BMA Statutory Advocacy guidance with IMCA Support Project

1. Background
Health professionals care for some adults who have difficulties representing their own interests or making decisions about their own care or treatment. Informal advocacy services have long existed to support these patients.

As health professionals are generally familiar with informal services, they are only mentioned briefly here. Additionally, the Mental Capacity Act 2005 (MCA) and the Mental Health Act 2007 (MHA) introduced statutory obligations to provide advocacy services in certain circumstances.

This guidance focuses particularly on these statutory advocacy services and when health professionals must involve them.

Informal advocacy services developed piecemeal to help people who have difficulty making decisions, securing their rights, exploring care options or accessing information and services. Such advocates act independently of carers and of other support services and function in various ways.

- **Self advocacy** helps people to develop the skills to speak for themselves. Self advocacy groups often consist of people who use the same services and can work together to influence how they are run.

- **Peer advocacy** occurs when people speak up for others in a similar situation to themselves, but who have difficulty making their views known. People living with mental health problems, for example, might use peer advocacy.

- **Citizen advocacy** involves lay volunteers representing the interests of a person whom they come to know. It entails a partnership between the volunteer and the vulnerable individual, in which the vulnerable person’s wishes are clarified and communicated to relevant people.

- **Professional advocacy** is usually issue based where a paid independent advocate use their skills and expertise to support a person to express their views on issues which may include, for example, moving home, safeguarding or access to appropriate health and social care. The advocate also provides the person with information about their options and rights to ensure they are able to make an informed decision, even if this decision is only about what they would like the advocate to progress. This type of advocacy is often *instructed* i.e. the person has asked for an advocate to support them.

- **Non-instructed advocacy (NIA)** is where a professional will request an advocate on behalf of someone because that person is unable to request the support themselves (usually because of comprehension or communication difficulties). The role of the non-instructed advocate is to ensure that they ask relevant questions about the person’s rights, they will put forward any observations they have made about a person’s preferences, likes, dislikes, or interactions with others to inform those responsible for that person’s care which will support their decision making. The non-instructed advocate will also meet with the person and attempt to ascertain what is important to them in terms of their cultural or religious issues, local community factors, family and friends as well as determining whether the person has previously expressed their wishes, beliefs or feelings. The non-instructed advocate’s role is to ensure that they have represented what is important to that person as closely as they are able to and to ensure their rights are upheld.
• **Statutory advocacy services:** the MCA and the MHA introduced statutory obligations in England and Wales to provide advocacy services. Independent Mental Capacity Advocates and Independent Mental Health Advocates provide safeguards for people in specific situations defined in the MCA and MHA.

### 2. The Mental Capacity Act 2005

The MCA provides a statutory framework in England and Wales for the provision of care and treatment to adults who lack the capacity to make decisions on their own behalf. It is designed to empower and protect these individuals. The provision of a dedicated independent mental capacity advocacy service is a key part of the protection.

**Independent Mental Capacity Advocates**

Independent Mental Capacity Advocates (IMCAs) provide specialist support to vulnerable adults who lack capacity to make specific decisions, in particular those who lack family or friends who can be consulted about their welfare. IMCAs support and represent such patients when best interests decisions are being made. The information they provide feeds into the decision making process rather than the IMCA making the decision for the patient. When the decision relates to a health matter actual decision making about treatment always remains the responsibility of health professionals.

Under the terms of the MCA, an IMCA must be involved where a decision relates to ‘serious medical treatment’ or a change in place of residence (this includes stays in hospital of more than 28 days). When a course of action is proposed, the IMCA should check that the decision maker has considered all relevant options, they will also ask questions and present information based on the best interests checklist (which is required to be followed when responsible bodies make best interests decisions). Consideration must also be given to the least restrictive option, which is the option that is the least restrictive of a person’s fundamental rights; although it does not automatically follow that this is the option that will be chosen. IMCAs can also suggest alternatives which appear more consistent with the incapacitated person’s known wishes.

**Obligation to instruct an IMCA**

Health professionals must instruct an IMCA in the following circumstances:

- the person is at least 16 years old and lacks the capacity to make the specific decision in question; and
- the decision involves ‘serious medical treatment’; or
- a change in accommodation, i.e. where an NHS body is proposing to either place a person in hospital, or move them to another hospital for a stay likely to last longer than 28 days, or place them in a care home, or move them to another care home for a stay likely to last longer than eight weeks.

And there are no family or friends who are considered ‘appropriate to consult’.

IMCAs can also be instructed, although there is no obligation to do so, when the decision involves a care review or an adult safeguarding case. Decision makers have a responsibility to familiarise themselves with locally agreed policies and guidance on these matters.

