) volunteers at a local café and (ii) goes to a drama session at the local theatre with some of his co-residents. David has a girlfriend who lives with her parents. They have been together for over two years. They meet at the drama group and at a café.

When a social worker was asked to review David's care arrangements (which had not been reviewed for five years), to decide whether they continued to be in David's best interests, she spent time with David, asking about his fish, watching his drama session and generally sitting with him since David was very quiet. A review of the care home's records suggested that David lacked capacity to make decisions about where he should live. There was a minuted Best Interests meeting which was attended by the care home's manager and the parents of David's girlfriend. This determined that it was in David's best interests that he should be prevented from spending time with his girlfriend.

The social worker asked David whether he had thought about living somewhere else. She used pictures to find out what he thought was important when thinking about where to live. David became very animated. He selected pictures about being safe and having a garden. He started to talk about wanting to walk to work and being near to his girlfriend. After several weeks, David gained confidence and started to talk – and he had a lot to say. He was introduced to an advocate who went on to assist him in developing a plan for his move. Eventually, David

moved to a supported living service. He has a house in his local community. He has started to cook, he walks to work and his social worker notes that he smiles a great deal.

**Commentary**

There was no assumption that David had capacity. The review of his care arrangements was overdue. This was a significant obstacle because it inhibited exploration of the ways in which David could be supported to contribute to decisions about his care and the potential “practicable steps” which could be taken to enhance his capacity. However, the picture prompts helped David to understand, weigh and communicate his thoughts about his future. That is, they were critical in enabling David to make particular, life changing decisions. Once a way of communicating was identified and information exchanged, a very different future opened up for David. The social worker could not replace an absent family but did fulfil the critical role of trusted professional interested in understanding David’s will and preferences.

*The MCA’s 4<sup>th</sup> principle states “An act done, or decision made under the Act for or on behalf of a person who lacks capacity must be done, or made, in their best interests” – and S.4 sets out how a person’s best interests may be determined. David’s social worker understood that a review is a critical occasion to discuss a person’s decision-making – and the different ways in which a person may be assisted to participate.*

**As a man with quadriplegia, Sam’s favoured means of communication is a letter-frequency scanning chart. The process is laborious. When his family reported Sam’s wish to discontinue PEG-feeding, they understood that he could not take his own life. Although Sam had experienced depression and had felt suicidal since his brainstem stroke, this was different – minimally, it required an assessment of his mental capacity whether to continue being PEG-fed.**

Sam is in his early 50s. He had a brainstem stroke 10 years ago which left him quadriplegic and with no volitional movement except eye movements. He has a tracheostomy to support breathing and a PEG tube for all nutrition and hydration. Sam requires support with all personal care and he lives in a nursing home. He communicates with a letter-frequency scanning chart which he knows off by heart:

Space	E	A	R	D	U
<b>T</b>	O	I	L	G	V
<b>N</b>	S	F	Y	X	.
<b>H</b>	C	P	K	J	,
<b>M</b>	B	W	Q	Z	?
Delete letter	Start again				

Sam’s conversation partner uses the chart by asking him to select which line the letter he wants is on by running through the numbers in the left margin. When the conversation

partner hits the right row, Sam moves his eyes upwards. The conversation partner then runs through the letters on that row and Sam moves his eyes upwards when they have hit on the letter he is looking for. The conversation partner writes down the letters and sentences are formed. Communication takes a long time.

Over the years more high-tech communication aids have been tried with Sam, but he finds them too tiring or confusing and prefers to use the letter-frequency chart which was first used with him just after he had his stroke.

Sam's cognition is largely unaffected by his brainstem stroke although detailed formal assessment was not possible. However, he has had episodes of depression, suicidal ideation, disorientation and confusion over the past 10 years.

Sam has shared with his close family that he no longer wants to live and wants to stop his PEG feed to bring about the end of his life.

### **Commentary**

This situation highlights the need for clarity as to the wider legal context within which the MCA sits. It is entirely lawful for an adult with capacity to ask for treatment (which would include a PEG feed) to stop, even if that will bring about the end of their life. Those providing care for Sam are under a duty imposed by Article 2 of the European Convention on Human Rights to consider with care whether Sam does, in fact, have capacity to make that decision before acting on it. They should also consider whether other steps could be taken to improve the quality of his life.

If those caring for Sam conclude that he lacks capacity to make the decision whether or not to continue with the PEG tube, then the decision will have to be taken whether or not to continue it on a best interests' basis. It is important at that point to have in mind that the question is not whether it is in his best interests to stop it, but whether it is in his best interests to continue it. It is also important for all concerned to be clear that placing Sam's wishes at the centre of the process (which would include what is understood about his wishes to no longer continue the PEG feed) would not be motivated by a desire to bring about his death, but rather to ensure that the decision is constructed around him. There is a useful flowchart and practical assistance to be found in guidance<sup>13</sup> produced by the RCP and BMA and endorsed by the GMC.

***The MCA requires the objective analysis of an incapacitated person's life. That is, it is their welfare, in the context of their wishes, feelings, beliefs and values that is critical. Professionals invested skill and time in finding out what was the most effective means of enabling Sam to communicate and participate in decision-making about his life.***

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<sup>13</sup> [bma-clinically-assisted-nutrition-hydration-canh-full-guidance.pdf](#) (accessed 16 June 2023)

**Health and social care professionals sought to establish Colin's mental capacity to determine his post-hospital destination. His stroke had compromised his communication. It was with the assistance of a Speech and Language Therapist that an understanding of his capacity emerged.**

Colin was admitted to hospital with a left cerebral stroke which had left him with right-sided paralysis and aphasia - a communication disorder which occurs after stroke. He required all his care needs to be met by staff. He could not call for help or use a buzzer to let staff know when he needed something. He had some understanding of language. Although he could respond with "yes" or "no" when asked a simple question, his responses were not always accurate. He could manage a social conversation. Colin experienced word-finding difficulties and often used words that sounded like real words but weren't recognisable as words. He has been admitted to the stroke rehabilitation ward for a period of rehabilitation.

Before he was admitted to hospital, Colin lived alone at home. He was in his late 60s and had been doing part-time work as a handyman at a local nursing home. He had been in the Navy for most of his career. He has two adult children who live over an hour's drive from him.

Colin spent twelve weeks on the rehabilitation ward working on his mobility, personal care routines, basic tasks in the kitchen and communication strategies. His mobility had improved and he could stand using a transfer aid supported by two care staff. Colin still requires personal care from two staff and needs support with doing simple tasks in the kitchen. Although his communication improved, his speech was still mainly made up of unrecognisable words and phrases, but his yes/no responses were more reliable. He could indicate some simple needs when staff asked him direct yes/no questions.

As Colin's stay on the rehabilitation ward was coming to an end, he had to make a decision about where to live when he left hospital. The options for him were to go back home with a package of care or to go to a nursing home. There were risks associated with returning home but this, to him, represents the least restrictive option. He was still unable to use a buzzer to call for help and would not be able to call the emergency services. At home, he would be seated all morning until the carers came at lunchtime to return him to bed. He would not be able to have personal care between visits. He would be alone at night and would require a tilting mattress to reduce the risk of pressure sores. But he would be in his own home.

When these options were proposed to him by the social worker, Colin was unable to express his views clearly. The social worker decided that a capacity assessment is required to see if Colin understands the risks and benefits of each option. The social worker asked Colin's Speech and Language Therapist (SLT) to join the capacity assessment to support his communication. The SLT assessed Colin's communication and was aware that his understanding and expression were helped by using written words, drawings and pictures to support the spoken word. The SLT and the social worker met him together.

First, they put the two options to Colin using photos of his house and of a nursing home. He dismisses the nursing home by pushing the photo away. The SLT then describes the care package that Colin could expect at home. Using a pre-prepared visual timetable, the SLT explains that two carers will come to the house four times a day and what they will do at

those times. The SLT explains that he will be alone in between those visits. Colin appeared happy with this plan but the social worker was concerned about how he would manage when he was alone.

The SLT and social worker wanted to get an understanding of what Colin believed he could do for himself. The SLT used some images of everyday tasks such as showering, making a cup of tea or shaving and asked Colin to put all the images of tasks he can do into one column and those he couldn't do into another. It became clear that Colin over-estimated his abilities. He put the picture of walking and making a phone call in the 'can do' column. The SLT and social worker explored this further. They used photos of events that could happen at home such as having a fall. They give him pictures of different options such as: press a lifeline buzzer, get up and walk away, or phone an ambulance. Colin chose the impossible option of getting up and walking away.

Through using pictures and visual timetables, it was clear that Colin lacked capacity to consent to his discharge destination. A decision was therefore, required in his best interests. The social worker convened a best interests meeting with all those involved in his care in the hospital and his adult children.

#### **Commentary**

This case highlights the crucial role of SLTs as discharging the obligation under s.1(3) MCA to support the person to make their own decision, but also the need to recognise the point at which such support cannot achieve that goal. The probing undertaken by the SLT and the social worker is sensitive, but rigorous. Colin is fortunate in that there are two clear options identified between which a choice can be made at the best interests meeting. There are many situations where this clarity is lacking, often because of confusion as to who is responsible for the decision-making process and/or how the options are generated, especially in relation to those drawing upon services. Such problems are exacerbated by pressure to secure rapid discharge from hospital, in particular where such pressure is driven not by the interests of the person, but wider interests in securing hospital beds. At that point, there is a real tension both between the personal and public interests, and between making a rapid best interests decision and making the right best interests decision.

***The 2nd statutory principle of the MCA states "A person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success." Speech and Language Therapy is valuable in highlighting such communication elements as attention, listening, looking and understanding verbal and non-verbal strategies.***

**When Mrs Fisk became homeless late in her life she was placed in a care home as a temporary measure. A Deprivation of Liberty authorization was sought and a Best Interests Assessor determined that she had the capacity to decide where she wanted to live. It is not**

**known whether securing another tenancy was perceived as a priority since she had a temporary care home address.**

Following correct legal process, Mrs Fisk was evicted from her property. She had not paid her portion of the rent. She was placed in a hostel for a night and then a local Bed and Breakfast. Since this was not successful, she was placed in a care home by the local council as a temporary solution to her homelessness. This was achieved by telling Mrs Fisk that she was going for a walk.

At 82, Mrs Fisk had previously been found to lack capacity in relation to finances and managing her tenancy. However, she received no support before she was evicted. Her only identified care and support need was “finances.”

Prior to the eviction Mrs Fisk had a daily routine of going into the town centre by bus. She shopped daily, met friends, went to the library, to Greggs and other shops for drinks and meals. She was well known in all these places and there were no incidents of her being unable to find her way or being disoriented.

In the care home Mrs Fisk was self-caring, orientated to her surroundings and her homelessness. The care home requested a DoLS authorisation and a Best Interests Assessor was commissioned. The Best Interests Assessor found her to have capacity. In brief, she recognised that she was in a care home setting. She commented *“it is a place where people who are vulnerable live, who are at the end of the line with dementia. Who sit around in chairs and sleep. Not me, I speak three languages and I am not like that. I have had legal training. I know my rights”*.

She knew where she was and where she had lived previously. Mrs Fisk did have some suspicious views as to why the landlord wanted her out of the property and she did have probable, early stages Alzheimer’s type dementia.

Mrs Fisk recognised that by being in a care home she was ‘out of the system’ in terms of housing. She even acknowledged that she may need to remain in the care home whilst efforts were made to identify a new tenancy. She knew that her only support needs were, in fact, related to housing. She had some memory deficits but was able to understand and retain the salient points. Her Care Act needs would not justify residential care.

Mrs Fisk was able to use and weigh the information and give a reasoned response.

When asked to explain the steps she would take to find another property and what she would do in the meantime. She described that she would do *“what anyone else would do,”* that is, she would *“look in the newspaper and visit the estate agents.”*

Mrs Fisk understood that it was likely that finding a tenancy either through her own efforts or with support by others would take some time. When asked what she would do for somewhere to live in the meantime. She said, *“well I have no option do I? I will have to stay here”*.

Unprompted she told the assessor “*I think that for someone to pat me on the head and think just put her in a care home is absolutely horrendous. I have my life. I want to do things and visit my friends. They will be wondering where I am.*”

#### **Commentary**

The evidence required to utilise the DoLS scheme is the person’s inability to choose whether or not to be accommodated for the purpose of care and treatment and the presence of a mental disorder. The BIA concluded that Mrs Fisk did not lack capacity, nor was she being accommodated for the purpose of care and treatment. She was being accommodated entirely as a result of homelessness and, possibly, age related discrimination due to her being 82.

The local authority did not take note of Mrs Fisk’s need for housing support advocacy. Most importantly, it imposed restrictions which she did not consent to and which were consequently unlawful.

***The Best Interests Assessor considered Mrs Fisk’s previous housing decisions and her independence. The BIA was well placed to complement and represent her efforts to become a tenant once again.***

Overall, the case studies confirm that the MCA is deeply consequential as professionals’ work with the bigger picture of legislation, priorities, resources and needs. In addition, they reveal that we live and work as though we have all the time in the world.

We spend our childhoods developing mental capacity. We learn a great deal from the daily routines of our parents and guardians in terms of how they lived, related to others and engaged in activities, for example. Added to such learning is formal schooling which heralds significant inter-relationships and catalyzes an appreciation of difference and vulnerabilities, for example.

By the time that adulthood ceases to be a distant prospect, our personal trajectories may include preparation for work, work itself and then retirement. Our autonomy, adult relationships, experience of personal disruptions, networks and resources are given expression in our every-day environments and, possibly, the exceptional settings of hospitals and/ or services designed for specific populations. Although the impacts may not be immediate,

*“[the]...job is not to confine people’s choices, in the name of safety, but to expand them in the name of living a worthwhile life.” (p141)<sup>14</sup>*

<sup>14</sup> Gawande, A. (2014) *Being Mortal – Illness, Medicine and What Matters in the End*, London: Profile Books, Wellcome Collection



## Priorities for 2023-2024

Four assumptions are shaping the NMC Forum's work:

1. a long-term perspective is merited if the Forum is to grow people's interest in mental capacity and promote a bedrock of competent and lawful practices;
2. cultivating partnerships and influencers is essential to generating and sustaining valuable ideas and approaches;
3. pragmatism prevails in professional practices concerning mental capacity in England and Wales; and
4. people who may lack capacity have rights which must be honored and professionals have duties. Professionals must apprehend the decisions to be made "in the moment" and reflect on what the resulting outcomes mean for the individuals concerned.

The Forum involves and engages with people who are passionate about enabling people whose mental capacity is compromised to make decisions and, when they cannot do so, ensuring that their best interests are central. Its collective hope is inclusive, and since the Mental Capacity Act is for all of us, ways have to be identified to influence families, schools and all services as sources of protection, nurturing and support for decision-making.

