The involvement of Independent Mental Capacity Advocates (IMCAs) in Serious Medical Treatment Decisions

BEST PRACTICE GUIDANCE FOR HEALTHCARE PROFESSIONALS and IMCAs
Introduction

This guidance was developed by the Action for Advocacy IMCA Support Project in consultation with a wide range of stakeholders including organisations providing IMCA and professionals working within the NHS. It is aimed at medical practitioners who may provide treatment and care to people who lack capacity to make decisions about their treatment and have responsibility for instructing IMCAs as well as IMCAs who are supporting and representing people when best interests decisions about serious medical treatment are being made.

The guidance is split into three sections. The first section clarifies the roles and responsibilities healthcare professionals have when working with patients who lack capacity and provides guidance on when IMCAs must be instructed. Whilst the responsibilities are explained from the premise that an IMCA will be involved, it is envisaged that where a person has appropriate representation from family and/or friends and therefore the criteria for IMCA is not met, the guidance will still inform and underpin practice.

The second section of the guidance covers the specifics of the IMCA’s role and responsibilities as well as suggested best practice for IMCA providers. Part of the IMCA’s role is to ensure that what is important to the person is considered when the decision is being made. The guidance aims to also support the IMCA’s work and provides practice, policy and report examples. It is hoped this information will also be useful for medical practitioners and will provide a greater understanding as to the advocacy safeguard (IMCA) that the Mental Capacity Act 2005 introduced. Whilst there are elements only applicable to IMCAs, for example best practice in writing an IMCA report, it is hoped this will allow NHS professionals to assess the quality of the IMCA provision for patients as well as offering further information about patient-centred ways of working.

The third section contains example documents which are useful to NHS organisations and IMCA providers. A checklist to help NHS staff to identify when a patient is eligible for the IMCA safeguard is included in this section.

NHS bodies are expected to have a policy on the Mental Capacity Act 2005 where the criteria for instructing an IMCA are set out. An example of appropriate wording is
included in Appendix 4. The Code of Practice sets out the responsible body’s (NHS and Local Authority) duties and responsibilities in 10.13 and 10.141

This guidance should be read in conjunction with A4A Instruction Guidance and Report Writing Guidance for IMCAs2 if further clarity is needed for either of these factors.

A4A has also developed decision specific guidance for IMCAs involved in the following Serious Medical Treatment decisions:

- Do Not Attempt Resuscitation (DNAR)
- PEG Feeds
- Chemotherapy
- End of Life Care
- Dental Treatment
- ECT Factsheet

The SMT resources, including the checklist and a leaflet which explains the role of IMCA in SMT decisions is available on the Action for Advocacy website

www.actionforadvocacy.org.uk

2 http://www.actionforadvocacy.org.uk/articleServlet?action=display&article=1817&articletype=68
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Best Practice Guidance for Healthcare Professionals
SECTION 1 – guidance healthcare professionals

IMCA instruction for a serious medical treatment (SMT) decision

There is a duty for NHS bodies to instruct an IMCA when a serious medical treatment decision is being considered and the person lacks capacity to give or withhold consent to the treatment. IMCAs provide a safeguard for people when decisions are being made and there is nobody (other than paid staff) who can support or represent them or be consulted.

The Code of Practice (10.42) says that an IMCA must be instructed by an NHS body ‘whenever they are proposing to take a decision about ‘serious medical treatment’ or proposing that another organisation (such as a private hospital) carries out treatment on their behalf’. The IMCA must be instructed prior to any decision being made, including a decision not to provide treatment at that time. This is so that the options can be fully explored and the IMCA is involved throughout the decision-making process.

The only exception for the need to instruct an IMCA is if there is an emergency situation requiring an urgent decision to be made, for example, to save a person’s life. The Code of Practice (10.46) advises that the reason for non-instruction due to urgent treatment should be recorded as such in the person’s medical notes. However, once the emergency has passed, there is a duty to instruct an IMCA for any subsequent serious medical treatment decisions.

To ensure the IMCA service/organisation is able to carry out the duties required by the Mental Capacity Act 2005 it is imperative that the relevant responsible body (NHS or Local Authority) instructs the IMCA service in as timely manner as possible. If this is not done, the ability of the IMCA to deliver a comprehensive service within the given timeframe may be adversely affected.

SMT Definition

Regulations for England and Wales define ‘serious medical treatment’. It 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 benefits and the burdens to the patient
• a decision between choice of treatments is finely balanced, or
• what is proposed is likely to have serious consequences for the patient

**Serious consequences**

Serious consequences are defined in the MCA Code of Practice as those that could have a *serious impact* on the patient either from the treatment itself or due to wider implications and may include treatments which:

• cause serious and prolonged pain, distress or side-effects or
• have potentially major consequences such as stopping life sustaining treatment or amputation or major surgery or
• have a serious impact on a patient’s future life choices

A person may have numerous side effects where each one may not be considered serious; however, cumulatively they may amount to having a serious impact on the person.

A person who lacks capacity to give or refuse consent will have a right to the support and representation of an IMCA if such treatment is being considered on their behalf and there is nobody appropriate who can be consulted about the decision.

**Which treatments are ‘serious medical treatments?’**
The MCA Code of Practice (10.45) offers some examples of treatments, which may be considered as serious medical treatment, however, it is impossible to provide a definitive list of all serious medical treatments. It is for the clinician responsible for the person’s treatment to consider the implications of what is proposed and to decide if the consequences are serious *for that individual*. Examples of treatments where IMCAs have been involved include surgery, treatment for cancer, insertion of a PEG, amputation, dental treatment, blood tests, cataract operation, withdrawal of antibiotic treatment and Do Not Attempt Resuscitation (DNAR) orders.
A minor treatment may not in itself be considered as serious medical treatment but depending on the person’s circumstances, as well as the impact on them from providing or withholding treatment, it would be SMT. Examples are minor treatment for an eye infection where the person only has one eye or prescribing laxative, which may be routine but could become SMT if it’s part of initial treatment for bowel obstruction.

**Serious Medical Treatment instruction checklist**
A checklist to assist NHS staff in identifying when there is a duty to instruct an IMCA is provided in appendix 1.

**Requirement for instructing an IMCA for hospital stays over 28 days.**
When unplanned admissions to acute general hospital care occur it is often the case that the decision to treat and the decision to admit are made as urgent decisions and therefore exempt from instruction at that time but may turn out to be a sustained admission, however, if it is likely that a person will be in hospital for more than 28 days, there will also be a duty to instruct an IMCA for an accommodation decision. The Code of Practice advises that the ‘**responsible body should involve an IMCA as soon as they realise the stay will be longer than 28 days**.\(^5\) However for others it may be less evident as the course of a patient’s recovery or deterioration is not foreseeable. The progression through hospital services may also incur changes in ward or place of care. It is important that NHS bodies have systems in place to recognise those patients who meet IMCA criteria and follow their overall length of stay, so that instruction can be made to meet this statutory duty in a timely manner before the admission extends past 28 days. Instruction should be made regardless of whether the person is still recovering from treatment, due to receive further treatment or if a decision about whether they are fit to be discharged is yet to be determined. The IMCA’s work in such cases will be focused on whether or not it is in the person’s best interests to remain in hospital.

The majority of IMCA instructions for a change of accommodation occur when the person is in hospital\(^6\) and they lack capacity to make a decision about accommodation at that time. It is highly possible that those same people lack capacity to make a decision about serious medical treatment and yet instructions for

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\(^5\) MCA Code of Practice 10.55.

\(^6\) The third year of the Independent Mental Capacity Advocate Service (IMCA) 2009/10 Department of Health
SMT are considerably lower. This means that often IMCA is instructed for the change of accommodation decision and yet a serious medical treatment decision will have been made earlier on in the person’s stay in hospital without the involvement of IMCA.

Who makes medical decisions?
Patients must make informed decisions about their medical treatment wherever possible. If there are concerns about a patient’s ability to make their own treatment decisions then medical practitioners must assess their capacity to do so. If they are found to lack capacity, treatment decisions must be made in their best interests by medical staff. The exception to this is if the person has made an advance decision to refuse treatment, which is applicable to their particular situation.

No one can consent to treatment on another person’s behalf, unless they are an attorney with the appropriate authority, under a Health and Welfare Lasting Power of Attorney, to make treatment decisions or a Court appointed Deputy with the relevant authority.

Assessing capacity
In order to establish whether there is a duty to instruct an IMCA for a particular person, their capacity to consent to or refuse a particular treatment or procedure must be assessed. The Act sets out a two-stage test of capacity in which firstly proof is required that the person has an impairment which may affect their ability to make decisions, for example, dementia, an acquired brain injury or significant learning disabilities. The impairment may be temporary such as the person being unconscious or under the influence of drugs or alcohol. The second part of the assessment requires finding out if the impairment is impacting on the person’s ability to make a particular decision at the time it needs to be made and determines whether the person is able to:

- understand the relevant information
- retain it for long enough to make the decision
- use that information to come to a decision
- communicate their decision by any means

For serious medical treatment decisions the person would need to understand information about:
• proposed treatment or reasons for withdrawal/withholding of treatment
• potential risks, benefits or burdens of any proposal
• likely consequences of any proposal
• potential side effects
• likely recovery time and any rehabilitative treatments
• prognosis
• potential outcome of taking no action
• alternative options

There is no legal requirement for IMCAs to have sight of the written capacity assessment before they start to work with the patient; however, assessments to establish that a person lacks capacity in relation to the decision being made will need to be undertaken prior to instructing an IMCA.

**Delegating responsibility to assess capacity**
The person responsible for making the best interests decision is the person who is providing the treatment (or is proposing it) often described as the ‘decision-maker’. For serious medical treatment it is likely to be the consultant. The decision maker has a responsibility to ensure capacity is assessed but this task can be delegated to another professional, for example if a colleague knows the patient better or there is specialist community input for the patient. Whoever is carrying out the assessment of capacity and is looking at whether the person has or lacks capacity to consent to or refuse the treatment must:

• be trained to carry out capacity assessments according to the Trust’s policies and procedures
• have full knowledge of the procedure/treatment being proposed and the risks of that treatment (even if they are not the person who will carry out the procedure)
• assess capacity specific to the decision to be made

Healthcare professionals should consult the Trust’s consent policies.

**Maximising the person’s involvement in their own medical decision**
There is an obligation on the part of medical staff to ensure that the person has received support which will enable them to be as involved as much as they possibly can be in the decision making process. This could include providing information for
people in an accessible format, explaining the decision using accessible language or
the use of interpreters where appropriate.

Consent
Consent is the legal means by which a patient agrees to treatment or care. Patients
may indicate consent non-verbally (for example holding out their arm for blood to be
taken), orally or in writing. It is not valid for another person, for example the
patient’s spouse or other relative, or an IMCA, to consent to treatment on
behalf of a person who lacks capacity to give consent unless they are
authorised to do so under a Lasting Power of Attorney or as a Court appointed
Deputy. So once it has been established that a person lacks capacity to make a
decision about the treatment, consent cannot be gained from anyone else. In this
situation, a best interests decision needs to be made. The factors that need to be
considered before making best interests decisions are defined in Chapter 5 of the
Code of Practice.

Prior to the Mental Capacity Act the Department of Health provided a template
(consent form 4) to record medical decisions where the person lacked capacity. A
revised version of this form that complies with the MCA, to be used when an adult
lacks capacity to consent to the proposed treatment, is provided in appendix 2. The
form guides professionals through the best interests decision making process and is
signed by the consultant once the capacity assessment has taken place and any
relatives, friends or an IMCA have been consulted.

Good practice is for all NHS Trusts to use this form or their own similar version and
for the form to include guidance on when an IMCA must be instructed.

Who instructs the IMCA?
The Act does not impose the duty to instruct on any specific role but rather places the
duty to instruct on the relevant responsible body, which means for decisions about
treatment the NHS have a duty to instruct and for social care decisions the Local
Authority have a duty to instruct an IMCA. With this in mind it is therefore important
that each responsible body ensures a wide range of professionals understand and
carry out their duty to instruct an IMCA when a patient is eligible thus enabling timely
instructions to be made. The following list (not exhaustive) gives examples of
professionals who can instruct an IMCA:
Engagement protocols, policies and commissioning contracts should specify any restrictions on who is authorised to instruct and this information should be made available to the relevant professionals. Example policy wording (which should be part of a general MCA policy) for instructing IMCAs is included in appendix 4.

**Instruction when a patient is treated outside their local area**

The MCA Code of Practice (10.12) advises that the IMCA service to be instructed is the one wherever the person is at the time the person needs support and representation. To clarify further, if a person is receiving treatment as an inpatient the IMCA service to be instructed is the one based in the same area as the hospital.

Where a client has an outpatient appointment or their treatment is being provided in a regional unit which provides healthcare and treatment to patients who live in different areas of the country, as a rule of thumb, the IMCA service to be instructed will be where that person ordinarily resides. This can then ensure the person is placed at the heart of the decision making process e.g. the IMCA in their locality can easily meet with the person and have their discussions with the decisions maker via email or on the phone, or depending on the location of the outpatients appointment it may be feasible for the IMCA to travel there also.

The responsibility for instruction rests with the medical practitioner who decided that the person should attend the regional unit.
Frequently asked questions by healthcare professionals

What training must IMCAs have?

