Royal College of Physicians

Conversations for ethically complex care

A framework to support discussion and documentation of decision making for levels of care in clinical practice

Introduction

Discussing the available options for treatment and care with patients is part of everyday clinical practice. Many decisions are straightforward, where the options are evidence-based, available within the particular healthcare setting and patients are clear about their wishes regarding treatment and the outcomes they would value. In these circumstances the healthcare team are well placed to determine the best care for the patient.[1]

Decisions regarding the escalation, de-escalation or a change of level of care have a significant impact on the patient – and the patient, their family members and healthcare staff may find it challenging to accept the proposed changes to care. Some decisions can be complex or contested, others highly contextual, and some take place in the context of resource limitations over which the clinical team or organisation has no control.

This guidance has been designed to provide a clear framework for ethical **discussions** to support decision making and documentation in clinical practice. It outlines a structured, patient-focused approach suitable for use by **all professional groups, specialties and in all care settings**. It is intended to be disease- or diagnosis-agnostic and to ensure fair and equitable care for all, irrespective of the individual's background, and without causing harm to their long-term health and wellbeing. For more complex situations, we recommend you use the accompanying Ethical Care Decision-Making Record (ECDMR). It is specifically designed to facilitate a discussion about care, and to assist with the recording of all relevant information, discussions held and decisions made by the clinical teams in conjunction with the patient, their carers or their family members. The ECDMR can be adapted for local use, and can guide structured clinical recording. Relevant parts of the ECDMR are cross-referenced in this guidance with the annotation **ECDMR** and its section or sub-section.

This guide provides detailed support on the information necessary to facilitate discussions about escalation, de-escalation or a change in the level of care for a patient and how this can be recorded. It conforms to the shared decision-making policies of the NHS. It has been designed with an appreciation of the complexity of these decisions and the need for clinical judgement that is specific to the patient and their situation. It encourages a focus on the patient's outcome and includes their wishes (and those of their family or carers where appropriate) as much as is feasible for the given situation.

There will be circumstances where this approach is not appropriate. There may be situations beyond the scope of this process that require external expert and/or legal intervention and judgement.

Key guiding principles

The Royal College of Physicians (RCP) proposes the following six key guiding principles for ethical decision making which leave room for judgement to be applied appropriately in specific circumstances:[2]

1. Respect for patients
2. Duty of care
3. Equity of care
4. Accountability and transparency
5. Inclusivity
6. Reasonableness

Levels of decision making

ECDMR: Step one

Certain factors will influence the type and complexity of information used and also the level of detail of discussion and documentation that may be required in the decision-making process. Table 1 outlines the factors that may be considered to ensure the most appropriate and proportionate approach, and to ensure a consistent and effective structure in more challenging situations. We have defined three levels for potential application of the ECDMR: standard practice, greater complexity and special circumstances.

Table 1. The levels for potential application of the ECDMR format

Application →	Standard practice	Greater complexity	Special circumstances
Factors ↓			
Patient's wishes	Clearly stated and undisputed	Uncertain or challenged, further information required	Disputed by one or more source; legal services involved
Mental capacity	Clearly defined and undisputed	Uncertain or challenged, further assessment required	Patient assessed under the Mental Capacity Act or treated under the Mental Health Act
Family/carers	Wishes clearly identified; no conflict with care plan	Disagreement or uncertainty regarding the care plan	Significant dispute with care plan; active complaint process
Clinically focused	Clear treatment plan/options with outcomes defined	Treatment plan and/ or outcomes unclear or uncertain	Tertiary/highly specialised or prolonged care needs identified
Team-focused	Single clinician/team or specialty managing all care	Multidisciplinary team and/ or higher level (critical) care needs	Single or multidisciplinary with multi-organisational interaction
Level of expertise	Routine activity; established pathway or guideline-driven	Expert opinion; 'off-guideline' or novel application of care	Delivery of trial or experimental technology or therapeutics
Organisational	Infrastructure and resources appropriate to deliver all care	Some limits of infrastructure or resources restricting care	Serious limits of infrastructure or resources preventing care
External (contextual)	No external factors or no impact from external factors	External factors with individual or local impact on care delivery	Significant factors at a regional or national level restricting care
	↓	↓	↓
Process	Routine clinical conversation, engagement with patient and/or carer/family. The ECDMR is offered as a template for discussions	'Clinical conference' with relevant specialties, patient and/or carer/family. Consider using the ECDMR to guide discussions	Higher-level discussion (eg CD or MD/CMO-managed), trust ethical committee or an external advisory agency/ authority using the ECDMR to guide discussions*
Documentation	Routine entry in patient's clinical record; additional forms for care escalation decision, consent or DNACPR as required	Routine clinical records and forms augmented by the ECDMR	Potential to use the ECDMR with any additional evidence or direction added as supplementary information

