

National Mental Capacity Forum

Chair's Annual Report 2019 – 2020

Fourth Report of the National Mental Capacity Forum

August 2020

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Fourth Annual Report of the National Mental Capacity Forum



Executive summary

After the first three years of the National Mental Capacity Forum, the nation's situation changed dramatically with the advent of the coronavirus pandemic.

This report therefore spans three main aspects of the Forum's work:

- Evaluation of the efficacy of the Forum over its first four years in changing awareness of the Mental Capacity Act (MCA) and its implementation;
- The legislative changes that resulted in the Mental Capacity (Amendment) Act 2019
 to move from Deprivation of Liberty Safeguards (DoLS) to Liberty Protection
 Safeguards (LPS). As this was fully debated in Parliament and the full transcript is
 available on Hansard, the legislative process has not been covered in detail in the
 text of this report;
- Actions taken from the outset of the pandemic to meet the needs of those who are
 protected by the MCA and support those providing care and having responsibility for
 the wellbeing of people with impairments of mental capacity.

The adoption of the handprint logo (see page 10) has raised awareness of the Forum and (as an easy aide memoire) assisted in teaching the five core principles of the MCA. However, difficulties remain, particularly in supporting people to make their own decisions and, where that is not possible, to helping them to participate in the decision-making process as much as possible.

For the evaluation of the efficacy of the Forum, the 2015 House of Lords post-legislative scrutiny committee report on the MCA¹ was revisited and its recommendations used as a basis for an on-line survey. This ascertained how many of the recommendations, relevant to the National Mental Capacity Forum, had been fulfilled.

All those for whom correspondence details were available, from across all disciplines and members of the public, were contacted. The survey was held over the last four months of 2019 and there were 1244 responses. The majority of respondents classified themselves as from health (44%) or social care (36%). These groups were large enough to provide comparisons between sectors.

Overall results were encouraging with over two thirds (69%) reporting improved implementation of the MCA overall, irrespective of the sector with which they identified. 12% did not think implementation had improved.

The Forum functions by working with the Ministry of Justice and the Department of Health and Social Care teams who have responsibility for the MCA. The report from the 2015 House of Lords post-legislative scrutiny committee had recommended establishing a distinct oversight body but it was decided by Ministers at the time to employ only the part-time chair, and that the Forum would neither hold a budget nor have distinct dedicated premises. Given this, it was heartening to find that only twenty (<2%) respondents felt the Forum had not helped them disseminate their ideas to improve practice, with many encouraging and positive comments in free text, such as 'The Forum is always very informative and a great place to meet and liaise with different professionals'. Some highlighted the need for senior executives to understand the importance of the MCA as part of the work of all staff.

When the five core principles of the MCA were individually explored improvements were reported. However, slightly better implementation was reported from across social care than from healthcare. This may reflect the greater involvement of social care staff in direct ongoing care and support provision to those with long term impairments of capacity, such as through learning difficulties, dementia or brain injury. This indicates ongoing initiatives in education, training and awareness raising in health care are particularly needed.

The Liberty Protection Safeguards implementation has been delayed by the pandemic. Although the experience of having had to modify the DoLS processes may provide valuable lessons for the future, those experiences need to be gathered systematically to be of value to the new Code of Practice. As the whole Code of Practice for the Mental Capacity Act is

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¹ https://publications.parliament.uk/pa/ld201314/ldselect/ldmentalcap/139/139.pdf

being revised, there has been a call for illustrative case stories that could be used, anonymised and in outline only, to help illustrate how good practice can resolve complex dilemmas. Unfortunately, despite several calls from the Forum, such stories have not been forthcoming despite the massive amount of experience that has been evident amongst those joining the webinars through the general calls that were put out.

During the pandemic three webinars were organised that proved very popular and clearly met a need. The Forum's leadership group has been particularly supportive in planning and contributing to the webinars. This new way of holding meetings has been successful and reached far more people than the one-day Action Days were able to, and at almost no cost. Over the coming year these should be built on.

Prior to each webinar, those wishing to register were invited to briefly describe problems they were experiencing and to share solutions they had found. The first webinar was held a week after lockdown commenced, the second four weeks later and the third a further five weeks later.

Although some of the problems remained the same the responses were seen to shift in emphasis. Initially there was great concern about how to undertake assessments of people, particularly for DoLS, when face to face contact was not possible. Later the emphasis moved to concern for the mental health of those who were confined in care homes, to the way some decisions were being taken and for the bereaved, who often had not been with the person they loved when dying. Throughout concern for the wellbeing of front-line staff and the supply of personal protective equipment was a concern.

There was a strong sense throughout that people who were classed as vulnerable are valuable and at risk. Those responsible for any aspect of their support and care were using great imagination and creativity to try to ensure that the quality of life was as good as possible for those for whom they had responsibility, and staff reported many instances of generosity to others. There was also some relief at the shedding of some bureaucratic processes, with attendees at the webinar expressing vocational devotion to their roles, whatever sector they came from.

Going forward, as we emerge from the pandemic this warm human concern and creativity must not be lost as it will help to shape services that are better focused on the needs of the individual. The importance of social care and support has been evident. Many families who have been shielding someone at home have done so at great personal cost and are becoming exhausted. Their needs must be recognised and addressed.

It is worth noting the obvious – that the Mental Capacity Act has withstood the test of the pandemic and provided to be an important framework and benchmark for moral and ethical behaviour and decision making at a time of national crisis.

1. The current situation and the recent past

This report originally aimed to deal with events over the last four years. Its original intention was to look at the impact the National Mental Capacity Forum has had on the way the Mental Capacity Act 2005 (MCA) is being understood and used to the benefit of those with capacity impairments of any kind, how attitudes have changed in different sectors and where further work is needed.

However, at the beginning of March 2020 everything changed. The emergence of Covid-19, a unique coronavirus infection that had originated in Wuhan, China, was first reported in early January 2020. On 1 January Wuhan market, thought to be the epicentre, was closed and by 5 January The World Health Organisation (WHO) had published its first disease outbreak news. By 22 January Chinese authorities had conceded that there was evidence of human to human transmission and on 30 January WHO reported 7,818 confirmed cases worldwide, across 19 countries. As cases rose rapidly a worldwide pandemic was declared on 11 March, declaring Europe as the active centre of the pandemic on 13 March, and plans to deal with an overwhelming infection were put in place. On 23 March the UK was put into lockdown.

From the beginning of the infection the implications of Covid-19 were a priority for the Forum. The direction of activities changed and new priorities emerged. It was rapidly evident that implementation of the Mental Capacity (Amendment) Act 2019's Liberty Protection Safeguards, designed to replace the cumbersome processes of Deprivation of Liberty Safeguards, would need revision and possible delay. At the time of writing the planned start date of October 2020 has been officially deferred, but no new commencement date issued.

An urgent priority was to provide support to front line staff in health and social care to manage their responsibilities towards those individuals with impaired capacity, and particularly if they became ill. To do this, three webinars were swiftly planned to replace the three Action Days which had been organised (pre-Covid-19) for Spring 2020.

2. Background to the Forum

In 2014 the House of Lords Select Committee on the MCA, chaired by Lord Hardie, reported. It had been set up as a post legislative scrutiny committee to examine the working of the Act in practice². Its report was damning.

In launching the report in March 2014, the Chairman said:

"Vulnerable adults are being failed by the Act designed to protect and empower them. Social workers, healthcare professionals and others involved in the care of vulnerable adults are not aware of the Mental Capacity Act and are failing to implement it. That is the key finding of the House of Lords Committee established to scrutinise how the Act is working in practice, as outlined in its report published today."

As a result of this report the Government adopted many, but not all the committee's recommendations.

The "principal recommendation to address the failure to embed the Act in every day practice is that responsibility for oversight of its implementation should be given to a single independent body. This body could be freestanding or located within an existing organisation. Its role would be to oversee, monitor and drive forward the implementation of the Act. We provide a 'job description' for the independent oversight body below. The independent oversight body would not remove ultimate responsibility for the Act from Ministers, but it would locate in one place ownership of the Act and thereby provide a form of accountability, and a focus for enhanced activity."

Rather than take the principal recommendation wholesale, the Government decided to appoint one person, not an independent body, to drive forward improved implementation of the Act, without allocating additional staff or budget to do this. Despite the challenge this presented, it has been a most rewarding and exciting time for me over the subsequent four years, driving forward improvements in the way that those with impaired capacity are approached by statutory and other services.

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 $^{^2\,\}underline{\text{https://publications.parliament.uk/pa/ld201314/ldselect/ldmentalcap/139/139.pdf}}$

Getting started

My first task as Chair of the National Mental Capacity Forum was to establish the Forum, with the voice of the person with lived experience at the centre of all activities. As in Roman times, the role of a Forum is to bring together people with ideas over ways to improve something, and encourage dissemination of approaches that result in improvements and to bring about change. In this case the aim was to improve implementation of the Mental Capacity Act (MCA).

To empower people to live as independently as possible, despite restrictions imposed on them by impairments in their mental capacity, it was important to involve the financial sector, the utilities and the commercial sector, as well as health and social care.

Social care is managed in many ways separately to the NHS in England and Wales, with much delivered through contracts with private providers. Those bodies representing the sector such as Social Care England, the Social Care Institute for Excellence and several individual providers have been extremely supportive in embracing the challenge.

'Change agents', who were enthusiasts for improving the MCA implementation, from each of the relevant sectors involved in improving the lives of affected by the Act, were invited onto the Leadership Group of the Forum.

The Forum itself is responsible, via the Chair, for reporting to the Mental Capacity Implementation Group, which is a committee of statutory body leaders, with ultimate answerability to the Secretary of State for Justice and the Secretary of State for Health and Social Care in England and the Minister for Health and Social Care in Wales.

The Forum was set up to meet as far as possible as many of the recommendations of the House of Lords Select Committee as possible. The report had recommended that the Independent oversight body should:

- Have responsibility for oversight, co-ordination and monitoring of implementation of the Act;
- Work closely with relevant regulators and professional bodies to ensure that the
 Act is given a higher profile in training, standard setting and enforcement;
- Provide support for professionals required to implement the Act;

- Drive improved public awareness of the Act, and introduce robust awareness measures:
- Present a report on its activities to Parliament annually.

From the outset the Forum had to establish a modus operandi, harnessing the good will and commitment of members, who were undertaking all activities unpaid and on top of their normal day job, with Leadership Group members having no reimbursement of travel expenses or time to attend meetings.

Annual Action Days

The Forum set up annual Action Days as a way of sharing good practice and to inspire attendees to maintain their energy for change and improvement. Premises for these days were generously donated by several health care bodies, the Royal College of Anaesthetists, the Royal College of Physicians, the British Medical Association and the Royal College of Nursing.

An additional Research Action Day on 16 March 2017 was supported by Welsh Government to improve the research involvement of those with impaired capacity and to ensure they could benefit from research findings. On this day a series of workshops, each co-chaired by a person with the relevant lived experience, explored the complexities of research with different groups, such as those with learning difficulties, those with mental illness, those with acute traumatic head injury and the challenges to ambulance first responders in managing the unconscious or semiconscious patient. Guidance over consent and research methodology evolved from this day, in an easy read format to ensure the person with impaired capacity was as involved in research development as the clinical teams.