Whilst IMCAs are by and large employed within the voluntary sector the IMCA service is a statutory one. The Act requires that IMCAs have specific experience, specific IMCA training and have integrity and a good character (demonstrated by CRB checks and registration with the Independent Safeguarding Board) and be able to act independently. IMCAs in practice come from a range of backgrounds and experience but all access initial training before undertaking the role and are then expected to achieve the City and Guilds IMCA qualification whilst working as an IMCA.

What if the person has friends and/or family? – Are they ‘appropriate to consult’?
The IMCA safeguard is primarily intended for people who do not have family or friends who can be consulted about the decision.

The MCA Code of Practice (10.77) suggests some situations where there are family or friends but it may not be possible, practical or appropriate to consult with them. It is not possible to provide a definitive list of situations where family or friends would be considered not ‘appropriate to consult.’ However if there is a family member or friend (someone who is not paid to provide care or support) they should be deemed appropriate to consult unless there are reasons to dispute this. Therefore prior to considering whether there should be IMCA involvement professionals will want to consider if family and friends:

- **Have an insight into the person’s views, wishes, feelings and beliefs in relation to the decision through knowing the person well enough to be able to provide this information.** Sometimes when a person is in hospital family members will come forward who haven’t been in the person’s life for a while and they may have lost touch with what is important for the person, therefore it may be appropriate to instruct an IMCA, equally however they may be able to offer an insight as to the person’s past wishes therefore minimal contact should not always be viewed as a reason to instruct an IMCA.

- **They can be contacted by some means** including email or phone for example. Sometimes people aren’t able to visit the person whilst they are in hospital but they are able to be consulted about the decision and are able to
contribute valuable information about the person to the decision-making process. As long as family and/or friends can input and do so they should be deemed appropriate to consult with unless there are other reasons to dispute this.

- **They are willing to be consulted about the treatment decision.** Some family members or friends may want to be in the person’s life but may not want to be involved in any discussions about medical treatment. Therefore it may be appropriate to instruct an IMCA if family and/or friends only want to be informed about a decision rather than contribute.

- **Where there is a concern about the person’s ability or willingness to faithfully represent the person’s views,** although it is important that concerns are addressed with family or friends and equally important that family and/or friends understand their role is to be consulted only, they are not expected to make a decision. It would be expected that this occur before instructing an IMCA, to ensure IMCAs are not viewed as mediators.

- **There are concerns, allegations or proven instances of abuse** (any concerns should have already triggered a safeguarding alert and a safeguarding case may run alongside an accommodation/SMT decision) Perhaps the person is in hospital as a result of neglect by a family member or care staff or safeguarding concerns arise whilst the person has been on the ward for a while. An instruction to the IMCA service should take place at this point (unless there are other family and/or friends that are deemed appropriate to consult with).

- **There are concerns family or friends present their own views over and above the person** (perhaps the family/member or friend finds it difficult to separate best interests of the person from their own self interests). However the impact of any decision on family or friends will have a bearing on the decision making process and therefore should not be disregarded or viewed as the reason to instruct the IMCA service.

Healthcare staff will want to establish whether there is somebody who can be consulted about the decision as quickly as possible in order to know whether there is a duty to instruct an IMCA. The following may help:

- Ask the person who they want to be contacted
- If the person lives in a care home, contact the staff there to ask about any regular visitors or people who have been in contact in the past
• Look back at previous medical notes to see if any contact details of family or friends are recorded there
• If the person has been in receipt of social care in the past, their social worker may know whether there are any family or friends
• Contacting the person’s GP

It is not acceptable for family or friends to be judged ‘not appropriate to consult with’ simply on the basis that they are not in agreement with the proposed best interests decision or because there is some conflict between family or friends and the decision maker.

‘If a family disagrees with a decision-maker’s proposed action, this is not ground for concluding there is nobody whose views are relevant to the decision’

Where family and/or friends are considered not ‘appropriate to consult with’ the responsible body (NHS or Local Authority) should give the reasons for this and the rationale for involving an IMCA should also be provided to them. The onus is on the responsible body rather than the IMCA, to inform the family and/or friends. For example, if a patient has an elderly relative and they are not able to visit the hospital and find it difficult to talk on the phone due to a hearing impairment and are therefore deemed not ‘appropriate to consult’ with, the relative should be informed about the appointment of an IMCA. It is good practice for the IMCA service to request that the decision maker documents why they believe family and/or friends are not appropriate to consult. This information can be in the form of an email or recorded on the instruction form. The Act does not distinguish between either family or friends as being more appropriate to consult about the best interests decision. The quality of the relationship they have with the person is the important factor

Next of Kin status
Normally when a person is admitted to hospital they provide details of who their next of kin is. This is usually so that in case of an emergency this person will be contacted. Someone who lacks capacity may not be able to offer this information in which case the Local Authority that provide or fund the package of care should be approached. The term ‘next of kin’ does not appear in the Act or the Code of Practice and it has no legal standing but rather has become common practice to

7 MCA Code of Practice 10.79
record this in patients’ notes. Because of this anyone can choose their next of kin, it
does not have to be a blood relative.

If a person has stipulated who their next of kin is this would suggest they would like
this person to be contacted and personally view them as appropriate to consult,
however, it is important that healthcare professionals ascertain whether that person
is able to provide support and representation and is willing to be consulted about the
decision.

Someone may nominate a next of kin although no longer have a relationship with the
person but would wish him or her to be informed of an emergency situation. This may
be a common agreement for some families so professionals will need to consider the
absence of any relationship when deciding whether the nominated next of kin are
appropriate to consult with or not.

Family members or friends cannot make the treatment decision, the final decision is
always made by the person responsible for providing the treatment, however,
consulting them about the decision is a requirement under the Act.

*See Action for Advocacy Instruction Guidance for further information* ⁸

**What will the IMCA do on initial instruction?**
Within the Act the IMCA has a range of responsibilities, which they are required to
undertake for every case they work on. An IMCA will initially meet with the person
concerned and attempt to ascertain their views in relation to the proposed treatment.
Most patients are still able to articulate their views, wishes, feelings and beliefs
despite lacking capacity to make a particular decision and it is the IMCAs role to
establish this. An IMCA is a statutory advocate and their responsibilities are laid out
within both the Act and Code of Practice however the basis of the role is to advocate
on the person’s behalf, that is to promote their rights, ask questions on their behalf,
obtain information pertinent to the decision, suggest alternative courses of action
where they believe these reflect the person’s wishes and feelings and conclude this
by submitting a report to the decision maker that articulates their findings as well as
providing a representation on the persons behalf about the decision.

IMCAs will liaise closely with medical staff throughout the decision-making process so that information obtained by the IMCA from a number of different sources is shared and likewise relevant information about the patient and the decision to be made is shared with the IMCA by the medical staff. This communication and sharing of information is essential to ensure that the decision-making process runs smoothly.

An example of the IMCA role pathway is given in Appendix 6 at the back of this guidance.

Does the IMCA make the decision?
The IMCA does not make any decisions but is there to ensure that those who are making decisions do so according to the principles of the Act and the best interests checklist. The Code of Practice sets out in chapter 5 how best interests decisions should be made and lists what a person should do when trying to work out the best interest of a person who lacks capacity to make a particular decision. This is sometimes referred to as the ‘best interests checklist’.

Can the IMCA see medical records?
IMCAs have a legal right to see and take copies of relevant medical records. Section 35 (6) of the Mental Capacity Act states that the IMCA may, at all reasonable times examine and take copies of

(i) any health record
(ii) any record of, or held by, a local authority and complied on connection with a social services function, and
(iii) any record held by a person registered under Part 2 of the Care Standards Act 2000 or Chapter 2 of Part 1 of the Health and Social Care Act 2000

which are relevant to their investigations (MCA sections 35(6) and 131, amended by Section 17 of the Health and Social Care Act 2008 (Consequential Amendments No.2) Order 2010).

The IMCA therefore accesses relevant medical information and records and will seek to gather evidence in order to input into the decision making process as if the person lacking capacity was able to themselves. In practice this means that IMCAs will request any assessments that have been carried out that are relevant to the decision as well as accessing day to day case notes including those of ward round entries. The Act states, in line with data protection, the holder of the record (NHS or Local
Authority) needs to decide what is relevant. Medical staff will need to assess on a case-by-case basis any requests from an IMCA to see information, which is relevant to the current medical decision.

What do IMCAs include in their reports?
IMCAs are required to write a report, which medical staff have a legal duty to consider before making their decisions about treatment. This ensures there is a formal representation on behalf of the person whom the decision is about. IMCAs will refer to the Act, the best interests checklist, any relevant case law or specific guidance as well as articulating as far as possible what the person would have wanted when/if they had capacity to make the decision or what their expressed wishes are now. Based on this information gathering and evidence building, IMCAs may be advocating within their report for a certain course of action to be considered by those responsible for making the decision. The IMCA is not making a recommendation nor stating what they personally believe should occur but they are advocating i.e. they are promoting the person’s rights and representing the person to ensure that what is presented is the best picture possible of what decision that person would make if they were able to as this needs to be the basis of all best interests decisions regardless of whether the actual outcome is in line with this.

A copy of any report, which is provided by the IMCA, should be filed in the patient’s healthcare records. In situations where prompt action is required (not emergency) the IMCA may give a verbal report, which the IMCA will also document in the patient’s medical records and sign. A formal written report will follow as soon as possible after this.

Two example IMCA reports are included in Appendix 7 and Appendix 8

What happens if IMCAs disagree with the decision made?
The IMCA role is to provide a safeguard for the person and their best interests. If the IMCA has concerns about a decision that has either been made or is about to be made they should raise these with the medical staff involved as soon as possible. Often disagreements can be resolved informally. IMCAs have the same right to challenge as any other person that cares for or is interested in the welfare of the person and this includes the right to make applications to the Court of Protection.

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9 MCA Code of Practice 10.20
This right of challenge applies to both decisions about the person’s best interests or their lack of capacity. The likely reasons for any challenge being made (through informal discussion with the decision maker, using local complaints procedures or instigating legal action) are concerns about the person’s rights not being upheld or a belief that the person has capacity; concerns about the impact of the decision upon them or a belief that the MCA has not been adhered to which may include a belief the decision about to be made is not in the person’s best interests based on the evidence.

Where there are disputes and/or disagreements that cannot be resolved locally the MCA Code of Practice (8.8) expects the relevant body (Local Authority or NHS Trusts) with responsibility for the decision making to make the court application.

What happens when the decision is made?
The IMCA’s role is time limited so once a decision has been made and the IMCA has been informed of the final decision, the IMCA is required to close the case. If they are intending to challenge the decision the case would remain open until this is resolved. If there is a further decision that requires their involvement (for example a change of accommodation is proposed after a person has been admitted to hospital for treatment) then a new instruction to IMCA will need to be made. There is also a discretionary role for their involvement in care reviews or adult safeguarding.

Instruction (referral) process

Practical application of instructing an IMCA
As already stipulated, the responsible body for serious medical treatment is the relevant NHS Trust providing the treatment, who must instruct the IMCA service where the eligibility criteria are met for SMT decisions. But what does this mean in practice? The following offers some guidance to the practical application of the MCA 2005 and instructing an IMCA. It is important to remember that, whoever is responsible for making the final treatment decision will be the decision maker and it will be this person that the IMCA provides a report to, which must be taken into account by the decision-maker before making a decision.

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10 MCA Code of Practice 10.33
Instruction of an IMCA - GP Case example
Sarah is a 35-year-old woman with learning difficulties. She communicates largely through gestures and pictures and those who know her have developed a good understanding of her needs based on her behaviour and communication methods. Sarah has been prescribed Clonazepam for some years for epilepsy and generally remains well although occasionally refuses to take the medication when she experiences changes in her home life. Recently her seizures have increased; this is demonstrated on a recording chart the residential care home staff keep in Sarah’s notes. Sarah’s care team arrange a visit to the GP to discuss this, who suggests a blood test to check the levels of Clonazepam to determine the efficacy of the medication. Sarah is deemed not to have the capacity to consent to the blood test, as she is unable to weigh up or understand the purpose of it. Although this would normally be viewed as a routine procedure, which the GP can carry out in Sarah’s best interests, Sarah becomes very distressed when he tries to examine her, becoming tearful and hitting out at the GP. The GP therefore determines a best interests meeting needs to take place to discuss the potential options, including sedation, and the risks, benefits and burdens of each option.

An IMCA needs to be instructed, as Sarah has no family or friends to represent her. The IMCA quickly commences their work and meets with Sarah, examines relevant records including both health and social care, consults with those that provide care in Sarah’s home as well as asking relevant questions about the risks, benefits and burdens within each option presented. The IMCA submits a report that is both balanced in terms of highlighting the risks and benefits of each option as well as identifying the least restrictive option and advocating Sarah’s wishes.

Who instructs the IMCA when the person is in an acute hospital?
Every patient is under the care of a medical consultant when in hospital and in most cases this consultant will make the best interests decision about medical treatment. In order for best interests decisions to be compliant with the MCA, it’s crucial that the correct decision-making process is followed, which includes identifying where there is a duty to instruct IMCA. The form in Appendix 2 can be used to follow this process.

It is likely that the ward staff will determine whether the criteria for IMCA involvement is met (or that a best interests decision needs to be made). So who instructs the IMCA, the ward staff or the decision maker? In many cases it may be easier for the ward staff themselves to complete the IMCA instruction form given they know the
patient and are likely to know some key information that the decision maker may not such as whether there are any family and/or friends who are appropriate to consult. Although it is for the decision maker to decide this, they will be looking for guidance from those who provide the care. Where ward staff complete the instruction form, those responsible for making the best interests decision must be told about it. The IMCA will make contact with the medical professional who will make the decision as soon as feasible so will need their details. They will also visit the person themselves and access relevant records so will need to know who to contact on the ward to arrange this.