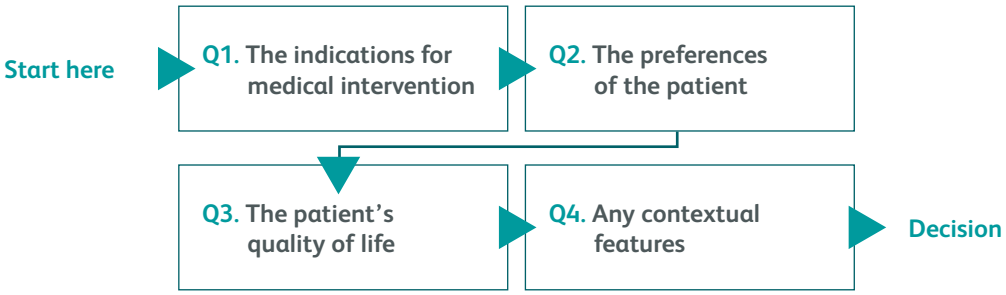
* Higher-level authority may be delegated under certain circumstances and with clear policy direction.

A four question (4Q) approach[3]

ECDMR: Step two

Influenced by the four quadrant approach of Jonsen, Siegler and Winslade (1982), four key questions are used to facilitate and support conversations for ethically complex care.

Figure 1. The 4Q approach



The 4Q approach is used in this guidance as a framework to aid ethical decision making. The emphasis on indications for medical intervention has been modified to more broadly capture any clinical decision, its anticipated impact on a patient's quality of life and the intended outcome in keeping with the guiding principles as outlined above. The ECDMR/4Q format is described below.

Q1. What specific clinical decision is being discussed, and what are the possible outcomes?

The nature of the decision should be clearly stated and the option(s) and potential outcome(s) defined as best as can be offered with the information available at the time. This question is critical to set the clinical context in which to answer the next three questions. In practical terms, this question is exactly the one that would initiate a conversation with the patient, their carer or family member regarding their care or a multidisciplinary or multi-agency team discussion in more complex circumstances. There is no predetermined format or agenda for this conversation. The methodology chosen would be at the discretion of the clinical team on a case-by-case basis.

Q2. What are the patient's values and preferences?

This question is split into five parts:

A. The presence and particulars of any advance care plan (ACP), do not attempt cardiopulmonary resuscitation (DNACPR) decision or recommended summary plan for emergency care and treatment (ReSPECT[4]) document would need to be briefly summarised, along with their validity and date of writing. These would be referenced as relevant to question 1 (Q1) and confirmed, if necessary, in the case of any dispute or change in circumstances.

B. Consider the patient's mental capacity, and if required a Mental Capacity Assessment should be carried out in relation to Q1 at the time of the discussion.

C. The patient's wishes, if they have capacity to express them, in relation to Q1 should be documented. The emphasis should be on their understanding and opinion regarding the potential outcome(s) of the decision.

D. The views of the clinical team about the decision being considered in Q1 should be documented; specifically what is felt to be in the patient's best interests. This is especially relevant if the patient is unable to state their wishes. Opinions may differ between parts C and D, and this will normally be part of discussions prior to agreeing the final decision or course of action.

E. Any other relevant source of information, such as the name and details of a family member or carer involved in the discussion.

Q3. What are the anticipated effects on the patient's quality of life?

This question is split into four parts:

A. The patient's views (if they have capacity) on the effects of the decision, or outcome on their quality of life.

and

B. The views of the clinical teams regarding any likely effects of the decision on the patient's quality of life.

C. Consideration given to multiple conditions and underlying health conditions and, for older adults, the current level of dependency – measured on the Clinical Frailty Scale.[5,6]

D. The influence of any discerning features such as a prognostic score or performance measure (see page 7).

Q4. What contextual factors, if any, have an impact on the decision or outcome?