The five principles of the MCA

It rapidly became evident that in many areas teaching about the MCA had started from a legalistic standpoint, yet often the core five principles of the Act, from which all else flows, were poorly understood. Shropshire Council, in conjunction with its local stakeholders had developed the teaching tool of the handprint to teach these principles. The logo was adopted as the logo for the Forum and as a core teaching tool.

Mental Capacity Act 2005 – 5 principles



3. Responding to the House of Lords Select Committee

To evaluate the effectiveness, or not, of the approach taken in response to the Select Committee report, an open survey was circulated to stakeholders in late 2019, using the recommendations of the report as the basis for questions in the survey.

The survey and its results form the body of this report.

One recommendation of the report related to the Deprivation of Liberty Safeguards that had been put in place to deal with the 'Bournewood Gap' and following the Cheshire West judgement from the Supreme Court. The Committee had reported:

"Our other key recommendation concerns the Deprivation of Liberty Safeguards. We considered the safeguards separately from the rest of the Act, which is largely how they were perceived by our witnesses. They were inserted into the Mental Capacity Act by the Mental Health Act 2007, designed to fill a gap in the legislative framework identified in the case of HL v UK in the European Court of Human Rights. The intention behind the safeguards—to provide protection in law for individuals who were being deprived of their liberty for reasons of their own safety—was understood

and supported by our witnesses. But the legislative provisions and their operation in practice are the subject of extensive and wide-ranging criticism. The provisions are poorly drafted, overly complex and bear no relationship to the language and ethos of the Mental Capacity Act. The safeguards are not well understood and are poorly implemented. Evidence suggested that thousands, if not tens of thousands, of individuals are being deprived of their liberty without the protection of the law, and therefore without the safeguards which Parliament intended. Worse still, far from being used to protect individuals and their rights, they are sometimes used to oppress individuals, and to force upon them decisions made by others without reference to the wishes and feelings of the person concerned.

The only appropriate recommendation in the face of such criticism is to start again. We therefore recommend a comprehensive review of the Deprivation of Liberty Safeguards with a view to replacing them with provisions that are compatible in style and ethos to the rest of the Mental Capacity Act."

This recommendation became the subject of the Mental Capacity (Amendment) Act 2019 and therefore was not covered in the survey as each part of the legislation was subject to extensive scrutiny, especially in the House of Lords, where significant amendments to the Bill were accepted.

Meeting the Select Committee's requirements

The Forum was established with very little resource but aimed to be a catalyst for change. This section recaps on the history of the last four years of the Forum and how it maps across to the recommendations initially made by the Select Committee of the House of Lords. For ease, these recommendations are listed above each relevant commentary section.

Recommendation 3: We recommend that overall responsibility for implementation of the Mental Capacity Act be given to a single independent body. This does not remove ultimate accountability for its successful implementation from Ministers, but it would locate within a single independent body the responsibility for oversight, coordination and monitoring of implementation activity across sectors, which is currently lacking. This new responsibility could be located within a new or an existing body. The new independent body would make an annual report to Parliament on the progress of its activities.

Recommendation 4: The Mental Capacity Act Steering Group is a welcome first step in this direction, and we recommend that it be tasked with considering in detail the composition and structure of the independent oversight body, and where this responsibility would best be located. The former Mental Health Act Commission strikes us as an effective, cost-efficient and credible model from which lessons may be learned.

Recommendation 12: We recommend that, in the first instance, the Mental Capacity Act Steering Group give consideration to how the specific information needs of the different groups affected by the Act can best be met. We recommend that the Steering Group take into account the needs of different audiences for different types of information: for example, legal practitioners will be interested in latest developments in case law; a carer may need a brief summary of their responsibilities under the Act; a person lacking capacity may need their rights presented in an accessible format. In future, ensuring the regular review of such information resources would be the responsibility of the independent oversight body.

Some of the recommendations of the Select Committee were impossible to meet with the resources available. No formal oversight body was established (contrary to recommendation 3), but the Forum was created with one part-time Chair appointed for 3 years in the first instance. A steering group (recommendation 4) was established with key stakeholder groups from official bodies represented, but over four years changes in personnel have meant that very few original members of that group are the same and collective memory does not exist. However, the steering group is a useful group to maintain pressure on different agencies to support raising awareness and in tackling issues that arise. The steering group is separate from the Leadership Group, who were drawn from individuals with a great enthusiasm and commitment, and a positive progressive attitude, to improving the implementation of the MCA over and above their normal role and who shared a common vision.

An initial exercise of 'listening to the voice of the person' was undertaken to establish priorities from the perspective of those who had been subject to the MCA and to identify areas where implementation remained in deficit. This then provided a guide to the workplan as the Forum was established, to ensure concerns were addressed across different sectors. A Leadership Group was established from those individuals who were keen to improve the implementation of the MCA, they committed to working as part of the Leadership Group in a voluntary capacity, and membership came from a wide range of relevant disciplines. All

members of the Leadership Group have shown great commitment to improving the understanding and implementation of the MCA.

Recommendation 1: In the first instance we recommend that the Government address as a matter of urgency the issue of low awareness among those affected, their families and carers, professionals and the wider public.

Recommendation 2: We recommend the Government consider urgently the need for assessing usage of the core principles across the range of decisions affecting people lacking capacity, including in sectors such as banking and policing.

In particular, recommendations 1 and 2 (increasing awareness of the MCA across all walks of life) were addressed/considered by the work of the Forum in its early years, with engagement of stakeholders across Health and Social Care, banking and finance, emergency services, the utilities and educational sectors. The logo was adopted to ensure a simple aide memoire, as were other tools such as pens, coffee mugs and leaflets that stated the principles of the MCA clearly and succinctly.

Addressing poor implementation of the Act

Recommendation 5: We recommend that the standards against which the CQC inspects should explicitly incorporate compliance with the MCA, as a core requirement that must be met by all health and care providers. Meeting the requirements of the empowering ethos of the Act, and especially in terms of actively enabling supported decision-making, must be given equal status with the appropriate use of the deprivation of liberty safeguards, or their replacement provisions.

The need for the Care Quality Commission (CQC) to inspect services against standards relevant to the MCA was addressed early on with specific training of inspectors. This work was initially led by Rachel Griffiths, then at CQC, who then later on advised Public Health Education England about all their learning materials and comprehensively revised their offer.

Lasting Powers of Attorney (LPAs)

Recommendation 25: We recommend that the Government, working with the independent oversight body recommended in chapter 4, and the Office of the Public Guardian (OPG):

- address the poor levels of understanding of LPAs among professional groups, especially in the health and social care sector, paying specific attention to the status of Lasting Powers of Attorney in decision-making;
- consider how best to ensure that information concerning registered Lasting
 Powers of Attorney can be shared between public bodies, and where appropriate with private sector bodies such as banks and utilities;
- issue guidance to local authorities that their new responsibilities for provision of information in relation to care contained in the Care Bill should include information on Lasting Powers of Attorney;
- consider how attorneys and deputies faced with non-compliance by public bodies or private companies can be supported in the absence of specific sanctions;
- review the apparent anomalies in the current arrangements with regard to successive replacement attorneys, and the status in England of Scottish Powers of Attorney.

The principal focus of recommendation 25 fell to the Office of the Public Guardian (OPG) and was outside the remit of the Forum, but the need to raise awareness across all sectors demanded action by the Forum, working with these other professional bodies. They needed ongoing pressure to ensure the medical professional bodies did not let action on these slip down their list of priorities.

Frequent work with the OPG has enabled close links and progress to establish awareness across health and social care of Lasting Powers of Attorney (LPAs) and ways to check validity when using an LPA. Work with solicitors has looked at fees for solicitors' involvement and tried to ensure that high fees are not charged for assisting people drawing up an LPA, particularly now that the process can be done online relatively easily.

Work has also been undertaken, with a specific work stream from the leadership group, looking at fraud and scams and working with relevant agencies.

Recommendation 26: We recommend that the Government, working with the independent oversight body:

 urgently address the low level of awareness among the general public of advance decisions to refuse treatment;

- promote better understanding among health care staff of advance decisions, in order to ensure that they are followed when valid and applicable;
- promote early engagement between health care staff and patients about advance decisions to ensure that such decisions can meet the test of being valid and applicable when the need arises;
- promote the inclusion of advance decisions in electronic medical records to meet the need for better recording, storage and communication of such decisions.

Recommendation 6: We recommend the Government work with professional regulators and the medical Royal Colleges to ensure that the Act is given a higher profile. This work should emphasise the empowering ethos of the Act, and the best interests process as set out in section 4 of the Act. In future, we would expect the responsibility for this to sit with the independent oversight body.

Recommendation 7: In particular, we recommend that the GMC:

- ensure that there is leadership in psychiatry within all medical schools in order to give a higher profile to mental health;
- place proper emphasis on the MCA in its publication 'Good Medical Practice';
- enhance training on the MCA in all post-graduate education, especially for GPs.

Recommendation 8: The proposed fourth year of training for GPs provides an opportunity to embed and enhance understanding of the MCA with this group of practitioners. We recommend that the Government supports the proposal in light of the vital role which GPs play in providing health care in the community.

In my role chairing the Forum I have met with the Academy of Medical Royal Colleges and hence the College Presidents. I have also interacted on many occasions individually with the Presidents of the Royal College of Physicians, the Chairs of Council of the Royal College of General Practitioners, the President of the Royal College of Anaesthetists and the President of the Royal College of Emergency Medicine. Working with the British Medical Association ethics committee, relevant guidance has been produced on several aspects of the MCA. I have also had relevant meetings with other College Presidents including the Royal College of Nursing and the Chartered Society of Physiotherapy. All these meetings aimed to ensure that the principles of the MCA become deeply embedded in clinical practice and that decision-making processes and consent procedures improve in relation to those with impaired capacity, particularly in emergency situations.

In particular, the Deans of Medical Schools, through the Medical Schools Council, have been contacted to ensure that Medical Schools establish good education about the MCA at all points in the curriculum, that the subject is included in the final medical examination for medical licensing and that it is part of postgraduate medical and dental training.

Recommendation 9: We recommend that the Government, and subsequently the independent oversight body, work with the Association of Directors of Adult Social Services and NHS England to encourage wider use of commissioning as a tool for ensuring compliance.

Recommendation 11: We further recommend that NHS England and ADASS take steps to ensure that the empowering ethos of the MCA is understood and given visibility within commissioning, even where this may appear to conflict with the safeguarding agenda.

From the outset, awareness of the MCA amongst the social care sector was moving slightly faster than in the health professions. The Social Care Institute for Excellence, Care England and various Directors of Social Services across England and Wales have engaged constructively at many meetings, to improve implementation of the Act.

Recommendation 10: We recommend that the 'refresh' of the NHS Mandate in 2014 include requirements explicitly connected to the implementation of the MCA, based on evidence of good practice gathered from Clinical Commissioning Groups.

The Forum was unable to influence the NHS Mandate directly and the changes occurring in Clinical Commissioning across England made it much harder to interact with these groups. However, meetings with Health Board representatives in Wales were productive.