### Addressing the implications of the delayed LPS

During 2022-23, Forum members invested in responding to the 2022 consultation concerning the MCA's Code of Practice; the Mental Health Act; Human Rights; and Safe Care at Home. Waiting for the outcome of consultations is characterised by frustration and uncertainty, and the delay in implementing the Liberty Protection Safeguards has drained momentum. Lorraine Currie and Alex Ruck Keene have been instrumental in bringing pragmatism to the foreground in outlining the ways in which (i) practitioners may respond lawfully to the challenge of operating a system which is wholly ill-suited to address the existing volume of referrals and (ii) a revised Code may be simplified, more cost-effective and responsive to practitioners' feedback. They will set out their thinking in the Forum's Autumn webinar. Specifically, the Forum will work to:

- address the impact of halting preparation training for the LPS
- support professionals using the DoLS
- promote the revised MCA Code of Practice.

### A Consensus Statement

The value in the cumulative experience of the Forum was shown in its responsiveness to the challenges associated with the pandemic. Forum members are keen to retain and exemplify this flexibility in addressing the LPS setback.

The topics identified for the Forum’s four webinars revealed a hunger for up to date relevance and a long term perspective. For example, the first webinar reassured health and social care participants that Do Not Attempt Cardio Pulmonary Resuscitation recommendations are *not* legally binding. Although such recommendations received a lot of media coverage during the pandemic, the policies shaping them did not feature. These policies are so consequential that Professor Wayne Martin and the Essex Autonomy Project have pioneered the production of accessible materials. In addition, Professor Mark Taubert, the Chair of the Advance and Future Care Planning Group in Wales and Clinical Director and Consultant in Palliative Care Medicine, has encouraged conversations about Cardio Pulmonary Resuscitation for people affected by life limiting and palliative illnesses and promotes the National DNACPR Policy for Wales.<sup>15</sup> How Wales adopted a single policy remains to be set out during 2023-24. Both developments are instrumental in creating a Consensus Statement which was identified as a post-pandemic priority.

### Nurturing Partnerships and Networks

During 2023-24, it is envisaged that such partnerships will be sustained to set out the valuable lessons from each and extend to embrace professional bodies and regulators, for example.

How other jurisdictions are supporting decision-making over the life course is of keen interest to the Forum. To this end, engaging with people who are tackling similar challenges is illuminating and necessary. The Essex Autonomy Project has a track record in bringing people with support needs, relatives, practitioners and lawyers together in a collegial setting to learn with people who are themselves learning. Inspiration and ideas from presentations at the 2023 Summer School will feature on the Forum’s webpage.

### Questioning Education and Learning about the MCA

The first webinar was prefaced with the question, “Have you personally granted Lasting Power of Attorney to another person in relation to your health and welfare decisions?” The fact that the majority of participants, all working in health and social care, did not have LPAs illuminates the necessity of long-term professional and public education which takes in the arts and literature. For example, the BBC’s 2023 series, *Best Interests*, concerned a parent’s fight to halt the withdrawal of treatment from her comatose and brain damaged child with a life-limiting condition. Although not associated with the traditional trappings of education, it resonated with real life experiences and introduced viewers to clinical ethics and the MCA.

Despite the congruence of interests and agreement on necessity of the MCA, the case studies in this report and on the Forum’s webpage confirm the “lack of awareness and a lack of understanding” reported by the House of Lords Select Committee in 2014, fact-finding across Norfolk during 2022,<sup>16</sup> and in reported safeguarding reviews. The task of bringing supported

<sup>15</sup> <https://executive.nhs.wales/networks/programmes/national-palliative-and-end-of-life-care-programme/resources-for-health-care-professionals/dnacpr/> (accessed 20 July 2023)

<sup>16</sup> <https://autonomy.essex.ac.uk/wp-content/uploads/2022/11/Norfolk-Mental-Capacity-Workshops-2022.pdf>

decision-making to life may be seen as fundamentally educational by experienced practitioners, trainers and educators. However, experience suggests that poor professional practice may not be resolved by investment in awareness and understanding. If there is no resulting behavioural change, such as specific professionals doing something that they do not currently do, then we must draw on the wisdom of people with first-hand experience of being subject to the MCA, their relatives' experiential knowledge, the raw material of case law, professional education and its outcomes in terms of valued practice. The Forum is keen to explore ways of seeing beyond teaching fragments of the MCA and treating them as though they are isolated from the rich and complex worlds that we inhabit. The Forum's contribution to this task is via its webinars and its creation of a Case Studies' Resource across the life span which illuminate the occasions when the MCA is invoked across settings.

Professor Keith Brown and Forum colleagues are exploring ways of shaping the MCA content of pan-disciplinary professional training. The springboard is the poor practice concerning the MCA in too many safeguarding reviews. Further upstream, it is a curiosity that an 18<sup>th</sup> birthday, heralding adulthood, does not prompt consideration of the MCA. Since this may not exercise educationalists, engagement with those responsible for and interested in the schools' curriculum across England and Wales is pivotal.

The Forum is well-placed to direct people to relevant websites, events and resources such as Alex Ruck Keene's shedinars<sup>17</sup> and Rosie Harding and Ezgi Taşcioğlu's Everyday Decisions Project<sup>18</sup> - and will continue to do so.

## For the Long Haul

Just as creating a Lasting Power of Attorney requires each of us to think ahead, discussion with Forum members has identified specific topics which are not easily constrained within a 12-month timeframe. In the spirit of food for thought and with no intention of binding our successors, the Forum is interested in:

- keeping track of Do Not Attempt Cardio Pulmonary Resuscitation recommendations are operationalized and the prosecutions associated with these;
- retaining an online presence - currently realised on the websites of the Essex Autonomy Project and the Social Care Institute for Excellence and via the Forum's webinars;
- the increase in fraudulent transactions and scams associated with banking – and the closure of local banks;
- the MCA interfaces with the Mental Health Act (1983) and its awaited reforms,<sup>19</sup> the Children Act 1Care Act (2014) and the Social Services and Well-being (Wales) Act (2014) for example;
- the promotion of decision-making skills for children and young people;

<sup>17</sup> <https://www.mentalcapacitylawandpolicy.org.uk/shedinars/>

<sup>18</sup> [http://epapers.bham.ac.uk/3067/1/Everyday\\_Decisions\\_Project\\_Report.pdf](http://epapers.bham.ac.uk/3067/1/Everyday_Decisions_Project_Report.pdf) (accessed 14 June 2023)

<sup>19</sup> <https://www.gov.uk/government/publications/draft-mental-health-bill-2022> (accessed 30 June 2023)

- highlighting developments in “effective MCA training” for health and social care professionals;
- highlighting the role of regulation in monitoring the use of the MCA
- information about the MCA for parents and others with unpaid care-giving responsibilities;
- a form for GPs, hospitals and care providers to ask who is “the nominated person to consult;”
- the MCA’s use in restriction and restraint;
- and more generally, putting the MCA in context – including considerations of how poverty and inequality impact on supported decision-making; the contexts within which the MCA is invoked, e.g. are practitioners acting on the basis of consent or best interests? and whatever problems and challenges make new claims on the MCA practice.

## Concluding Thoughts

*“There is no one day in real life when a person wakes up and suddenly gains sufficient capacity to make decisions for themselves. In real life it is a continuum, dependent on a number of variables that include context, intellectual ability and life experience...”<sup>20</sup>*

Progressing the implementation of supported decision-making confronts generations over the life course. It is an ongoing and occasionally urgent task that requires attention and renewal in different contexts throughout our lives. Developmental maturity may be promoted or inhibited. Different decision-making situations require different skills and understanding. From infancy, childhood, adolescence and adulthood through to older age, our capacity to make decisions evolves in fits and starts so that, over time, it may extend to a greater variety of decision-making tasks and may subsequently diminish. The contexts within which we make decisions matter. For example, we may over-identify with our peers, our teachers, parents, partners or other influencers which prompts the question: who is the real decider?

It cannot be assumed that what has been judged as successful practice in one place will be successful in another. Sustained investment is required in public and professional education, post qualification training, supervision and assessment and, most crucially, political leadership if we are all to benefit from supported decision-making.

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<sup>20</sup> Ruth Henke QC (2021) speaks for the motion “Should the age of majority be reduced to 16?” The 14<sup>th</sup> Annual Debate of the Family Justice Council:  
[https://www.youtube.com/watch?v=ls4GF1rQaSA&list=PLEF1\\_bG92bxscC9GVgigiz3H8HbmkBAa4&index=2](https://www.youtube.com/watch?v=ls4GF1rQaSA&list=PLEF1_bG92bxscC9GVgigiz3H8HbmkBAa4&index=2)  
 (accessed 14 June 2023)

## Annex A: The NMCF's Terms of Reference

1. to advocate for the Mental Capacity Act 2005 and its principles as individuals, as active members of networks and/or professional associations

*by widening the Forum membership to embrace marginalized voices, the Global Majority, new networks and associations;*

The Mental Capacity Act is for all of us. We tell as many people as we can about the law that helps us to make decisions if we cannot make them for ourselves.

2. to provide "oversight...across sectors"<sup>21</sup> of the implementation of the Mental Capacity Act, and to share what is being learned

*by inviting Forum members to draw from personal and/ or professional experience the exemplars – as well as ways of addressing the persistent challenges which arise when the MCA is invoked; and to highlight personal, professional, ethical and legal perspectives in the Forum's considerations;*

We talk about and write about what we know happens when the Mental Capacity Act is used.

3. to give presence and recognition to the ideas, interests and concerns of people whose lives are affected by the MCA by enhancing cooperation across difference/ different lived experience

*by giving coverage to illuminating, real-life accounts of the occasions when respect for difference is absent because of constructions of belonging and exclusion; and using Forum funds to pay for specific contributions;*

We listen to people who have needed help to make some decisions – and the people who love them - and ask them about how help can be improved.

4. to identify priorities for action across England and Wales

*by sharing the topics identified by the Forum with individuals, networks and professional organisations with similar interests; and by fine-tuning topics in*

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<sup>21</sup> House of Lords, Select Committee on the Mental Capacity Act 2005, Report of Session 2013/14 *Mental Capacity Act 2005: post legislative scrutiny* London: House of Lords, March 2014

*co-produced webinars to disseminate, test and develop learning prompts and guidance;*

We decide what to do to grow people's interest in mental capacity.

5. to seek out and add to an evidence base concerning the identified priorities

*by promoting research findings; learning from complementary disciplinary approaches; and hosting up to five co-produced webinars per year, including such situational topics as Do Not Attempt Cardio-Pulmonary Resuscitation - and seeking to build consensus;*

We put together everything that is being learned about the Mental Capacity Act.

6. to "make an annual report to Parliament on...progress"<sup>22</sup> and everyday practice. This will reflect

(i) what is being done by individual members in the Forum's name,

(ii) what is being learned in Forum members' networks and regions, and

(iii) the critical matters which have been identified during the preceding 12 months

*by adopting an interactive – rather than extractive – approach to information-gathering and sharing - always crediting ideas and their sources; contributing to generic and specialist consultation events and invitations which go with the grain of Forum priorities; and advising Ministers about developments and the changes required.*

Every year we tell politicians about how the Mental Capacity Act is working and what needs to change.

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<sup>22</sup> HM Government (2014) *Valuing every voice: respecting every right* The Government's response to the House of Lords Select Committee Report on the Mental Capacity Act 2005. HMSO Cm8884

## Annex B: Members of the National Mental Capacity Forum

Professor Keith Brown
Andy Butler
Sir William Charles
Lorraine Currie
Dr Yo Dunn
Chelle Farnan
Jo Giles
Rachel Griffiths
Baroness Professor Sheila Hollins
Betsey Lau-Robinson
Clementine Maddock
Professor Wayne Martin
James O'Sullivan
Joe Powell
Ashok Roy
Alex Ruck Keene
Ramona Murray
Hilary Paxton
Professor Mark Taubert
Duc Tran
Anna Volkmer
Claire Webster
Cathy Williams
Sarah White

In addition, the Forum is supported by civil servants from the Department of Health and Social Care and Ministry of Justice and the Welsh Government.

## Annex C: The NMCF Chair's Diary

### During **May 2022**

I established contact with civil servants in the DHSC and MoJ; read (i) the Terms of Reference of the Forum, (ii) previous annual reports, (iii) the consultation document concerning *Changes to the MCA Code of Practice and implementation of the LPS* and (iv) the 2014 House of Lords Select Committee post-legislative scrutiny report of the Mental Capacity Act 2005 (MCA); I chaired a seminar session at Keele University: *Mental Capacity, Intimacy and Sexuality*; I gave a keynote address at Suffolk's Safeguarding Adults' Board; and talked to Forum members and practitioners with a view to understanding the achievements and discontents accompanying the implementation of the MCA.

### During **June 2022**

I discussed with civil servants an introduction/ engagement letter to Forum members outlining potential priorities and a dedicated Forum webpage; met Office of the Public Guardian personnel with lead responsibility for *Modernising Lasting Powers of Attorney*; I was invited to review *Supporting legal capacity in socio legal context*;<sup>23</sup> met with members of the Welsh Government's Mental Health Legislation Team; worked with academic lawyer colleagues on a proposal to the Law Commission concerning Corporate Criminal Liability; and visited websites such as 39 Essex Chambers, the Small Places, the Essex Autonomy Project and the Social Care Institute for Excellence.

### During **July 2022**

I wrote to Forum members, had one to one discussions with some, and with the assistance of the Essex Autonomy Project, hosted a Forum meeting. This confirmed that the Forum's rapid response webinars during the pandemic were a valued means of delivering training in a fast-moving clinical and policy environment. In addition, it challenged the necessity of the Forum having a Leadership Group and an Implementation Group; also, I attended the Essex Autonomy Project's Summer School, co-sponsored with the Essex Human Rights Centre, at which the topic of Do Not Attempt Cardio Pulmonary Resuscitation cried out for a Consensus Statement. Notes arising from this event comprised my initial blog;<sup>24</sup> and I contributed to a round table discussion concerning the *Safe care at home review*.

### During **August 2022**

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<sup>23</sup> <https://autonomy.essex.ac.uk/wp-content/uploads/2022/12/A-recommended-book.pdf> (accessed 20 April 2023)

<sup>24</sup> <https://autonomy.essex.ac.uk/from-the-nmcf-chair/> (accessed 20 April 2023)



I opted to merge the Leadership and Implementation Groups within the Forum and negotiated its Terms of Reference (see Annex A); and discussed the implications of professional training with the Chairs of the Independent Chairs' Network of Safeguarding Boards.

**During September 2022**

I attended four days of Mental Capacity Act workshops hosted by Norfolk Safeguarding Adults' Board (see blog). All participants could have been giving evidence to the 2014 House of Lords Select Committee post-legislative scrutiny report of the Mental Capacity Act.

**During October 2022**

I redrafted and circulated the Forum's revised Terms of Reference; contributed to the launch of *Supporting legal capacity in socio legal context*; chaired the Forum's first webinar of 2022 re *CPR decisions and the MCA*,<sup>25</sup> and met the Chief Executive of the Office of the Public Guardian.

**During November 2022**

I gave evidence to the Joint Committee on the draft Mental Health Bill; made email contact with potential Forum members; and met with a National Investigator of the Healthcare Safety Investigation Branch.

