

Decision-making for ICU admissions: Understanding and improving the decision-making process surrounding admission to the intensive care unit

REC: WM/15/0025

Report of the stakeholder conference for conference delegates

Dear [Conference delegate],

Thank you once again for attending and contributing to the decision-making for ICU admissions stakeholder conference on the 1st July 2016 at Warwick University. At this event we described the problems with the way that decisions are currently made regarding admission to the intensive care unit, and we presented a draft intervention (decision-support intervention) to improve this process. The focus groups you participated in helped give us valuable insight and feedback on the intervention.

After the conference the notes taken by the focus group scribes were read by members of the study team: From these notes we identified the issues that participants raised, and the group(s) discussed, resulting in the emergence of agreement within the group(s) of how the issue should be taken forward within the Intervention. All elements of the decision-support intervention were discussed by one or more groups, and we have taken particular note of issues that emerged from more than one focus group. We are now sending you this brief summary of what was said in these focus groups. We have not included everything that was said in the focus groups in this report, as this is intended to remind participants of the discussions, to summarise the key points, and explain potential changes to the intervention. We have revised the decision-support intervention in light of what was said at the conference, and also included new versions of the forms that contain these changes.

We hope that you will find time to read this report, and examine the new drafts of the referral form, the decision-making form, and the patient/family information sheet. Once again we would like your feedback: particularly we would like to know if there are any major issues you think we should consider, whether or not they were raised in the focus groups, or if you disagree strongly with the amendments we propose.

Once you have read the report we would be very happy to hear from you. You can do this by directly replying to this email, contacting us by telephone, or sending us information at the address below.

Thank you once again for participating in this project

Yours Sincerely

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This report is a summary of the focus group discussions at the stakeholder conference on the 1st July 2016 at the Scarman centre at Warwick University. It is a summary of the notes taken in each of the focus groups, which have been analysed to extract the key messages. These have then been used to adapt the draft decision-support intervention presented at the conference, which is intended to improve the process by which the decision whether or not to admit a patient to ICU is made. The report is divided into the following sections:

1. Issues related to both referral and decision-support forms
2. Issues specific to referral form
3. Issues specific to decision-support form
4. Issues related to the educational package
5. Issues related to family information sheet
6. Barriers and facilitators to uptake

Each section ends with a brief description of how we have changed the intervention, in light of the comments made at the conference.

Issues related to both referral and decision-support forms

A concern voiced in some of the groups was that admission to ICU is only one aspect of escalation of care, and the decisions being addressed should reflect all aspects of critical care, including outreach support and high-dependency care. It was suggested that the forms should not be so narrowly related to ICU admission, but should be a referral for general critical care/intensive care support. One suggestion was to list all forms of intensive care service including HDU and ICU outreach

The question re “appropriate monitoring of patient” was challenged. The language was seen as ambiguous and subjective. A suggested rewording from “Is patient being appropriately monitored?” to “Can the patient be monitored on the ward?” was offered.

Another concern was the use of the term “family member” in the documents. It was suggested that this should be changed to reflect the fact that it is not only family members who best know the patient and reflect their views. Changing the wording to ‘outcomes relevant to the patient’ was suggested. Information specifying who has provided information, or who has been contacted should be added to the form.

Changes made:

- The focus of the documents has shifted: rather than being restricted to decision-making regarding admission to the intensive care unit, we have broadened the focus to include decision-making regarding the initiation of all critical care support. This will allow for more nuanced, patient-centred decision-making that is not as limited in scope by its outcome.
- In the section on patient's values and views the term (what is important to the patient' has been added.
- Family member has been changed to "person closest to the patient" to reflect the fact that other people may be better placed than family members to reflect the views of the patient. The question re appropriate monitoring of the patient has been removed

Issues specific to referral form

A range of suggestions and comments were made regarding the referral form. Participants suggested some additional sections including:

1. a section for recording which other health professionals had been consulted in particular nursing colleagues and members of the immediate multidisciplinary team;
2. a section to record the views of the family (other than their views on the patient's wishes)
3. a section to indicate any existing ceiling of care, DNACPR orders, any advance directive or Lasting Power of Attorney known about.

Participants also thought it was important to document on the form whether the referral had been discussed with a consultant and if so the name of the consultant.

Two further additional suggested options for reason for referral were: admission for a "trial of ICU"; and 'senior opinion' for patient requiring extra nursing support but not necessarily ICU intervention.

The focus groups questioned whether treatment initiated needed to be on the form and a suggestion made that this would be better worded as treatment already given. It was suggested that a prompt to check if any national or local guidance had been followed could be included in this section. There was also some question about whether the "recommendations for care" box was required and an alternative wording of 'referring clinician's recommendations for care' suggested.

The focus groups suggested that the form should follow the SBAR template as clinicians are familiar with this as a referral mechanism (SBAR is an acronym that is recommended to improve the quality of communication when referring a patient to another clinician. It prompts individuals making a referral to communicate the *situation*, the *background* to that situation, their *assessment* of what is happening, and their *recommendations* for action). More specific points included clarifying whether

multiple boxes could be ticked and that there is a requirement to specify if information is not available (not to leave section blank). Some specific comments on use of language were made including the use of the word appropriate. Finally, there was a reminder that the form should not replace face to face discussion between clinicians.