The Court of Protection

Recommendation 27: We recommend the Government considers increasing the staff complement of authorised officers, following consultation with the Court of Protection, to achieve a significant reduction in the time taken to deal with non-contentious property and financial affairs cases.

Recommendation 28: We also recommend that the Government consider as a matter of urgency the updating of the 'Rules of the Court', as recommended by the ad hoc Rules Committee and, as necessary, in light of subsequent changes.

Recommendation 29: We recommend that the Government consider enabling the Court to address the needs of its audiences either by giving it greater control of the information provided on the Gov.uk website or by enabling the Court to have a dedicated website.

Recommendation 30: We are persuaded that mediation would be beneficial in many more cases prior to initiating proceedings in the Court of Protection. We recommend that consideration be given to making mediation a pre-requisite for launching proceedings, especially in cases concerning property and financial affairs where the costs fall to P.

Recommendation 31: We recommend that the Government, and in future the independent oversight body, provide clearer guidance to public authorities regarding which disputes under the Act must be proactively referred to the Court by local authorities. This should include situations in which it is the person who is alleged to lack capacity who disagrees with the proposed course of action. Efforts must be made to disseminate this guidance to families and carers as well as to local authorities.

Recommendation 32: We note the pressures on legal aid, but we are concerned by the inconsistent provision of non-means tested legal aid for cases concerning a deprivation of liberty, including those where there is a dispute over whether a deprivation is taking place. We cannot see a justification for such inconsistency and we recommend that the gap in protection that it creates be remedied as a matter of urgency.

Recommendation 33: We recommend that the Government reconsider the provision of resources to the Official Solicitor, with a view to determining whether some cases merit the same unconditional support as is currently afforded to medical treatment decisions.

Recommendation 34: We further recommend that the Government review the policy underlying the availability of legal aid for those who lack the mental capacity to

litigate and therefore cannot represent themselves. For such people, denial of legal aid may result in having no access to Court. No-one who is found to lack the mental capacity to litigate should be denied access to Court solely because they do not have the means to pay for representation

Recommendation 35: We recommend that the Government initiate a review of whether the offence in section 44 of the Act meets the test of legal certainty; and if it does not, to bring forward new legislative provisions. The results of this review should be published within 12 months of publication of our Report.

Regarding the recommendations relevant to the Court of Protection (recommendations 27-35), the Forum has sought to engage with the judiciary of the Court when issues arose which related directly to its functions and processes.

Measuring success

Recommendation 36: We recommend as a matter of urgency that the Government take steps to establish regular and dedicated monitoring of implementation of the Act, and that this should include all the sectors across which the Act applies.

Recommendation 37: We recommend that the independent body with overall responsibility for implementation of the Act, be given responsibility for ensuring such monitoring takes place.

Recommendation 38: We recommend that the Government introduce a robust method for measuring public and professional attitudes to issues of capacity, in order to be able effectively to measure any change in the prevailing culture. Ideally, benchmarking of this sort would have taken place prior to the implementation of the Act, but there would still be benefits in starting such activity now. This would be a key task for the independent body to be given overall responsibility for the Act.

Recommendation 39: We recommend that, no more than 12 months after publication of this Report, the Liaison Committee seek evidence from the Government on the actions they have taken in response to the two key recommendations made in the summary of this report.

There was a clear need to assess whether the Forum had made any difference to the implementation of the Act and to assess whether awareness and practice had changed and

improved. To do this without any dedicated funding posed challenges. It was agreed to construct a questionnaire, based on the main overarching recommendations of the House of Lords report, and distribute this as widely as possible. It was constructed, piloted and then distributed to everyone who had attended the four Annual Action Days as well as those I who had been asked to distribute information about the Action Days. The results of the survey form the second section of this report.

Deprivation of Liberty Safeguards (DoLS)

Recommendation 13: We therefore recommend that the Government undertake a comprehensive review of the DoLS legislation with a view to replacing it with provisions that are compatible in style and ethos with the Mental Capacity Act. The model of widespread consultation that preceded the Mental Capacity Act itself should be followed, with adequate time allowed for effective Parliamentary scrutiny.

Recommendation 14: We further recommend that the independent body with responsibility for oversight and coordination of implementation of the Mental Capacity Act develop a comprehensive implementation action plan to accompany new legislation, in consultation with professionals, individuals, families and unpaid carers.

Recommendation 15: We recommend that replacement legislative provisions make a clear link to the principles of the Mental Capacity Act to ensure consistency with the empowering ethos of the Act as a whole.

Recommendation 16: We recommend that replacement legislative provisions and associated forms be drafted in clear and simple terms, to ensure they can be understood and applied effectively by professionals, individuals, families and carers.

Recommendation 17: Better understanding of the purpose behind the safeguards is urgently required, and we recommend that achieving this be made a priority by the independent oversight body.

Recommendation 18: We recommend that the Government consider how the role of the Relevant Person's Representative could be strengthened in replacement legislative provisions to provide an effective safeguard. Recommendation 19: We recommend that effective oversight of any future supervisory body function be provided for in the replacement provisions for the Deprivation of Liberty Safeguards.

Recommendation 20: We recommend that replacement legislative provisions extend to those accommodated in supported living arrangements.

Recommendation 21: We consider that a 'new Bournewood gap' has been inadvertently created by the attempt to prevent overlap with the Mental Health Act 1983. We recommend that replacement legislative provisions close this gap.

A great deal of concern arose regarding Deprivation of Liberty Safeguards (DoLS). An independent Law Commission review of DoLS began in 2014, with the expectation that it would produce recommendations on a system to replace DoLS that would ensure protection of the vulnerable and would be streamlined, addressing the many criticisms of the DoLS processes. The Law Commission undertook extensive work and a consultation and reported in March 2017.3 However new legislative proposals were not brought forward in the format initially recommended and further consultation was undertaken. The backlog of cases waiting for assessment grew and public pressure mounted resulting in the Mental Capacity (Amendment) Act 2019.

The legislation provoked a great deal of discussion and debate as it incorporated some but not all the Law Commission's recommendations, and several stakeholder groups expressed concerns, which were reflected in extensive debates over amendments tabled in Parliament⁴. As result, much of early 2019 was taken up with looking at the legislation, listening to the widespread concerns and addressing ways to mitigate potential problems that may arise.

The Bill was finally passed by Parliament in May 2019, as the Mental Capacity (Amendment) Act 5, but the guidance over its implementation is still awaited. At the time of writing, the new system of Liberty Protection Safeguards, designed to replace DoLS, has not been introduced.

³ http://www.lawcom.gov.uk/app/uploads/2017/03/lc372 mental capacity.pdf

⁴ https://services.parliament.uk/Bills/2017-19/mentalcapacityamendment/stages.html

⁵ https://www.legislation.gov.uk/ukpga/2019/18/enacted/data.htm

Independent Mental Capacity Advocates (IMCAs)

Recommendation 22: We recommend that local authorities use their discretionary powers to appoint IMCAs (independent mental capacity advocates) more widely than is currently the case. To support this, we recommend the Government issue guidance to local authorities and health service commissioners about the benefits of wider and earlier use of IMCA services. We believe the costs of greater IMCA involvement should be balanced against the resources required in lengthy disputes or ultimately in litigation.

Recommendation 23: Given the importance of the role of IMCAs in the lives of vulnerable adults we believe that the role requires further professionalisation to ensure consistency of service. This should be achieved through national standards and mandatory training in the Mental Capacity Act and the role of the IMCA within that. We recommend that responsibility for such standards and training be undertaken by the independent oversight body which we recommend in chapter 4, enabling peer support and consistency between IMCA services.

Recommendation 24: We recommend that the Government consider the establishment of a form of self-referral for IMCA services to prevent the damaging delay that occurred in the case of Mr Steven Neary.

4. National Mental Capacity Forum Awareness Survey 2019

The questionnaire

In November 2019, the Forum conducted a survey to ascertain awareness of the MCA and assess whether improvements had been made in empowering and supporting those with impaired mental capacity to live as fully and independently as possible.

The questions were created using the recommendations that the Forum was able to influence. They were designed to assess the efficacy of the Forum in raising awareness and in improving application of the act in everyday practice.

The questions were piloted through the Leadership Group and refined prior to the launch. All questions referred to changes in the previous four years, since the establishment of the Forum.

The survey was undertaken on behalf of the Forum's Chair, by an independent postgraduate law student, to ensure impartiality and that people would feel able to be open and frank in their responses. Respondents were asked to identify their particular sector of work.

The questionnaire was web based and analysis of the results was in part provided by the survey tool used (FreeOnLineSurveys.com) and in part by analysis of the raw data using Excel database pivot tables and statistical tests applied as appropriate.

The survey was publicised by circulating emails to all known contacts who had previously attended Action Days, and through promoting a link to the questionnaire on the Social Care Institute for Excellence (SCIE) website. In addition, Leadership Group members were asked to disseminate the questionnaire link as widely as possible.

The results

A total of 1,244 responses were received during the period that the survey was open (1 November 2019 to 31 December 2019). Of these, the majority of responses received were from health (556) and social care (444); those classifying themselves as private care included some in nursing homes (see table 1). Of those who classified themselves as 'other', 21 stated they worked in advocacy services, 10 in the third sector and 5 in hospice / palliative care. Other respondents included those from academia, prisoner custody, community security, leisure facilities, mental health tribunal, housing, homelessness

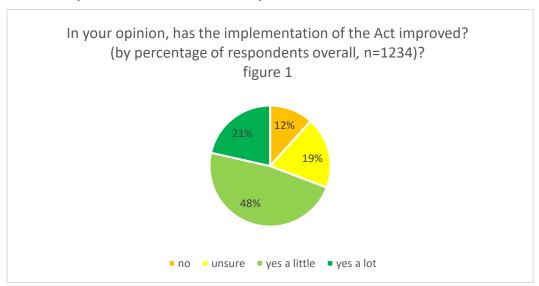
prevention, regulators, youth work, plus other service users and family members. As some respondents left questions blank, the number responding to each question is given.

Table 1

SECTOR	RESPONDENTS
Ambulance	3
Healthcare (NHS)	478
Private healthcare	78
Social care	444
Carer	42
Legal	28
Education	24
Financial	21
Utilities	2
Other	115
Not declared	9
Total	1244

Survey questions (based on the past four years):

Has the implementation of the MCA improved?



Overall (Figure 1) over 2/3 (69%) of respondents felt the implementation of the MCA had improved, but the differences between the sectors show statistically significant less improvement in the NHS sector, compared to Social Care (Table 2; Chi-squared test, p< .01). Other groups were not included in the analysis as the numbers are much smaller, although the pattern of responses reflects those from social care.

