

## Is there a broader role for Independent Mental Capacity Advocates (IMCA) in Critical Care? An exploratory study

### Abstract

**Background:** This research explores current and potential future role of Independent Mental Capacity Advocates (IMCAs) in Critical Care. The Mental Capacity Act (MCA) 2005 introduced IMCAs as advocates for patients without anyone to represent their best interests, but research suggest this role is not well understood or implemented. No existing research explores the role of IMCAs in Critical Care, or their potential use when families are judged “appropriate to act” on the patient’s behalf. It is suggested that families may not be best placed to advocate for their family when they themselves are in a state of shock.

**Aim:** To investigate existing levels of knowledge and awareness of the MCA and understanding of the role of IMCAs in critical care as a prelude to considering whether the role of IMCAs might usefully be extended. The concept of “IMCA clinics” is introduced and explored.

**Design and Methods:** A small-scale mixed methods study using thematic analysis of 15 interviews across two NHS sites and a survey of IMCA services were undertaken.

**Results:** Some knowledge of the MCA was evident across both study sites, but training on MCA remains unsatisfactory with confusion about the role of IMCAs and when they should become involved. Overall, participants felt the broader involvement of IMCAs on a regular basis within critical care could be useful.

**Conclusion:** There was evidence of good practice when instructing IMCAs but further work needs to be done to ensure critical care staff are informed about the referral process. It was clear that expanding the role of an advocate warrants further investigation.

**Relevance to clinical practice:** Further training on the role of IMCAs within critical care is required and good practice examples should be shared with other units to improve referral rates to the IMCA service and ensure vulnerable patients are properly represented.

## Introduction

Loss of capacity is a common consequence in critical illness, either because of underlying disease, severe organ failure, or the common use of sedative drugs to facilitate mechanical ventilation. Against this background, important decisions frequently need to be taken in critical care. Many of these decisions are complex and must be considered in line with the Mental Capacity Act 2005 (MCA)<sup>1</sup> and its Code of Practice<sup>2</sup>, which creates a statutory framework in England and Wales for decision-making on behalf of any individual aged 16 or over, lacking capacity to make a decision for themselves. Research to date has demonstrated poor implementation and understanding of the MCA and poor referral rates to the IMCA service, although this has not been investigated specifically within critical care<sup>3,4,5,6,7,8</sup>.

The MCA 2005<sup>1</sup> (sections 35-41) introduced the role of the IMCA as a safeguard to protect the best interests of patients who may lack the capacity to make decisions for themselves<sup>9</sup>. It requires an IMCA to be consulted when serious medical treatment decisions are made for these patients and who have no relatives or friends who are appropriate to consult about what course of action would be in the person's best interests. The role of the advocate, whether as professional, family or friend is to provide support to enable the person to participate as fully as possible in any relevant decision and to ascertain what the person's wishes, beliefs, values and feelings would be. This role requires considerable knowledge, skill and familiarity with medical-legal issues – and a sense of confidence and entitlement to ask what can be experienced as challenging questions of senior medical staff. Not surprisingly therefore, some concern has been raised that families are not always well-placed to act as advocates for relatives within the critical care setting when they are themselves experiencing loss and shock following the precipitating event.<sup>10,11</sup>

Such concerns were raised at a Multi-disciplinary Wellcome Trust sponsored symposium held to discuss the challenges of making decisions about medical treatment concerning individuals with severe brain injuries who lack capacity to make treatment decisions<sup>12</sup>. It was argued during the symposium that IMCAs might have a useful role within the critical care setting, crucially even where there are family members present and being consulted, since the IMCA brings specialist knowledge and experience that family members do not usually possess which can be used to advance the best interests of the patient. Although there is some discussion in the literature<sup>3,4</sup> surrounding the implementation of the IMCA role and clinician attitudes to this role, there has been no study to date which looks specifically at expanding the role of IMCAs to support family and friends of patients in the this setting. Therefore the researchers decided to investigate whether the role of IMCAs might usefully be extended within this setting to offer advocacy for a wider range of patients.

## METHODS

## **Aim and design of the study**

The aim of this research was to explore knowledge and awareness of the MCA and understanding of the role of the IMCA in the critical care context as a prelude to investigating the feasibility of expanding the role of the IMCA service in this setting via the format of regular IMCA consultation clinics to aid the decision-making process for serious medical treatment decisions. A mixed methods approach was used. Interviews were undertaken to derive comprehensive data and better understanding of the MCA knowledge and the role of the IMCA in CCU and whether this role warrants expansion. In addition, questionnaires were sent to IMCA service in England and Wales to ascertain current utilisation and referral rates of patients from CCUs. The questionnaires included free text insertion to obtain IMCA views on expanding the service.