This may include (although not exclusively) religious, cultural, legal or resource-related factors. The key feature of this question is whether or not the contextual factor has any material impact on the decision being considered or its outcome. There may be no contextual factors. If the decision-making process **has been initiated due to contextual factors** it should be referenced in **Step one**

For example, religious beliefs may limit certain options for medical treatment (eg blood product administration for a Jehovah's Witness), meaning an acceptable alternative should be sought and discussed with the patient. There may already be a legal precedent to consider in terms of what kind of care should (or should not) be delivered from, for example, the Mental Capacity Act, the prior decision of a court, advance directive, power of attorney or similar legal document.

Special circumstances such as a large-scale or prolonged critical incident or national emergency which limits resources or infrastructure would also introduce non-clinical factors which constrain the level or scope of clinical care that would otherwise have been available. This situation would often require further prioritisation of patient care, including potentially novel triage processes, or limited access to experimental treatment or clinical trials. It can also be referred to as 'scarce resource allocation' (see page 8).

Where contextual factors are introduced through the activation of regional or national policy in response to an incident, this should be referenced appropriately. This will ensure that the provenance of the decision-making process is clear, can be reviewed and will stand up to scrutiny in the event of investigation or enquiry later.

Making the decision

The following general principles should always apply:

- The patient's wishes regarding ongoing care (as much as is feasible for the given situation) and, if appropriate, those of their carers, should always be discussed, considered and recorded.
- Decisions should ideally be made by the most qualified, usually senior clinician, involved in the patient's care. If this is not the consultant, then they should be informed at the earliest opportunity and work with junior staff to support them through this process.
- Decisions should ideally be made by more than one clinician and, wherever possible, involve the entire multidisciplinary team. There will be occasions when a second opinion may be beneficial.
- Decisions should be taken inclusively, transparently and documented robustly.

If further important patient or circumstantial information is required then this should be recorded and appropriate plans made to either seek this before agreeing the decision, or to review the decision once this information becomes available.

Any subsequent changes to the decision or care plan should be documented carefully and in a manner which clearly demonstrates this change. Such entries should be signed and dated accordingly. Previous decisions may be crossed through for clarity. After gathering the information through the 4Q process, a decision can be made in most cases. This can either take the form of a clinical conversation within the clinical setting or may be conducted as a formal 'clinical conference' chaired by a nominated clinician or the multidisciplinary lead for complex cases.

In urgent, time-critical situations it may be that a more junior member of the clinical team will be required to undertake decision making. The framework provided is intended to offer a process to facilitate this rapidly, confidently and comprehensively, while waiting for the support of a senior clinical decision-maker.

It may not always be possible to obtain all the necessary information that may influence the decision such as the patient's wishes, their quality of life, or relevant background medical information. In these circumstances, decisions should be made according to the patient's best interests, following the principles as fully as possible. Certain circumstances may also limit to what extent patient autonomy can be respected. (eg clinical care in waiting ambulances).

Agreed decision / course of action

ECDMR: Step three

The agreed decision should be documented along with any relevant action plan. Specific dates and times should be recorded. If further management steps, such as follow-on investigations or discussion are required these should also be noted as well as reference to any other relevant documents, for example a consent form. Where a change of escalation level or DNACPR decision has been agreed, this should be noted as appropriate. If the decision is subject to any future review this should also be documented, and the specific date noted as planned.

There should be clear communication of whom this decision has been shared with, including the patient (as appropriate), carers or family members. If the decision is required to be shared externally with another organisation, for example the patient's GP or another clinician, this should also be recorded for coherency and continuity.

The location for ongoing care should also be clearly documented, especially if there will be a change of care location, eg a new department or external organisation.

Responsibilities

ECDMR: Step three

The names and roles of all those involved in the decision-making process should be recorded with specific identification of the clinical lead (or the clinical conference or multidisciplinary team leader) and any individual team member or specialty representatives.

The clinical lead would take the responsibility of ensuring documentation, appropriate sharing of information and enacting the action plan. Any handover of clinical responsibility can also be recorded at this stage.