Changes made:

The referral form has been changed although not all of the suggestions have been included to ensure that the form remains practical, and simple to complete.

- The reference to ICU admissions has been changed in the title to “intensive care support”.
- The form has been modified to be closer to the SBAR format, and this has been directly referenced on the form.
- The name of the consultant with whom the referral has been discussed has been requested.
- The type of help requested options have been modified to include options for review alone, and to reflect the option of full or limited organ support (this would practically include increased nursing care). This section is now called ‘Recommendations’ in line with the SBAR format.
- The previous “recommendations for care” section has been removed to keep the form brief.
- The form has been modified to be closer to the SBAR format, and this has been directly referenced on the form.
- Language has been changed as suggested
- A reminder to engage directly with the ICU team has been added.
- A prompt is included that requires a reason to be given if no information on the patient’s views is recorded.
- A prompt to note any advance directive/lasting power of attorney or ReSPECT form has been included
- Treatment initiated has been removed from the form

Issues specific to decision-making form

A strong message that came out of the focus groups was the concern about recording the number of available ICU beds at the beginning of the form. Participants thought that this shifted the focus for

decision making away from patient centred care. There were concerns about the legal implications and impact on a patient's family's perception or fear that care would be limited because of resources. One group suggested that there be a prompt to advise clinicians not to think about resources while making a patient centred judgement. There was disagreement within the groups about whether resource limitations did actually affect these decisions in practice. However there was consensus that if this question was on the form it should be at the end not at the beginning, and that the wording should be changed to: "Is there likely to be a delay to admission?" and "What are you doing to ensure patient safety in the interim?"

For the sections on clinical background groups suggested that more prompts, with examples or tick boxes, would be helpful to guide clinicians as to what was required, for example frailty scores, residency, and other scores that are related to prognosis. Tick box prompts were also suggested to assist in balancing of burdens and harms. However some groups thought that this section required a more narrative approach for clinicians to justify their decision. There was a concern that the terms benefits and harms might generate generic rather than patient specific responses.

There was some difficulty in understanding what should go in the "combination of therapies" box. One group pointed out that expertise as well as treatments was important. Some groups thought that this box was unnecessary or could be combined with the burdens and benefits section. Additional options such as care on HDU were suggested. Groups agreed that the outcomes section should include an option for a trial of ICU, and a re-ordering of outcome tick boxes was suggested.

The groups noted that the recording of a patient's perspective should state the source of information (patient, advance directive, family or someone close to patient). They also suggested an additional text box specifying who was responsible for informing the patient or their family, and recording when this had occurred.

A further suggestion was that there should be space to allow for additions or corrections to the documentation.

Changes made:

- We have changed the text of the box requiring a balancing of benefits and harms, to balancing the benefits and burdens of escalation of care.
- The initial draft had a text box for recommended combination of therapies as well as for plan; these have been changed to a single box for recommended care and arrangements for review. As our qualitative data suggested a shortcoming of current practice was poor planning and communication regarding review of patients not admitted to ICU, this latter element was kept, but free text is not needed. This will also help to shorten the form, a key barrier to implementation.

- We have removed the section of the form relating to the context of decision-making (number of ICU beds and ward safety/monitoring). Although these factors have been seen to influence decision-making, referral to them on the form was thought to potentially adversely impact on relationships with patients and their families, put doctors at risk of complaint and litigation, and decrease uptake of the intervention.

Issues related to the educational package

The focus groups made suggestions about how the education might be delivered and taught. They commented that it would be important for training to be integrated throughout the NHS and multidisciplinary, with support of professional organisations. Specific suggestions included linking it to multi-disciplinary team meetings and providing an online resource. The scope of the teaching in terms of target audience was not clear.

All focus groups suggested that teaching methods should include practical application of knowledge with case based discussion, sharing of experiences and examples of good practice. The use of simulation based training was identified as very useful for this kind of teaching. The education should be aimed at enhancing and improving quality of decision making, rather than implying that staff are performing poorly.

Suggestions and issues raised regarding the content of any education intervention were wide ranging and could be grouped into the following areas:

1. Clarification of how and when to use the referral form and decision support framework..
2. Factors that are or should be considered in making decisions. These focussed mainly on age and ability to recover as criteria for admission to ICU. The difficulty and subjectivity in assessing ability to recover was seen as a key problem for clinicians with different views in the groups on the use of disability scores as an aid to decision making.
3. All groups identified communication with patient and family as important, for information gathering, understanding and respecting the patient's wishes, and explaining the limitations of ICU. Concerns about misunderstanding of the precise role of the family in decision making were raised as needing clarification, for both clinicians and families. Communication skills teaching was identified as important, including inter professional communication, including communication with outreach teams, nursing staff, and community staff.