The Act does not define who might be ‘appropriate to consult’. The person may have friends and family but they may not be able or willing to get involved in the patient’s decision and therefore would not be considered appropriate to consult. Sometimes, practical problems may arise such as the patient’s friends or family may live in another country or feel that they don’t know the person well enough to be able to give a view. In all these cases, health professionals are required to instruct an IMCA. Further guidance is given in the MCA Code of Practice at 10.74 and in Action for Advocacy’s Best Practice IMCA Instruction Guidance.
There may also be times when health professionals are concerned that although the patient does have family or friends, there may be conflicting interests involved, thereby making it beneficial to have an IMCA involved as an independent safeguard.

People with conflicting interests, such as those who may stand to inherit from the person’s will, may still have a right to be consulted about the person’s care or medical treatment although health professionals are advised to ensure that the interests of those consulted do not influence the process of determining a person’s best interests.

Factors to consider when deciding whether or not to involve IMCA are whether it is practicable and appropriate to consult with family and or friends, whether the person has already requested someone speak on their behalf (another advocate, neighbour or family member) or whether family and/or friends are able and willing to be included in the decision making process. Family and or friends are not making the decision themselves, they are merely inputting into it by providing information as to the person’s wishes (past or present), beliefs or anything that may be relevant to the decision.

‘Serious medical treatment’
All care and treatment carried out by professionals for those who lack capacity to make those decisions (consent to or refuse treatment or care) for themselves is covered by the Act.

With respect to Serious Medical Treatment, the Act defines this as:

Treatment which involves giving new treatment, stopping treatment that has already started or withholding treatment that could be offered in circumstances where:

- If a single treatment is proposed there is a fine balance between the likely balance between the likely benefits and the burdens to the patient and the risks involved or
- A decision between choice of treatments is finely balanced, or
- What is proposed is likely to have serious consequences for the patient’

MCA Code of Practice chapter 10.43

Serious consequences are those that could have a serious impact on the patient either from the treatment itself, side effects or wider implications such as prolonged pain, distress or, stopping life sustaining treatment, having major surgery or having a serious impact on a patient’s life choices. This could include decisions that range from a blood test, treatment for cancer, pregnancy, major amputations or a Do Not Attempt to Resuscitate (DNAR) order where the person has nobody who can be consulted about that decision.

Serious Medical Treatment decisions encompass the impact of any treatment on that individual as opposed to only prescribing what treatment decisions are deemed serious or not. IMCAs must be involved where there is an element of uncertainty and gravity about the proposed treatment and the person lacks capacity to make that specific decision.

In these circumstances, IMCAs check that the principles defined in the MCA and the best interests checklist in the MCA Code of Practice have been followed and ensure that the individual’s wishes and feelings have been considered. They can also request a second medical opinion if they think it necessary and health professionals should facilitate this.
Case example:
Tom, a 42 year old man who has cerebral palsy and learning difficulties, is experiencing problems with his swallowing which is getting progressively worse. The insertion of a PEG is being considered by the consultant gastroenterologist.

Tom has a brother who gets in touch infrequently and after contacting him and finding out he wants to be kept informed of Tom’s situation but would prefer not to be part of making a decision, the consultant instructs an IMCA. The IMCA thoroughly investigates Tom’s situation, spending time with him to ascertain his views and also speaks to his support staff. Tom has difficulties with communication and the IMCA uses pictures to support Tom to express his views. The IMCA’s report is very detailed, including Tom’s views on the proposed treatment and highlights information not previously known to the clinical team.

The consultant is able to use the information in the report to make the best interests decision and is satisfied that due to the IMCA’s input into the decision-making process, the decision is compliant with the MCA.

The IMCA’s role
IMCAs have a statutory responsibility to support and represent patients who lack capacity to make specific decisions who do not have relatives or friends who can represent their interests. They must gain as much knowledge and insight as they can about the individual’s wishes and values, as well as provide an independent representation of the person’s needs. Where practical and appropriate they should interview the patient in private and take reasonable steps to find out any known views that the person had when competent. IMCAs have a right to relevant patient information and may need access to patient records. They deal with specific decisions rather than provide ongoing support and once the decision is finalised, the IMCA's involvement ceases, unless they are challenging the final decision or the way in which the decision was made. IMCAs work collaboratively with health professionals and can help to ensure that best interests decisions made on behalf of a person who lacks capacity to consent to or refuse treatment are compliant with the Mental Capacity Act.