**During December 2022**

I chaired the Forum webinar, *Families and the MCA*; and began commissioned work concerning a CMHT's support of a person whose gender identity varied from that which featured on their birth certificate.

**During January 2023**

I am working with a charity, Anheddau, on how adults with learning disabilities and autism are supported to exercise simple and complex decisions and how employees are working with professionals across sectors; and I chaired the Forum webinar, *Speech and Language Therapy and the second principle of the MCA*.

**During February 2023**

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<sup>25</sup> <https://autonomy.essex.ac.uk/nmcfevents/> (accessed 20 April 2023)

I met with senior members of the Office of the Public Guardian with two Forum members. We were briefed on the implementation of its digital services and we were given an illuminating overview of the supervision and investigations. I drafted a note to Forum members requesting contributions to the Annual Report; and during a mini-break in Dublin, I took the opportunity to meet the Director of the Decision Support Service.

During **March 2023**

I contributed to a seminar and conference in the Republic of Ireland concerning safeguarding and decision-making. A Forum meeting underlined the importance of exploring mental capacity over the life course highlighting the pressing challenges to which it gives rise.

During **April 2023**

I had further discussions with the National Investigator of the Healthcare Safety Investigation Branch. Forum members were invited to submit anonymised “case study” contributions to the annual report. The DHSC announcement concerning Liberty Protection Safeguards led to a lot of conversations with practitioners and Forum members concerning ways forward.

During **May 2023**

I gave evidence to the Muckamore Abbey Hospital Inquiry in Belfast; and I concluded the drafting of the annual report.

## Annex D: The NMCF Webinar Series 2022-23

In collaboration with the Essex Autonomy Project, the NMCF conducted a series of four webinars in 2022-23. A summary of data pertaining to and arising from these webinars follows.

### Webinar 1: CPR Decisions and the MCA

An NMCF Webinar focusing on *CPR Decisions and the MCA* took place on 20 Oct., 2022; 1-2pm.

Total Registration	1084
Total Attendance	748
Attendance Rate (=Attendance/Registration)	69%
Most Represented Professional Group	Nurses (>150)
Average Subjective Confidence Level Prior to Webinar <sup>26</sup>	5/10
Rate of High Confidence Pre-Webinar <sup>27</sup>	42%
Average Subjective Confidence Level After Webinar <sup>28</sup>	8/10
Rate of High Confidence Post-Webinar <sup>29</sup>	85%

Participants responded to both to pre-registration questions and to an end-of-webinar Zoom poll. In addition to marked increase in reported confidence in the subject matter among participants, there are three points in this data are noteworthy:

- 95% of respondents either Agreed or Strongly Agreed that the webinar had advanced their understanding of how to apply the MCA in decisions about initiation of CPR.
- Before the webinar, only 21% of the responses to registration questions demonstrated an understanding that DNACPR recommendations are *not legally binding*. At the end of the webinar, 91% gave the legally correct answer to the question: “True or False: DNACPR recommendations are binding.”
- Before the webinar, only 36% of the responses to registration questions demonstrated an understanding that DNACPR recommendations do not require the consent of the person. At the end of the webinar, 83% gave the legally correct answer to the question:

<sup>26</sup> As part of the registration process, delegates were asked to respond to the following: Q3: *On a scale of 1 – 10, with 1 being the least confident and 10 being the most confident, how confident do you feel in your knowledge of the law around DNACPR?* Mode response: 5; n=944.

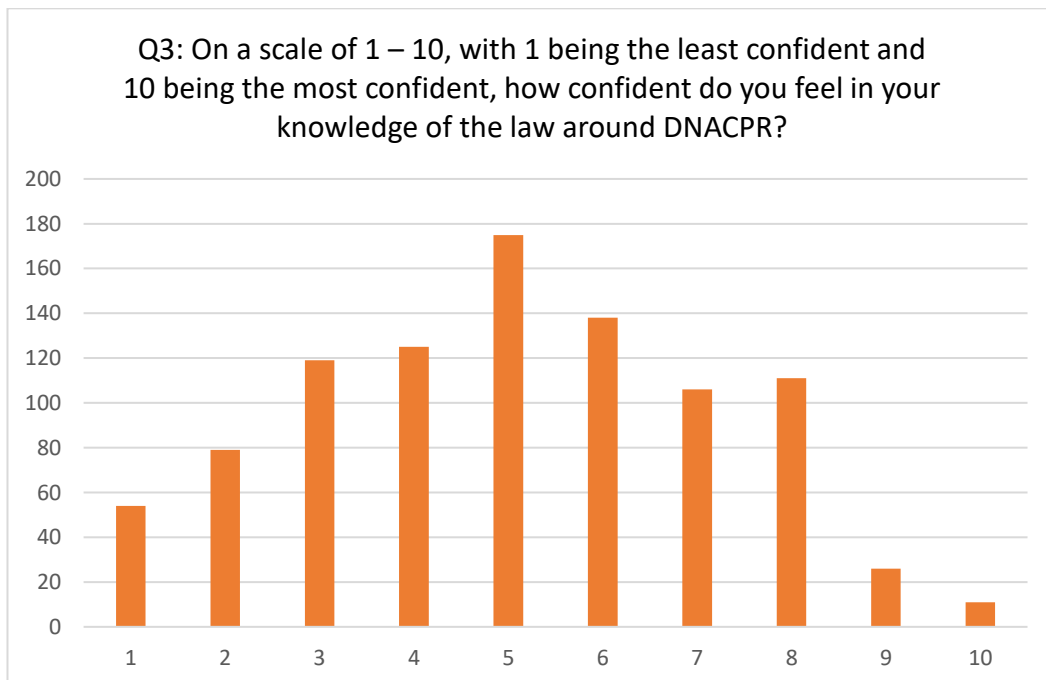
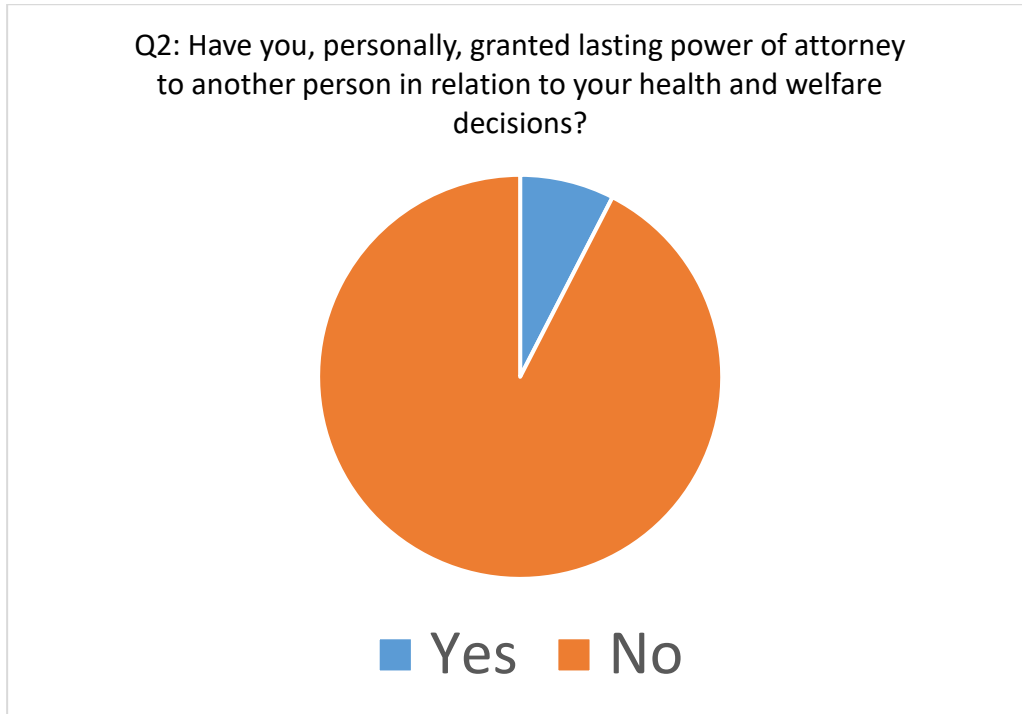
<sup>27</sup> Percentage of respondents to registration questions who rated their confidence level  $6 \leq x \leq 10$ . Scale of 1-10; n=944.

<sup>28</sup> At the end of the webinar, delegates were asked to respond to a Zoom poll, which included the same question. Mode response: 8; n=435.

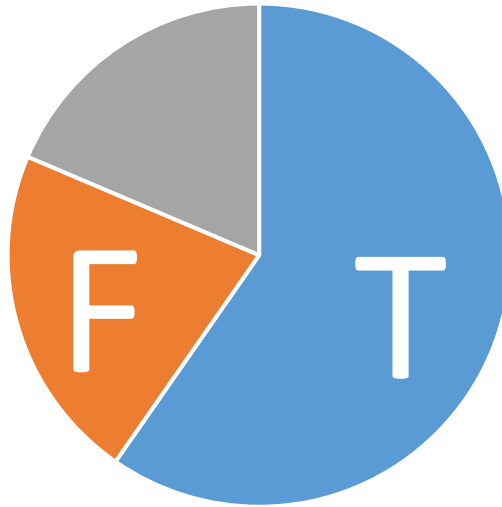
<sup>29</sup> Percentage of respondents to end-of-webinar Zoom poll who rated their confidence level  $6 \leq x \leq 10$ . Scale of 1-10; n=435.

“True or False: A doctor needs the consent of the patient (or those close to them) to place a DNACPR in their medical records.”

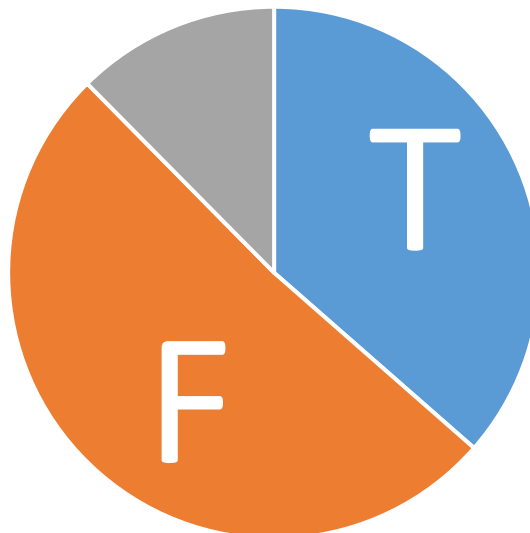
A. Responses to Registration Questions 2-8.



Q4: True or False: CPR should never be performed if there is a valid DNACPR in place.



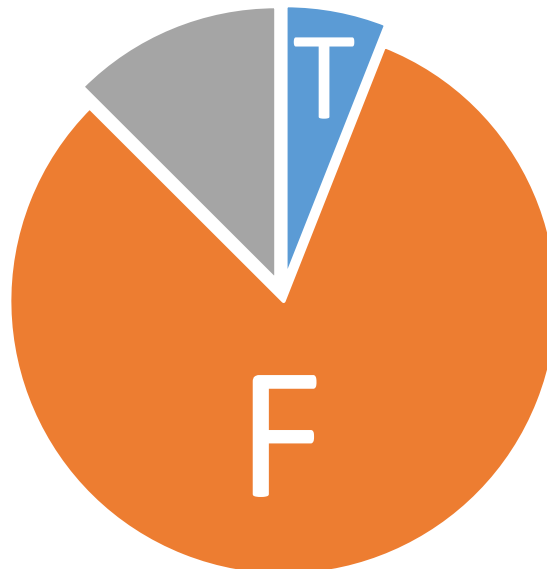
Q5: True or False: A doctor does not need the consent of the patient (or those close to them) to place a DNACPR in their medical records.

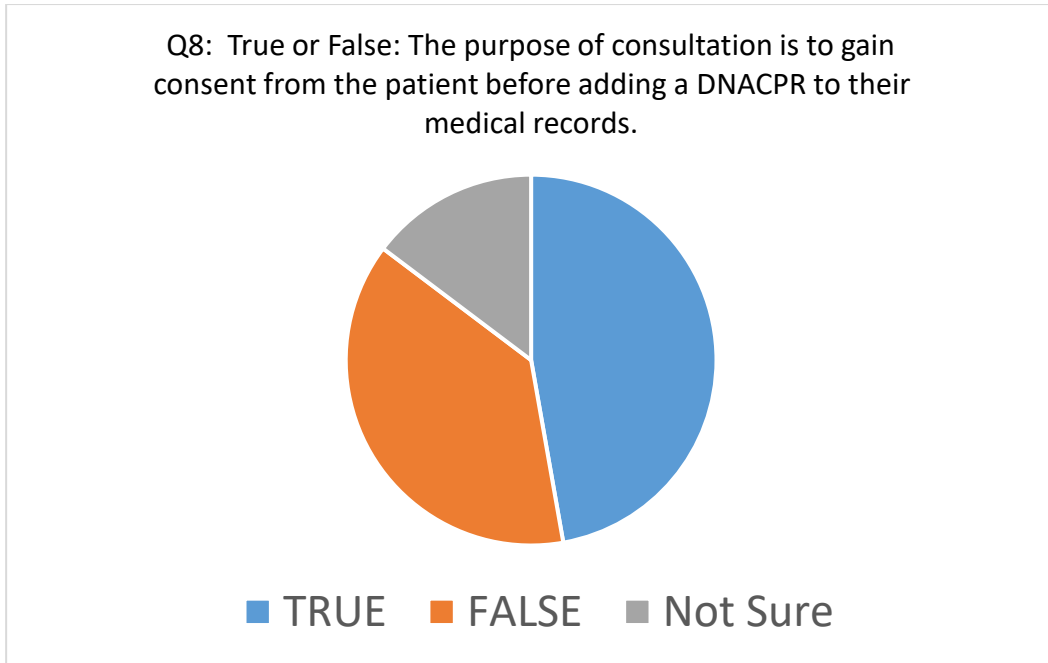


Q6: True or False: DNACPR is a clinical decision that is always made by doctors alone.