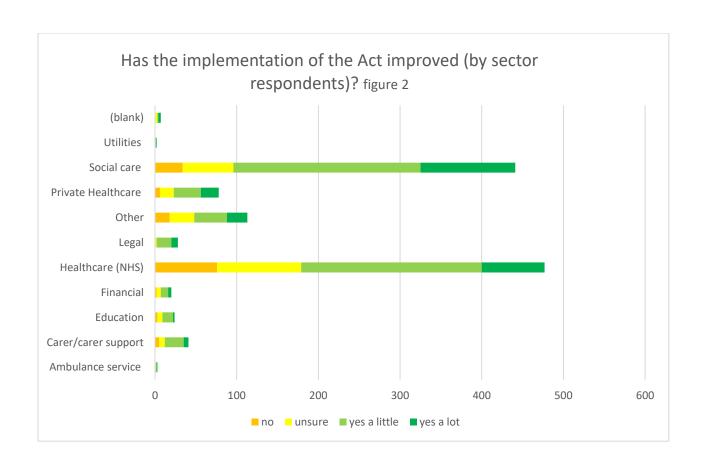


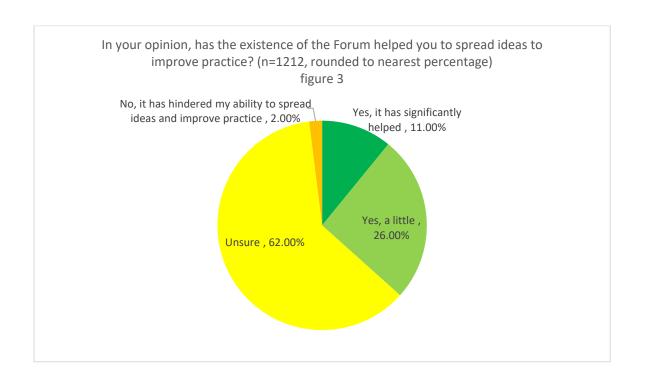
Table 2. Responses by main declared sector on improved implementation of the MCA.

	Left blank	No improvement	Unsure	Yes (a little / a lot)	
NHS	1	76	103	298	478
Social care	3	34	62	345	444
Column Totals	4	110	165	643	922 (Grand Total)

The effect of the National Mental Capacity Forum

The effect of the Forum was difficult to disaggregate from the direct effect of initiatives prompted or stimulated by the Forum that were not jointly badged as part of the Forum's work. The results are therefore not surprising and reflect a hesitancy to 'advertise' the Forum or to self-promote, but rather to encourage and stimulate others to take ownership of ideas and lead in their sphere of influence.

It may be that after the Covid-19 pandemic and the webinars, the profile of the Forum will be higher.



However, in the free-text section of the survey, comments were overwhelmingly positive about the Forum and its work, for instance:

- The Forum has been enormously helpful in my recent work as a researcher exploring the practical application of the MCA in history, heritage, archive and arts project settings for adults with complex learning disabilities. Here the issue has been decision-making about whether or not people want to share their work more publicly, through physical or online archives
- The Forum has also been extremely helpful to my work with people with learning
 disabilities and families across a range of practice settings and research projects.
 The forum days have consistently provided up to the minute advice and research
 and has enabled us to create some very valuable support networks
- Good work providing a platform and presence for minds and good practice to meet and discuss
- Still a lot of work to be done. Executive management still has very little appreciation of the need to be proactive on these issues. We can train as many people as we can and make as many people aware of the issues but if senior executives do not support implementation, we will not get anywhere. It is no good scapegoating staff at the coal face for the failings of senior executives
- The Forum is a great network and the resources on SCIE are good

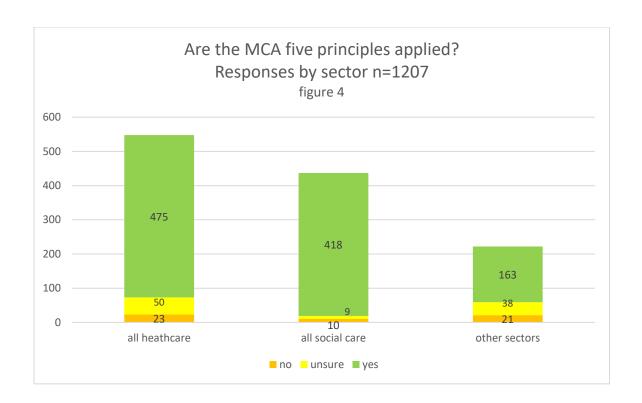
- I attended a conference of yours which had Office of the Public Guardian in attendance; it was really useful to get a better sense of their work
- I feel the Forum has been one of the biggest factors in improving the implementation of the MCA and encouraging best practice, I am very proud to be a part of that and wholeheartedly support it and its aims
- The Forum is always very informative and a great place to meet and liaise with different professionals

Do you think the five core principles of the MCA are applied in your sector?

Respondents were asked how the core principles of the MCA are applied in their sector. A total of 1207 responses were obtained. For analysis the NHS and private healthcare were grouped together as there was no significant difference between the replies from these two parts of healthcare provision.

Table 3

5 principles of MCA	not applied	unsure	applied most/all the time	Totals
all healthcare	23	50	475	548
all social care	10	9	418	437
other groups	21	38	163	222
Totals	54	97	1056	1207 (Grand Total)



There are significant differences in how well the five core principles of the MCA are applied in different sectors, with social care showing better adoption of the principles than other sectors (chi-squared n=1207 responses; X^2 =64.49; significant at p<.01)

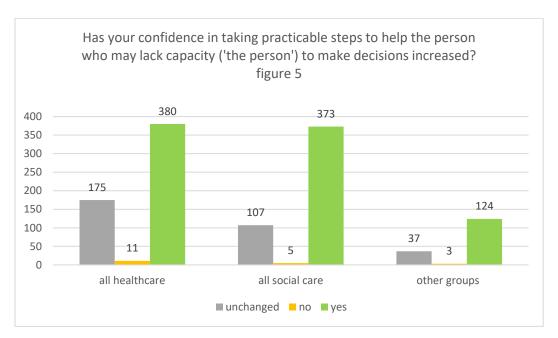
For analysis, responses from other sectors than healthcare or social care were grouped together as there was no significant difference between groups, and the number of respondents in each group was very small. These sectors were: legal, education, financial services, utilities, carer/carer support or not specified.

Supporting a person to make their own decisions

This second principle of the MCA has been described as the 'orphan principle' because although it features at the beginning of the Act, there are no further references to it within the Act and support of the person who lacks capacity has been reported as a neglected area for teaching. The Leadership Group has focused in year 4 on the need to build on the individual's strengths, including asking 'why support has failed', before proceeding to assessing capacity.

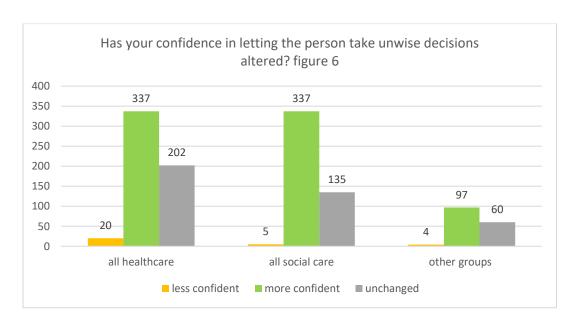
When asked about their confidence in taking practical steps to help the person who may lack capacity (figure 5), significantly more respondents from health sectors reported lacking confidence than respondents from other sectors (chi-squared n=1215 responses; X^2 =13.52;

significant at p<.01), Of those reporting no increase in confidence, 319 reported no change to their level of confidence and 19 reported they were less confident, compared to 877 who reported increased confidence. There were also more respondents from social care reporting an increase in their levels of confidence than from healthcare or other groups (chi-square n=1215; X^2 =14.03; significant at p<.01).



Unwise decisions

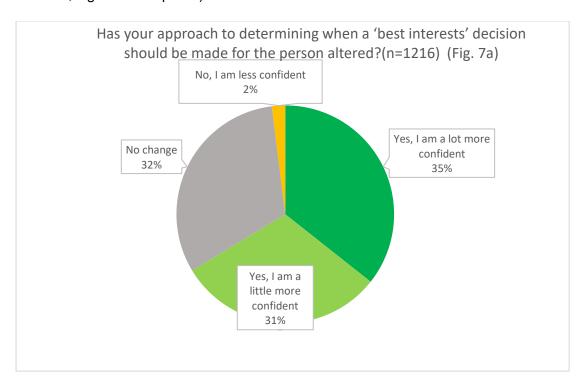
Similarly, confidence in this third principle of the MCA regarding recognising capacitous unwise decisions (figure 6), those in the social care sectors reported becoming significantly more confident in letting a person take unwise decisions than respondents form healthcare or from other groups (chi-squared n=1197 responses; χ^2 =17.30; significant at p<.01).

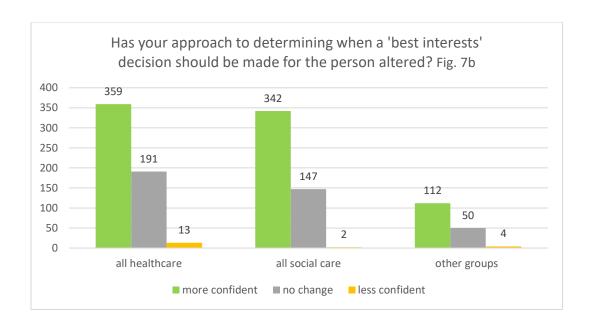


This is a difficulty increasingly encountered during the Covid-19 pandemic, but these responses all predate the crisis. It is likely from anecdotal reports that more unwise decisions have been encountered and difficult decisions either supported or formally objected to, such as visiting someone who may have the infection, or the desire of those who are homeless to return to living on the streets rather than remain enclosed in the hotel accommodation that had been procured for them by local authorities.

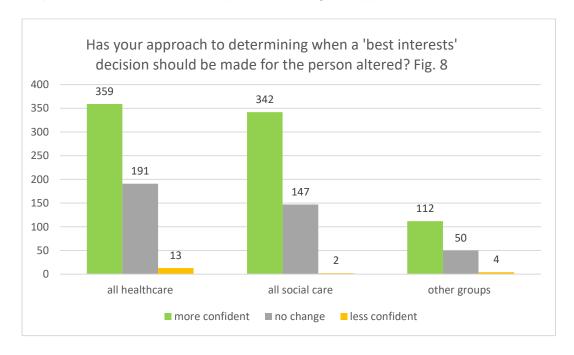
Best Interests decision-making

When asked about whether their approach to determining when a 'best interests' decision should be made for a person (all respondents, figure 7a and analysed by sector figure 7b), just under a third of respondents (n=450; 32% of all responding to this question) stated their approach had not changed. There was a difference between sectors, again with social care reporting feeling more confident than other sectors (chi-squared n=1220 responses; X^2 =9.85; significant at p<.05).



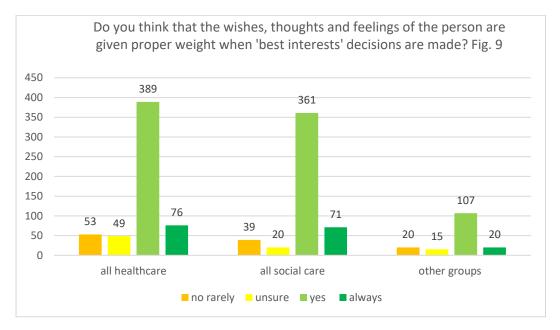


When asked whether their approach to determining when a 'best interests' decision should be made for the person had altered (figure 8), again a slightly greater proportion of respondents from social care reported a change in approach than those from other sectors.