## **Participants**

The study participants included six critical care unit clinicians, five relatives of critical care patients and four IMCAs. Clinicians and IMCAs were recruited via invitation letter and relatives were recruited via CCU Follow-Up Clinics across two NHS Trusts in England, both of which have large Critical Care Units (CCU). Questionnaires were sent to all 50 IMCA services in England and Wales. Fifteen responses were received.

## **Data collection**

Each interview was approximately 30 – 60 minutes, either face to face or over the telephone, and was based on a semi-structured interview schedule. The interviews were audio-recorded and then transcribed. No participant was excluded from the data analysis.

The anonymous online survey sent to the IMCA service used SurveyMonkey®. The survey allowed for free text insertion and data obtained from these responses are clearly detailed in the results section.

## **Ethical Considerations**

Research Ethics Approval and site-specific authorisation was obtained. Participants gave informed written consent prior to participation in the study.

## **Data Analysis**

Interviews were analysed using thematic analysis<sup>13</sup>. This provides flexibility of analysis with rich and detailed description of the data. The interviews were transcribed by the authors and read several times to ensure familiarity with the data. Initial codes were identified and colour coded with refining of codes occurring on further reading before themes emerged. (See examples in table 1.) The codes and themes were reviewed between the authors, enhancing the trustworthiness, dependability and credibility of the findings<sup>14</sup>.

Free text data from the survey is included in this paper, however due to low response rate to the survey, quantitative data could not be reliably extracted, and is not included in the results. However, free text data from the questionnaires *is* included and, like the interviews, was analysed using thematic analysis.

## Results

### Participants' knowledge of the Mental Capacity Act

The clinicians and relatives were asked what they understood about the MCA. Only one of the five relatives we interviewed had heard of it (due to having to deal with property issues). Although all clinicians were familiar with the MCA not one of them could remember having been provided with formal training about the Mental Capacity Act 2005.

In response to the interviewer's question: "Has the hospital Trust provided Mental Capacity Act training that you've been able to access and if so what form did it take?" one clinician answered simply: "None that I've been aware of". Others said:

"I have not had any formal mental capacity act training from the Trust or otherwise and I don't know if the Trust has any formal MCA training package available". (C3)

"The Trust provides a mountain of training of all things. Whether in that haystack there was something about Mental Capacity Act, I can't tell you". (C5)

"The hospital management may well have provided training but I've got to say it has not been visible, I'm not actually aware of it". (C6)

These clinicians had picked up their knowledge of the Act from internet sources (C1, C2) and reading relevant articles (e.g. Medical Protection Society newsletters, BMA articles, C3 and C6) and referred in particular to the role of informal peer education "talking to people who knew more about it than me" (C4). Several spoke about learning "on the job":

"I've gained sort of a little bit of an insight into the function of IMCAs within the Mental Capacity Act when I needed to refer to them".(C3)

"When one of my consultant colleagues was working at a national level on the Mental Health Capacity Act [...] through her we had a very informed and updated briefing". (C5)

One clinician was occasionally involved in educating junior doctors on certain aspects of the MCA and had "organized some [training] myself" due to the lack of training provided by the hospital trust" (C4).

## **IMCAs' views**

We consulted IMCAs on their experience of working with clinicians in critical care and their perceptions of whether clinician knowledge of the MCA was adequate – and they tended to say that it was adequate or even 'quite good'. Comments included:

"Most clinicians have a good enough grasp of the MCA and how they need to apply it to their work". (IMCA1)

"A lot of the nurses are straight on to it if they think the person lacks capacity and they need someone to stick up for them". (IMCA4)

One felt clinician knowledge was "pretty good" and "better than average" (IMCA 3). Another highlighted changes over time: "I've been doing this for nearly four and a half years. I think in that time I have seen a general improvement in knowledge". (IMCA2)" A third went as far as to suggest that it might be seen "as a bit of an insult" to offer MCA training at one hospital "because [...], they really are good" (IMCA4).

## **When an IMCA must be involved**

Asked whether they were aware of, and what they understood about the role of the IMCA service, clinicians virtually always said that IMCAs are for people who lack mental capacity. As one put it: IMCAs are "the voice for a patient who isn't competent at that point in time" (C6). There was also a widespread understanding that IMCAs were employed for incapacitated patients without family suitable to represent them.