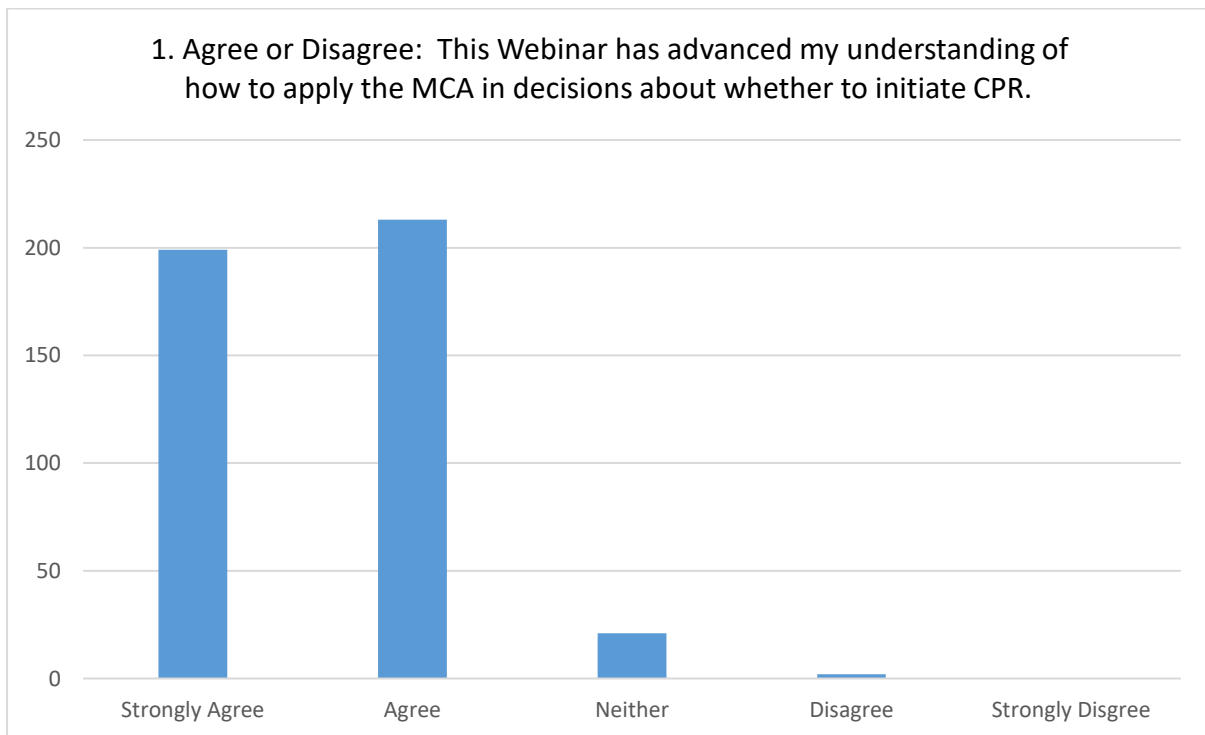


Q7: True or False: When the reasons for adopting a DNACPR are purely clinical, there is no need to consult with the patient.

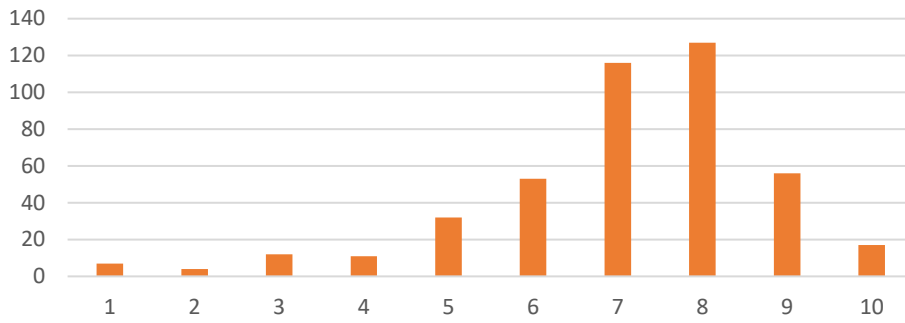




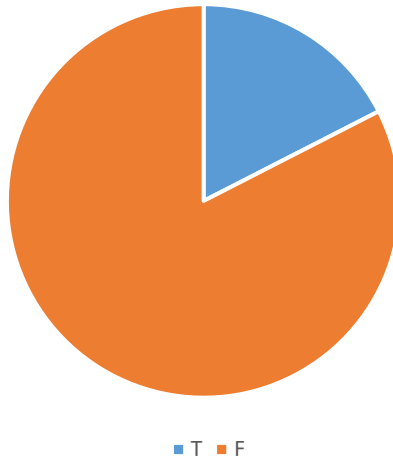
B. Post-Webinar Zoom Poll



2. On a scale of 1 – 10, with 1 being the least confident and 10 being the most confident, how confident do you feel in your knowledge of the law around DNACPR?

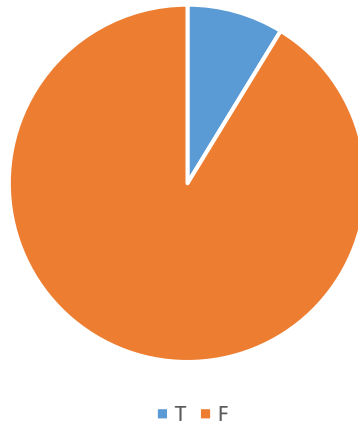


3. True or False: DNACPR recommendations are binding.





4. True or False: A doctor needs the consent of the patient (or those close to them) to place a DNACPR in their medical records.



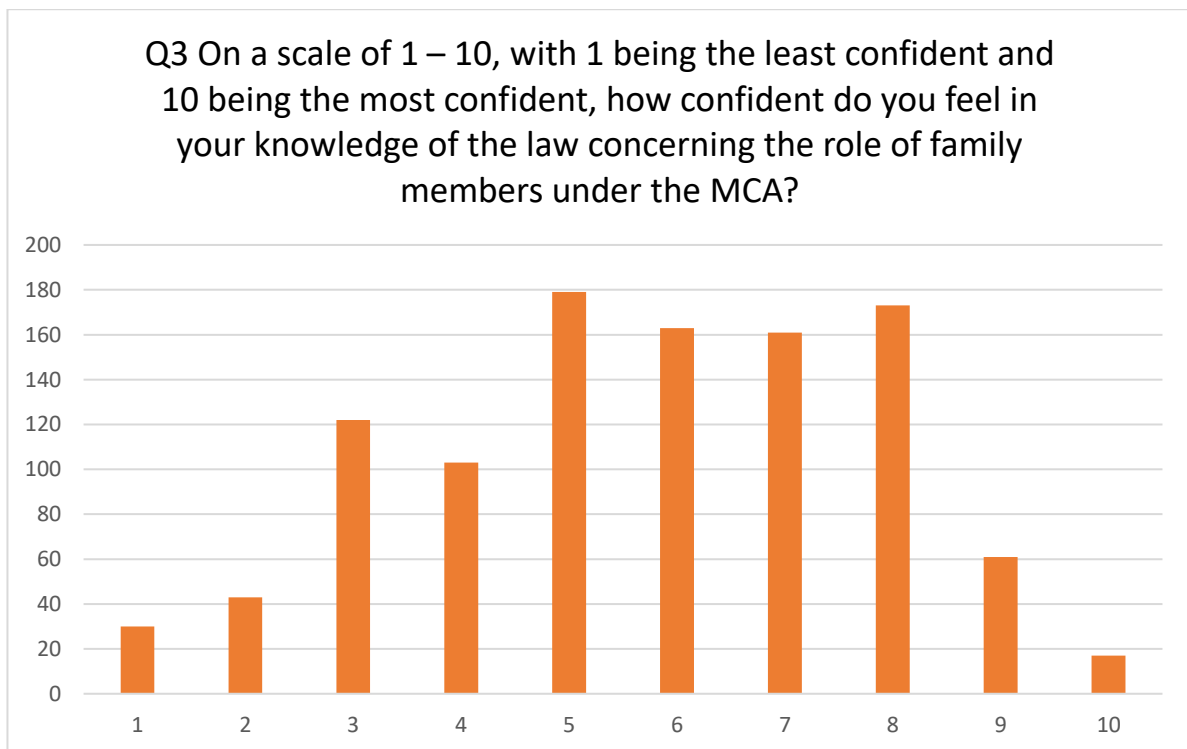
Webinar 2: Families and the MCA

An NCMF Webinar focusing on *Families and the MCA* took place on 7 Dec., 2022; 1-2pm.

Total Registration	1107
Total Attendance	675
Attendance Rate (=Attendance/Registration)	61%
Average Subjective Confidence Level Prior to Webinar <sup>30</sup>	5/10
Rate of High Confidence Pre-Webinar <sup>31</sup>	54.7%
Average Subjective Confidence Level After Webinar <sup>32</sup>	8/10
Rate of High Confidence Post-Webinar <sup>33</sup>	94.9%

Delegates were invited to respond to substantive pre-registration questions and end-of-webinar Zoom poll.

A. Responses to Registration Questions 3-8. (n=~1050)



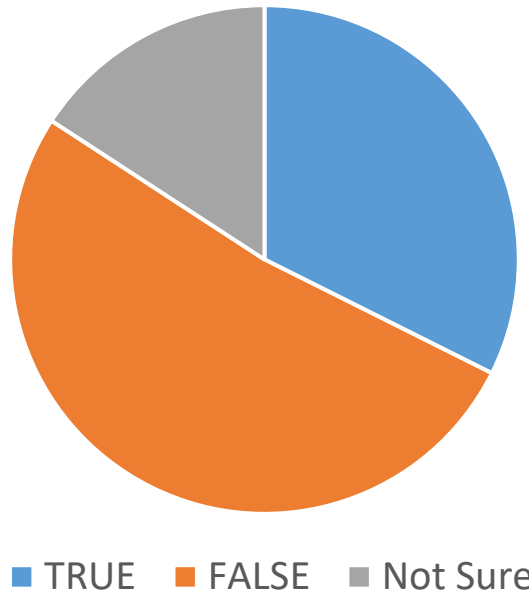
<sup>30</sup> As part of the registration process, delegates were asked to respond to the following: Q3: *On a scale of 1 – 10, with 1 being the least confident and 10 being the most confident, how confident do you feel in your knowledge of the law concerning the role of family members under the MCA?* Mode response: 5; n=1052.

<sup>31</sup> Percentage of respondents to registration questions who rated their confidence level 6≤x≤10. Scale of 1-10; n=1052.

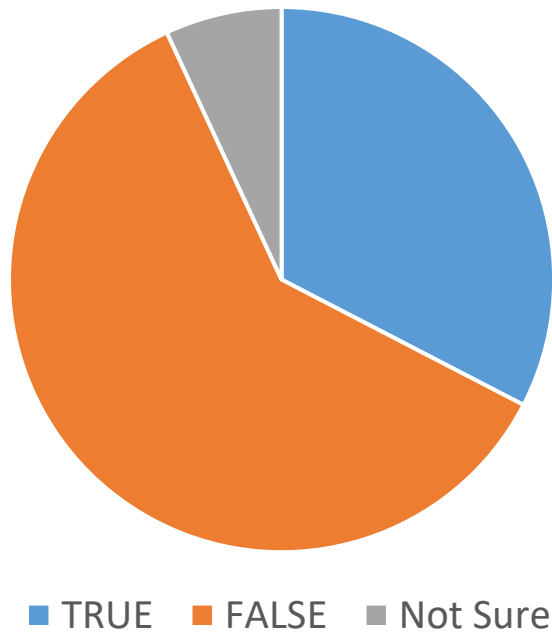
<sup>32</sup> At the end of the webinar, delegates were asked to respond to a Zoom poll, which included the same question. Mode response: 8; n=313.

<sup>33</sup> Percentage of respondents to end-of-webinar Zoom poll who rated their confidence level 6≤x≤10. Scale of 1-10; n=313.

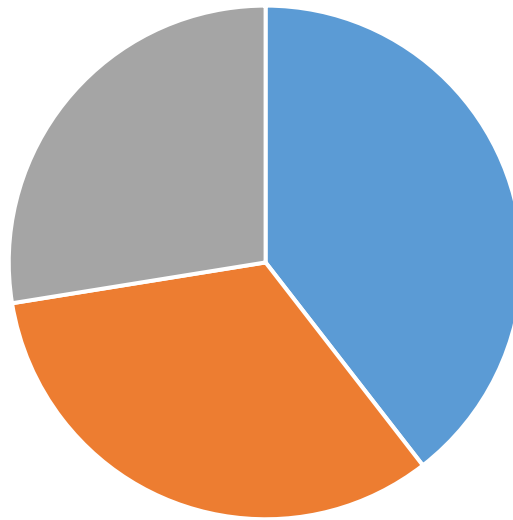
Q4: True or False: Under the MCA, a person's next of kin has specific rights and responsibilities in circumstances where a best interests decision needs to be made.



Q5: True or False: IMCAs (Independent Mental Capacity Advocates) have a role to play in best-interests decision-making only if no family member is available.

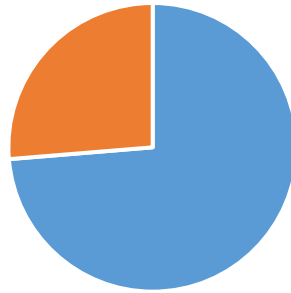


Q6: Agree or Disagree: In my experience, IMCAs are available in a timely fashion when their advocacy services are required.