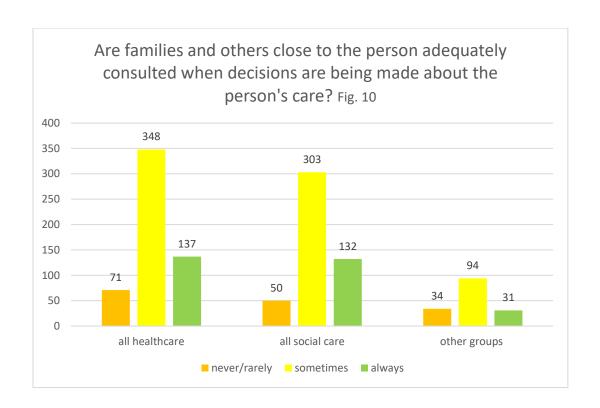
The way that 'best interests' decisions are taken was explored with questions on whether the wishes, thoughts and feelings of the person are given proper weight when best interests decisions are made, and with questions on whether families and others close to the person are adequately consulted when decisions are being made about the person's care. Respondents were also asked whether in their sector, it is understood that the MCA only authorises a 'best interests' decision to be made on behalf of the person when the second

principle has been complied with, and when all practicable steps to help the person make their own decision have been taken without success.

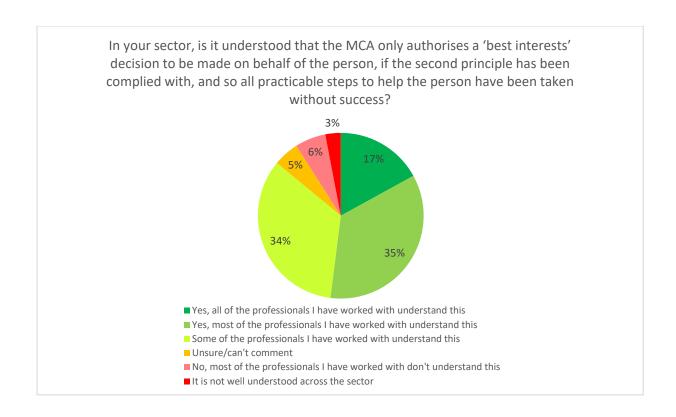


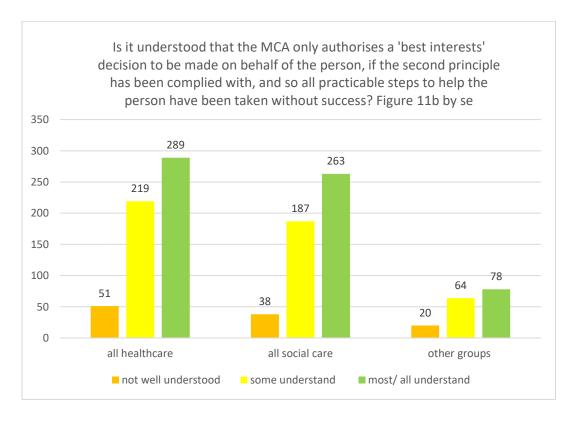
The MCA is clear that a person's wishes and feelings must always be considered when a best interests decision is made. The Act is also clear that the person must be consulted and involved as much as possible in the decision-making even when unable to make that decision at that time for themselves. When the results for 'yes some of the time' and 'always' are aggregated for analysis, there is a significant difference between groups, (X^2 = 13.92; n=1220; significant at p < .01). It is of concern that 11% of healthcare respondents, 9% of respondents from social care settings and 16% of those from other groups reported that the person's wishes, thoughts and feelings were 'rarely' given proper weight when best interests decisions are made.

The MCA also lays out that those who know the person well should be consulted for information when a 'best interests' decision is made. Worryingly, 13% of respondents reported this happens rarely or never. Figure 9 shows there was no significant difference between health and social care respondents to the question about families being consulted when a 'best interests' decision is being made.



When asked, 'In your sector, is it understood that the MCA only authorises a 'best interests' decision to be made on behalf of the person, if the second principle has been complied with, and so all practicable steps to help the person have been taken without success?' (figure 11a and 11b), there was no difference between sectors for reported awareness that all steps to support the person to make their own decision must be undertaken, before a 'best interests' decisions can be taken.





Commentary

This poor understanding of 'Best Interests' decision making did not come as a surprise as anecdotal reports had been received over the previous year. Therefore, The British Medical

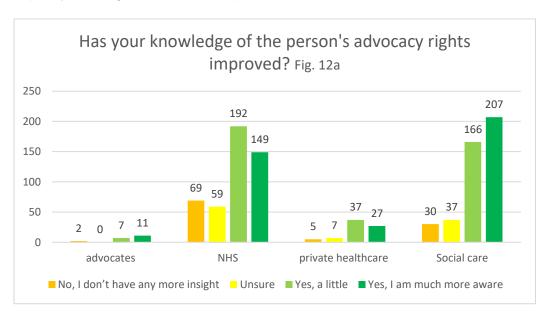
Association (BMA) Medical Ethics Committee were approached about the difficulties around 'best interests' decision making and in March 2020, after consultation, the BMA produced guidance for doctors across all branches of medicine. It is also applicable across all of health and social care and written with clarity and appropriately nuancing. 'Best interests decision making for adults who lack capacity' can be found on the BMA website.

Advocacy rights of people

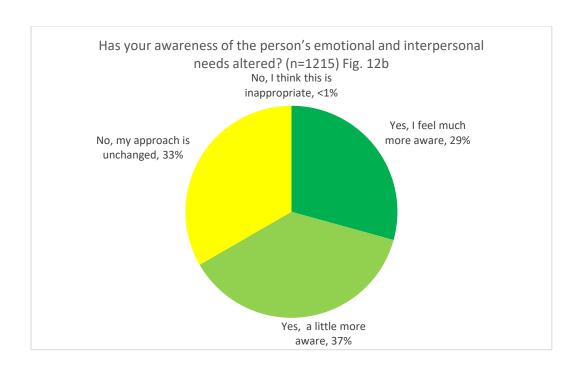
Respondents were asked, "Has your knowledge of the person's advocacy rights improved?" When NHS healthcare (n=468) was compared with social care (n=452) but excluding those who identified as being part of advocacy services, (figure 12a) there was a significant difference with greater awareness reported from amongst social care (X^2 = 19.36; n=920; significant at p < .01).

Those who identified as being part of advocacy services (n=20) showed no significant difference in the responses from others in the social care sectors. Those in private healthcare reflected the responses from NHS healthcare.

There is no registered qualification or accredited training for those acting in an advocacy capacity, making it difficult to set specific standards.

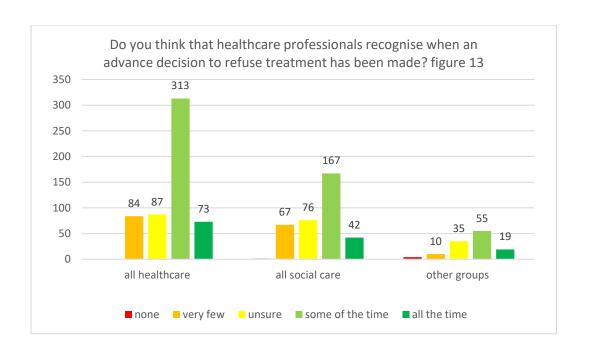


Awareness of the emotional and interpersonal needs of individuals had increased across all sectors (figure 12b), which was reassuring as this had been a specific focus of the 4th National Mental Capacity Forum Action Day (2019).

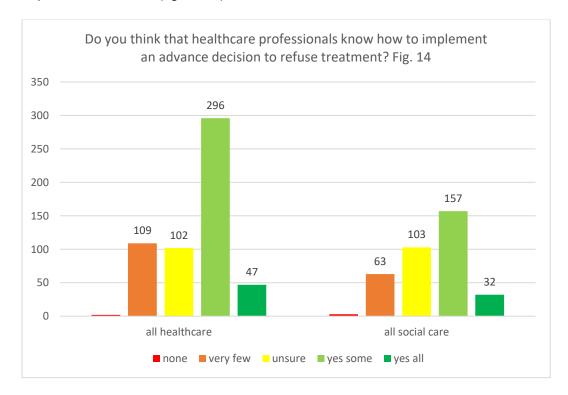


Advance Decision to Refuse Treatment (ADRT)

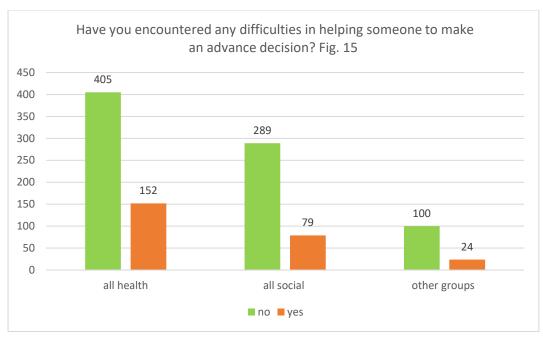
The MCA created an option for Advance Decisions to Refuse Treatment and required that, when certain conditions of validity were fulfilled, these are legally binding documents. Respondents from healthcare reported that ADRTs are recognised in their sector more often than respondents from other sectors, possibly because those not working in healthcare were aware of poor practice while good practice can go unnoticed. As ADRTs apply in healthcare, the 15% of healthcare respondents stating that few recognise when an ADRT has been made, and 69% confident that ADRTs are recognised, indicates the need for targeted awareness raising across healthcare and further promotion work with the Office of The Public Guardian about the importance of Health and Welfare LPAs.

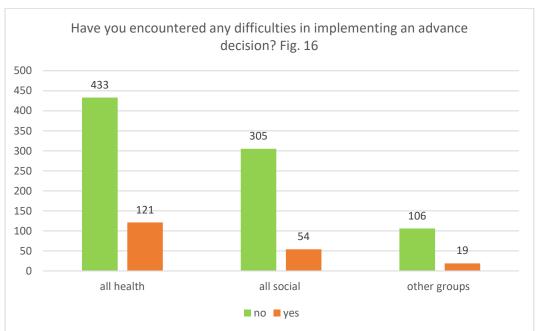


This confidence was reflected when asked whether health care professionals know how to implement an ADRT (figure 14).



A minority of respondents from all sectors had encountered difficulties both in supporting a person to make an ADRT and in implementing an ADRT (figures 15 and 16).