**Process of instructing an IMCA**

This will be person and decision specific but good practice is at the point of the treatment being proposed and the patient is eligible for IMCA, the decision-maker either instructs an IMCA, or delegate’s responsibility, to someone who will complete the IMCA instruction form. This may be a doctor, the ward manager, named nurse or another health professional within the hospital involved in the person’s treatment. This should be recorded within the person’s medical notes and accessible to all who are involved in the person’s care and treatment. Whoever fills in the instruction form needs to have enough information about the person and the decision to be able to complete the form and this must be borne in mind if the responsibility is delegated to another person by the decision-maker.
When a patient has an impairment which is affecting their capacity to make a particular treatment decision:

Outpatients procedures
Most initial outpatients appointments will come as a result of a person visiting their GP who subsequently makes a referral to the relevant outpatients unit. There will be times where it is evident to the GP at this stage that the person lacks capacity to consent to either investigations or treatment at an outpatient appointment. In these circumstances the GP can take one of the following routes to ensure IMCA instruction has occurred.

**Option 1:** Instruct an IMCA prior to completing the referral for an outpatient appointment. Instructing an IMCA at this point can ensure the best interests process commences straight away including whether the referral for an outpatients appointment is in the best interests of the person and if it is can begin to underline the next step i.e. highlight factors to be taken into account before carrying out any investigations or treatment. An example could be where there is evidence to suggest that the attending of any outpatients appointment will be so distressing for the person that it may not happen, leaving the decision about the original health concern unmade or to be re-visited.

**Option 2:** Where there is a concern about the person’s capacity to make decisions related to the outpatient appointment the GP could highlight within their referral letter that an IMCA may need to be instructed and to give a rationale for this including a
summary of the person’s capacity. The responsibility for decision-making at this point is within the outpatient clinic and they will need to carry out their own capacity assessment to support their decision-making process but in the interim they can instruct an IMCA based on the GP’s reasonable belief that the person lacks capacity to make further SMT decisions based on their knowledge of the patient and history. Alternatively the person responsible for making the final best interests decision in the hospital may feel it more appropriate to assess the person’s capacity themselves before instructing an IMCA, for example if the GP has limited knowledge of their patient.

**People detained under the MHA 1983**
If a patient is detained under the Mental Health Act 1983 (MHA) and there is a proposal for them to receive treatment for their mental disorder, there is no requirement for an IMCA to be involved. However if there is a proposal for treatment for a physical condition that they lack capacity to consent to or refuse (and there is no-one appropriate to consult) then an IMCA must be instructed. This is because the Mental Health Act does not allow for treatment for a person’s physical health regardless of their status under the MHA 1983.

**Cultural, religious & ethical considerations**
This is included in the IMCA section (section 2) page 32.
Example Instruction (referral) Form

<table>
<thead>
<tr>
<th>Client Name: Michael Delorean</th>
<th>DOB: 09/06/1961</th>
</tr>
</thead>
<tbody>
<tr>
<td>Current Location: Twin Pines Hospital</td>
<td>Home Address:</td>
</tr>
<tr>
<td>If hospital, which ward: Peabody Unit</td>
<td>9303 Roslyndale Ave Arleta, California, USA</td>
</tr>
<tr>
<td>Telephone number: 0171 123456</td>
<td>14 West Moreland Place, Kirby.</td>
</tr>
<tr>
<td>Decision maker: Eileen Brown</td>
<td></td>
</tr>
<tr>
<td>Client contact telephone: as above</td>
<td></td>
</tr>
<tr>
<td>Gender: Female ☐ Male ✓</td>
<td>How does the person communicate?</td>
</tr>
<tr>
<td>African</td>
<td>Chinese</td>
</tr>
<tr>
<td>African/Caribbean</td>
<td>Indian</td>
</tr>
<tr>
<td>Bangladeshi</td>
<td>Irish</td>
</tr>
<tr>
<td>Black British</td>
<td>Pakistani</td>
</tr>
</tbody>
</table>

Nature of client's impairment

<table>
<thead>
<tr>
<th>Mental Health Problems</th>
<th>Acquired brain injury</th>
<th>Learning Disability</th>
<th>Serious Physical Illness ✓</th>
</tr>
</thead>
<tbody>
<tr>
<td>Unconsciousness</td>
<td>Dementia</td>
<td>Other (please state)</td>
<td>Not known</td>
</tr>
</tbody>
</table>

Decision

Serious Medical Treatment ✓ Change in Residence ☐ Care Review ☐ Safeguarding

What is the specific decision to be made?

Mike has a diagnosis of Huntington’s disease, which has from all accounts been well controlled at home although Mike’s communication ability has deteriorated greatly over the last 18 months. On a recent trip out with family Mike had a fall (it is believed Mike had a seizure) and was admitted to hospital. Mike is now experiencing pronounced difficulties with feeding and it is proposed a PEG procedure take place. A decision needs to be made within 1 week.

Others Involved

Any family or friends? No ☐ Yes ✓ but not appropriate/willing/able to be consulted about the decision

If family/friends not appropriate to consult please say why:

Although Mike was visiting family, this is the first time they have met in over 15 years and the family feel they cannot fully represent Mike therefore it is deemed an IMCA should be consulted as a safeguard for his best interests. Mike has paid carers in the USA who are contactable via email (due to the time difference it has been found more useful to contact this way rather than the telephone).
Please confirm that the client lacks capacity to make the specific decision at this time

<table>
<thead>
<tr>
<th>Has a capacity assessment been done?</th>
<th>Yes ☑</th>
<th>Name of person who assessed capacity: Jennifer Parker (SALT)</th>
</tr>
</thead>
<tbody>
<tr>
<td>For information on assessing capacity go to:</td>
<td><a href="http://www.publicguardian.gov.uk/mca/assessing-capacity.htm">http://www.publicguardian.gov.uk/mca/assessing-capacity.htm</a></td>
<td>Date of assessment: Oct 25th 2010</td>
</tr>
<tr>
<td>Yes ☑</td>
<td>No</td>
<td></td>
</tr>
<tr>
<td>Name of person who assessed capacity: Jennifer Parker (SALT)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Contact Details

<table>
<thead>
<tr>
<th>Details of person completing this form</th>
<th>Who will make the best interests decision?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Name: Clara Clayton</td>
<td>Name: Dr Brown</td>
</tr>
<tr>
<td>Job: PA to Dr Brown</td>
<td>Job: Consultant</td>
</tr>
<tr>
<td>Organisation: Edmonton Teaching Hospital &amp; NHS Trust</td>
<td>Organisation: Edmonton teaching Hospital &amp; NHS Trust</td>
</tr>
<tr>
<td>Address: Riverside Drive, Kirby</td>
<td>Address: Riverside Drive, Kirby</td>
</tr>
<tr>
<td>Telephone</td>
<td>Telephone</td>
</tr>
<tr>
<td>Email</td>
<td>Email</td>
</tr>
</tbody>
</table>

Please detail any risk issues or incidents the IMCA service should be aware of:

No risks that we are aware of but it is preferable to visit Mike mid morning when ward rounds are occurring and also Mike is more alert during this time.

I am instructing the IMCA service to do this work. I am authorised by the NHS organisation or local authority responsible for making this decision.

Signed: Dr E Brown                     Date: November 5th 2010

Name: Dr E Brown                       Relationship to client: Consultant
Independent Mental Capacity Advocates (IMCAs) and Serious Medical Treatment Decisions

BEST PRACTICE GUIDANCE FOR IMCAs
SECTION 2 – guidance IMCAs

IMCA best practice guidance

Introduction
The following pages are intended as guidance for IMCAs who are supporting and representing people who lack capacity to make a serious medical treatment decision and provide information specifically in relation to the role. However, the information may also be useful to health professionals who have responsibility for instructing and working alongside IMCAs.

Responding to instruction and prioritising cases
IMCA services need to ensure they have prioritisation policies and procedures in place with respect to all decisions where they will be instructed. Given the nature of SMT decisions it is likely they will need a quicker response than a change of residence instruction but the time frame for when any decision needs to be made will impact on this ultimately. Good practice would be that all instructions (regardless of decision) to the IMCA service receive an acknowledgement of receipt within 1 working day and that there is an allocation system in place that is clear and transparent to those who are instructing the service as well as other relevant stakeholders.

A prioritisation policy example is in Appendix 4.

Obtaining and evaluating information
IMCAs will need to gather information about the proposed treatment and the likely impact it will have on the individual including the risks, benefits, burdens and ethical issues related to the particular treatment decision. Good practice is that IMCAs are able to ascertain the following:

- the views, feelings, wishes and beliefs of the person
- how the person has been/will be supported to take part in the decision-making process
- the views of professionals/carers
- the risks associated with the treatment
- the benefits and/or burdens of the proposed treatment
- whether the proposal is in line with current identified best practice
• whether the person may experience pain/discomfort and how this will be managed
• the impact on the person if the treatment is not provided
• if any discrimination due to age or disability etc is evident
• the balance between clinical outcomes and social outcomes
• what is known about the person’s views on previous treatment
• the individual’s cultural and religious beliefs
• whether it is likely that the person may resist treatment
• whether restraint is being considered
• if there is a DNAR in place or if it is being considered
• the likely impact of the treatment/ non treatment on the person’s quality of life
• if there is an advance decision to refuse treatment in place applicable to this particular situation
• what aftercare and support will be needed and if the person will tolerate this

Second medical opinion
IMCAs have a right to seek a second medical opinion on behalf of the person they are supporting and representing and the request should be treated in the same way as if the person requested this themselves. Good practice is that IMCAs do so in the following situations:

• Uncertainty about the diagnosis or prognosis, for example a patient presents with bleeding but refuses treatment or where there is differing information from professionals involved based on their area of expertise.
• There is a fine line (in terms of benefits/risks) between treatments being proposed or the overall decision is finely balanced, for example major surgery may prolong a person’s life but impact negatively on their emotional and mental health whereas not proceeding with treatment may ensure their emotional well being remains settled but has a serious impact on their mortality. A second opinion may support the decision-making process if only to offer another safeguard for the person.
• Evidence that what is proposed may not be in the person’s best interests, for example, the level of emotional distress may be too great on the person albeit medically it would appear to be in the person’s best interests.
• Concerns about the proposed treatment or decision not to treat
- A dispute about the person’s best interests including whether the decision should be progressed to the Court of Protection.

The responsibility for finding a suitable consultant to provide a second medical opinion rests with the person's referring GP, however, it may be helpful if the IMCA asks the consultant to suggest the name of another consultant with the relevant expertise which the IMCA can then discuss with the GP. The IMCA will want to liaise with the GP regarding the progress and outcome of the involvement of another consultant.

It is important that the person’s consultant knows that the IMCA is requesting a second medical opinion, partly out of courtesy and partly to make sure that all the relevant information is passed on to the second specialist. IMCAs should be clear about the reasons why they are requesting this and be prepared to explain.

Further information about the process of requesting a second medical opinion is given on the British Medical Association website.\(^\text{13}\)

**SMT Report Writing**

All reports, regardless of the decision proposed, should detail actions undertaken by the IMCA, such as investigative work which includes speaking to the person and finding out their wishes, beliefs, preferences and identifying any other factors to be considered. Contact with relevant professionals, carers (paid or informal), family and/or friends (where deemed inappropriate to consult with but appropriate to gain their views). Researching and gathering facts about the decision proposed (risks, benefits, burdens, effects of treatment including not having the treatment) from the decision maker and including other sources of information e.g. Internet, national guidance, and be able to outline this in a report. The decision maker where possible “should make decisions based on a full understanding of a person’s past and present wishes\(^\text{14}\) and the IMCA will want to ensure as the person’s advocate that they present a report that articulates what these wishes are or where these are not known the IMCA can ensure that relevant questions are asked on behalf of the person including proposing or enquiring about alternative options. Therefore to ensure the report is beneficial and provides a true sense of the person with respect to the

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\(^\text{13}\) [www.bma.org.uk](http://www.bma.org.uk)
\(^\text{14}\) MCA Code of Practice 10.21
decision IMCA's will want to consider the wording of the report including specific headings they might address (depending on each decision) so that it is a clear report.

**Options available when unable to submit a report**
Where time is a factor it may be more appropriate that representation is provided via an email or letter highlighting issues, which the IMCA asks for particular consideration to be given until the actual report can be submitted. Writing in the person’s notes on the ward may also be necessary in circumstances where time is a factor or it has not been possible to discuss fully with the decision maker the outcome of a meeting with the person. It is unlikely that only writing in a person’s notes or sending an email will provide a full representation of the IMCA safeguard i.e. notes or assessments read, a record of those who were consulted including the person themselves and the outcome of this or questions asked by the IMCA on behalf of the person. This level of detail not only evidences the IMCA role but also ensures there is a record that can be passed on to relevant professionals in the person’s best interests e.g. another IMCA or advocacy provider, NHS or Local Authority colleagues. This does not mean however that reports need to be detailed or lengthy where it is not relevant, but merely present an accurate representation on behalf of the person for the present decision-making and future consideration.