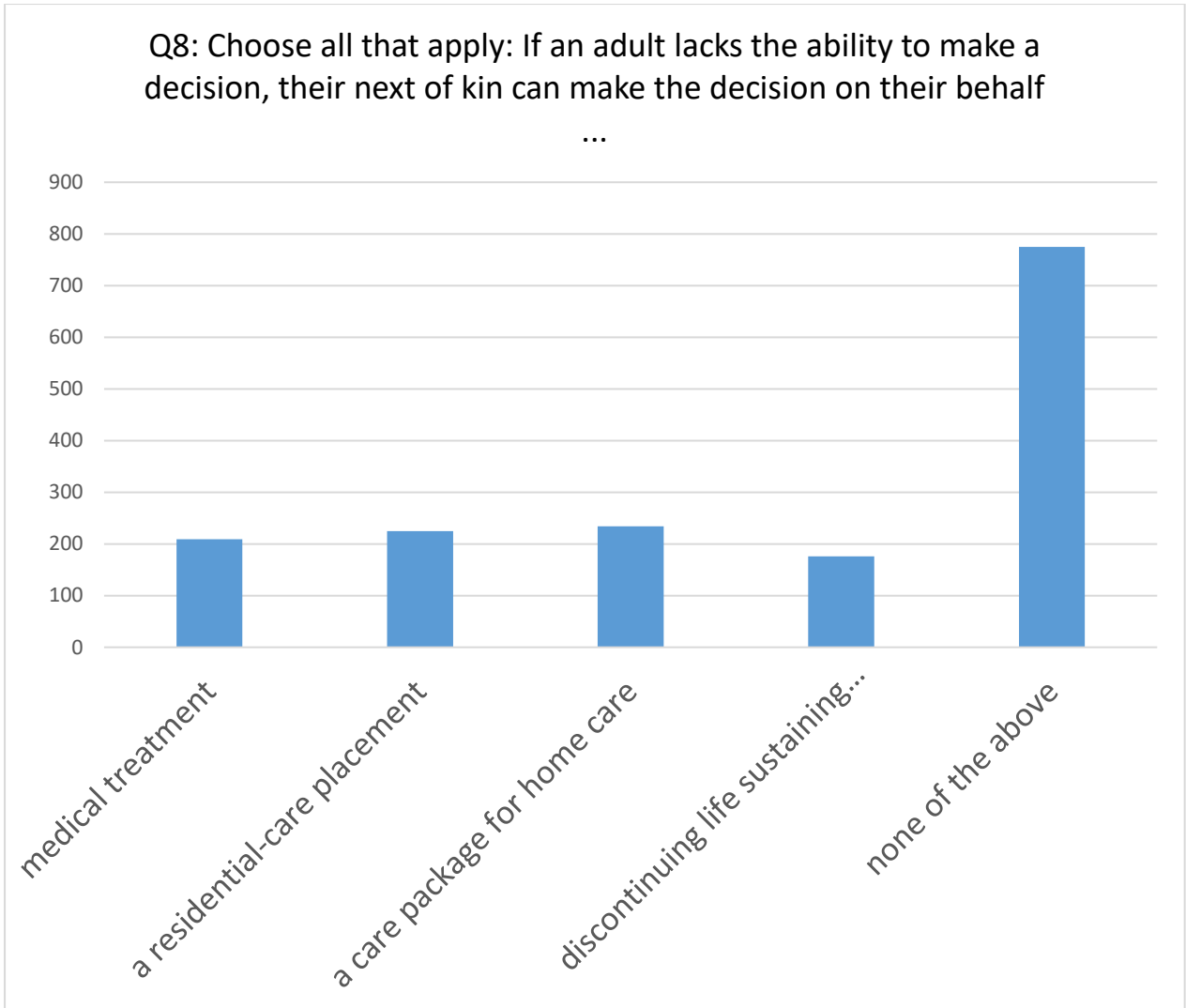


■ Agree ■ Disagree ■ Don't Know

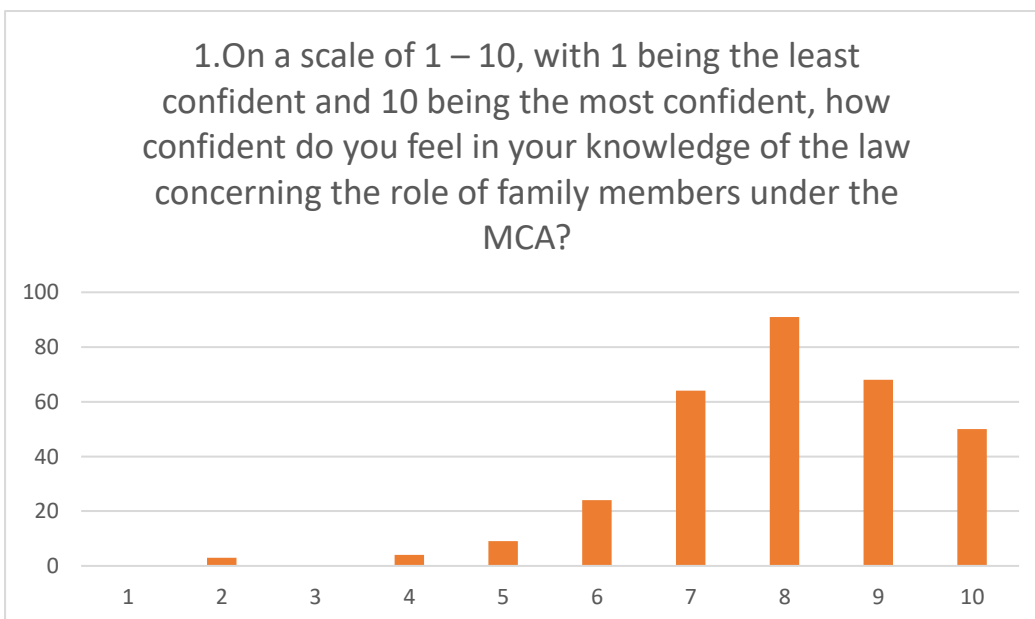
Q7: Agree or Disagree: I know how to report a concern if I suspect that an Attorney or Deputy is not acting in the best interests of the person they are responsible for.



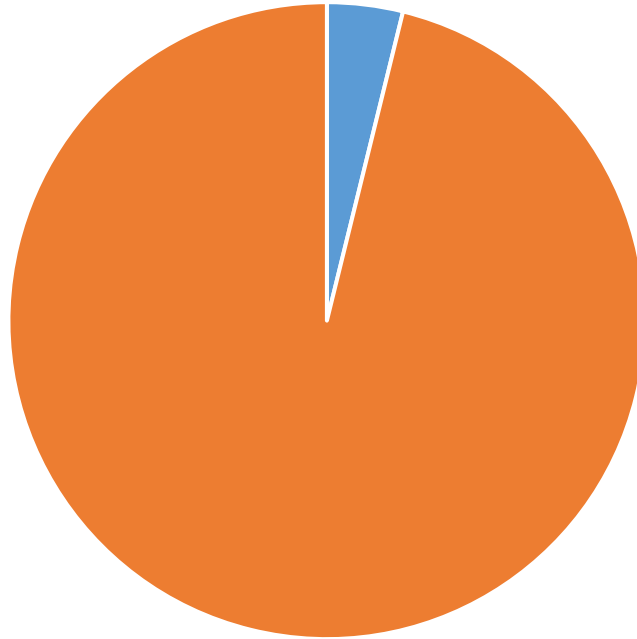
■ Agree ■ Disagree



B. Post-Webinar Zoom Poll (n=313)



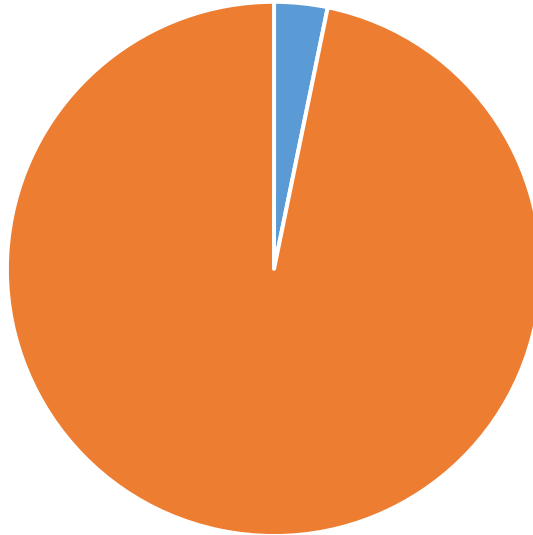
2. True or False: If an adult lacks the ability to make a decision and has not appointed an LPA, their next of kin can consent on their behalf to medical treatment.



True: 25 (8.0%)

False: 288 (92.0%)

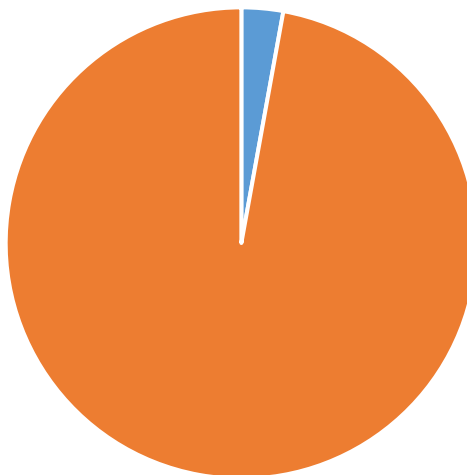
3. True or False: If an adult lacks the ability to make a decision and has not appointed an LPA, their next of kin can consent on their behalf to a residential care placement.



True: 30 (9.6%)

False: 283 (90.4%)

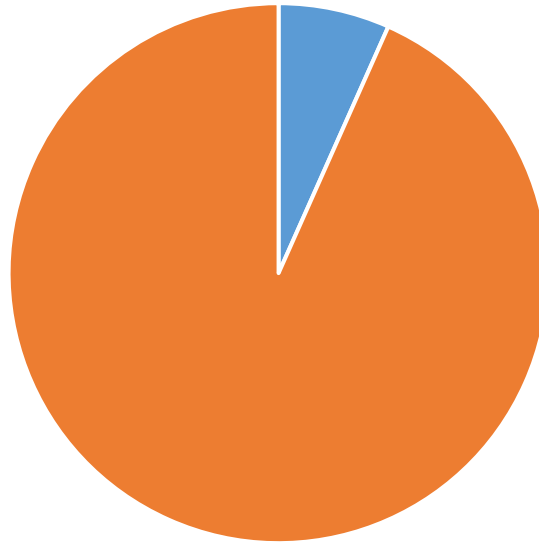
4. True or False: If an adult lacks the ability to make a decision and has not appointed an LPA, their next of kin can consent on their behalf to a care package for home care.



True: 30 (10.9%)

False: 279 (89.1%)

5. True or False: If an adult lacks the ability to make a decision and has not appointed an LPA, their next of kin can consent on their behalf to discontinuation of life-sustaining treatment.



True: 14 (4.5%)

False: 299 (95.5%)



Webinar 3: Practical Steps for People with Communication Difficulties

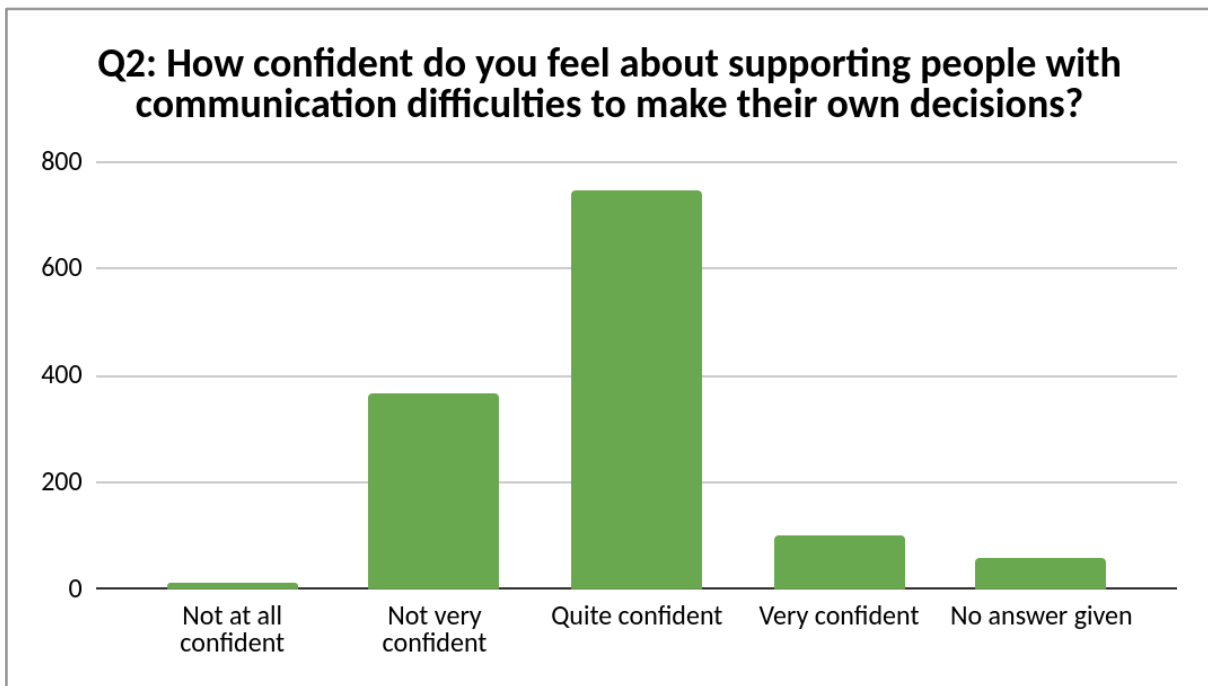
An NMCF Webinar on *Practical Steps for People with Communication Difficulties* took place on 19th January 2023 at 1-2pm.

Total Registration:	1258
Total Attendance:	975
Attendance Rate (=Attendance/Registration):	77.5%
Most Represented Professional Group:	Social Workers

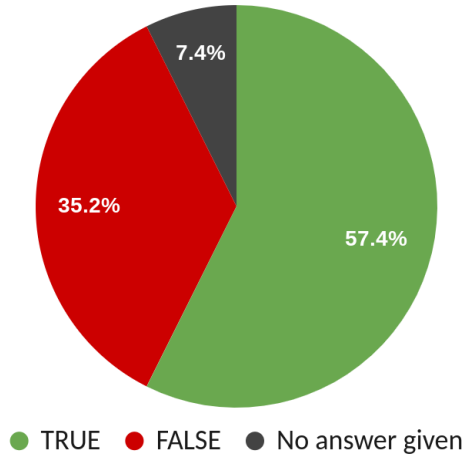
Delegates were invited to respond to substantive pre-registration questions (1000≤n≤1200) and an end-of-webinar Zoom poll (n=436). A few observations drawn from the data:

- 92.2% of respondents in the post-webinar Zoom poll Agreed that they felt better prepared to support people with communication difficulties after the webinar.
- Only 49.2% of respondents reported that they had received training on how to support people with communication difficulties.
- In response to the question “would you like to propose a topic that would be a useful focus for future NMCF webinars?”, 81 respondents requested a webinar on the topic: “capacity assessment.”

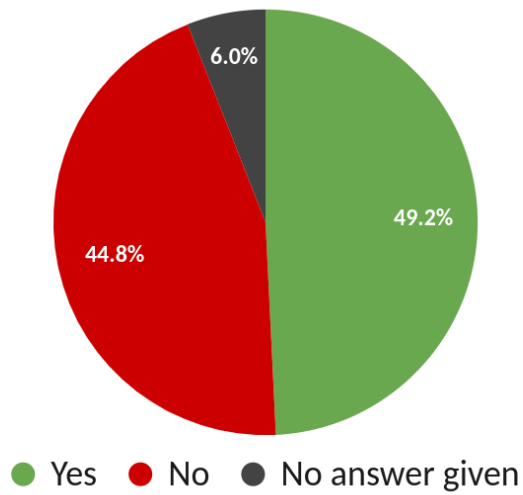
A. Responses to Registration Questions (Q2-Q9)

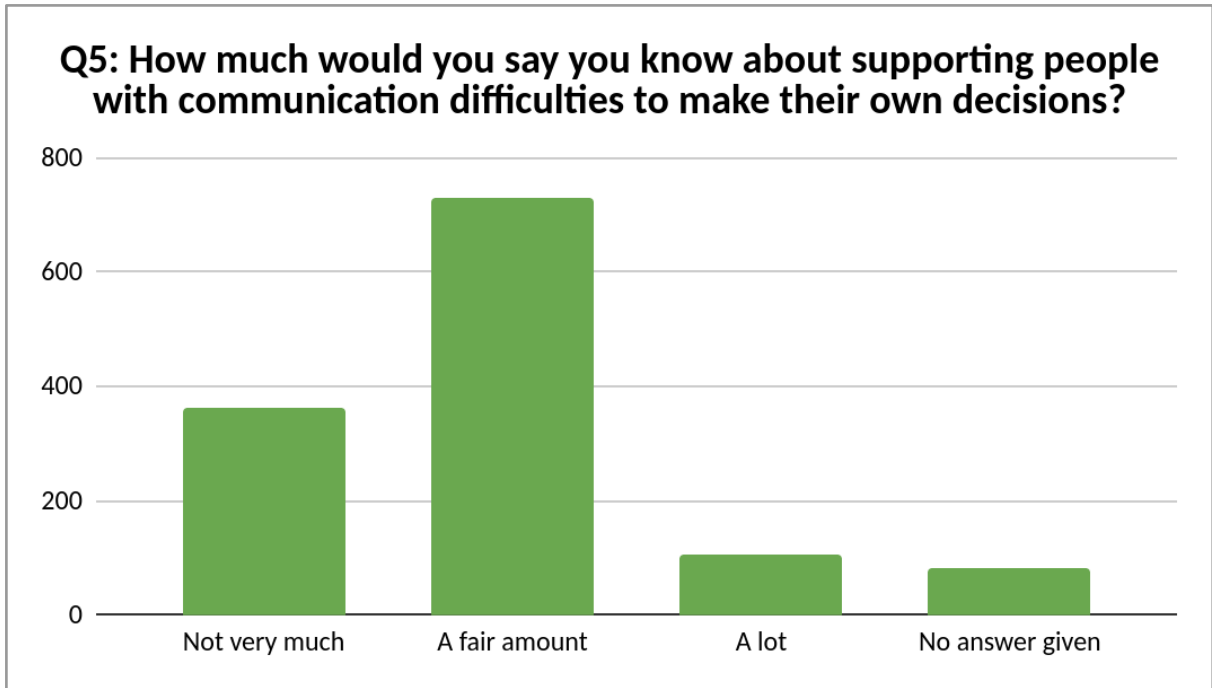


**Q3: True or false? Given the right support, everyone with communication difficulties can demonstrate the capacity to make their own decisions.**