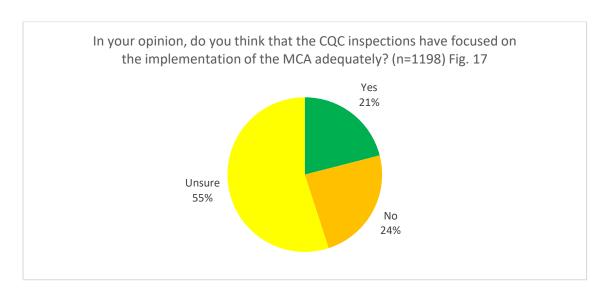


The difficulties encountered by respondents when either helping someone make or implement an ADRT were wide ranging. Some related difficulties in end of life care and the reluctance of patients to discuss advance care planning; this has implications for the work being undertaken across health and social care to encourage advance care planning in conjunction with promoting the role of a Lasting Power of Attorney. Examples of quoted comments are:

Many people leave it until it is too late, and capacity is an issue

- Some NHS staff not wishing to follow these when there is medical treatment available which could work
- It is difficult to get GPs to discuss it with the person
- LPA did not carry out the wishes of P as they had wanted
- GP didn't take decision into account when admitting a patient
- Unsure how to document advance decisions in a way to ensure that all services are aware of it, given separate systems for recording and retrieving information. It can also be difficult to ascertain whether a person has made an advance decision in a timely way due to difficulties getting hold of GPs – a single system to record such vital information would be beneficial.
- Many healthcare professionals do not know how to recognise if one is valid and applicable. Many wrongly see it as an 'indication' of someone's wishes to aid 'best interests' decision-making, rather than a binding treatment decision that must be followed.
- Other professionals are not aware of the MCA and the client's rights and aren't aware
 of the different areas of advocacy which can be provided
- No advance decision in place and the patient did not want treatment. The patient was
 assessed by a rapid response nurse to have capacity and the patient's son
 supported his mother's decision not to be admitted for treatment. The GP was noncommittal and contacted the ambulance crew who overrode the patient's decision
 and took the patient to hospital where she died.
- In terms of DNACPR (Do Not Attempt Cardio-Pulmonary Resuscitation), many practitioners will often check the agreement and support the decision, but paramedics often override it.
- Finding the right paperwork is difficult

Care Quality Commission inspections' focus on the MCA



Comments about the Care Quality Commissions (CQC) inspections were mixed; some examples are:

- CQC focus on risk and not the overral MCA implementation
- [a carer commented] inspectors led staff moving too quickly to a 'best interests' decision when the use of accessible communication tools such as photographs could have substantially increased her ability to make her own decision She had previously made all these decisions independently but the new staff team had not been aware of this
- There remains inconsistent acknowledgement as to the role of speech and language therapists in supporting people with communication difficulties make decisions within the MCA. All too often, necessary steps to make information accessible is ignored
- The CQC will look for capacity assessments but do not follow through always to see
 if 'best interest' documents are there and if a wide discussion with other parties has
 occurred. Past wishes are often not taken into account
- Care staff are regularly questioned on MCA during inspections and paperwork relating to 'best interests' decisions are routinely checked
- We have reported concerns about care homes and hospitals to them they always respond by saying 'we cannot investigate single allegations or concerns' which is poor, even when safeguarding concerns are raised
- Care homes don't have sufficient guidance on how to deal with funds of those who lack capacity
- Inspections focus on processes but do not dig down enough to get a real view;

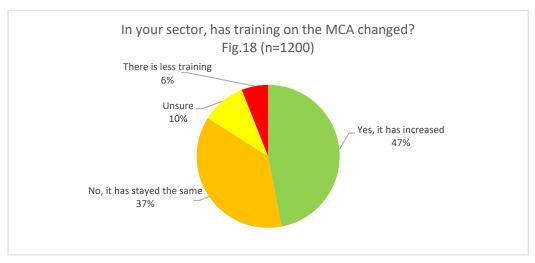
- During inspections, CQC inspectors look for the service users consent to their care and treatment through their care plans and daily notes
- Still tick box exercises
- Inspectors do focus on MCA and DOLs

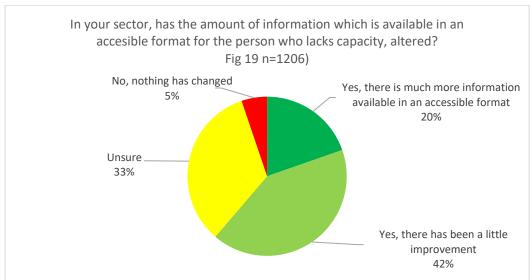
Disseminating information

Health and social care professionals were asked what they had done to ensure that the Act was given a higher profile. A wide range of comments described education and training in formal sessions, in regular training and during staff supervision. There were examples of staff using each encounter as a unique educational opportunity, as well as through modelling good practice in acute health care settings, such as:

- Discuss with trainees in supervision with Multi Disciplinary Team in team meetings;
- I believe we do a good job of understanding the Act but we do encounter difficulties when working with professionals in some statutory services. Very few people had heard of the Court of Protection or knew what a financial deputy was
- We apply the principles of the Act in interface with the Mental Health Act all the time and I have done work for community DOLs applications and S21(a) appeals
- Modelling good practice in acute hospitals
- Through my involvement with adults with learning disabilities Social History
 Learning Disability research group have written up and published work, developing
 a website tool, publicised the SCIE website, shared MCA resources with colleagues
 and families
- Regular multi-agency training
- Supervise staff and make sure that the MCA is always given priority
- Discussed with colleagues and ensured that this is a focus in my CPD
- In-house training and discussion [in] my department and wider MDT setting. A
 section to record consideration of mental capacity has been added to casenote
 templates. We are trying to raise awareness of communication strategies to support
 people to make informed decisions about their care rather than opting for best
 interest decisions too quickly
- Training, policy and information on company intranet

Overall, over the last four years there has been an increase in training on the MCA (figure 18) and information in an accessible format for the person who lacks capacity (figure 19).

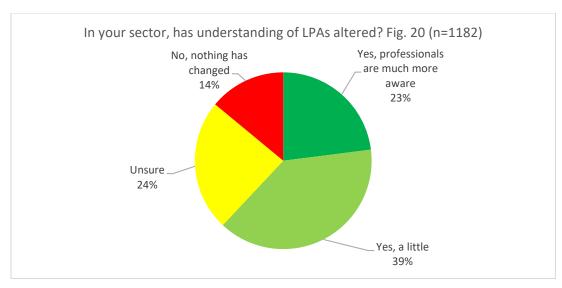


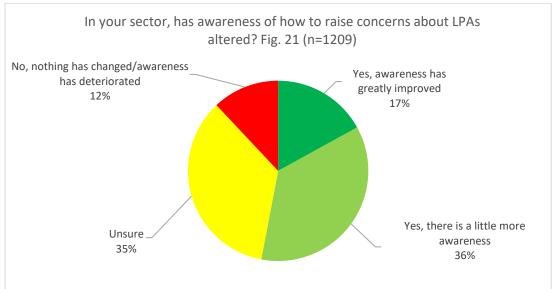


Lasting Powers of Attorney (LPAs)

Although not a direct responsibility of the Forum, close working with the Office of the Public Guardian has demonstrated the extensive efforts of that office to raise awareness of LPAs and to ensure that they are easy to complete, that fees are kept as low as possible and sound security systems are in place to investigate fraud and inappropriate behaviour by attorneys.

It was therefore of concern that just under two thirds (61%) of respondents (figure 20) reported that in their sector there had been an increase in understanding of LPAs. However, 53% (figure 21) reported improvement in awareness of how to raise concerns about LPAs.





Current and future initiatives

Free text responses commended several initiatives. The dementia-friendly campaign from charities, using high profile celebrities, had improved public understanding. Practical video demonstrations of how to assess capacity, how to maximise capacity and how to support people in decision making were also commended. There were requests for more podcasts, for more material to be hosted on the SCIE website (the current material was also commended) and for more general guidance on different aspects of the MCA.

Some respondents wanted the Forum to prioritise a wide range of activities, but it was clear that there is a lack of understanding in many areas that any assessment that a person lacks capacity must be relevant to the specific decision and time. There were concerns expressed about nutrition and hydration of those at risk, about the interface between the MCA and

mental health legislation, lack of awareness of hidden disabilities, inconsistencies in responsibilities delegated to families and concerns over legal fees.

The need to maintain and increase education and training on the MCA was a recurring theme.

Conclusion

The survey demonstrated improvements in all areas 'n' response to the questions posed, supporting the way the forum and leadership group had approached the work over the previous four years with very little resource. The ability to inspire change has been a credit to the energy and commitment of the leadership group and their tenacity at working to improve the experience of all those who, for whatever reason, are at risk.

Detailed subgroup analysis also revealed that social care staff responding to the survey had seen slightly more improvements than those working in healthcare, underlining the need to ensure there is no decrease in educational and training opportunities across all aspects of healthcare provision.

The number of respondents from other sectors was small and their responses mirrored the trends seen in health and social care. Over a quarter of respondents (29%) were not aware that the MCA Code of Practice is being comprehensively revised. Much of the revision work on drafting the code has been delayed by the Covid-19 pandemic.

5. Coronavirus lockdown and revising the Action Days

When the coronavirus pandemic hit and lockdown occurred on March 23rd, there was a sudden move to remote working wherever practical. It was immediately obvious that staff were having to adapt remarkably rapidly, and guidance and support was urgently needed.

The Action Days for 2020 had been planned as three days, outside London: one in Manchester supported by the Mayor of Greater Manchester, Andy Burnham, in Cardiff supported by Cardiff Metropolitan University and in Bournemouth supported by Bournemouth University. Each Action Day had anticipated up to 100 attendees. All three venues were cancelled because of the pandemic, and the Leadership Group decided to quickly three online webinar events for people concerned with implementing the MCA in the new environment of social distancing and shielding those at risk from contact with others who may be viral carriers, even when asymptomatic.

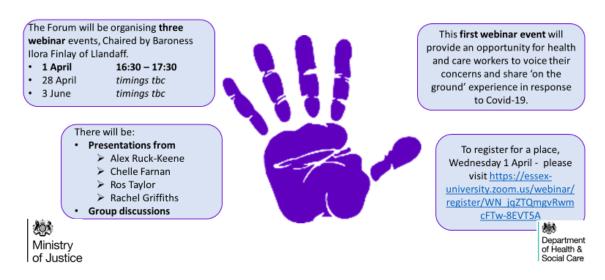
The Essex Autonomy Project department (Essex University) immediately and very generously offered to help establish the webinars. A small steering group was formed to guide the programme. The three dates that had been scheduled for the Action Day were each used instead for a webinar event, as the dates were already in people's diaries. The ability to run a webinar of up to 500 participants was a welcome solution and for each webinar the registration places were fully booked within days of registration opening, with a waiting list for up to 100 additional registrants.

It was important that the webinars met the concerns of those having to adapt to the new environment. To ensure that the content of the planned webinars met expectations, all registrants were asked to describe problems they had encountered and solutions they had found, with these questions adapted for registration to join the second and third webinars as the pandemic situation changed.

Each webinar was recorded and then posted on the Essex Autonomy Project website and on the SCIE National Mental Capacity Forum webpages. In total there were over 3,200 online views to the recorded sessions, which demonstrated people's need to be able to access good information.

Sharing Voices - the first webinar

National Mental Capacity Forum 'Sharing Voices' in Response to Covid-19



The first webinar on April 1st, 2020 was entitled 'Sharing Voices' (recorded here) and all 500 registrants' places were rapidly filled, with a waiting list for aspiring attendees established Applicants registering for the first webinar were asked:

- What are the big issues affecting you in the context of the pandemic?
- What is the one practical tip that you have found helpful in supporting individuals?

Their responses were analysed by Professor Wayne Martin and Dr Emily Fitton of the Essex Autonomy Project, and can be summarised as follows.