**Email, letter or insert in notes examples.**
Client details: Michael Delorean, DOB: 09/06/1961
Decision summary: There is a proposal for Michael to have a PEG feed

**IMCA’s representation**

_I met with client B on DATE. Due to the urgency of the decision being made I am unable to submit a full written report however this will follow shortly._

_Having made contact with Michael’s carer’s in the USA (via email) it appears Michael in the past expressed his wishes about having a PEG feed._

- Michael had said that he would strongly consider having a PEG feed should the time come (based on his diagnosis, carers in the USA had spent some time discussing future care with him).
- Whilst Michael has not stated he would definitely have consented to this (were he able to) I would ask the decision maker to strongly consider the above information when making the decision._
I would also ask that consideration be given to supporting Michael to have some form of contact with his carers in the USA e.g. via email or phone given this is a stressful situation for him presently.

Lastly I am aware that respite care is being considered. There is no duty to instruct an IMCA in this situation (as I understand it would be for up to a maximum of 6 weeks), however, as Michael’s advocate I would highlight the need for Michael’s paid carers in the USA to be fully involved in this decision given Michael is only in the UK on holiday. Whilst it has been difficult due to the time difference to contact the carers, they are more familiar with Michael’s views, wishes and beliefs than anyone in the UK at present.

I will send a full written report by DATE to be held on the persons file.

SMT Report headings
It is good practice for IMCA services to have a standard template to use when completing a report (Action for Advocacy’s Best Practice in Report Writing has a suggested template that is used in the example reports). This template can be adapted for each decision to ensure the reader of the report is able to clearly identify the key points the IMCA is highlighting and/or asking the decision maker to give consideration to. In order to present a report that is individual to the person, below are some suggested headings:

- The different options being considered
- What the IMCA has done since receiving the instruction
- The wishes, feelings, beliefs and values of the person and how these have been determined
- The views of other people who have been consulted
- Risks, benefits and potential burdens of proposed treatment
- Ethical considerations
- Cultural considerations
- Consensus of opinions/differing opinions
- Consideration of least restrictive principal
- Whether a second medical opinion is being requested by the IMCA
- Conclusion
Two IMCA example reports are given in Appendix 7 and Appendix 8

See Action for Advocacy Report Writing Guidance for further information.¹⁵

Ethical and Legal Issues
It is not possible to explore all the ethical issues that are faced by professionals who work in medicine or health care provision and this can become more complex when working with someone who does not have the capacity to make a decision for themselves. Equally working as an advocate and representing the person that the decision is about can be just as challenging. Although there will be decisions where there is no necessity to consider legal factors when there are ethical issues similarly where there are clear legal considerations that need to be made but no ethical concerns, often the two can be interlinked and this is detailed below.

Factors that impact on whether an issue becomes an ethical dilemma or consideration can range from religious or cultural beliefs (particularly when these are not in line with the accepted treatment of whichever society the person lives in, in this context, western medicine). Other decisions may be about end of life or DNAR orders, and the concept of futility i.e. where the medical view is that further treatment will have no benefit for the person but their family, friends or others in their life argue against this (based on either their values or what they know of the person’s wishes).

Cases that require Court of Protection intervention
The Code of Practice (6.18) highlights the following decisions that need referring to the Court of Protection (unless a person has made a LPA for healthcare decisions or there is a valid and applicable advanced decision).

- the proposed withholding or withdrawal of artificial nutrition and hydration (ANH) from a patient in a permanent vegetative state (PVS)
- cases where it is proposed that a person who lacks capacity to consent should donate an organ or bone marrow to another person
- the proposed non-therapeutic sterilisation of a person who lacks capacity to consent (for example, for contraceptive purposes)
- cases where there is a dispute about whether a particular treatment will be in a person’s best interests.

Cases that may have an ethical and/or legal implication

IMCAs can be involved in the following decisions that may have ethical considerations or legal implications depending on the circumstances: This list is not exhaustive and there is no clear cut answer for each decision but rather may indicate the need for the IMCA to seek external support or information which could include enquiring about the level of guidance there is including national guidance e.g. National Institute for Health and Clinical Excellence (NICE)

- PEG feeds
- End of Life Care
- Pregnancy (including whether the pregnancy should be terminated, to the method of delivery)
- Blood transfusions
- Stopping of dialysis
- HIV testing
- Decisions about life support continuation
- Amputation
- Major surgery
- Contraception
- Artificial hydration

What can be seen, as relatively straightforward decisions for someone who has capacity and can therefore decide for themselves can be complex where the person does not. Ascertaining a person’s wishes as they are now as well as past preferences is vital although ethically difficult where they may not be in line with current medical opinion. IMCAs should not feel that they have to find the right solution. Instead their role is to ensure that the person’s safeguard is met through research, questions, exploration and ultimately ensuring the person's individual views and needs are at the centre of the process. The role of the IMCA is to find out and then represent on the person’s behalf what would be important to them with respect to the decision. The crucial aspect within this is to give particular consideration when meeting with that person or those who know them to all of the factors that relate to how we all make decisions (values, personal ethics, beliefs, political convictions, past behaviour as well as explicit written preferences).
Further guidance may need to be sought from:

- NHS Trusts Ethics Board/Committee
- National Institute for Health and Clinical Excellence (NICE)
- British Medical Association
- Organisations that provide national support such as the MS Society, Terrence Higgins Trust, Stroke Association, National Autistic Society.
- Official solicitor (IMCA services can approach the OS for a view as to whether they could become involved and represent the person that lacks capacity, alternatively the OS may recommend seeking legal advice locally. It is important that IMCA services familiarise themselves with local legal solicitors that specialise in this aspect of the law).
- The NHS Trust’s legal team (the Trust can approach their legal team for advice and guidance or IMCAs may highlight the need for the Trust to seek legal advice before a decision is made).
- Court of Protection

**Cultural & religious considerations**

Most people are able to identify who they are through their culture. All societies have different cultures based on traditions, beliefs, language, experiences, surroundings, and interactions with others. Faith and spirituality can also impact on cultures. Culture is not particular to one group nor is it only applicable when it is different to the society a person lives in. Culture is not only relevant to a society; it may pertain to an individual’s family but not their local community. Indeed many stereotypes come from a generalised view of one society, religion or culture where assumptions are made based on how a person looks, their language, the religion they were born into (whether they now practice this or not), their dress or traditions of their community. It is important not to presume a person’s culture is not relevant or applicable because they were born in the same country as us and look, dress, speak the same (therefore a belief arising that they must have the same views or values). In the same context a person’s culture cannot be assumed because their first language is different, their appearance, dress or their interaction with others is different to what is familiar within our culture (whatever that may be).

With this in mind, whilst it is not possible for IMCAs to be able to know everything about a person when it comes to their beliefs or values, it is important to consider the
following when advocating on a person’s behalf and attempting to find out how their values can impact on a decision:

- If a person was born into a particular faith, do they still practise this? If not is this a choice or determined by circumstances (for example they’ve been unable to leave the house for some time so been unable to get to church).
- If a person’s religion or faith is known, does their religion stipulate any views on the decision (this may highlight what would have been important to the person)?
- Does a person’s culture indicate any views on the proposed decision, for example the process of dying; for example, some cultures ensure the person is surrounded by family. Although this may not be possible in all circumstances it is important to consider where relevant.
- In the event that the person is known to have or had non-religious, cultural or lifestyle-related beliefs and attitudes that have been an integral aspect of their identity, have these been investigated (and, where appropriate, input been sought from significant parties) in order to determine their relevance to the decision and ways in which they may be promoted or upheld.
- Has consideration been given to the person seeing their priest, reverend, rabbi, imam (where applicable) with respect to the decision or circumstances relating to the decision.
- Are the person’s values, traditions, and beliefs known in relation to their culture? Consideration should be given to how this would relate to the decision being proposed and what they would consider if able to make the decision themselves.

End of life Care
The National End of Life Care Programme (EoLCP)\(^\text{16}\) was developed to support health and social staff that work with adults who are at the end of their life. The majority of deaths according to the EoLCP occur after someone has been chronically ill. The aim therefore is to ensure that everyone has the opportunity to die with dignity and respect according to their personal values and beliefs and are able to plan their care including how they would like this to be offered and where they would prefer to die.

\(^{16}\) [www.endoflifecareforadults.nhs.uk](http://www.endoflifecareforadults.nhs.uk)
IMCAs may be involved in End of Life Care decisions for a variety of reasons, for example, being instructed for a change of accommodation, SMT, care review or safeguarding and the person’s health deteriorates to the point they reach End of Life care planning. Or the reason for instruction is related to End of Life for example a change of accommodation is proposed to provide End of Life care or a certain course of treatment is proposed within End of Life care planning. It is therefore important for IMCA services to familiarise themselves with the relevant framework that is being used to plan for the person’s end of life. For example, if someone is in a care home this could be the Gold Standards Framework\(^\text{17}\). Someone in hospital may be placed on the Liverpool Care Pathway\(^\text{18}\) for the Dying Patient (LCP).

There are 6 steps to the End of Life Care Pathway\(^\text{19}\) which begin with Step 1, open discussions with the person, Step 2 is the care planning stage Step 3 is co-ordination of the care required, Step 4 is the delivery of this care when the time comes. Stage 5 is about providing care in the last few days of a person’s life recognising their previously expressed wishes. Some patients will begin this pathway at stage 5 rather than stage 1, for example if they become acutely unwell. Stage 6 is about care after death in terms of verification, certification of death and support for family and friends of the person. The IMCA may be involved in either step of the process depending on the person’s capacity and understanding, it may be that a person can express their wishes in terms of End of Life but yet still be deemed to lack capacity to make some decisions relating to this or it may be they have had capacity until step 5 and there is a decision that needs to be made requiring IMCA involvement that was not care planned and they are now too unwell and lack capacity to make decisions. Alternatively a person may become acutely unwell and be placed at step 5 and the IMCA is instructed with no prior information regarding End of Life care planning.

Where a person has had the capacity to express their preferences and is involved from stage 1 this will already be documented. The role of the IMCA in this event would be to continue representing a person’s wishes particularly giving attention where their preferences may not be adhered to (see case example below).

\(^\text{17}\) [www.goldstandardsframework.nhs.uk](http://www.goldstandardsframework.nhs.uk)


\(^\text{19}\) [http://www.endoflifecareforadults.nhs.uk/assets/downloads/pubs_EoLC_Strategy_1.pdf](http://www.endoflifecareforadults.nhs.uk/assets/downloads/pubs_EoLC_Strategy_1.pdf)
End of Life Case example

Sarah, a 63-year-old woman with chronic renal failure has been admitted to hospital. An IMCA is instructed as she has been in hospital approaching more than 28 days and she does not have the capacity to consent to or refuse this. Sarah is also placed on an End of Life Care Pathway, as it is believed she will not survive the week. Sarah already has a care plan in place with regards to this, however her preference was to be cared for within her own home and that she die at home when the time came. Hospital staff believe Sarah’s care is more appropriately met in hospital particularly given the fact that Sarah lives on her own. The IMCA’s role at this stage is to familiarise themselves with Sarah’s care plan and her expressed preferences and advocate Sarah’s wishes on her behalf whilst also ensuring relevant questions are asked as well as accessing her medical and social care records. The IMCA would be advocating for Sarah’s wishes to be strongly considered given she has made an advanced decision.

The EoLCP highlights that many people express a preference to be cared for and die at home, however most people die in hospital which is against their wishes and it is therefore important that their preferences are strongly considered within the decision-making process.

Where IMCAs become involved in end of life decisions as SMT or accommodation decisions it is important they establish whether the person had expressed any preferences with respect to end of life care. This will include talking to staff in a care home (where applicable) or where there are family or friends, being able to sensitively tackle the discussion with them about what would be important to the person in these circumstances. Unfortunately for many patients that are at the End of Life stage, there will be a balance between what is recommended from a medical or social care perspective, for example if someone lives on their own and is unable to care for themselves without nursing intervention, it may be deemed more appropriate for discharge to a hospice or nursing home rather than their own home. Indeed their own home may no longer be suitable for them to live in due to increased needs. However the role of the advocate is to ensure relevant questions are asked, appropriate representation is provided of the person’s wishes, beliefs and preferences including any cultural, spiritual or religious needs and that consideration is given to the best interests checklist by the decision maker.
Do Not Attempt Resuscitation (DNAR) order
A joint statement from the British Medical Association, the Resuscitation Council (UK) and the Royal College of Nursing, Decisions relating to cardiopulmonary resuscitation. October 2007 outlines the circumstances where there is no need to instruct an IMCA.

*It can be argued that a decision not to attempt CPR because it will not work will not have ‘serious consequences’ for the patient, because the patient will die with or without attempting CPR. For this reason, in our view, an IMCA does not need to be called when it is clear to the medical team that CPR would not re-start the patient’s heart and breathing for a sustained period.*

Therefore an IMCA should be instructed when a DNAR order is to be placed on a patient unless it is evident that there is no decision to be made because the person would not survive regardless. It is crucial that DNAR decisions comply with the Mental Capacity Act 2005. This means that assumptions must not be made about a person including what their quality of life is. There is no blanket “best interests” decision for a given situation, and particularly not when relating to whether someone’s quality of life will be so impoverished as to support a decision not to attempt resuscitation. Though the components of a decision may be broadly similar in a number of cases, they must each be considered in relation to the unique individual concerned.

Where there is a widespread or inappropriate use of DNAR this may indicate a safeguarding issue and necessitate an alert to be made by the IMCA. Further guidance can be found in the Action for Advocacy DNAR guidance.