4. Knowledge of the law and relevant professional guidance was identified as necessary for good decision making. Clarification of how the referral form and DSF fitted with the ReSPECT form was sought and the need to work within the Mental Capacity Act emphasised. Several groups also highlighted the need to ensure against discriminatory behaviour with specific groups of patients: e.g those with a learning disability or mental health disorder.
5. The need to provide an ethical framework for the decision making was identified as a key element of the educational package. The challenges of balancing burdens and benefits of treatment for a particular patient, balancing clinical assessments and patient's values, prioritising different values such as prolonging life or quality of life, and issues of distributive justice were all identified as difficult for clinicians and where support/education was needed. The importance of being able to make a transparent and justifiable decision was noted.

Changes made:

- All of these suggestions will be taken into account in the development and delivery of the educational package.

Within the study intervention the educational package will of necessity be focussed and tailored to be delivered in a single session for staff. However, the focus group comments on wider aspects of education for health care professionals related to this topic will inform discussions on development of a national educational initiative outside the remit of this project.

Issues specific to the family information sheet

Discussion of the patient /family information sheet provided several helpful suggestions for improvement. A key message from the groups was that the information sheet needed to convey the message that ICU was only one of a range of options of care for a patient; that ICU often had harmful consequences for a patient and that for some seriously ill patients the best option would not be to admit to ICU but to provide good end of life care. A more honest acknowledgement of death as a possible or even likely outcome for the patient was called for. Groups also noted that if a patient is not admitted to ICU they may continue to be monitored by ICU outreach or have other interventions and this also needs to be clear to families who may think that their loved one has been abandoned by the decision not to admit to ICU. The burdens on those close to the patient when their loved one was in ICU were not apparent in the current information leaflet and were seen as important to raise with families.

In general, clearer and less ambiguous language was thought to be required.. Words such as “benefit”, “need” and “appropriate” needed to be explained. Translations into other languages and possibly pictorial information was suggested to ensure that the leaflets were widely accessible. A specific

point was made that this information leaflet should not just be for families but for anyone close to the patient, including friends and informal carers.

The focus groups agreed with the need to provide information about where to go and who to talk to if they had any concerns and about the process for resolving disputes. The timing of giving the leaflet to family and friends was discussed. The groups thought it may not be so useful in an acute situation but would be useful in care planning. It was suggested that timing of providing the leaflet would need to be flexible depending on the situation. It was also suggested that there should be a tick box on the referral form to indicate whether the information leaflet had been given.

Changes made:

- The notes from focus groups were read and analysed by lay members of the study team, who led the development of a revised information sheet. A new draft of the patient and family information sheet has been developed. This new draft has tried to balance the need to explain the complex nature of these decisions with clarity, providing sufficient information in a readable way, without becoming overly complex. It has expanded to include the care options for critically ill patients more broadly, but still retain a focus on decision-making for admission to an intensive care unit. The new draft is attached, and we would appreciate feedback.
- A prompt and tick box has been added to the referral form to indicate that an information sheet has been given to the patient or their family.

Barriers and facilitators to uptake

The key barriers to implementation of the intervention related to time and timing of the use of the referral and decision support forms.

Focus group participants were concerned about the time it would take to complete the forms, and that clinicians may avoid completing them. A further concern was whether completion of a form would interfere with decisions being made in a timely manner. These decisions often need to be made urgently, and participants noted that completion of the form should not delay this. There were reminders that the goal is to improve the decision making process, not to complete a form. But the form (or framework) may facilitate improvement in the decision making process.

It was noted that much of the information required should already be documented in the patient notes but that the forms required this in more detail. Duplication of information on the two forms was also seen as a poor use of time and a suggestion to have integration of the forms, or for some information to be only documented on one form might increase their use by clinicians.

A further barrier to implementation noted is the lack of clarity/understanding about the intervention illustrated by questions about who should complete the form and whether an inability to complete a section would mean the form was not completed at all, or that a referral was not made. Participants shared experiences of problems with paperwork in clinical practice. Ensuring the paperwork (forms) is available at the right time and in the right place, and is transferred with the patient between departments is important to facilitate its use.

A major barrier to implementation of the interventions as it stands is the inclusion of the question in ICU bed number and the perceived negative consequences of completing this including: biasing decision making; impact on the relationship with the patient and family; risk of complaint or litigation.

There was a general view that standardised forms to be used across all Trusts would facilitate uptake, although some participants suggested modifications might be needed for different referring departments, with the option for individual Trusts to add to the forms but not omit anything. Colour coding of the forms would make them less likely to be missed. Support from professional bodies was also seen as facilitating uptake of this kind of intervention.

Changes made:

- The forms involved have been shortened and focussed. The use of the forms will be covered in the educational package accompanying their implementation including who should be completing them, and at what point, and the importance of ensuring care is not delayed. Determining whether this method of prompting a process and documenting the decision-making will work in practice is one of the goals of the implementation feasibility study.

The question regarding number of ICU beds available has been removed (please see earlier section on issues relevant to both documents).

Conclusion

Thank you once again for attending the stakeholder conference for the decision-making for ICU admissions project, and for taking time to read this report. Our intention remains to develop methods to improve decision-making on behalf of critically ill patients, and your help is greatly appreciated. If there are any comments you wish to make regarding the report, or suggestions for further development of the intervention we would be very grateful for your feedback. Please contact us using the details below.

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