IMCAs bring to each case a wealth of knowledge including relevant case law and information about the Act and will include this in each report they complete. Reports by IMCAs will usually be advocating for a certain course of action to occur, however, the IMCA is not making a recommendation nor stating what they personally believe should occur but merely using evidence gathered from the person themselves, and the best interest checklist (which will include accessing records, speaking to professionals, gathering information about the decision) to ensure the person is fully represented and that what is presented is the best picture possible of what decision that person would make if they were able to. Decision makers must in all circumstances where an IMCA is instructed take into account the report the IMCA submits or the information they present before a decision is made. They must also inform IMCAs of the decision and the reasons for it.

It is unnecessary to instruct IMCAs for patients with mental health disorders who are being treated under the MHA. If, however, there is a serious medical treatment decision that needs to be made, and it is not related to the mental disorder for which the individual is being treated under mental health legislation, an IMCA should be instructed according to the guidance in this note. It is also unnecessary to instruct IMCAs where the patient has already somebody with the legal authority to make the decision on their behalf, such as a court appointed welfare deputy or personal welfare attorney. In some cases, the incapacitated patient may have previously nominated someone to be consulted and then also it would be inappropriate to instruct an IMCA.
IMCA services are generally only available in office hours. Although health professionals are normally obliged to instruct IMCAs for incapacitated patients who lack an alternative representative, treatment should not be delayed in an emergency. If, however, further treatment is being considered after the emergency has been handled, health professionals are obliged to instruct an IMCA.

3. Working with the IMCA service
Making contact
Health professionals need to consult their local NHS Trusts or Local Authority to find out about local IMCA providers and commissioners. This information is also available via the DH and Social Care Institute for Excellence websites. Information about who provides the IMCA service in the local area and how to instruct an IMCA should be readily available to health professionals within NHS Trusts.

Dealing with disagreements
Ultimately health professionals have responsibility for decision making but disagreements may arise if the IMCA raises concerns about whether the MCA has been complied with in decision-making. In many respects, this is not substantially different to the disagreements that can arise in any situation where incapacitated patients cannot speak for themselves and their relatives seek to interpret their wishes. In all cases, differences of opinion are best discussed openly and resolved informally as it cannot be in the best interests of an incapacitated adult for there to be protracted disagreement. IMCAs can seek advice from a variety of sources including Action for Advocacy, Social Care Institute for Excellence (both of whom have IMCA Support Projects) and may seek guidance from the Official Solicitor (including asking for their involvement on a case) as well as through their own organisations. Other sources of advice include an IMCA service steering group, or the NHS complaints procedure. Where disagreements cannot be resolved locally and informally, health professionals should take advice from appropriate bodies, such as trust lawyers. Ultimately, it may be necessary to involve the Court of Protection.

Sharing information with IMCAs
All patients have a right to confidentiality but this does not prevent the appropriate sharing of information with other care providers and with the IMCA who is supporting the patient. Depending on the decision to be made, IMCAs are likely to need access to relevant parts of the patient’s health record, care plan, social care assessment documents or care home records. They may also need to discuss aspects of this information with health professionals or paid carers. IMCAs have a statutory right to access and take copies of relevant records. It is for health professionals to decide what is relevant to the decision.

4. The Mental Health Act
The MHA governs the compulsory treatment of people who have a mental disorder and may present a risk to themselves or others. One of the key features of the Act is the introduction of a comprehensive advocacy service. The Act places a duty on the Primary Care Trusts to make arrangements for Independent Mental Health Advocates (IMHAs) to support patients being treated for mental health disorders. The IMHA service was implemented in England and Wales in April 2009.

Independent Mental Health Advocates
IMHAs are statutory advocates, trained to work within the framework of the MHA. They provide an additional safeguard for patients subject to the Act but can also work in conjunction with other types of advocates in specific cases. They inform patients about their own rights under the Act and about the rights of other people, such as their relatives. They also explain how the Act’s provisions apply to specific patients, as well as the services, conditions or restrictions applicable to them.
Professionals must provide information to patients about how the Act applies to them as well as their rights within it, they must provide information as to the rights of nearest relatives and the full facts of grounds of their detention including information about their disorder, any treatment for it and the role of Second Opinion Appointed Doctors (SOADs). IMHAs can add information about the legal authority for compulsory treatments and the legal safeguards that apply. A fundamental part of the role of IMHAs is to help patients exercise their rights by representing them, speaking on their behalf or supporting them in decisions about their care and treatment.

**Working with IMHAs**

In almost all cases where a patient is treated under mental health legislation, there will be a duty to inform patients of their right to an IMHA and ensure they understand how the IMHA service is available to them, what they offer and how they can obtain that help. This information must be given orally and in writing. Most IMHA providers will ensure they have an active presence on the ward to support this awareness raising. Rare exceptions to receiving the support of an IMHA arise when:

- a patient has clearly refused to have IMHA involvement
- the patient is detained under an emergency application until the second medical recommendation is received
- under the holding powers in section 5 (Application in Respect of Patient Already in Hospital); or
- when a patient is held in a place of safety under section 135 (Warrant to Search for and Remove Patients); or
- under section 136 (Mentally Disordered Persons found in Public Places).