**Key questions for IMCAs involved in DNAR decisions to ask:**

- What is the likelihood of CPR being successful?
- What is known about the person’s current/previously expressed views (including advanced decisions)?
- What is the likelihood of the person experiencing unmanageable pain?
- Should a second opinion be requested (see page 22 for further guidance)?

Raising concerns regarding SMT Decisions

There may be situations where the IMCA will want to raise concerns and the process for this should be included in policies and procedures. The MCA Code of Practice suggests that IMCAs should raise concerns informally before considering a more formal process. The following process for raising concerns is suggested:

- Speak to the appropriate professional/decision maker when concerns arise
- Put concerns in writing to the decision maker
- If not resolved, involve senior managers in NHS organisation & IMCA provider
- Include any concerns in the IMCA report
- Use complaint procedures if appropriate
- Progress to the Court of Protection if necessary

Where an urgent resolution of the issues may be required, the IMCA may want to seek permission to apply to the Court of Protection prior to considering the use of relevant complaint procedures.

IMCAs may want to raise concerns in the following situations:

- that the proposed treatment/investigation is not in the person’s best interests
- that a decision not to provide treatment is not in the person’s best interests
- there are other options which are not being considered
- what is proposed is not in line with accepted best practice
- what is proposed will have a significant impact on the person’s quality of life
- whether the person has capacity to make the decision

IMCA Top Tips

- Ensure there is a prioritisation policy in place that explains how cases are prioritised and offers a framework for this.
- Where time is a factor submit reports via email, letter or document key factors for consideration within the person's notes.
- Where possible identify other relevant staff who can be contacted should the decision maker not be available.
- Identify the framework hospital or care home staff are working under when dealing with End of Life.
- Establish whether any care plans have been developed with respect to End of Life decisions.
- Consider whether other legislation can be referenced to support the representation of the person for example Articles of the Human Rights Act 1998.
- Establish whether there is any further guidance from the decision-makers member’s bodies e.g. British Medical Association or General Medical Council.
- Research the person’s particular diagnosis/proposed treatment as thoroughly as time permits and write a list of key questions to put to the appropriate clinician.
- Where a person has a particular condition or diagnosis find out if any patient focused information or guidelines have been produced relating to this, for example, from a national organisation that supports people with certain conditions or needs (for example MS Society, National Autistic Society, National Association for Colitis and Chron’s Disease or NICE). This information may be gained from the relevant professionals involved with a person e.g. a nurse advisor or SALT.
- Ask whether a decision has been made about DNAR and how this was made.
- If medical staff are concerned about the time they need to give to the IMCA then it is important to highlight that in other situations they would be still likely to need to give this time to the patient if they were making their own decision, or in consulting with family/friends if not.
- Where the role of decision-maker may be passed from one person to another in the course of the IMCA’s work on a case, it will be useful to identify a consistent ‘contact person’ who will understand and respond to the need to pass communications (such as the IMCA report or other correspondence) to the current holder of the role, in a timely fashion.
- When it is evident that a decision has been made without involvement of an IMCA when the criteria was met or that a decision was made without being compliant with the Act, IMCAs may wish to consider making a safeguarding adult alert with a concern that the person has not received appropriate care or treatment including their right to be safeguarded by the Act (this includes instruction of an IMCA). Other options include alerting the MCA lead for the Trust, formally writing to the Chief Executive of the Trust with concerns, contacting the Care Quality Commission or making a formal complaint.
The involvement of Independent Mental Capacity Advocates (IMCAs) in Serious Medical Treatment Decisions

Instruction checklist, example policies, forms and IMCA reports
## Appendix 1 - SMT Checklist

### CHECKLIST for IMCA INSTRUCTION

**Independent Mental Capacity Advocate Service**  
When to instruct an IMCA for a patient with regard to Serious Medical Treatment

<table>
<thead>
<tr>
<th>Checklist</th>
<th>Description</th>
<th>Reasoning</th>
</tr>
</thead>
</table>
| ✓         | A decision needs to be made about serious medical treatment | Serious medical treatment can be providing treatment, stopping treatment already being provided or deciding not to start treatment that could be offered and **one or more** of the following apply:  
  - Where a single treatment is proposed, there is a fine balance between the benefits, burdens and risks to the patient  
  - Where there is a choice of treatments, a decision as to which one to use is finely balanced  
  - What is involved is likely to have serious consequences for the patient  
  *For more information see MCA Code of Practice 10.42* |
| ✓         | The patient has an impairment, disability or illness which is affecting their ability to make the decision | For example, dementia, a brain injury or learning disability. It can also be a temporary condition such as unconsciousness or a person who is under the influence of alcohol or drugs. |
| ✓         | The patient lacks capacity to make the specific decision at the time it needs to be made | Patients should be supported to make the decision, for example, by simplifying information about a particular procedure. If after this support is given there are reasons to believe the patient may lack capacity to make the particular decision, an assessment of their capacity should be done. |
| ✓         | There are no family or friends who can be appropriately involved in discussions about the decision | IMCA is primarily intended for people who have nobody who can be consulted about the decision. However, if there are family and friends but they have limited contact with the patient or know little about their wishes and views or do not want to be involved in the decision making process, a referral to IMCA should be made. |

4 ticks means there’s a duty to instruct an IMCA for the patient. Emergency treatment should not be delayed.

The local IMCA service is: Example IMCA Service 0849 000000
Appendix 2: Example form for adults who lack capacity to consent to treatment
(adapted from DH consent form 4)
(NHS Trust inserted here)

Form for adults who lack capacity to consent to investigation or treatment

This form should only be used where it would be usual to seek written consent but an adult patient (16 or over) lacks capacity to give or withhold consent to treatment. If an adult has capacity to accept or refuse treatment, you should use a standard consent form and respect any refusal.

Responsible health professional/job title ........................................................................

Patient’s special requirements.........................................................................................

(E.g. other language/other communication method)

All sections to be completed by health professional proposing the procedure

A Details of procedure or course of treatment proposed

(NB see accompanying guidance to health professionals for details of situations where court approval must first be sought)

B Assessment of patient’s capacity

I confirm that the patient lacks capacity to give or withhold consent to this procedure or course of treatment because of an impairment of the mind or brain or disturbance affecting the way their mind or brain works (for example, a disability, condition or trauma, or the effect of drugs or alcohol) and they cannot do one or more of the following:

- Understand the information about the procedure or course of treatment
- Retain that information in their mind
- Use or weigh that information as part of the decision making process, or
- Communicate their decision (by talking, using sign language or any other means)

Further details (excluding where patient unconscious): for example how above judgements reached; which colleagues consulted; what attempts made to assist the patient make his or her own decision and why these were not successful:
C Assessment of patient's best interests

I am satisfied that the patient has not refused this procedure in a valid advance decision to refuse treatment. As far as is reasonably possible, I have considered the person’s past and present wishes and feelings (in particular if they have been written down) and any beliefs and values that would be likely to influence the decision in question. As far as possible, I have consulted other people (those involved in caring for the patient, interested in their welfare, IMCA, or the patient has said should be consulted) as appropriate.

I have considered the patient's best interests in accordance with the requirements of the Mental Capacity Act and believe the procedure to be in their best interests because:

(Where incapacity is likely to be temporary, for example if patient is unconscious or where patient has fluctuating capacity)

The treatment cannot wait until the patient recovers capacity because:

D Involvement of the patient's family and others close to the patient

The final responsibility for determining whether a procedure is in a patient's best interests lies with the health professional performing the procedure unless the person has an appropriate attorney or deputy. However, the Mental Capacity Act requires that those close to the patient (e.g. spouse/partner, family and friends, carer, supporter, or advocate) are consulted as far as is practicable and appropriate unless you have good reason to believe that the patient would not have wished particular individuals to be consulted, or unless the urgency of their situation prevents this. “Best interests” go far wider than “best medical interests”, and include factors such as the patient's wishes and beliefs when competent, their current wishes, their general well being and their spiritual and religious welfare.

The following have been involved in a discussion with the relevant health professionals over the treatment of ...........................................................................................................

(patient's name).

I/We understand that he/she is unable to give his/her own consent, based on the criteria set out in this form. I/We also understand that treatment can
lawfully be provided if it is in his/her best interests to receive it.

Any other comments (including any concerns about decision):

Name ………………………………………
Relationship to patient……………………………………
Address
………………………………………………………………………………………………
………………………………………………………………………………………………
………………………………………………………………………………………………
Signature …………………………………………

Date…………………………..

NAME (print)……………………………………

If a person close to the patient was not available in person, has this matter been discussed in any other way (e.g. over the telephone?)

☐ Yes  Details:
☐ No

E Involvement of an Independent Mental Capacity Advocate

For decisions about serious medical treatment, where there is no one appropriate to consult other than paid staff*, has an Independent Mental Capacity Advocate (IMCA) been instructed?

*Note that an IMCA does not need to be instructed when the person has a Health and Welfare Lasting Power of Attorney that covers this decision but does need to be instructed when the statutory criteria is met and there is no LPA in place.

☐ Yes  Details:
☐ No

Signature………………………………………………..  Date…………………..
F The patient has an attorney or deputy
Where the patient has authorised an attorney to make decisions about the procedure in question under a Lasting Power of Attorney or a Court Appointed Deputy has been authorised to make decisions about the procedure in question, the Attorney or Deputy will have the final responsibility for determining whether a procedure is in the patient’s best interests.

NB There is a responsibility on the staff involved in the treatment of the patient to ensure there is sight of a copy of the Lasting Power of Attorney to ensure it is specific to the treatment in hand. The Code of Practice 7.30) advises life-sustaining treatment, can only be refused by the attorney on behalf of the patient where the donor has specifically stated that they wish the attorney to have this authority.

I have been authorised to make decisions about the procedure in question under a Lasting Power of Attorney/Court Appointed Deputy (delete as appropriate). I have considered the relevant circumstances relating to the decision in question (see sections A&C) and believe the procedure to be in the patient’s best interests.

Signature of attorney or deputy ................................................. dates........................

G Concluding medical statement
The above procedure is, in my clinical judgement, in the best interests of the patient, who lacks capacity to consent for him or herself. Where possible and appropriate I have discussed the patient’s condition with those close to him or her, and taken their knowledge of the patient’s views and beliefs into account in determining his or her best interests.

I have/have not sought a second opinion.

Signature:............................................................................................................................
Date ........................................
Name (PRINT) ...........................................................................................................................
Job title .....................................................................................................................................

Where second opinion sought, s/he should sign below to confirm agreement:

Signature:.............................................................................................................................
Date ......................................................

Name (PRINT) .................................................................................................

Job title .................................................................................................

Name (PRINT) .................................................................................................

Job title ..............................................
Appendix 3: Copy of the Department of Health - Guidance to health professionals on completing form for adults who lack capacity to consent to investigation or treatment

This form should only be used where it would be usual to seek written consent but an adult patient (16 or over) lacks capacity to give or withhold consent to treatment. If an adult has capacity to accept or refuse treatment, you should use the standard consent form and respect any refusal. Where treatment is very urgent (for example if the patient is critically ill), it may not be feasible to fill in a form at the time, but you should document your clinical decisions appropriately afterwards. If treatment is being provided under the authority of Part IV of the Mental Health Act 1983, different legal provisions apply and you are required to fill in more specialised forms (although in some circumstances you may find it helpful to use this form as well). If the adult now lacks capacity, but has made a valid advance decision to refuse treatment that is applicable to the proposed treatment then you must abide by that refusal. For further information on the law on consent, see the Department of Health’s Reference guide to consent for examination or treatment (www.dh.gov.uk/consent).

When treatment can be given to a patient who lacks the capacity to consent all decisions made on behalf of a patient who lacks capacity must be made in accordance with the Mental Capacity Act 2005. More information about the Act is given in the Code of Practice. Treatment can be given to a patient who is unable to consent, only if:

• the patient lacks the capacity to give or withhold consent to this procedure AND
• the procedure is in the patient’s best interests.

Capacity
A person lacks capacity if they have an impairment or disturbance (for example, a disability, condition or trauma, or the effect of drugs or alcohol) that affects the way their mind or brain works which means that they are unable to make a specific decision at the time it needs to be made. It does not matter if the impairment or disturbance is permanent or temporary. A person is unable to make a decision if they cannot do one or more of the following things:

• Understand the information given to them that is relevant to the decision.
• Retain that information long enough to be able to make the decision.
• Use or weigh up the information as part of the decision-making process.
Communicate their decision - this could be by talking or using sign language and includes simple muscle movements such as blinking an eye or squeezing a hand.

You must take all steps reasonable in the circumstances to assist the patient in taking their own decisions. This may involve explaining what is involved in very simple language, using pictures and communication and decision-aids as appropriate. People close to the patient (spouse/partner, family, friends and carers) may often be able to help, as may specialist colleagues such as speech and language therapists or learning disability teams, and independent advocates (as distinct from an IMCA as set out below) or supporters. Sometimes it may be necessary for a formal assessment to be carried out by a suitably qualified professional.

Capacity is decision-specific: a patient may lack capacity to take a particular complex decision, but be able to take other more straightforward decisions or parts of decisions. Capacity can also fluctuate over time and you should consider whether the person is likely to regain capacity and if so whether the decision can wait until they regain capacity.