It was clear from the interviews that not all eligible patients were being referred. One consultant was "100% certain that there are patients who are eligible but not referred" (C3) and that there are frequently situations where there's a case for involving an IMCA but none is appointed. It was not always clear whether clinicians realised there was a statutory obligation to refer to the IMCA service. "There's quite a lot of confusion around when to actually instruct an IMCA" (C3).

Although the IMCAs interviewed appeared satisfied with clinicians' knowledge and understanding of the MCA, and some IMCAs were satisfied with the level of referring (e.g. "they tend to err on the side of caution [...] they are very timely in their referrals" IMCA3) there was clear disparity between the two Trusts in the timings of IMCA referrals, and some IMCAs were concerned about breaches of the MCA that left vulnerable patients without support.

"Some [consultants] have a slightly cavalier attitude to it; in the sense of they feel it's not necessary". (IMCA1)

"I can't help wondering if there is sometimes people in there [CCU] who technically should have an IMCA". (IMCA 2)

When clinicians were specifically asked about the timings of referrals we continued to notice a disparity between the two trusts involved in this study. One of the NHS Trusts tended only to involve IMCAs towards the end of a person's life.

"I certainly have a slant that it's (IMCA referral) because it's an end of life withholding treatment option". (C1)

"I think that we would realistically need IMCA when you are considering limiting or withdrawing treatment". (C2)

Unlike families and friends who can often be contacted in urgent situations at evenings and weekends, the IMCA service operates 9-5 weekdays and cannot be accessed outside these times. Given the nature of the work in critical care where many decisions have to be made immediately, this was recognized as a challenge by both clinicians and IMCAs.

"the problem is so many decisions [...] the time line is often so quick to actually get someone there". (C2)

"there is a perception that it may take quite a long time (to get an IMCA) and my experience is that was true". (C3)

This issue is exacerbated if clinicians are not referring to IMCAs in a timely manner. Referral at an early stage would result in an IMCA becoming involved at the start of the patient's treatment, leading to more effective relationships and subsequently better outcomes<sup>15</sup>.

The lack of time for decision-making in the critical care setting was also a challenge acknowledged by our respondents. One clinician (C5) suggested the role of IMCA within critical care was "not fit for purpose" due to the nature and severity of the patient's illness.

### **Knowledge of the IMCA's role**

Although clinicians had some knowledge of *when* to instruct an IMCA, some appeared unclear about the role of the IMCAs once instructed.

One thought that the IMCA will "make a neutral decision" (C2), and IMCAs' view was that "people can be quite confused by what our role is" (IMCA4) and that "I don't think in general doctors understand the IMCA role" (IMCA3).

There also appeared to be some confusion about the role of the IMCA as capacity assessor or mediator. When asked about his experience of IMCA, one clinician explained that he referred to the IMCA service because "there was some conflict between the clinicians and the family" (C3).

The IMCAs interviewed stressed that a key part of the role was to establish a person's past or present wishes. This was expressed by every IMCA interviewed in the study. In contrast some clinicians talk about the IMCA's role as making sure "that we've gone through due process" (C2).

## **Involving IMCAs in end of life decisions**

In one of the Trusts, it became apparent there was a perception that IMCAs are mainly involved when end of life decisions are to be made and it is in these situations that the Trust would consider instructing an IMCA (C1, C2,C6). C2 explains that “most of the time I think that we would realistically need IMCA is when you are actually considering limiting or withdrawing treatment.”

The need for an IMCA in end of life decisions made in the best interests for a person who lacks capacity to make treatment decisions was linked to evolving case law in this area (“treatment withdrawal is actually changing”, C2).

One clinician provided some insight into why some critical care environments are more likely to instruct IMCAs for end of life decisions than for other decisions: “If I’m honest with you, a few weeks of court judgments have made end of life decision making tricky” (C6).

Although the IMCAs reported often being involved when the decision is about end of life, in one Trust the IMCA described how they were instructed in different situations. IMCA 4 explained that sometimes they are “instructed early because there hasn’t been a decision yet”.

## **Clinicians’ perceptions of IMCAs’ approach to the work**

Some clinicians felt that IMCAs are always pro-life and that this is not always appropriate if treatment is futile:

“I think sometimes IMCAs saying that we need to give the person the opportunity to be involved in the discussion so we have to carry on until their delirium improves or they recover from their stroke [...] but then at the end of that process the situation is still hopeless” (C3).