Problems/issues identified at the start of lockdown

Some clear themes emerged at the outset, as identified by registrants:

Lack of face to face contact: The majority of registrants for the webinars highlighted a
range of difficulties with lack of face to face contact associated with all aspects of
individual assessment under the MCA. In particular lack of face to face contact made
DoLS assessments and capacity assessments more difficult and potentially unreliable

as new techniques had to be developed. This was particularly problematic, as was the inability to enter care homes. Training of staff in all areas was suspended and difficulties in arranging training compounded staffing difficulties. Lack of personal contact also created difficulties in arranging financial support for individuals and in arranging court hearings.

- 2. Staff wellbeing: The second most frequently reported type of concern related to the safety and wellbeing of staff. The concern about keeping staff of all grades safe, including students and volunteers, centred around a lack of personal protective equipment, high levels of staff anxiety and staff shortages. Working from home was difficult for many, particularly when also juggling childcare and trying to meet the changing needs of the workforce.
- 3. Vulnerable people: Concerns were raised over many aspects of the general safety and wellbeing of vulnerable and isolated individuals and their families. Isolation deprived those with mental health problems of visits from family. It was also difficult for many vulnerable individuals to understand the pandemic, its implications and why their hard-learnt longstanding routines were abandoned. The lack of respite put pressure on the families of vulnerable individuals. In isolation, the risk of undetected neglect or abuse increased. Some were concerned that non-Covid-19 conditions would be undetected and therefore untreated, and that regular medication support was difficult. Specific problems were raised about families being unable to visit when a person was dying. Again, many referred to difficulties with the DoLS processes and possible lack of protection during lockdown.
- 4. Lack of information, guidance and clarification over the law: Many called for clear guidance over DoLS and all aspects of the MCA, stating how lack of clear definitive guidance made it harder for staff to provide appropriate support and instructions for those needing clear support and messaging. The tension between the coronavirus legislation and the human rights of those subject to the MCA created practical difficulties for those responsible for the welfare and for defining boundaries for others in their charge.

Practical tips

Solutions were reported by many, particularly regarding using technology to facilitate video links (Zoom, Skype, webchats etc) in place of face to face assessments.

- Listening: A powerful message that came through was the importance of listening, of believing the lived experience of all those with whom participants in the webinar were in contact, and how active listening was possible over virtual communication platforms and the telephone.
- 2. Using prior assessments: In undertaking DoLS assessments, prior assessments were also used to help establish a reference point or relied on when visiting was not possible, particularly if there was no relevant change reported. Other sources of information were those close to the person and past documented evidence.
- 3. Remote assessments: Video meetings also allowed staff to remain in contact, to share ideas, their stresses and creative solutions. Telephone availability was extended by many to ensure they were available when needed. This also provided time to listen to concerns, help people find creative solutions within the resources they had available. These contacts were important to maintain infection control and provide emotional support to those who were vulnerable and to those providing support in the same household. Some had developed visiting rotas and new routines, created tools to help people understand the pandemic and proactively provided telephone support, including providing contact telephone numbers to those at risk. Part of this was to provide a message to people that they were not alone. Different sources of information: Helping people understand the pandemic required creative solutions. Many developed short, simple, practical messages, providing clear information to patients and the families by using simple, uncomplicated language to explain care and treatment plans. Creative solutions included creating pictures, providing information slowly and in bite sized chunks, and easy read information.
- 4. Greater multi-disciplinary links: Self-isolation also required innovative solutions, with responses tailored to novel situations. Many attendees at the webinar had linked closely with those from other disciplines across health and social care, the Court of Protection judges and many others. This allowed better links across organisational boundaries and encouraged mutual respect of roles and better understanding of different professions' responsibilities and pressures.

5. Information from briefings: The principles of the MCA, briefings from NHSE, and ethical guidance had clearly acted as a framework for decision-making in many difficult and unique situations, helping staff keep the needs of the individual at the forefront of their minds.

The webinar programme addressed the issues that had been raised, some basic information in relation to infection control guidance that was extant at the time, the guidance over DoLS assessments that was being developed, practical solutions to individual difficulties, the NHS ethical guidance framework for social care, legal interpretation of the guidance, resources available including Books Beyond Words, frameworks for decision-making and some simple staff support exercises to use in video conferencing within a team.

Feedback from participants suggested they greatly appreciated the sharing that the webinar provided. The interim emergency DoLS guidance⁶ was published following the first webinar and in response to the issues raised by participants, who appreciated they had been listened to. There was a clear desire for the second webinar, which was developed as an extension of the first and in the light of feedback.

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 $^{^{6} \, \}underline{\text{https://www.gov.uk/government/publications/coronavirus-covid-19-looking-after-people-who-lack-mental-capacity}$

Covid-19: DoLS and Best Interests - the second webinar

National Mental Capacity Forum 'Covid-19: DoLs and Best Interests'



The second webinar on April 28th 2020 was entitled 'Covid-19, DoLS and Best Interests' (recorded here) and again all 500 registrants' places were rapidly filled, and a waiting list established.

Applicants registering for the second webinar were asked:

- What difficulties have you encountered in the context of the pandemic in making decisions for persons lacking capacity?
- What other difficulties are you encountering in applying the MCA in the context of the pandemic?
- How have you resolved decision-making difficulties in the context of the pandemic?

Again, responses were analysed by Professor Wayne Martin and Dr Emily Fitton

There was considerable overlap in answers to the first two questions and there was a pattern of points being developed in depth since the first webinar.

 The reality of conducting remote assessments: Concerns and difficulties encountered in remote assessments were flagged up by over 100 respondents:

- a. Technical difficulties relating to remote assessments had become evident, as several places had limited internet access or did not have portable IT equipment for such connections. Staffing difficulties also limited the ability to plan and to conduct remote assessments as someone was required to be with the person being assessed and manage the tablet/iPad or telephone being used.
- b. Concerns about the appropriateness of a remote assessment emerged, including the need to prepare a person for such an assessment and the call on staff time particularly in settings where health or social care staff were already stretched. Where the person to be assessed had language or other difficulties with communication, assessing capacity was particularly worrying. It is difficult to assess a person's true wishes and feelings as non-verbal cues are missed, and it may not be possible to detect any coercive or subtle influence from whoever is assisting at the side of the person. Risks are particularly difficult to assess when the environment cannot be seen. Fluctuating capacity and the absence of relatives or advocates also can make any assessment less reliable.
- c. Some respondents raised security concerns relating to virtual platforms. Accessing other documentation is difficult as it will be in a care home or a person's home. Communication with other staff is also difficult as a team is not gathering together, and time pressures are different in different environments but the person working from home conducting remote assessments may be unaware of these.
- 2. Processes intended to uphold human rights are side-lined: These concerns relate to a general sense that the MCA had been overruled by the coronavirus legislation (which it had not), that MCA and DoLS issues were falling to the bottom of the pile of priorities through time and staffing pressures, that advocates are not being involved and some expressed concerns about discriminatory attitudes that did not value the voice of the person.
- 3. Discharge form hospital and transfers: Testing and the risk of spreading infection were raised by many respondents. There was inadequate time to complete proper 'best interests' assessments prior to urgent placement changes. Easements of the Care Act were seen to work against adequately maintaining MCA practices.

- 4. Tensions between wider public health concerns and rights of individuals: Difficulties arose when deciding whether the interests of others should be considered yet a 'best interest' decision must be made for the person, because the MCA only relates to harm to the person. Concerns were also expressed over restrictive practices in some care homes and the use of medication for those individuals not complying with social distancing.
- 5. Advance care planning: Several concerns were raised over 'DNAR' do not attempt resuscitation orders and awareness that such orders are meaningless. There were also concerns about the way that 'DNACPR' conversations were conducted in primary care and the way such decisions were arrived at.
- 6. Compliance with lockdown: Many issues were raised over non-compliance and how someone suspecting non-compliance should proceed. It was unclear when and how infection control measures were to be managed, how to help people understand the social distancing and lockdown rules and whether there were circumstances when such rules could be broken.
- 7. Wellbeing: Fear was often generated by staff appearing in Personal Protective Equipment (PPE), and PPE could also create communication barriers. There were many difficulties associated with caring for very sick care home residents in isolation and some families were wishing to take relatives home from care homes to avoid infection. Concerns over a person's welfare, infection risk and decisions over place of care meant that DoLS conversations could seem inappropriate to a family. Several registrants expressed concern over the rise in domestic violence.
- 8. Lack of guidance: The lag in roll out of the emergency delay in DHSC guidance on DoLS and the MCA was creating uncertainty and difficulties, with guidance being seen as too broad. The uncertainty over the timing of implementation of Liberty Protection Safeguards was a cause of uncertainty and an added stressor.
- Time pressures: Time pressures meant decisions were being made at speed, but generally without consideration of whether the decision could wait and whether the process could be conducted more slowly to allow for adequate information gathering.
- 10. Specific difficulties in implementing the MCA: These could be summarised as difficulties with the core principles as well as the processes that followed in

assessment of every type. Maintaining the core principles of the MCA was difficult, in particular:

Principle 2 – complying with offering support via a virtual assessment;

Principle 3 – unwise decisions e.g. a homeless person wanting to return to the streets rather than remain in accommodation; and

Principle 5 – availability / appropriateness of 'less restrictive options'.

Ways that decision-making difficulties were being resolved in the context of the pandemic

Solutions offered by participants were sophisticated and creative. These included:

- Remote assessment procedures: Some teams had developed their own guidance and learnt from pitfalls. Suggestions included careful preparation by supplying the questions in advance, using telephone information gathering as much as possible, and using different platforms for assessment.
- 2. Past assessment information: Equivalent assessments were used where possible and staff divided the case load, so the assessment was done wherever possible by a person who had previously met / assessed the person.
- Collaboration: Multiagency collaboration across agencies had improved communication, particularly over complex cases. Delaying decisions had been helpful in some instances.
- 4. Reminders about the MCA: Reiterating the duties under the MCA had proved effective in ensuring there was awareness of the need to assess capacity and to consult widely over decision-making. Where a decision had to be made at speed or under pressure the decision was then reviewed as soon as practicable. Several respondents were realistic about the limitation of the current working situation and described falling back on 'reasonable and proportionate' as a principle.
- Involving family and carers: The family and carers were a useful source of information, although when there is a dispute, it can become more complicated to establish a person's wishes and feelings.

6. Creativity, imagination and ethics: A wide range of creative solutions were evident from the comments, with problem solving being a major priority.

These reported problems and some of the solutions were shared at the outset of the webinar.

This second webinar focused in greater depth on the guidance (Coronavirus (COVID-19): looking after people who lack mental capacity) over DoLS that had been published shortly before the webinar. The programme addresses the guidance that was published 9 April 2020, three weeks before the second webinar, with speakers from DHSC and the Government Legal Service. The reality of DoLS during the pandemic was covered by Lorraine Currie of Shropshire Council and issues that had arisen in Wales were highlighted by Elin Jones from the Welsh Government. The webinar then went on to address the law around 'best interests' decisions (Alex Ruck Keene of 39 Essex Chambers), and the practical experience of having to take 'best interests' decisions in clinical situations where decisions are made at speed and with constraints, in Intensive Care Units (Dr Jack Parry Jones, clinical lead for ICU in Wales).