**Best interests**
The Mental Capacity Act requires that a health professional must consider all the relevant circumstances relating to the decision in question, including, as far as possible:

- the person’s past and present wishes and feelings (in particular if they have been written down)
- any beliefs and values (e.g. religious, cultural or moral) that would be likely to influence the decision in question and any other relevant factors
- other factors that the person would be likely to consider if they were able to do so

When determining what is in a person’s best interests a health professional must not make assumptions about someone’s best interests merely on the basis of the person’s age or appearance, condition or any aspect of their behaviour. If the decision concerns the provision or withdrawal of life-sustaining treatment the health professional must not be motivated by a desire to bring about the person’s death.
The Act also requires that, as far as possible, health professionals must consult other people, if it is appropriate to do so, and take into account their views as to what would be in the best interests of the person lacking capacity, especially anyone previously named by the person lacking capacity as someone to be consulted and anyone engaging in caring for patient and their family and friends.

**Independent Mental Capacity Advocate (IMCA)**

The Mental Capacity Act introduced a duty on the NHS to instruct an independent mental capacity advocate (IMCA) in serious medical treatment decisions when a person who lacks capacity to make a decision has no one who can speak for them, other than paid staff. IMCAs are not decision makers for the person who lacks capacity. They are there to support and represent that person and to ensure that decision making for people who lack capacity is done appropriately and in accordance with the Act.

**Lasting Power of Attorney and Court Appointed Deputy**

A person over the age of 18 can appoint an attorney to look after their health and welfare decisions, in the event that they lack the capacity to make such decisions in the future. Under a Lasting Power of Attorney (LPA) the attorney can make decisions that are as valid as those made by the person themselves. The LPA may specify limits to the attorney’s authority and the LPA must specify whether or not the attorney has the authority to make decisions about life-sustaining treatment. The attorney can only, therefore, make decisions as authorised in the LPA and must make decisions in the person’s best interests.

The Court of Protection can appoint a deputy to make decisions on behalf of a person who lacks capacity. Deputies for personal welfare decisions will only be required in the most difficult cases where important and necessary actions cannot be carried out without the court’s authority or where there is no other way of settling the matter in the best interests of the person who lacks capacity. If a deputy has been appointed to make treatment decisions on behalf of a person who lacks capacity then it is the deputy rather than the health professional that makes the treatment decision and the deputy must make decisions in the patient’s best interests.
Second opinions and court involvement

Where treatment is complex and/or people close to the patient express doubts about the proposed treatment, a second opinion should be sought, unless the urgency of the patient’s condition prevents this. The Court of Protection deals with serious decisions affecting personal welfare matters, including healthcare, which were previously dealt with by the High Court. Cases involving:

- decisions about the proposed withholding or withdrawal of artificial nutrition and hydration (ANH) from patients in a permanent vegetative state (PVS)
- cases involving organ, bone marrow or peripheral blood stem cell (PBSC) donation by an adult who lacks capacity to consent
- cases involving the proposed non-therapeutic sterilisation of a person who lacks capacity to consent to this (e.g. for contraceptive purposes) and
- all other cases where there is a doubt or dispute about whether a particular treatment will be in a person’s best interests (including cases involving ethical dilemmas in untested areas) should be referred to the Court for approval. The Court can be asked to make a decision in cases where there are doubts about the patient’s capacity and also about the validity or applicability of an advance decision to refuse treatment.
Appendix 4: Example policy wording for NHS Trusts on instructing Independent Mental Capacity Advocates (IMCAs) in Serious Medical Treatment decisions.

All NHS Trusts in England should have a policy on the Mental Capacity Act 2005 where the criteria for instructing an IMCA is set out. This should include the statutory duty to instruct IMCAs for Serious Medical Treatment and Change of Accommodation as well as the discretionary power to instruct an IMCA for Safeguarding Adult procedures and Care reviews. The following defines the role and criteria of instructing IMCAs in SMT decisions only.

1 Definition of serious medical treatment
Serous medical treatment is defined in the Mental Capacity Act 2005 (Independent Mental Capacity Advocates) (General) Regulations 2006.

Serious medical treatment is:

- 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 benefits and the burdens to the patient
- a decision between choice of treatments is finely balanced, or
- what is proposed is likely to have serious consequences for the patient

Serious consequences are defined in the code of practice as those that could have a serious impact on the patient either from the treatment itself or due to wider implications such as:

- prolonged pain
- distress
- side effects of the treatment such as reduced immunity
- major consequences such as stopping life sustaining treatment or amputation
• serious impact on a patient’s future life choice

The MCA Code of Practice makes it clear that these are illustrative examples and that ultimately whether a procedure is regarded, as ‘serious medical treatment’ will depend on the individual circumstances of the person and the likely consequences for them. The treating clinician must decide for every person who lacks capacity to make the decision for themselves, whether or not the proposed treatment is ‘serious medical treatment’.

2 Emergency decisions
The only exception for the need to instruct an IMCA is if there is an emergency situation requiring an urgent decision to be made, for example, to save a person’s life. However, once the emergency has passed, there is a duty to instruct an IMCA for any subsequent serious medical treatment decisions.

3 Assessing capacity
A person must be assumed to have capacity unless it is established that they lack capacity. If all steps have been taken to support the person to make their own decision but their ability to make the particular decision is questionable, then their capacity to make the treatment decision must be assessed.

Two important questions must be addressed first:
1. Does the person have an impairment/disturbance of the mind and
2. Is that impairment affecting their ability to make a decision? If the answer is yes to both of these questions, then it is appropriate to assess the person’s capacity.

In relation to the proposed treatment can the person:
• Understand what is being proposed including the nature of the decision and why it is needed.
• Retain the information for long enough to make that decision
• Use or weigh up the information as part of making the decision
• Communicate their decision by any means (including non-verbal methods)

For serious medical treatment decisions the person would need to understand information about:
• proposed treatment or reasons for withdrawal/withholding of treatment
• potential risks, benefits or burdens of any proposal
• likely consequences of any proposal
• potential side effects
• likely recovery time and any rehabilitative treatments
• prognosis
• potential outcome of taking no action

There is no legal requirement for IMCAs to have sight of the written capacity assessment before they start to work with the patient; however, assessments to establish that a person lacks capacity in relation to the decision being made will need to be undertaken prior to instructing an IMCA.

The person responsible for making the best interests decision is usually the person who carries out a mental capacity assessment. For serious medical treatment it is likely to be the consultant but the task of assessing capacity can be delegated by the decision-maker to another professional.

4 Consulting family and friends
Consideration needs to be given to whether there are any family or friends (not anybody who is in a paid capacity) who know the person well enough to provide information about their views, wishes, feelings and beliefs and are willing and able to be consulted about the best interests decision.

If there is nobody who is appropriate to consult and the person lacks capacity to give or refuse consent for serious medical treatment, an IMCA must be instructed at the earliest opportunity.

5 When an IMCA cannot be instructed
An IMCA cannot be instructed in the following situations:
• A person who lacks capacity previously named a person who should be consulted and that person is available and willing to be involved.
• A person who lacks capacity has appointed an attorney under a Lasting Power of Attorney who has the appropriate decision-making authority. The relevant LPA for treatment decisions is a Health and Welfare LPA.
The Court of Protection has appointed a deputy who continues to act on the person’s behalf.

6 Instructing an IMCA

It is vital that accurate and timely information about the need for an IMCA is made in every case. Delay in instructing an IMCA may result in delays in medical treatment. Each NHS Trust is responsible for authorising staff within its organisation who can instruct an IMCA. Instruction will therefore be made by a range of healthcare staff.

The following staff within EXAMPLE NHS Trust are authorised:

Consultants
Ward sisters
Staff nurses/pre-admission nurses
Occupational Therapists
Physiotherapists
Ward Managers
Learning disability nurses

Initial instruction can be made either by telephone or by sending an instruction form to the IMCA service. If instruction is made by phone, the IMCA service will ask for relevant information pertinent to the decision to be made including:

- details of the decision
- how it is has been established that the person lacks capacity
- whether the person has family or friends who are appropriate to consult
- what support the person has received to enable them to make the decision for themselves
- timescales for the decision-making process

A record will be made in the patient’s notes of the decision to instruct an IMCA and the people involved in making that decision.
If there is uncertainty about whether a patient is eligible for IMCA and a discussion is held where the outcome is not to instruct IMCA, this must also be recorded in the patient’s notes.

The IMCA instruction form can be downloaded from the IMCA service website [www.exampleimcaservice.org](http://www.exampleimcaservice.org) or from the EXAMPLE NHS Trust intranet.

7 IMCA Service contact details

Example IMCA Service  
32 Bridge Street  
Anytown  
Fieldshire  
FL32 4XY

0849 000000  
info@exampleimcaservice.org

8 Availability of the IMCA Service

The IMCA service is available Monday – Friday during office hours excluding Public Holidays.

9 Outpatients

Most patients will have been referred to outpatients via their GP. Some GPs will have recognised the need for IMCA input and will either instruct an IMCA for the patient or may write to the appropriate consultant, indicating their belief that the person is eligible for IMCA.

Some patients will arrive in outpatients for their appointment and the consultant will realise at that point that IMCA is needed. Unfortunately it will be too late to instruct an IMCA to support the patient at that appointment, however, it is crucial that an IMCA is instructed as soon as possible if any follow up serious medical treatment decision is to be made.

10 Elective admissions

If an IMCA is instructed when (or before) the person is seen in outpatients, then IMCA will be involved in subsequent decisions and health care staff should liaise with the IMCA when the person is to receive treatment in hospital. The IMCA must be kept informed of any developments.
Pre-admission assessments must consider if a person is eligible for IMCA and may highlight the need for IMCA at that stage. Pre-admission nurses can instruct IMCA where appropriate and must liaise with relevant clinicians.

If the need for IMCA is identified once a person has been admitted to hospital, an IMCA must be instructed before any treatment decisions are made (unless urgent, life-saving treatment is needed).

The above is an example of wording to be used within a general MCA 2005 Trust Policy. Policies would also need to reference the statutory duty to instruct IMCAs for accommodation decisions where there is a proposal to place someone into care for 8 weeks or more or hospital for 28 days or more. Policies should also reference locally agreed guidance on when to use discretionary powers to instruct an IMCA in care reviews or adult protection proceedings.
Appendix 5: Example Prioritisation Policy for IMCA Services

The statutory nature of the IMCA service means that there is a necessity to prioritise cases (instructions or referrals) based on the nature of the decision as well as the time frame the decision needs to be made within. To ensure the IMCA service/organisation is able to carry out the duties required by Mental Capacity Act 2005 with respect to the IMCA’s role and responsibilities it is imperative that the relevant responsible body (NHS or Local Authority) instructs the IMCA service in as timely manner as possible. Whilst the service will endeavour to meet the following timescales in completing the work, this can only be achieved when the service has received the relevant information within an appropriate timeframe sufficient to the decision. The organisation will ensure that this information is clear and transparent to those instructing the service as well as relevant stakeholders and therefore an indication of timeframes is provided on receipt of instruction/referral.

Responsibility for prioritising and allocating cases
The manager of the IMCA service is ultimately responsible for allocating cases; however as a general rule of thumb cases will be allocated to the IMCA with the availability in regards to their caseload. The service has an agreed case limit that each IMCA is able to hold, where this becomes unmanageable for the individual IMCA this will be addressed with support provided by the manager. Where this is an overall organisational issue this will be discussed and raised with the commissioner/s of the service.

On receipt of the instruction/referral, formal acknowledgement (by way of letter or fax) will be sent to the decision maker informing them the case will be allocated within a certain time frame. Each referral is given a client ID and cover sheet (paper or electronic) service to ensure all further action is documented (regardless of whether this becomes an active case or not).

Response time frames of the IMCA service

Decision needs to be made within 1 week
Service makes contact with referrer/decision maker within 1 day of receipt of instruction/referral. At this point arrangements should be made to visit the person/access relevant notes within the next 1-2 working days.
A request will be made for any assessments to be faxed/emailed (where this is in line with data protection) in order to commence the process as soon as possible.

**Decision needs to be made within 2 weeks**
Service makes contact with referrer/decision maker within 1 day of receipt of instruction/referral. At this point arrangements can be made to visit the person/access relevant notes within 2 – 4 working days.

**Decision needs to be made within a month or longer**
Service makes contact with referrer/decision maker within 1 day of receipt of instruction/referral. An arrangement to visit the person within the next 2 weeks should be made. Any relevant assessments can be posted/faxed or emailed in the meantime or accessed when visiting the person. Appointments will be made to meet with or have telephone contact with the decision maker to request some basic information about the decision to allow this to feed into the initial meeting with the person.

Once the IMCA has met with the person they can then go back to the decision maker with any further relevant questions or requests for multi disciplinary meetings.

**Instruction of IMCA for specific decisions**

There is a **statutory duty** to instruct an IMCA where the criteria are met for **Serious Medical Treatment and Accommodation decisions**. There is a **discretionary power** to instruct an IMCA on decisions regarding **adult safeguarding and care reviews**.

Whilst all instructions that fulfil the criteria will be allocated to the IMCA caseload and as such will be treated as any other case once the work commences, the IMCA service will need to prioritise cases where there is a duty to instruct rather than a discretionary power to instruct given the legal basis for the role. However all circumstances will be considered within each decision.

**Serious Medical Treatment**
The nature of most SMT instructions means that the decision will usually need to be made within a short period of time, as often the person will already be in hospital and
the decision needing to be made has resulted from this admission. There are some SMT decisions where there is a greater opportunity in terms of time to explore the relevant factors that need to be considered as part of the best interests process and therefore the focus will still remain on when the decision needs to be made in terms of prioritisation. However SMT instructions will be treated as a priority for the service on initial receipt of them.