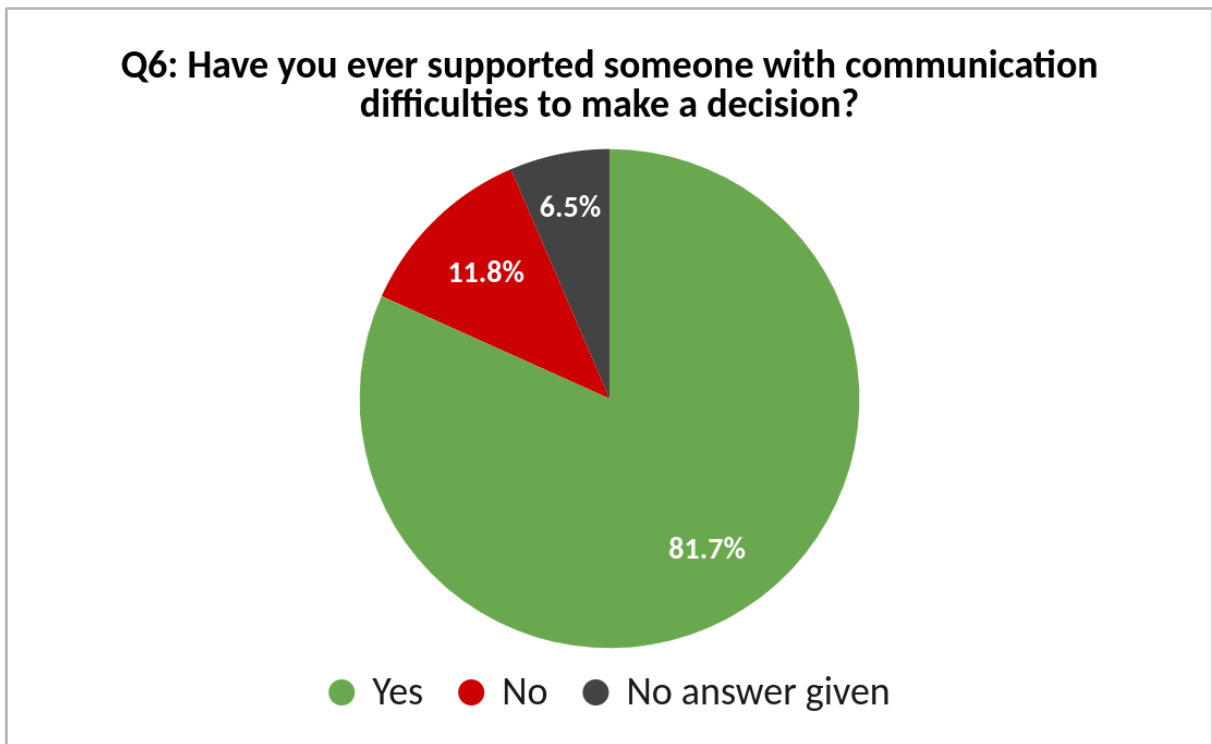


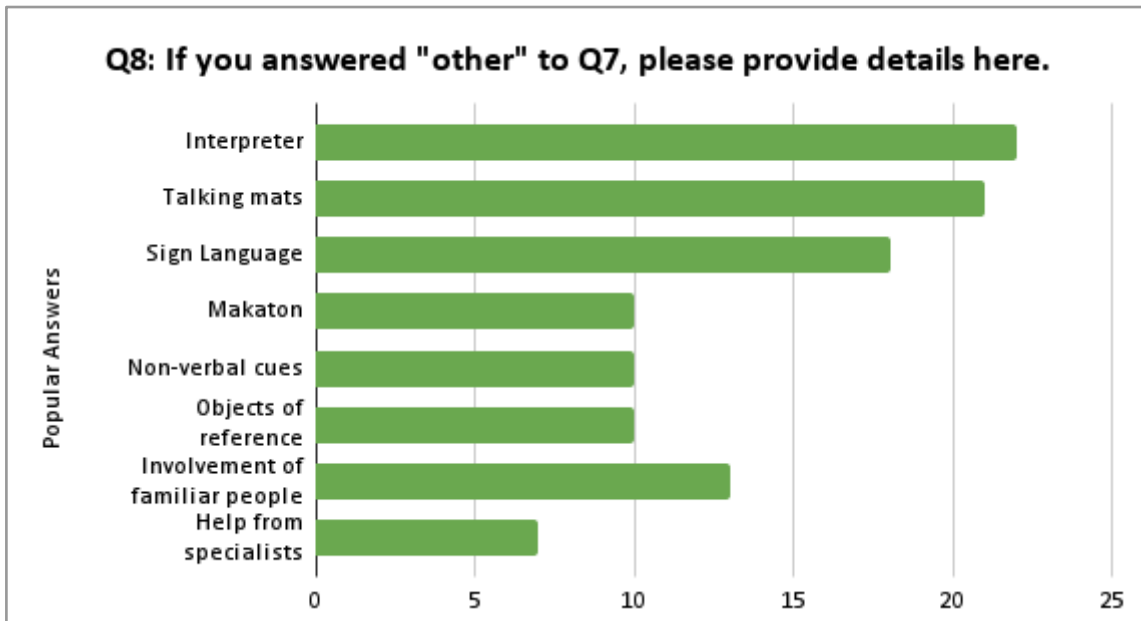
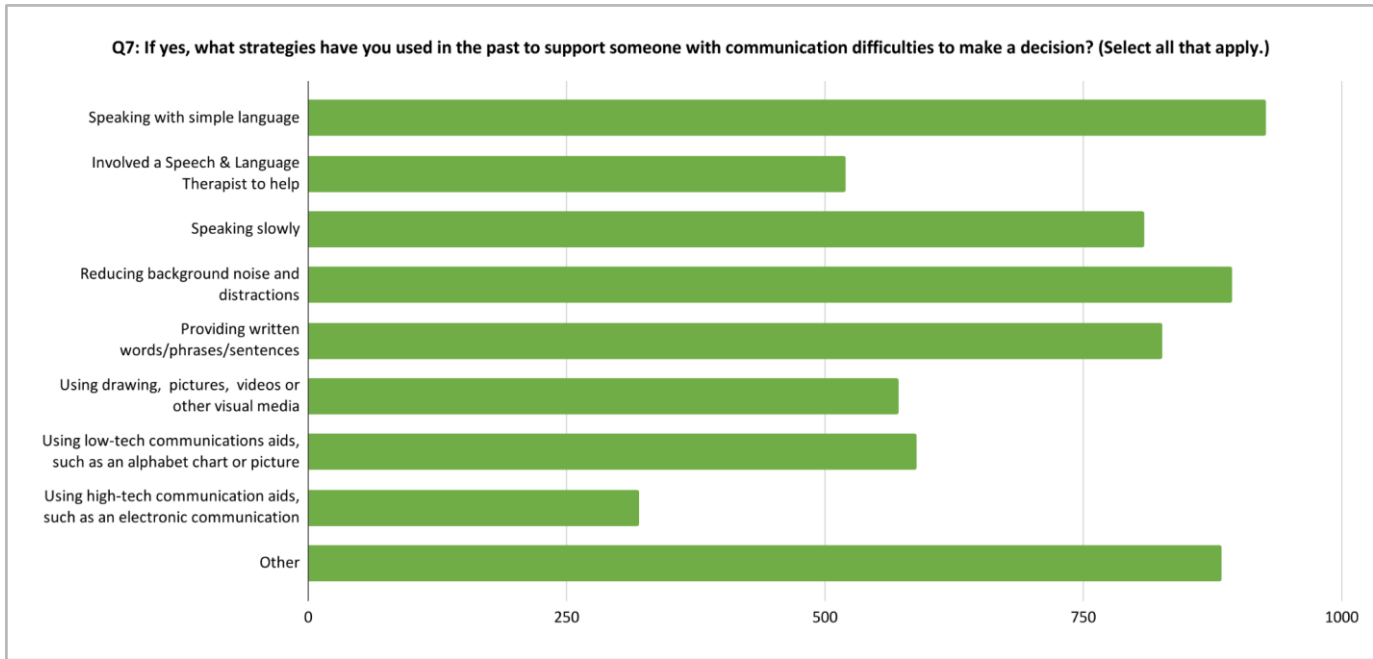
**Q4: Have you ever received training on how to support people with communication difficulties?**

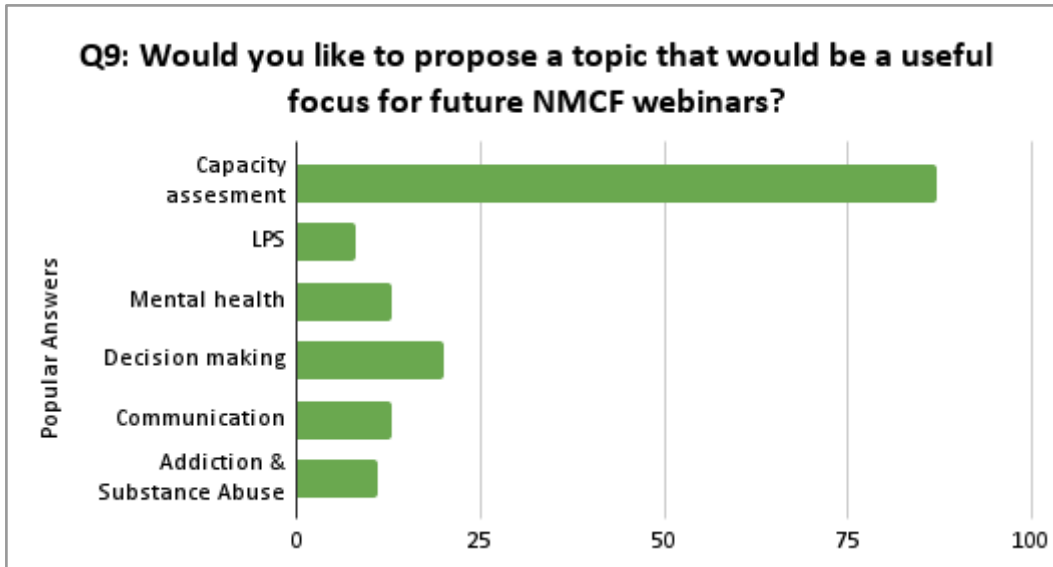




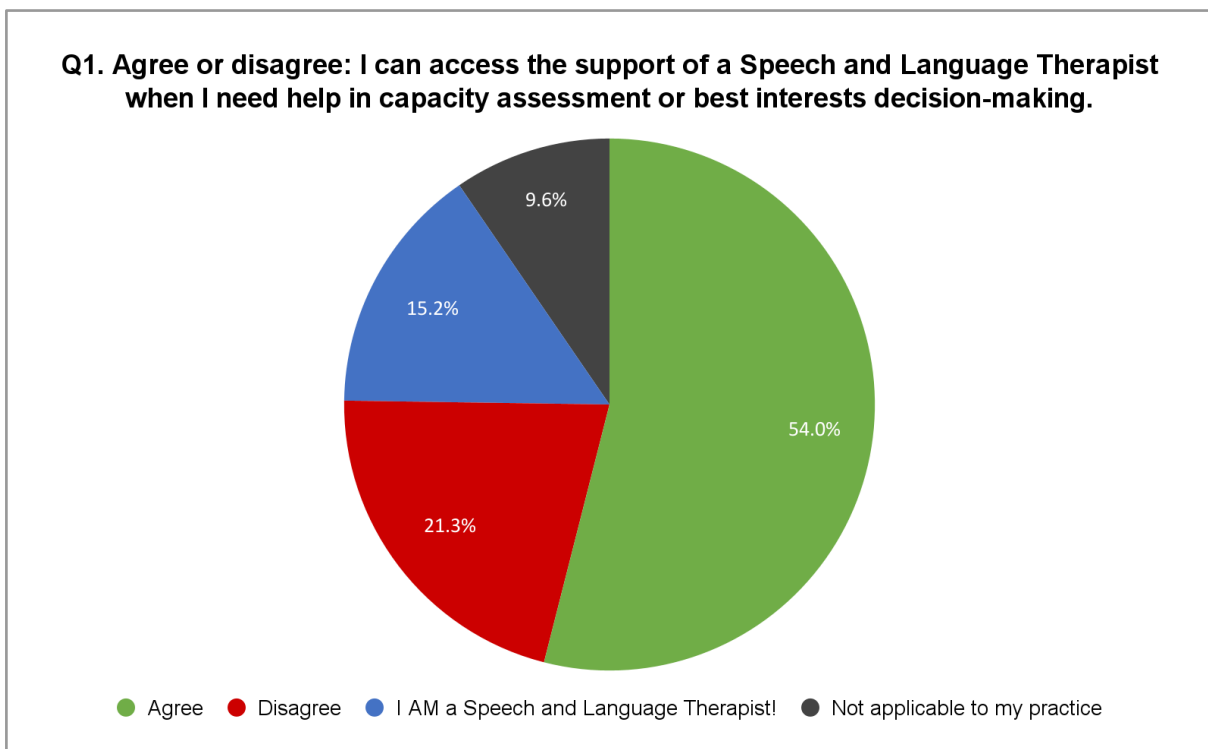
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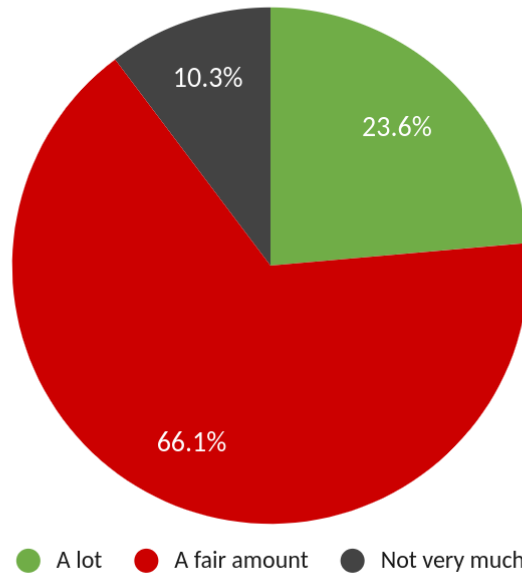