“So I think that there’s some animosity or difficulty in approaching IMCAs because there’s this assumption that they are going to come along and say you cruel evil doctor you know, what are you doing? [...] So I know that that’s the perception amongst clinicians and I’m pretty sure that the role that we’re using them for is narrower than their remit.” (C1)

Asked about how helpful IMCAs’ involvement had been, there was a mixed response from clinicians. On the positive side:

“we all felt better that somebody independently had been involved and that we were meeting the statutory requirements”. (C4)

“It has been very variable, when it comes to end of life decisions [...] I think critical care is particularly good at being a multi-professional specialty [...] I think there is a good role for IMCA within the service.” (C6)

However one consultant felt that IMCAs are more used to working with issues other than serious medical treatment decisions:

“Actually this is a service that has been set up to help incompetent and un-befriended to make decisions about housing and things like that and the response times and knowledge needed for that is very different in situations. I wasn't at all surprising when a very nice lady said 'oh OK whatever you say doctor, that seems fine, I'll write a report and send it to you' ”. (C5)

Some clinicians expressed concerns that IMCAs had not had specific training that prepared them for intensive care environments: “questions asked of IMCAs are a bit unfair because they are not trained to actually get involved in that process” (C6). This consultant went on to say “I think they (IMCA) are a very valuable addition to difficult decision-making but I think there is some way to go to developing the role even further”.

### **IMCA Clinic**

Given the challenges regarding access to the IMCA service, we sought participants' opinions on a drop-in IMCA clinic where an advocate would be available at specified times to be consulted by patients' families. We wanted to know whether this would alleviate the problem of timing (and possibly of understanding the ICU context) whilst at the same time expanding the IMCA role to provide advocacy support for the patient that would supplement the support already provided by friends and relatives. There was general consensus from the relatives that this would be “useful” (R1) or even “essential” (R3, R4 and R2). IMCAs felt it was a good idea in principle, but had understandable concerns over resources and commissioning of services.

“in principle, yeah [...] you would have to just give it a try and see how it worked out”. (IMCA 2)

“I can see how it would be useful [...] we're a useful source of information”. (IMCA 3)

Clinicians on the whole were also positive about the idea

“I can think of situations where it might be helpful [...] I can see that there would be benefit to the families”. (C3)

“Yes I do actually; I do think there is something in that. I think we have something to learn from IMCAs [...] I also think that IMCAs would benefit from collaborating with us to have a better understanding as what we want as well”. (C6)

### **Challenges of IMCA clinic**

We asked participants whether there would be any challenges associated with providing an IMCA clinic and there were a number of concerns including the observation that it would be outside their current remit (IMCA3). One perceived



problem was the risk of “stepping on people’s toes” (IMCA4) with families potentially misunderstanding the role. Clinicians too had concerns about “putting another person into that mix” (C2) and upsetting the relationship between staff and families (C1 and C3).

“The perception that the IMCA would not be encouraging the family to trust the medical team, which wouldn’t be helpful”. (C1)

“We would just stop functioning after a while if there’s another person who has to have their say [...] become a tool for angry families”. (C3)

IMCAs who returned the survey and completed the free text section had more mixed views on the provision of such an advocacy clinic. Some felt that it could be beneficial if the “outcome of a regular clinic was an increase in appropriate referrals and proper use of the IMCA service” and that having a presence “to remind staff about the MCA and advise families/friends” would be positive. Others felt that it is “not our role” and that “the Trust should be providing training for their staff who should be able to impart this knowledge in turn to patients and families” and some IMCAs said it was not appropriate as “it would put a drain on a limited resource”. Many of the IMCAs point out that if CCU staff used the MCA appropriately and referred eligible patients to the IMCA service, there would not be a need to be considering ways to improve referral rates to IMCA.

### **How might an ‘IMCA Clinic’ operate?**

Relatives were clear that the relatives’ room provided in CCUs, should be the focus of any information that is relevant whilst their family member is in CCU - “there is the family room there, they can put leaflets out” (R1),

IMCAs mentioned the importance of being in the environment “we would have to be on the ward regularly, more than once a week for it to work” (IMCA 3) and that the drop-in model would be the most appropriate one with the option to make contact by telephone at other times.

One IMCA thought that the best use of IMCA time would be as a point of contact for staff and explained that “we would see this as a chance for professionals to screen us with any possible referrals” (IMCA 1). The idea behind this is to support the clinicians to regularly refer all eligible patients.