There may be opportunities for a longer decision making process to occur in the following examples:

- Pregnancy – a decision about whether there should be a natural birth or caesarean section, these discussions are likely to start taking place early on.
- Cataracts operations – there will often be more of an opportunity to meet with a person and the decision maker prior to a decision needing to be made given the forward planning involved with respect to a final decision.
- Pre assessment appointments (notice of which are often given several weeks in advance)
- Outpatient appointments including those for major surgery (as above, there is usually advanced notice of when these will be or the IMCA has been instructed at the time of referral by the GP to the relevant hospital department).

Change in accommodation

There is a statutory duty to instruct an IMCA where there is a change of accommodation proposed therefore these instructions would also be treated as a priority. It is unlikely that change of accommodation instructions would require an urgent response by the IMCA service given the criteria to instruct is when it is proposed a person moves or remains in a care home for more than 8 weeks. This affords the IMCA sufficient time to meet with the person. Where the move is urgent an IMCA should be instructed soon into this 8-week period. Where a person is in their own home and there is a proposed long term move, it is hoped that given the nature of such a life changing decision that care planning (including any capacity assessments) would be carried out well in advance of any action required in terms of further decision making. The likely reason for IMCAs needing to respond on a relatively quick basis will be where the decision concerns a stay in hospital for more than 28 days, which will need to be prioritised over a decision that can be made over a period of time.
Factors to be considered

Decision makers have a responsibility to make decisions where there is an urgent basis to do so and are therefore not required to instruct IMCAs to be involved in the best interests decisions they take for their patients when these are of an urgent nature. When there is further action resulting from an urgent decision, for example a proposal for long-term care resulting from an emergency respite placement or further treatment is required after the provision of emergency life saving treatment then an IMCA needs to be instructed.

Adult Safeguarding

Whilst there will be many urgent decisions that need to be made with respect to safeguarding, IMCAs should be instructed in as timely manner as possible where it is believed to be of benefit to the person (as per ADASS/SCIE guidance\(^{21}\)). This means that the IMCA service will expect to be instructed once a safeguarding assessment indicates the involvement of an IMCA is required at the next stage of the safeguarding plan or process.

Care reviews

Where there has been prior IMCA involvement it is likely the service will be able to respond to care review instructions in a timely manner and the rationale for the care review as well as the necessity for IMCA involvement should be clear from the outset. Care reviews are unlikely to need an urgent response from the IMCA service given they will occur either on a yearly basis or 3 months after a major decision (both of which assume the relevant authority has the opportunity to instruct at an early stage). There may be evidence to suggest the care review (the purpose for it) will result in a statutory instruction i.e. change of accommodation or SMT in which case the IMCA service will prioritise these to ensure the person has IMCA involvement from as early stage in the process as possible.

Acknowledgement of receipt of instruction to the IMCA Service

Date: ..............................................
To: ..................................................
Fax/Email: .............................................

We have received an instruction for the following named client:

Name: ..................................................
DOB: ..................................................
Current address: ......................................

Brief details of the decision:
............................................................................................................................
............................................................................................................................
............................................................................................................................
............................................................................................................................

We will allocate the case to an IMCA within the following time frames.

**Decision needs to be made within 1 week:** Arrangements will be made to visit the person/access relevant notes within 1-2 working days or receipt of referral.

**Decision needs to be made within 2 weeks:** Arrangements will be made to visit the person/access relevant notes within 2 – 4 working days of receipt of referral.

**Decision needs to be made within a month or longer:** Arrangements will be made to visit the person within 2 weeks of receipt of referral.

Please note that whilst the service will endeavour to achieve the following timescales, this can only be achieved when the service has received the relevant information that is within an appropriate time sufficient to the decision.

Please forward any assessments via fax/email (where this is in line with data protection) in order for us to commence the process as soon as possible.

Yours faithfully

**IMCA Service Manager**
### Appendix 6: Example SMT IMCA role Pathway

**IMCA role pathway for involvement in Serious Medical Treatment Decisions**

<table>
<thead>
<tr>
<th>Instruction form completed by consultant or other healthcare professional and sent to IMCA provider.</th>
</tr>
</thead>
<tbody>
<tr>
<td>IMCA provider contacts instructor and/or decision maker within 1 working day to discuss the patient’s situation, to clarify any information about eligibility and to find out how the patient communicates.</td>
</tr>
<tr>
<td>The professional instructing IMCA may realise at this point that the person isn’t eligible. IMCA should suggest an alternative advocacy service if appropriate.</td>
</tr>
<tr>
<td>IMCA checks to see what support the patient has had to enable him or her to make the decision for him/herself.</td>
</tr>
<tr>
<td>IMCA makes arrangements to meet the patient and to consult with the clinician responsible for making the decision and any other person who knows the patient well.</td>
</tr>
<tr>
<td>The person’s views, wishes, feelings and beliefs about the proposed treatment/investigation/procedure or decision not to treat and any other relevant information is ascertained from the patient where possible and also through discussions with others involved in delivering care, support or treatment. The IMCA may speak to any family members or friends where relevant. IMCAs use alternative methods of communication if the person cannot communicate verbally.</td>
</tr>
<tr>
<td>IMCA ascertains if it is known whether the person has made an Advance Decision to Refuse Treatment and if so if it is applicable to the person’s situation at this time.</td>
</tr>
<tr>
<td>IMCA researches into the condition/diagnosis through web based search and/or discussions with relevant professionals and will examine the patient’s notes. Through this research the IMCA will find out:</td>
</tr>
<tr>
<td>- diagnosis</td>
</tr>
<tr>
<td>- the risks, benefits and burdens of the treatment</td>
</tr>
<tr>
<td>- prognosis</td>
</tr>
<tr>
<td>- information on person’s current health situation</td>
</tr>
<tr>
<td>- the potential impact of the treatment on the person’s health</td>
</tr>
<tr>
<td>- the person’s current clinical need</td>
</tr>
<tr>
<td>- the potential impact of the treatment on the person’s quality of life and life expectancy</td>
</tr>
<tr>
<td>- any other relevant factors</td>
</tr>
<tr>
<td>- consideration of the least restrictive principle</td>
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</tbody>
</table>
- any ethical considerations
- aftercare to be provided

| IMCA liaises closely with the clinician responsible for making the decision. |
| A second medical opinion may be requested by the IMCA if they feel it is appropriate for the patient’s particular situation. |
| IMCA attends MDT meeting and/or best interests meeting where one is held and inputs into the decision making process ensuring that the views of the person are taken into account and important and relevant information about the person is brought to the attention of the decision-maker. The IMCA will represent the patient, asking questions on their behalf and will advise on relevant aspects of the Act or the Code of Practice. The decision may be made at this stage and the IMCA’s report will follow. |
| The IMCA summarises their findings in a report, which the professional responsible for the best interests decision must take into account when making the decision. The report will contain useful, often essential information for the decision maker which will enable them to make a robust best interests decision which is in full accordance with the Mental Capacity Act. |
| The decision is made and the responsible clinician informs IMCA. |
| IMCA may challenge either the best interests decision or the way in which it was made if there is evidence that the proposed course of action is not in the person’s best interests. |
Appendix 7: Example SMT IMCA Report

Client details:

Name: Robert Smith  
DOB: 17.3.49  
Address: Bellamy House  
High Street  
Anytown  
Client ID: SH0936

Decision details:

SMT  
Date of Instruction: 14.5.10  
Report No: 1  
Date report submitted: 18.5.10

Summary of decision to be made (including options being considered)

Mr Smith is a 61-year-old gentleman who has an acquired brain injury. Following a recent admission to hospital after a fall he has developed a serious infection. The proposed decision is a DNAR order (which was put in place 6 days ago when Mr Smith’s health deteriorated) in the event that Mr Smith should suffer a cardiac arrest that resuscitation is not attempted.

Eligibility criteria

Assessment of capacity
I understand from my discussions with Dr Jones that an assessment of capacity has been carried out in accordance with the Mental Capacity Act. I have not seen a record of this assessment and whilst not disputing that Mr Smith is deemed to lack capacity would highlight that the code of practice advises, “to carry out a proper assessment of a person’s capacity to make particular decisions and to record the findings in the relevant professional records”. MCA Code of Practice (4.61)

Family or friends appropriate to consult
Mr Smith has no family or friends to consult with.

Actions undertaken by IMCA

Medical Records accessed ✓ Social Care records accessed ✓

Meetings/contact with people involved

- Met with client, Robert Smith on 16/05/2010
- Spoke to Laura Woods – Speech and Language Therapist on 14/05/2010
- Met with Diane Knowles – Specialist Nurse Care Manager on 16/06/2010
- Angela Richards – Manager at Bellamy House on 16/05/2010
- Spoke to Dr Osborne – GP on 15/05/2010
- Discussed case with Dr Steve Jones – Consultant on ward 3, acute medical ward at the Anytown Royal Infirmary on several occasions since instruction.
Records seen
- Medical records accessed on the ward.
- Previous 2010 IMCA report: BL0368
- Recent social care assessment (carried out on 14/04/2010 for Mr Smith’s yearly accommodation review).
- Daily records kept at Bellamy House and completed by key worker/care staff

The wishes, feelings, beliefs and values of the client:

I met with Mr Smith on 16th May on the ward. Angela Richards, Manager at Bellamy House and Laura Woods, community SALT accompanied him. He appeared to be aware of his surroundings and responded appropriately to questions I asked via the use of a picture book, for example, I asked how he was feeling and he pointed to a happy face and smiled. When asked where he is now he pointed to a picture of a hospital. When I asked where Mr Smith wanted to be right now he showed me pictures of home (photos staff had taken of the house and residents).

It has not been possible for me to ascertain what Mr Smith’s wishes are regarding this decision fully other than to outline the above that Mr Smith wishes to go home and that this makes him happy. Mr Smith visibly looked brighter when he saw Angela on the ward. Those that work with Mr Smith have informed much of the report with respect to Mr Smith’s wishes, preferences and daily living. Mr Smith’s faith is described by Angela Richards as ‘Church of England’, but she feels that his religion does not play a significant role in his life. Angela feels that “he would want to come back” should he suffer a cardiac arrest.

Support offered
Dr Jones explained that she had attempted to explain the decision to Mr Smith but he had not responded to her.

Laura Woods has spent some time with Mr Smith and whilst he has been unable to understand fully what the proposal is he has been able to convey that he knows he is in hospital, that he hadn’t been well and was very scared of this but that he feels much better and is keen to go home.

Staff on the ward have commented on the fact he smiles and holds hands with his care home staff whenever they visit so concurred he appears to have some awareness of where he is.

Information obtained

Background
Mr Smith has lived at Bellamy House for the last 12 years, his health began to deteriorate about 3 years ago and he has suffered from CVAs in 2004 and 2008. Dr Osborne, GP, states Mr Smith’s health “has gradually been deteriorating” which has resulted in increased care within the home including staff supporting him with eating, drinking and bathing. However he highlights that he has remained stable for over a year now, maintained his weight for the last 6 months although is still medically underweight, and is now quite frail with reduced mobility but that the package of care in place still means he has the support of 2 members of staff at all times so he is able to go out into the community quite regularly which he enjoys.

Information from other people
Laura Woods has spent a great deal of time in supporting staff to communicate more effectively with Mr Smith as his health deterioration has meant that he now mostly communicates through gestures, facial expressions and the use of pictures.
Dr Jones feels that there is a chance that Mr Smith could recover should he suffer a cardiac arrest and believes that there is still a small risk of a cardiac arrest despite the improvement in his health (this risk has decreased in the last 2 days) Dr Jones feels that in the event of CPR needing to be performed that this “could result in further brain damage by hypoxia caused by the aspiration” but that this was by no means certain. Dr Jones believes that if this occurs Mr Smith’s care at home would need to be increased and his quality of life with respect to any independence would be greatly diminished. Dr Jones feels the level of care, which may be required in these circumstances, would not be “indicative of a quality of life”. At present his health is improving and it is hoped he will recover from this infection and be able to go home.

Conclusion

The Code of Practice (5.31) states that, “All reasonable steps which are in the person’s best interests should be taken to prolong their life. There will be a limited number of cases where treatment is futile, overly burdensome to the patient or where there is no prospect of recovery. In circumstances such as these, it may be that an assessment of best interests leads to the conclusion that it would be in the best interests of the patient to withdraw or withhold life-sustaining treatment, even if this may result in the person’s death”.

However whilst Dr Jones has expressed concerns that resuscitation would be potentially burdensome to Mr Smith I feel it is important to note that Mr Smith’s health has improved since the DNAR order was put in place and that Dr Jones is confident as to his recovery from his current medical condition. The staff that work with Mr Smith in the care home describe his “quality of life” as “excellent” based on his previously expressed views and therefore I would ask that consideration is given to the fact that whilst Mr Smith has a great deal of physical health needs which are unlikely to change (regardless of the outcome of CPR) there is no evidence to suggest Mr Smith believes this is unduly burdensome on his life. His quality of life cannot be determined by the extent of his care needs either now or in the future.

As this decision appears to be finely balanced due to the uncertainty of the likely success of CPR and the views of those who know Mr Smith well clearly indicate that they feel CPR should be attempted and that there is a good possibility that the potential recovery would not be too burdensome. I would ask that consideration be given to the removal of the DNAR. Whilst Mr Smith remains in hospital I am aware that any decision will of course need to be reviewed regularly until his discharge when the DNAR order will no longer apply and Dr Jones will no longer have the decision making responsibility.