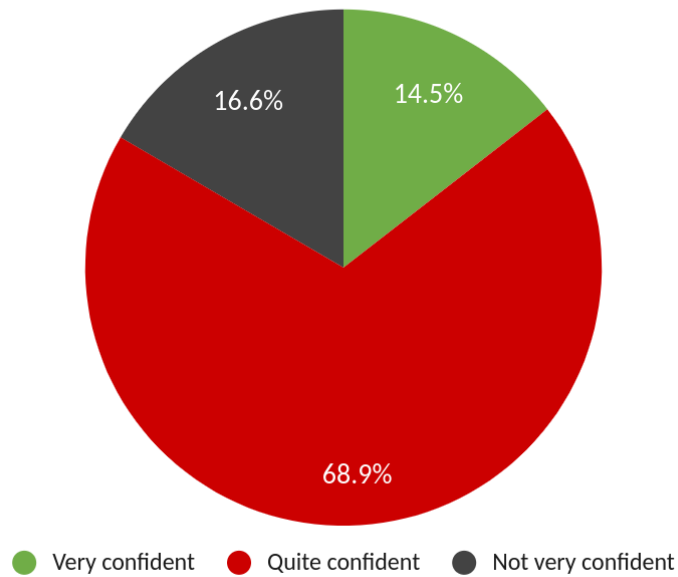
B. Post-webinar zoom poll (Q1-Q4)



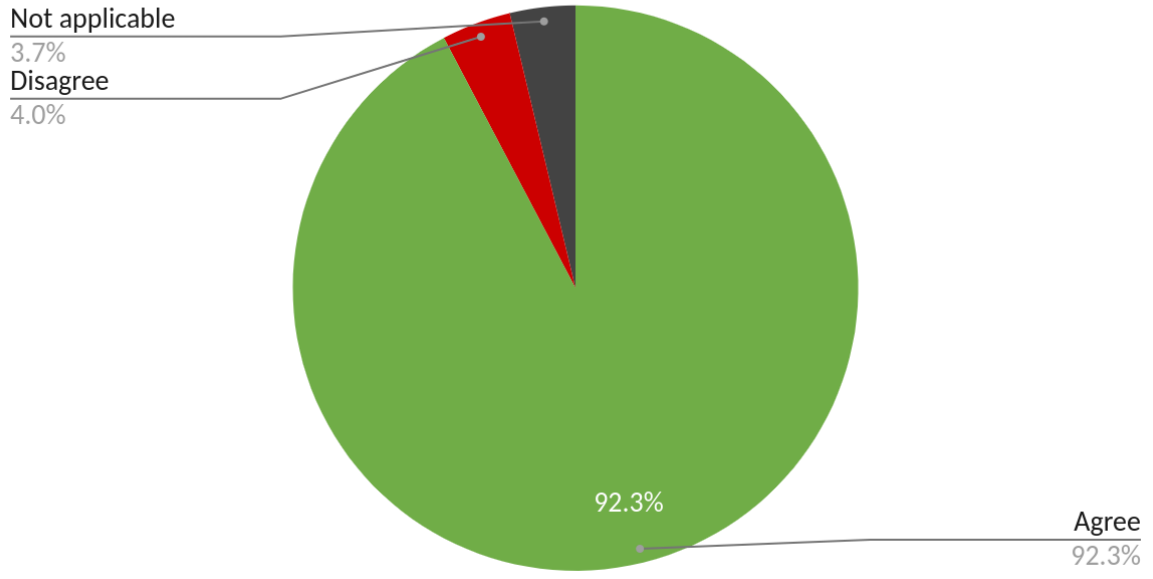
**Q2: "How much do you think you know about supporting people with communication difficulties to make their own decisions?"**



**Q3: How confident do you feel about supporting people with communication difficulties to make their own decisions?**



**Q4: Based on this webinar, I feel better prepared to support people with communication difficulties.**



Webinar 4: Executive Dysfunction and the MCA

An NMCF webinar focusing on *Executive Dysfunction and the MCA* took place on the 25th April 2023; 1-2pm.

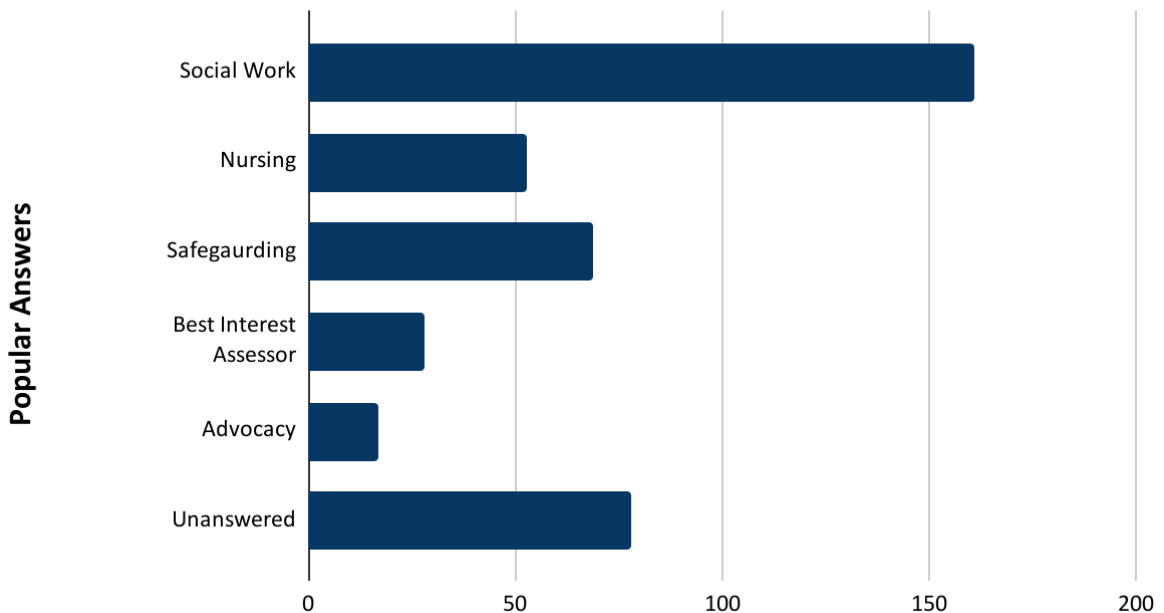
<b>Total Registration</b>	<b>1251</b>
<b>Total Attendance</b>	<b>982</b>
<b>Attendance Rate (=Attendance/Registration)</b>	<b>78.56%</b>
<b>Most Represented Professional Group</b>	<b>Social Workers</b>

Delegates were invited to respond to substantive pre-registration questions and two in-webinar Zoom polls.

Please note that a sampling method has been used to process the qualitative data generated by responses to Questions 1, 5 and 7). For Questions 1 and 5 a sample of the first 504 responses was used. With the data on question 7 an iterative tagging methodology was used to characterise a random sample of 100 registrants.

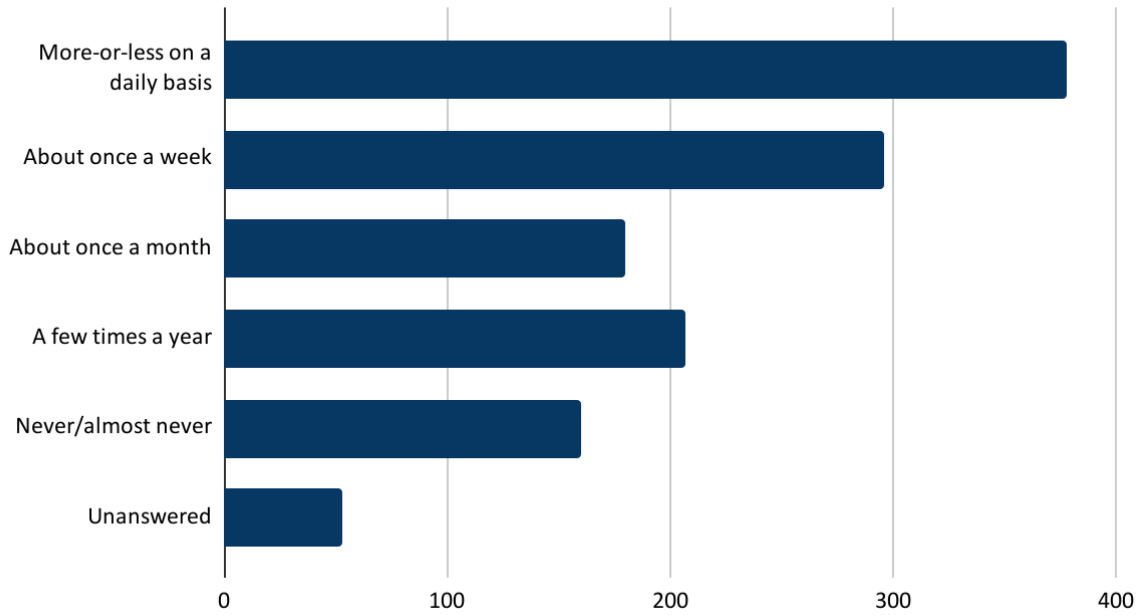
A. Responses to registration questions 1-10.

**Q1: What is your main professional role (if any)?**

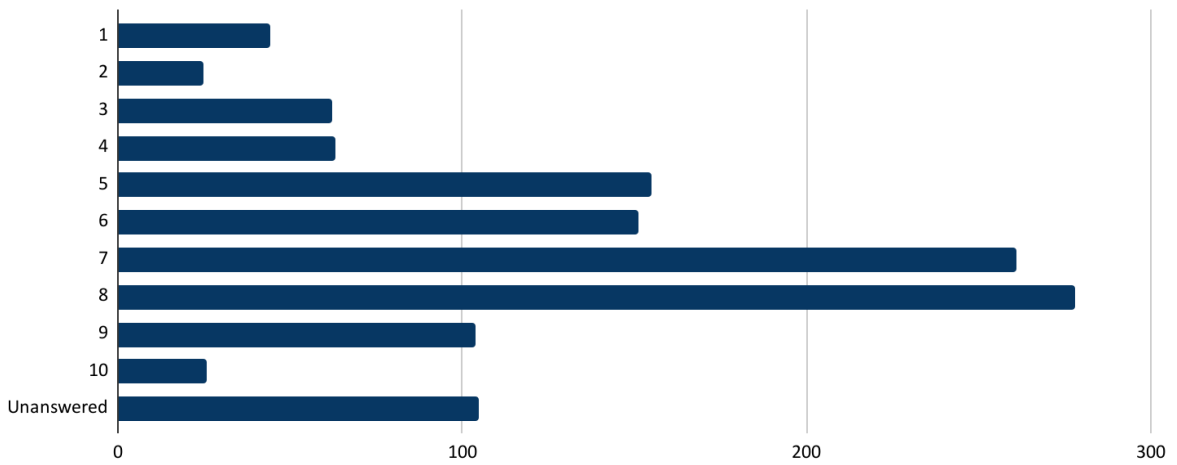




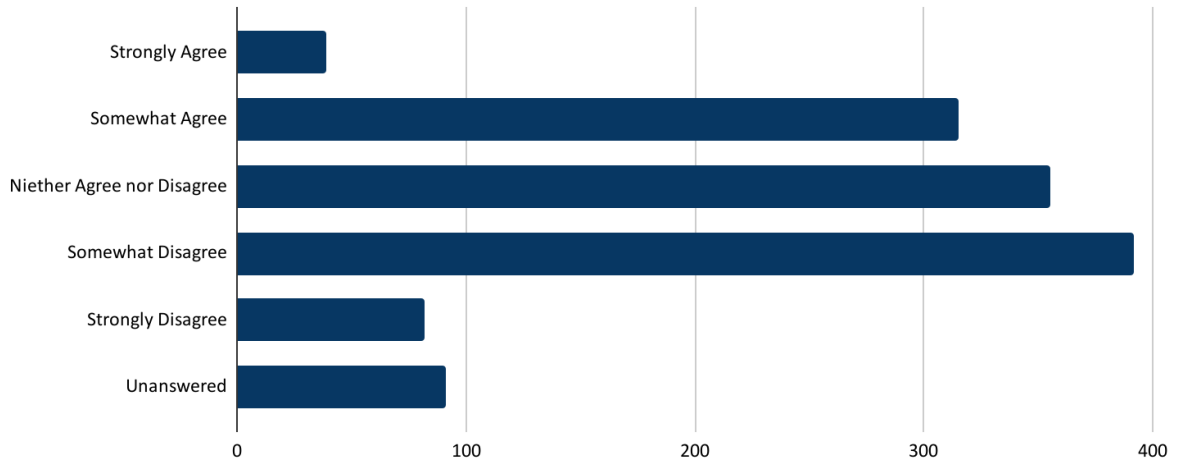
### Q2: How Frequently Do You Assess Mental Capacity?



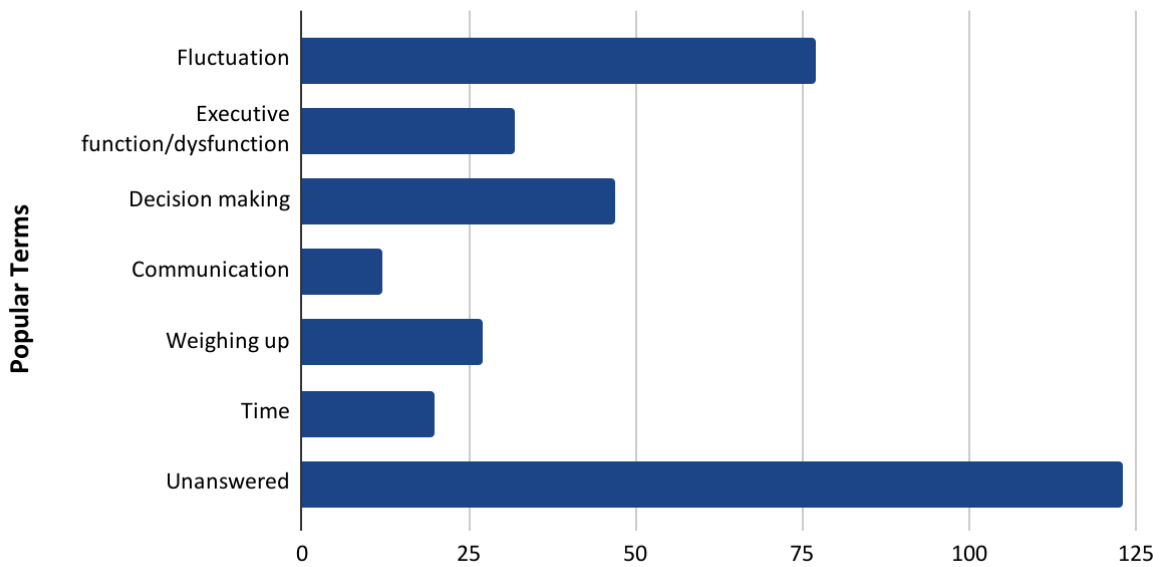
### Q3: On a scale of 1 – 10, with 1 being the least confident and 10 being the most confident, how confident are you in carrying out assessments of mental capacity?