When the clinicians were asked about how the clinic could operate the majority echoed the views of relatives: IMCAs “should be available around visiting times” (C1) and provide resources “like leaflets or a poster” (C1) – and staff could use IMCAs as a “sounding board” (C1).

### **Discussion**

This study explored the knowledge and understanding of the MCA and specifically the role of the IMCA within critical care as a prelude to investigating the potential expansion of the IMCA role in this setting. The data obtained provides continued evidence that further work is needed to raise awareness of the MCA with both

service users and health care professionals. The data suggest that, of the two NHS Trusts who participated, one Trust in particular finds statutory advocacy either impractical or irrelevant except at the point at which end of life decisions need to be made. Similar results were reported by Luke et al<sup>4</sup> during the pilot phase of the IMCA service implementation. This is not compliant with the Mental Capacity Act, according to which all patients who lack capacity to make a particular serious medical treatment decision, who do not have family or friends ‘appropriate’ to consult must be referred to an IMCA. Eligible individuals have a legal right to receive IMCA support and representation, and treating clinicians have a legal responsibility to ensure that they receive it<sup>1</sup>. The data in this paper, alongside previously reported referral rates<sup>8</sup> is worrying and may mean certain patients are not receiving the representation they are entitled to. This may be in part the result of continued confusion regarding when and IMCA should be contacted<sup>5</sup>. Access to the IMCA service is undoubtedly an issue that needs addressing to make the service fit for purpose in CCUs. However it is important to note that availability of IMCAs is not decided by individual services: rather the service limits have been set out in primary legislation.

Overall participants believed that an “IMCA Clinic” would be useful and, relatives, in particular, expressed the view that an advocate service of some kind would be invaluable. Understandably both clinicians and IMCAs had reservations but were principally in favour. However, there was no clear suggestion of how this might work in reality in critical care. This is an entirely new concept and would require considerable further discussion and funding to pilot such a service.

## **Conclusion and recommendations**

Our findings in regards to the lack of general awareness of specific elements of the MCA (e.g. statutory obligations re IMCA provision) and also poor training provision are in line with the recent House of Lords Select Committee review<sup>6</sup>. Recommendations following the Select Committee review state the urgent need to address the issues surrounding low awareness among professionals and also the wider public. There are clear and valuable resources available on the MCA<sup>16</sup> with specific guidance written for critical care staff<sup>17</sup> however, there is still a clear need to provide further and regular training on the MCA and the role of IMCAs in this setting. Additionally, relatives need to have easy access to information regarding the MCA and how the Act has an impact in their current circumstances. Without pushing forward to properly educate professionals and the public, we continue to run the risk that ‘unbefriended’ patients who lack capacity will not be appropriately represented. Expanding the role of the IMCA – including via providing IMCA clinics in CCU context which are accessible to families - may well be one welcome way of addressing these issues and therefore warrants further investigation.

## **Study Limitations**

This study is small-scale with only fifteen participants across two NHS trusts who were interviewed and the authors acknowledge that this may not be representative of other NHS Trusts. The authors also acknowledge that the response of the survey was lower than desired and therefore did not allow them to derive useful quantitative data for this paper.

### **What is already known about this topic?**

All patients who lack capacity to make decisions for themselves have a right by law to advocacy, but as The Mental Capacity Act review by the House of Lords Select Committee<sup>6</sup> recently demonstrated there is a lack of awareness of the Act within healthcare settings. As Taylor (2015) states, this potentially has a significant impact on patients which cannot be allowed to continue.

### **What this paper adds?**

This paper clearly demonstrates that further training is required to ensure all healthcare professionals have a greater understanding of the MCA. This in turn will ensure that vulnerable patients who are eligible for an IMCA receive this service – and not just in certain conditions (e.g. decision re withholding/withdrawing treatment). This is mandatory and best practice ideas need to be shared. Additionally, there is evidence that advocacy provision in the form of a drop in IMCA clinic, for family and friends of patients who lack capacity in critical care could be helpful and warrants further investigation.

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Table 1. Example of code and theme formation.

Interviewee talk/answers.	Initial Codes	Theme
<p>“I have not had any formal MCA training”</p> <p>“I’ve got to say it’s [MCA training] not visible”</p> <p>MCA knowledge gained by “reading article [...] emails or talking to colleagues.</p> <p>“it’s somethings that most of us [clinicians] are reasonably familiar with</p> <p>Have you heard of the MCA? Relative: “no”</p>	<p>MCA training</p> <p>Clinician knowledge of MCA</p> <p>General public knowledge of MCA</p>	<p>Participant knowledge of the MCA</p>