Therefore on discharge I would ask whether a referral for a care review be made to the IMCA service to allow continued advocacy representation for Mr Smith on the subsequent End of Life Care Plan that is to be made as my understanding is that this would include discussions on DNAR.

Signed:

Date:
Appendix 8: Example SMT IMCA Report

Client details:

<table>
<thead>
<tr>
<th>Name:</th>
<th>Pauline Brown</th>
</tr>
</thead>
<tbody>
<tr>
<td>DOB:</td>
<td>17.6.45</td>
</tr>
<tr>
<td>Address:</td>
<td>Flat 1, Beach View House</td>
</tr>
<tr>
<td></td>
<td>Seatown</td>
</tr>
<tr>
<td></td>
<td>Devon</td>
</tr>
<tr>
<td>Client ID:</td>
<td>12134</td>
</tr>
</tbody>
</table>

Decision details:

<table>
<thead>
<tr>
<th>SMT</th>
<th>Change of residence</th>
</tr>
</thead>
<tbody>
<tr>
<td>Date of Instruction: 29.3.10</td>
<td></td>
</tr>
<tr>
<td>Report No: 1</td>
<td></td>
</tr>
<tr>
<td>Date report submitted: 7.4.10</td>
<td></td>
</tr>
</tbody>
</table>

Summary of decision to be made (including options being considered)

Pauline Brown is 65 years old, has a learning disability and lives in her own flat with support from carers once a day. Pauline was diagnosed with bowel cancer in early March and underwent surgery to remove the tumour on 24th March 2010. Dr Hunt has informed the IMCA service that patients in Pauline’s circumstances would usually be offered chemotherapy following surgery within 3 months. The decision now needs to be made as to whether it is in her best interests to receive this treatment or not.

Eligibility criteria

Assessment of capacity

I understand that Dr Hunt has completed an assessment of capacity with the support of Rebecca Chorley, Learning Disabilities nurse, and Pauline Brown’s professional team. Pauline has not been able to comprehend the benefits of having the treatment, although she has a basic understanding of the side effects and how they would affect her lifestyle. Dr Hunt therefore concluded that she is unable to weigh all of the relevant information in order to make the decision for herself. I have not seen a record of this assessment and whilst not disputing that Pauline is deemed to lack capacity, would highlight that the code of practice advises, “to carry out a proper assessment of a person’s capacity to make particular decisions and to record the findings in the relevant professional records”. MCA Code of Practice (4.61)

Friends or family appropriate to consult

Pauline Brown has a brother and a sister. Anthony lives locally in Seatown however owing to his profound learning disability he is not considered as ‘appropriate to consult’. Dorothy lives in Barbados and has not been in contact with Pauline for several years so is therefore not able to support and represent Pauline through this decision.

Actions undertaken by IMCA

Medical Records accessed ✔ Social Care records accessed ✔

Meetings/contact with people involved

- Pauline Brown – client on 1st and 5th April 2010
- Dr Steven Hunt – Consultant Clinical Oncology on 29/03/2010 & 01/04/2010
- Richard Palmer – Team Leader, Seatown Community Learning Disability Support Services
- Diane Abottsley – Support Services Manager, Seatown Community Learning Disability Support
Meeting with client
I met with Pauline Brown on two occasions on 1st April and 5th April at her home.

Records Accessed
I read Pauline’s relevant healthcare records related to her diagnosis and treatment of cancer sent to me by Dr Hunt.

I looked at Pauline’s support plan drawn up by Richard and his team at Beach View House.

<table>
<thead>
<tr>
<th>The wishes, feelings, beliefs and values of the client:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pauline is currently feeling well and describes herself as a “picture of health” which she is clearly enjoying after many months of feeling unwell.</td>
</tr>
</tbody>
</table>

She enjoys an active and varied lifestyle, which includes swimming, bingo, shopping, pubs, and visiting friends at a local day centre. She also enjoys her job, working one day a week packing leaflets for distribution.

Living an independent lifestyle seems to be very important to Pauline. She told me she had lived with others in the past but much prefers it “on my own” as she likes to have her own space, and enjoys the freedom to “do what I like within reason”.

Pauline appeared to me to live very much in the ‘here and now’, she found it difficult to think about the future or reflect on the past with me. This impression was confirmed by all of the professionals who know her well, Richard felt “she lives for today” and it is difficult for her to “look to the future”. This seems to underpin Pauline’s lack of capacity regarding this treatment decision, but also highlights that the present (rather than the future) is most important to her.

Pauline does not wish to have the chemotherapy treatment, as she is very concerned about the impact that it would have on her lifestyle. Her main concerns seemed to be about the “diarrhoea”, having to “leave my flat” and not being able to work. She spoke about how frightened she is of hospitals telling me “I’m scared out of my wits”.

Furthermore my impression was that Pauline has a positive outlook on life, and whilst she recognises the cancer “might come back” she feels reasonably positive that “it might not”.

Pauline does not like having to go to hospitals or see doctors. Richard told me that she has been known to ‘hide’ symptoms from her carers in the past to avoid treatment, and has ‘sabotaged’ tests (i.e. when trying to diagnose her cancer she would eat lots of food before her scans when she had been asked not to).

Information obtained
Information from other relevant people
I understand from Dr Hunt that following her surgery Pauline now has a 55% chance of survival beyond 5 years. Pauline falls into the category (in terms of age and health) of patients who are appropriate for Chemotherapy. Providing the chemotherapy would increase Pauline’s current 55% chance of survival beyond 5 years, by a further 7%. This is based on Pauline receiving a 6-month course of tablet form medication. There are also additional injections that could be administered which would add a further 3%, however Pauline is needle phobic and therefore this treatment may not be in her best interests.
I understand from Dr Hunt the side effects from administering chemotherapy to be:

- Increased risk of infection due to suppressed immunity
- Diarrhoea
- Sore hands, feet and mouth
- Damaged nerves causing pins and needles and feeling the cold to a painful degree and that patients will get “some or all but always some” and that “almost everyone gets diarrhoea, sore hands and feet and reduced immunity”.

The side effects would have an impact on Pauline’s general lifestyle for the duration of the treatment; it’s expected that she would not be able to work for at least part of the duration and she would be severely restricted in the activities she is used to doing. Dr Hunt felt that the side effects would be “debilitating” for Pauline, and everyone I have spoken to agree with this. Diane Abbotsley, Support Service Manager, told me that “we all feel that the impact on her life would be horrendous”, and Richard Palmer, Pauline’s support worker, felt it would “disrupt her life too much, she enjoys her routine and loves her life at the moment”. Pauline is an active person who enjoys “going out and about when she wants” and Rebecca Chorley, Learning Disability nurse, felt that Pauline’s “quality of life is more important to her at the moment”. Furthermore Pauline had suffered with diarrhoea after her surgery, and Richard told me that this had “devastated her, she couldn’t cope at all”. In addition Richard felt that when Pauline was unwell she felt “depressed and anxious” as she “wanted to go back to work”.

Another key factor that Dr Hunt has highlighted is that these side effects can be life threatening and that patients can “become very unwell very quickly”. There is a 2% risk that anyone receiving chemotherapy will die from the treatment. Dr Hunt feels that Pauline may not be able to recognise if she had symptoms, which require attention, and therefore the risk to her would be higher. Diane felt that whilst Pauline may be able to recognise when she is unwell, she tends to “hide” her symptoms, as she is “scared of having to go to hospital”. For example she had an “ulcerated leg for months before she showed us”, she had “bladder incontinence and wasn’t telling us”, and regarding the beginning of her cancer symptoms she felt, “it must have been going on for ages but it wasn’t until a member of staff saw her being sick and she was losing weight that she finally admitted she was being sick”. Due to these risks, Pauline (similarly to all patients receiving chemotherapy, but especially considering the increased risks for her as outlined above) would require 24-hour support whilst the treatment was being administered. As Dr Hunt summarised it would “not be safe [for Pauline] to be alone at all”.

The options for providing 24 hour support to Pauline for the duration appear to be: moving to Sunnyside respite unit, or 24 hour carers in Pauline’s home. Sunnyside seems to be the most viable option as Pauline’s flat is one bedroom so it does not have a sleep-in facility for staff. Also Anne Peterson, Pauline’s social worker, felt that for carers to be in Pauline’s home would be “an invasion of her privacy and she would get fed up”. Her current carers cannot provide 24-hour support in Pauline’s home, and therefore a new care agency would need to supplement the care she currently receives. When considering these choices Diane felt that Pauline “knows us all well”, “we’re like her friends”, “she wouldn’t see us if she went to Sunnyside”, but equally she “wouldn’t like strangers in her house”. Pauline has lived in her flat for the last 6 years and told me that she really enjoys it; she also clearly has a good relationship with her support workers. She used to share with others but much prefers living on her own. Richard felt “she likes her own company” and Diane agreed, “she does like her own time, and quiet moments are very important to her”.

Finally it seems that Pauline’s understanding of time is another factor to be considered. Pauline could not tell me how long the treatment would last when I discussed it with her. Richard told me that Pauline “doesn’t understand the concept of time, but 6 months is a long time to her”. Diane agreed with this and gave me the example that “if I say [to Pauline] I’ll be back in 2 hours; she’ll be waiting for me at the window after 10 minutes”. Therefore the 6-month course of treatment would likely feel very much longer to Pauline.
Support offered
I have been very impressed with the support that Pauline has been given to provide her the best opportunity to make this decision herself. She has been totally involved throughout the decision making process.

Least Restrictive Principle
To provide this treatment would likely entail administering it against Pauline’s will. Richard feels that this would cause distress to Pauline, and that she would feel “very angry and would refuse”. Furthermore Richard also highlighted concerns that “if she feels too much pressure she will go walkabout”. Pauline has gone missing for up to 3 days in the past, most recently after a doctor’s appointment for thrombosis. Covert medication would not seem to be an option considering the associated side effects. Furthermore the consequences of having to move to Sunnyside while the treatment was administered may amount to a Deprivation of Liberty for Pauline. Bearing this and the other factors in mind, it would seem that to not provide the treatment would be the less restrictive option.

Second Medical Opinion
Not requested by the IMCA.

Conclusion
The people who know Pauline best have expressed their concerns that she will find the treatment very distressing and will have great difficulty in comprehending the duration of the treatment and managing the side effects. The benefit of Pauline having the treatment is that it may extend her life expectancy, however, Dr Hunt and others have expressed concern that there is a risk that Pauline would possibly not recognise when she is ill or would not seek help if she needed it, following chemotherapy treatment.

The Mental Capacity Act, Para 5.19 states: “when making a decision about major medical treatment, a doctor would need to consider the clinical needs of the patient, the potential benefits and burdens of the treatment on the person’s health and life expectancy and any other factors relevant to making a professional judgement”.

Dr Hunt proposes that Pauline Brown does not receive this treatment, as the associated burdens would seem to outweigh the benefits. Rebecca Chorley agrees that “it wouldn’t benefit her; the downsides seem more than the positives”. I am very satisfied that all of the factors, which are relevant to this lady, have been taken into account in formulating this proposed option.
Best practice guidance range
The IMCA Support Project has produced a range of guidance on the involvement of IMCAs in SMT decisions that can be accessed on the Action for Advocacy website under IMCA Support Project, articles and resources.

The involvement of Independent Mental Capacity Advocates in Serious Medical Treatment Decisions
Best Practice Guidance for Healthcare Professionals and IMCAs. Includes case examples, example policies and useful forms.

Serious Medical Treatment - Specific Decision Guidance for IMCAs
The guides cover some common SMT decisions IMCAs may be involved in.

- Do Not Attempt Resuscitation (DNAR)
- PEG Feeds
- Chemotherapy
- End of Life Care
- Dentistry
- ECT Factsheet

Serious Medical Treatment Checklist (for the involvement of IMCAs)
A useful A4 chart, which gives information aimed at health professionals about when to instruct IMCA.

IMCA involvement in SMT decisions leaflet
A leaflet aimed at healthcare professionals which gives information on the IMCA role and when and how to instruct IMCA.

www.actionforadvocacy.org.uk
# Acknowledgements

We would like to express our thanks to the following people and their organisations that contributed to the development of this guidance.

<table>
<thead>
<tr>
<th>Name</th>
<th>Position</th>
<th>Organisation</th>
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<tbody>
<tr>
<td>Gill Winter</td>
<td>IMCA</td>
<td>VoiceAbility</td>
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<tr>
<td>Katrina Miller</td>
<td>Mental Capacity Advocacy Manager</td>
<td>Lancashire Consortium</td>
</tr>
<tr>
<td>Clare Dodds/Rachel</td>
<td>Senior Advocate</td>
<td>Age UK Cheshire</td>
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<td>slack</td>
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<td>Jayne Astbury</td>
<td>IMCA</td>
<td>Rethink Manchester</td>
</tr>
<tr>
<td>Sharon Thompson</td>
<td>MCA Lead</td>
<td>Northumbria NHS Trust</td>
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<tr>
<td>Ken Hawkins</td>
<td>IMCA Manager</td>
<td>Rethink Norfolk</td>
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<tr>
<td>Deevette Short</td>
<td>IMCA Manager</td>
<td>Age UK Devon</td>
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<tr>
<td>David Thompson</td>
<td>Senior Practice Development Manager: Mental</td>
<td>SCIE</td>
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<tr>
<td>George Kirkman</td>
<td>IMCA</td>
<td>VoiceAbility</td>
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<tr>
<td>Tracy Brown</td>
<td>Adult Safeguarding Lead</td>
<td>Hinchingbrooke Hospital</td>
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