Health professionals have obligations to facilitate IMHAs visiting and interviewing qualifying patients, unless patients refuse. This means that IMHAs need access to wards and units where patients live, as well as opportunities to meet patients privately. They may need to talk to professionals providing care or to attend meetings between those professionals and the patient.

If Approved Mental Health Professionals (AMHPs) or clinicians believe that certain patients could benefit from the IMHA service but they are unable or are unlikely to request the service themselves, it should be requested for them. If possible, health professionals should first discuss the idea and give patients the opportunity to decide if they would like an IMHA. Where it is known that patients do not want help from IMHAs, that should be respected and the option should not be discussed.

- If a patient is assessed as not having the capacity to request support from an IMHA and they are refusing that support, professionals should attempt to ascertain whether when they had the capacity to request help if they would have wanted it. This is to ensure that those patients who refuse an IMHA but do not have the capacity to understand what they are refusing the opportunity for an IMHA to be involved and act in a non-instructed capacity (see bullet point 4 at beginning for further information)

The National Mental Health Development Unit (NMHDU) have produced further guidance as to the role of IMHAs, this includes Non Instructed Advocacy:  
Informing patients and relatives about IMHA services
There is a duty to provide patients treated under the MHA with information about IMHAs. Depending on the category of patient, this duty rests with different people within the health or social care system. For a detained patient, the duty rests with the managers of the hospital in which the patient is liable to be detained; for a Guardianship Patient, the social services authority is responsible for providing information; for a patient under a Supervised Community Treatment Order (SCT), the hospital management is responsible and, in the case of conditionally discharged patients, the patient’s clinician is responsible for telling the patient about IMHA services.

There is also a duty to tell informal patients about IMHA services unless the exceptions mentioned above apply. The responsibility for informing patients lies with the doctor or approved clinician who first discusses the possibility of treatment with them. All patients, regardless of category, should be informed as soon as possible.

The person with the duty to provide patients with information about IMHA services also has a duty to give that information to patients’ nearest relatives. This duty does not apply to the relatives of informal patients or patients detained in hospital under Part 3 of the Act, unless they subsequently become SCT patients. Information must not be provided to relatives (regardless of the patient’s category) if the patient has objected to them being told. When patients are provided with information about the service, they should be made aware that it will also be given to their relatives, unless the patient objects. The information should clarify that the IMHA service is for patients only and not for their relatives.

Patients requesting IMHAs
Patients who qualify for the service can request the services of an IMHA at any time. They can only request the IMHA service rather than ask for a specific IMHA but, where possible, it is good practice for the same IMHA to be involved throughout a case. Patients should be able to contact the IMHA service in private and they can choose to decline IMHA support at any time.

Sharing information with IMHAs
Health professionals can disclose personal health information to IMHAs with the patient’s consent. IMHAs may need access to clinical or other records relating to the patient’s detention or treatment in any hospital, or relating to any aftercare services provided to the patient. With patient consent, IMHAs also have the right to see patients’ social services records.

Where patients lack the capacity to authorise disclosure to an IMHA, the record holder must decide whether it is appropriate and in the patient’s interests to share information. Unless patients are known to have objected to the involvement of an IMHA, it is usually in their interests to be represented by one who is knowledgeable about their case. Nevertheless, the reasons for disclosure without consent must be considered in each case. As in other situations of disclosure on behalf of patients who cannot consent, only relevant information should be shared and IMHAs can be expected to explain what they need and why. Patient information should not be disclosed if the patient has previously objected, or if disclosure conflicts with decisions made on behalf of patients by their attorneys, deputies, or by the Court of Protection.

Further reading about advocacy generally
- British Institute of Learning Disabilities has information about types of advocacy [http://www.blid.org.uk](http://www.blid.org.uk)
- Care Services Improvement Partnership (2005) A summary of the key issues in the provision and commissioning of advocacy.
Further reading about advocacy under the MCA and MHA

- Department of Health (London 2007) Adult protection, care reviews and IMCAs: guidance on interpreting the regulations extending the IMCA role.
- Social Care Institute for Excellence website
- Action for Advocacy IMCA Support Project website
  http://www.actionforadvocacy.org.uk/articleServlet?action=list&articletype=68

General reading about mental capacity

  http://www.bma.org.uk/ethics/consent_and_capacity/assessmentmentalcapacity.jsp
- BMA guidance note and tool kit on The Mental Capacity Act.
  http://www.bma.org.uk/ethics/consent_and_capacity/mencaptoolkit.jsp