Again, the feedback was excellent from attendees.

Covid-19: Public Health and Human Rights – third webinar

This third webinar evolved in response to feedback from the social care sector in particular. It aimed to discuss the tension between public health priorities (as in the Coronavirus Act 2020) and the human rights of people with impaired mental capacity.

Part of this was designed to address the legal framework in which people are working, the need for consent to take samples for diagnostic testing and the difficulties around DNACPR decisions.

National Mental Capacity Forum Covid-19: 'Public Health and Human Rights'



As previously, applicants for the webinar held on 3 June 2020 were asked to provide reflections from their own experience on the following questions:

- Has the pandemic given rise to care dilemmas in which you have faced a choice between the protection of public health and respect for human rights? If so, please share an example.
- Please share an example of how you (or someone you are aware of) has managed to strike a balance between protecting public health and respecting human rights during the pandemic.
- Are you aware of any situations in which we seem to be getting the balance wrong between protecting public health and respecting human rights? Please share an example if you are able.

The responses were summarised by Professor Wayne Martin and Dr Emily Fitton.

The themes showed a change from those raised at the beginning of the pandemic lockdown, from the last week in March. Concerns continued over the supply of personal protective equipment, but the main source of distress related to the isolation of people in care homes and the difficulties associated with their protection from infection conflicting with their need for interaction with family in the face of their restricted liberty. The high death rate in nursing

home residents had become a cause of distress to staff, compounded by concerns about the ability of social care staff to continue to cope long term.

There was considerable overlap between topics listed in response to question 1 and in response to question 2.

Situations which posed a dilemma between the protection of public health and respect for human rights:

- 1. People wanting to wander either outside their home or out of their care home room: Concerns expressed related to (a) those who were known to have Covid-19 and were inclined to wander, thus presenting a risk to others in a care home, and (b) the difficulty of supporting those who are well but have impaired capacity to understand the lockdown. Lockdown rules have resulted with many having to spend a lot more time in their rooms in care homes. Some people have difficulty understanding that by going out they pose a risk to others on return, as they may spread virus if they become infected. This restriction on movements is particularly difficult with those who exhibit challenging behaviours and can become aggressive. Some with dementia benefit from exercise by walking but can't recall the need to maintain social distance when out.
- 2. Restriction of visits: Those desperate to have close contact time with their family members are denied much wanted visits, particularly in the learning difficulties setting where parents are denied visits. The blanket banning of families visiting was felt to be excessively restrictive, and to impinge on human rights, both in hospital and in care home settings, as emotional and support needs were being denied by restrictions:
- Difficulties with testing for Covid-19: Many concerns were raised over consent –
 those who lack capacity to consent, how refusal will be assessed, whether swabbing
 is mandatory, the frequency of testing, whether restraint can ever be used to obtain a
 test.
- 4. Hospital discharges and transfers and admissions to care homes: Several raised concerns about the speed with which patients were transferred from hospital to nursing home to free hospital beds, sometimes without testing for Covid-19 before discharge or after testing but before the result is available, risking Covid-19 infection

being brought in to a care home. Other restrictions on transfer to hospital for treatment or being allowed to go home were cited as problematic.

- 5. End of Life and DNACPR orders: Blanket DNACPR orders, use of the term 'DNAR' and lack of consultation over such decisions were all seen as needing challenge.
- 6. Assessments: Remote assessments and video assessments were posing dilemmas as they may be less accurate than face to face ones. Some were concerned that insisting on face to face assessment risked spreading the virus to others. Contact with people in care who were shielding was difficult.
- Other concerns: The high number of deaths resulted in staff being bereaved and many exhausted emotionally. Shortages of PPE, lack of clear guidance and staff safety concerns limited activity.

Examples where a balance was struck between protecting public health and respecting human rights during the pandemic:

- Assessments: Many cited using virtual assessments and video links, remote DoLS
 assessments, interviews and liaising with others to uphold the principles of the
 MCA.
- Combatting isolation: Innovative ways of bringing the outside world into care
 environments included through live streaming events, religious services, supplying
 personal tablet devices for videoconferencing, creating new routines, and recreating
 normality such as an on-site shop in a care facility
- Hospital and care home admissions, transfers and discharges: Control over transfers, using MCA guidance principles to protect patients
- 4. Honesty and information: These are essential to trying to 'do the right thing' for a person
- Remote working and collaboration: Interagency working, triangulation of information across agencies and use of videoconferencing all had increased respect for human rights
- Compliance with lockdown: This was achieved by imaginative personalised routines for those with learning difficulties

- 7. End of life: Care was improved by relaxing visiting restrictions when a person was dying, ensuring the ReSPECT⁷ process was used and that clear clinical guidance was produced on 'best interests' decisions
- 8. Other: A wide range of ways were cited, with a clear theme of ensuring the legal framework to respect the value of the life of the person irrespective of their disability or lack of capacity. People had widened their remit, taking on aspects of care that would previously have been delegated to others, resulting in personalised care.

Situations in which the balance between protecting public health and respecting human rights seems wrong

Powerful examples were cited which fell into several main themes, with an overarching theme highlighting the way that 'blanket policies' run counter to an individual's human rights under the MCA:

- 1. Visits from / contact with family: Many registering for the webinar were particularly concerned at restrictions on family and others visiting those who were at the end of life, both in care homes and on mental health wards in hospitals; and cited the distress this caused. Restrictions on visiting were exacerbated by a lack of PPE and testing availability, meaning that decisions were taken without adequate information to assess risk. In some care homes, blanket policies were felt to be overly restrictive. Restrictions on funerals were also seen as excessively risk-averse.
- 2. Individuals unable to go outside / confined to one room: Isolation was caused by staff shortages, blanket policies, an overreliance on the public health message over the risk of harm to the individual of isolation and seclusion. When a person in a care home was identified as having Covid-19, other residents were confined to their room for 14 days which resulted in serial periods of 14-day confinement. Instances of restrictive arrangements were described that seemed to go beyond the requirements in law.
- Individuals not being allowed to move out of care homes: People with capacity
 were being prevented from leaving supported housing or short-term care home
 placements to move back home.

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⁷The ReSPECT process creates personalised recommendations for a person's clinical care and treatment in a future emergency in which they are unable to make or express choices www.resus.org.uk

- Hospital discharges: There were concerns around hospital discharge processes being too rushed, not adequately focusing on the MCA with relevant assessment not being conducted, and people being sent to care homes without testing for Covid-19.
- 5. DNACPR: Several respondents raised concerns about DNACPR orders: There was confusion over DNACPR (do not attempt cardiopulmonary resuscitation) and DNAR (do not attempt resuscitation). Blanket DNACPR policies denied informed consent and did not comply with the MCA. In addition, some described general policy decisions against admission to hospital, rather than assessing each case individually.
- 6. Overly restrictive rules: Restrictions on people fell into several subcategories:
 - Motivated by anxiety: people being prevented from taking exercise even within permitted limits, isolation within care homes described by some as being 'confined to barracks';
 - Excessive rigidity in interpretation the official guidance: blanket restrictions imposed on mental health patients and care leavers;
 - Lowered threshold for determining lack of capacity, running counter to the first and second principles of the MCA.

7. Covid-19 testing policies:

- When the individual may lack capacity, issues were raised over valid
 consent to testing, other practicalities of obtaining a swab sample from a
 person who appears to object, whether blanket policies allowed restraint
 whilst taking a swab, and risks of taking swabs without adequate training.
- There was also concern that those with learning difficulties were not included in policies of swabbing to detect Covid-19 and therefore discriminated against.

Future webinars

The webinars have proven surprisingly popular and were oversubscribed with interest from more than the 500 registrants possible. Issues that have emerged have been fed back to DHSC, resulting in revision of guidance to address new questions and concerns.

Future webinars will attempt to respond to problems emerging as the situation changes. It will be important that the fourth webinar is a forum for people to air particular problems they are still facing and will attempt to promote discussion at local and national levels.

6. Closing remarks and next steps

Future direction of the National Mental Capacity Forum

The National Mental Capacity Forum must remain led by and responsive to the needs of those the MCA was designed to serve. The webinars proved very successful and met an urgent need. They have indicated that the use of such technology can reach many more people at much lower cost in terms of time and financial expenditure. The feedback has been excellent. The recording of the webinar allows people to refer back to it and for those who missed one to view it at their own convenience. This will be an important change for the Forum and further webinars are being planned, as well as a research project to harness the learning from participants front-line experiences.

Deficits identified in the survey

The survey showed that social care respondents overall felt they had a better understanding of the MCA than those in healthcare. There were not enough respondents from other sectors to be able to draw discipline-specific conclusions, although their responses mirrored the overall results.

These findings must inform future programmes of education and training that thread through ongoing professional development and service development.

Post Covid-19, revised MCA Code of Practice and Liberty Protection Safeguards

Sources of information are most powerful and authentic from those working in all services that engage with those with impaired capacity at any level. As recovery from the Covid-19 pandemic continues, financial pressures on services will be compounded by financial pressures on individuals who have lost income or have become unemployed and who have been supporting a person in their own family with impaired capacity. Many of these informal carers are exhausted, are concerned that those with learning difficulties may be subject to further rationing of support available and that some services from voluntary sector providers will not be available as charities become non-viable though lack of donations during the pandemic.

The challenge of implementing Liberty Protection Safeguards must not be underestimated. Lessons learnt from modifications to the Deprivation of Liberty Safeguards guidance during the pandemic need to be drawn on. The wide range of experiences can also inform the redrafting of the MCA Code of Practice.

Clinical services

As specialist and generalist clinical services produce their own guidance on managing Covid-19 patients, some attempts at clarifying triage in the event of the NHS being overwhelmed have caused distress amongst those with disabilities, their families and those who care for them. Those with disability have already been documented to have a shorter life expectancy than others without disability. As a result of some of the guidance, fears have been raised that they will not be treated as others are and that value judgements may be made about their lives.

Although guidance has been produced on 'best interests' decision-making, and has reinforced messages in previously issued guidance, there is a need to embed 'best interests' decision-making as always requiring wide consultation. It must gather all that is known about the person's wishes and feelings, be clearly in the best interests of the person and must not be motivated by a desire to bring about the person's death.

'Valuable and at risk'

There is a need to change the narrative to improve respect for those with capacity impairments. They are often referred to as 'vulnerable' and indeed are vulnerable to exploitation by those of malicious intent, are vulnerable to dangers that would be avoided by others, and are often physically vulnerable with complex care needs. But the language needs to recognise that they are 'valuable and at risk' to ensure that their lives are recognised as of value, and that society must make all reasonable adjustments as needed to help them meet their full potential.

Appropriate levels of protection through counter-fraud projects run by banks, finance and the utilities need to progress with findings available across other disciplines.

Conducting the National Mental Capacity Forum work programme over the coming year will require:

- Ongoing webinar programmes to maximise reach from 'meetings'.
- Developing guidance on Liberty Protection Safeguards
- Publishing the revised MCA Code of Practice

Ilora Finlay

August 2020