Guidance on prognostic, outcome or performance measure scores

ECDMR: Question three

Clinicians often use objective clinical scoring measures to facilitate patient-centred care and shared decision making. Used sensitively and pragmatically, certain prognostic scores may provide more objective and/or more accurate prognoses than clinician predictions alone.

A number of scoring systems and prognostic algorithms have been developed and validated. These range from widely used physiological scores for severity in acute illness, such as NEWS2, to critical care mortality prediction scores, such as APACHE II. Further examples are shown in Table 2.

Table 2. Examples of scoring systems

Score title	Consisting of	Purpose
NEWS2	Six simple physiological parameters	Universal severity score for acute illness
APACHE II	Patient demographics, acute physiology, blood results and pre-existing health conditions	ICU admission mortality prediction
SOFA	Cardiorespiratory physiology, blood results and GCS	ICU admission prognosis
Charlson (CCI)	Demographics and pre-existing health conditions	Comorbidity Index (10-year survival)
RESP	Cohort-derived score; clinical and intervention data	Determine chance of mortality from ECMO

GCS = Glasgow Coma Scale; ECMO = extracorporeal membrane oxygenation

The key factor to consider with all these scoring measures is that even the best estimated prognosis can change over time, as can the patient's wishes or appreciation of risk in relation to the effect on their quality of life. In such a dynamic situation, decision-making conversations may take place over several contacts, in different care settings and with different clinicians. Therefore, it is vital to ensure adequate documentation of which tool(s) has been used in the assessment and continuity of communication with other healthcare providers.

Scarce resource allocation – guidance for escalation decisions

ECDMR: Question four

Difficult decisions regarding prioritisation and resource allocation can arise in special circumstances, eg seasonal pressures, civil emergencies. Most recently this issue has been raised during the COVID-19 pandemic. The term 'asymmetric conditions' has been used where the rising intensity of an incident shifts the emphasis from conventional standards of care and full patient autonomy, to that of contingency and then to a crisis response when demand outstrips capacity and resources. While care will always be provided, as a result of scarce resources and rationing, patients' choices may become increasingly limited.[8]

In special circumstances requiring a scarce resource allocation policy to be adopted, the use of available resources is not decided upon in the interests of the individual patient alone, but also in the interests of other patients who could benefit from the same, acutely limited, resource. **It is important from an ethical perspective (with particular regard to integrity and trust) that prioritisation and best interests decisions are not conflated.** It is also important to avoid over-anticipation of the crisis stage, leading to inappropriate denial of care.

Situations where scarce resource allocation policies are applied should be exceptional and should not be invoked due to expediency such as temporary 'bottlenecks', eg a local intensive care unit being full when other local or regional provision might be brought on stream. Decisions made on the basis of limited resources should only be made due to the declaration of a national emergency where 'triage' (or other prioritisation processes for treatment allocation) has been authorised. It is also important that the moral burden is NOT placed upon frontline clinical teams.

Decisions that are based on triage principles should never be misrepresented as 'best interests' decisions to patients and their relatives. Those affected should be told honestly when access to a treatment is restricted by limited resources. This may also be considered under the policy of duty of candour. Clarity should be offered regarding the process and governance of such decisions, and the challenges involved.

> '…it is ethically equivalent to withdraw treatment instead of withholding treatment…'[7]

Although ethically equivalent, the impact will undoubtedly be greater when it comes to withdrawing treatment as compared to withholding it. As such, these decisions must be made with the patient and, if appropriate, their carers.

Individual doctors should never make a decision to withhold care due to resource constraints alone without specific instructions as delegated from a higher-level authority

If a decision is made due to resource constraints, this should be recorded as a contextual factor, providing as full an explanation as possible as to why the decision was made based on resource constraints and not clinical need and referring to relevant national guidance or policy, and cross-referenced with Step one

Sources of advice

Medical ethicists (sometimes referred to as bioethicists) can help frontline staff with difficult decisions.[9] National guidelines may also be provided to assist decision making in certain conditions, such as the critical care management of patients during the COVID-19 pandemic.[10]

Relevant guidance for clinicians regarding good practice in decision making and planning for resource-limited situations is also provided by the GMC.[11,12]

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The ECDMR is available to download at www.rcplondon.ac.uk/ethically-complex-care
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