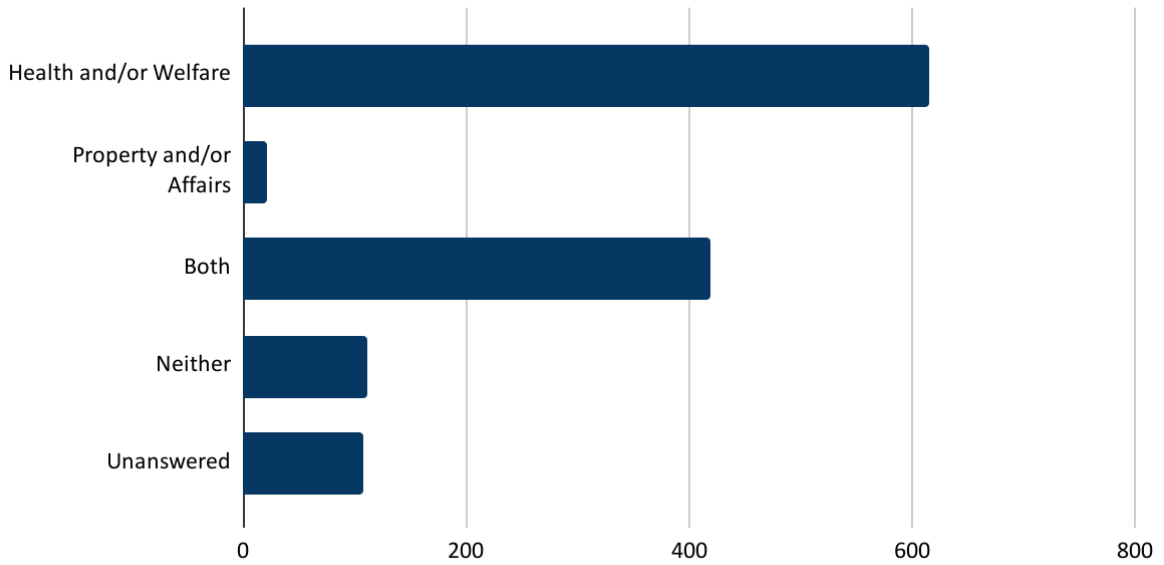
**Q4: Agree or Disagree: I often find myself uncertain as to whether a person in my care has mental capacity to make a decision that needs to be made.**



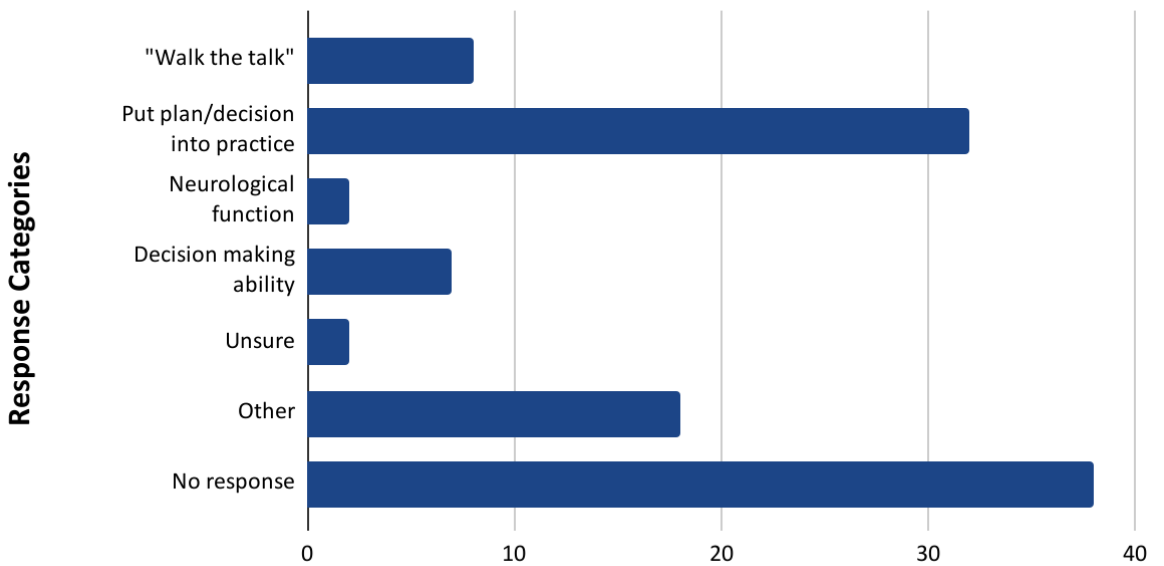
**Q5: The thing I find most challenging about the assessment of capacity is ...**



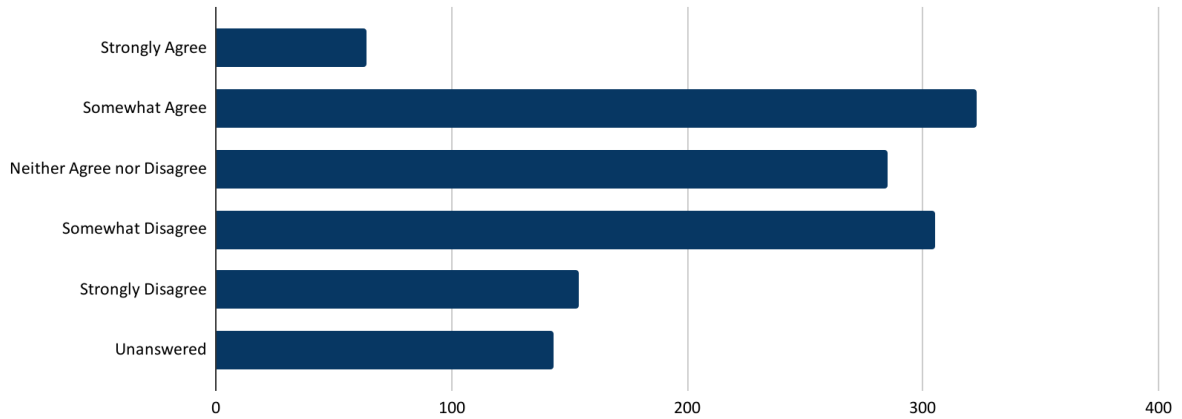
**Q6: The decisions for which I carry out a capacity assessment are usually in the area of ...**



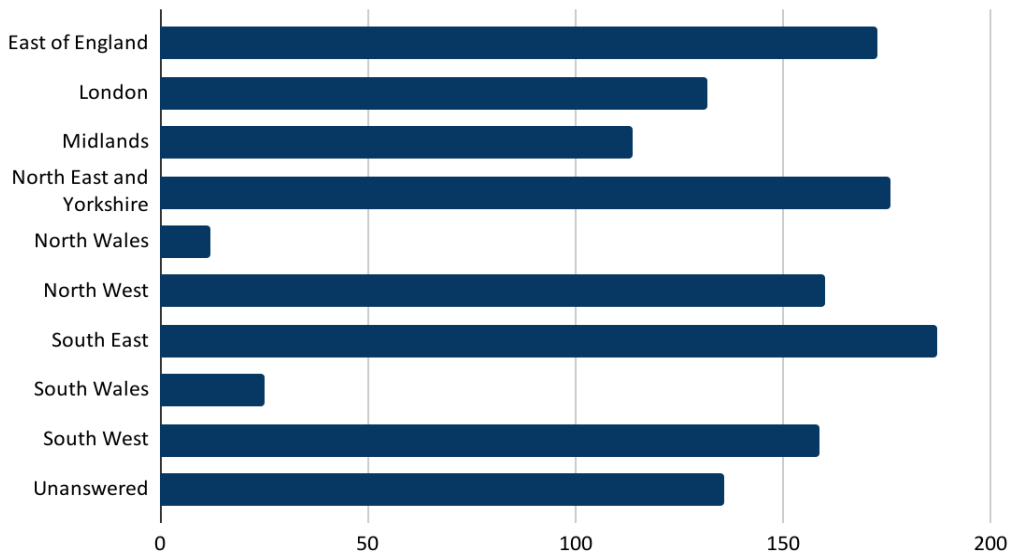
**Sample from Q7: Using your own words (max 128 characters), explain or describe executive function.**



**Q8: Agree or Disagree: Issues about executive function and dysfunction have been covered as part of my training on applying the Mental Capacity Act.**

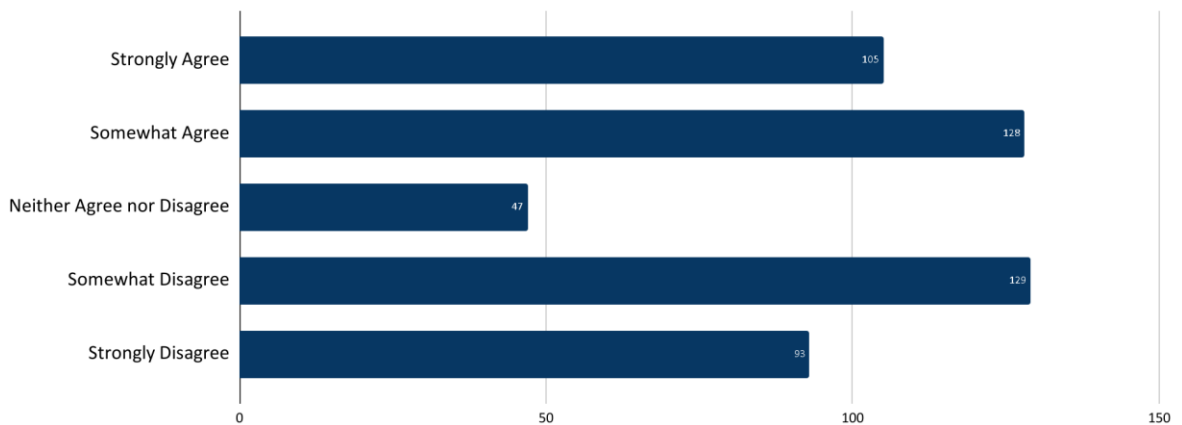


**Q9: In what region are you mainly based?**



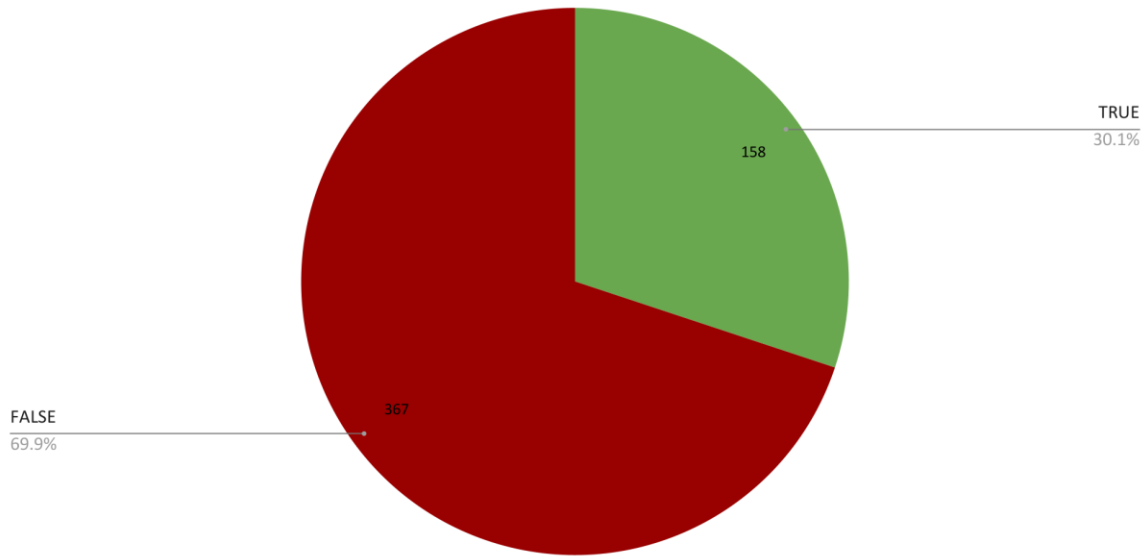
**B. Beginning of webinar Zoom poll (1 question).**

**Agree or Disagree: Under the MCA, a capacity assessment should focus on whether the person IS ABLE TO MAKE THE DECISION at the time it needs to be made. The question of whether they ARE ABLE TO CARRY OUT their decision is not**

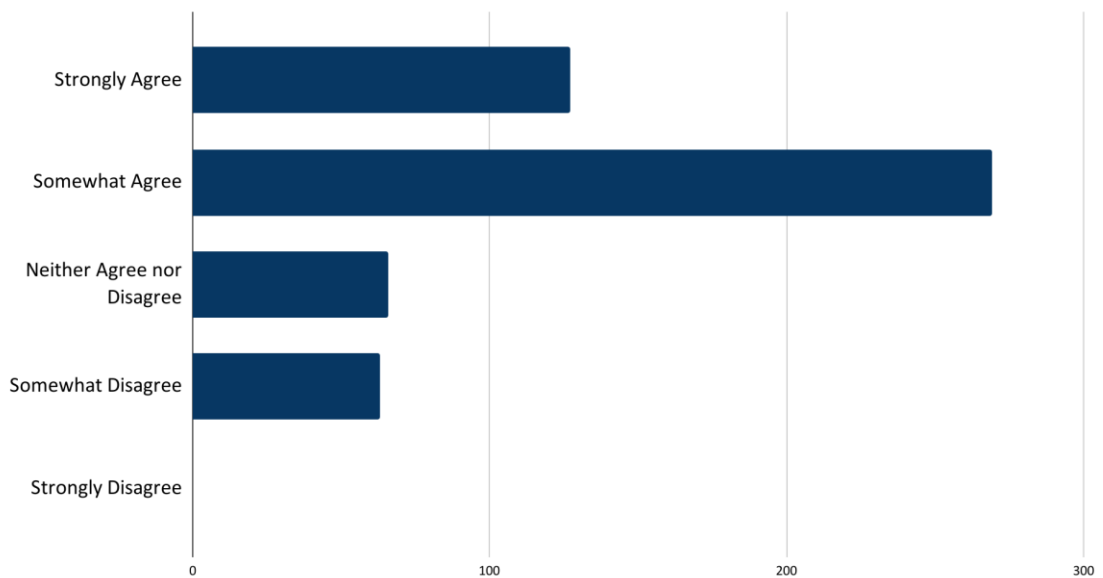


C. End of webinar Zoom poll (three questions).

**True or False: In assessing mental capacity for persons with impaired executive functioning, a face-to-face interview by a skilled assessor is usually sufficient.**  
(n=525)



**Agree or Disagree: Under some circumstances, a pattern of failure to carry out one's plan can be evidence of inability to use information.**  
(n=525)



**Based on this webinar, I have a better understanding of the concept of executive functioning and its relevance to capacity assessment.**

