Supplementary Material 13 – Topic guides for stakeholder conference focus groups

Focus group handout 1:

Referral protocol

A referral protocol should be developed at each Trust as part of the intervention. This should be publicized widely in the Trust and form part of the supporting education material to ensure it is used for all referrals to intensive care. A referral form is included as part of the intervention (**see separate form**). This gives a structured format for gathering information and communicating with the intensive care clinicians to support a collaborative decision making process.

The referral form may be in paper or electronic format. An electronic form would be part of the referral and workload tracking system (see component 3).

Results of our systematic review and observation study have shown that communication between senior and experienced colleagues is most likely to achieve optimum decision making for patient care. We recommend that referrals to intensive care are made and received by the most senior responsible clinician. Where the current Trust protocol assigns responsibility for referring or receiving referrals to a doctor below consultant level there should be a specified process for escalating the referral and admission decision process to a consultant if required.

Questions for focus group:

1. The referral protocol – does it make sense? Will it provide what is needed to support decision making?
2. Will it work in practice?

Affix patient sticker here

Admission date _____/_____/_____

Date of referral _____/_____/_____

Time of referral _____

Decision-making for ICU admission: Referral form

This form is designed to guide and record the referral of patients to intensive care. It should be completed by the person responsible for the decision whether or not to refer,

Current patient ward……. Outlier ward ……(yes/no)

Reason for referral to intensive care *(please indicate)*

☐ To consider admission to ICU for organ support

☐ To ensure all potentially beneficial therapies have been considered in decision-making for this patients care, but not necessarily to admit to ICU

☐ For assistance with a specific therapy to be delivered outside ICU *(venous access, help with NIV etc. Please specify)*……

☐ To help plan appropriate care in the event of deterioration

☐ Other *(please specify)*……

Background *(brief background of facts surrounding case and reasons for referral*

Acute illness *(diagnosis and physiological compromise)* **Current NEWS**……

ABG results……

Chronic conditions *(nature, severity and prognosis)*

Evidence regarding ability to recover from critical illness (*functional reserve, trajectory of illness, exercise capacity, dependence, frailty)*

Patient values and wishes *(what are the patient's values and views about escalation of care)*

Treatment initiated

Recommendations for care

Referring clinician

Name (PRINT)_____

Signature_____

Role_____

Registration number_____

Focus group handout 2:

Decision-making framework

Please read the next section together with the decision support form

The four stages of the decision-making framework are:

A. *The context of decision-making*

When a patient is being assessed for possible referral to the intensive care unit this decision is never made in isolation. Research has shown that a range of factors in addition to the medical condition of the patient affect the likelihood of a patient being admitted to ICU. Recording this information helps to remind doctors that these factors can influence a decision, and provides important information for managers in developing services and responding to patient safety issues.

B. *Information gathering*

In order to make a decision it is essential that accurate information is collected by a clinician trained to recognise its importance. Relevant information will include details of the acute illness and the present state of the patient; whether the patient has any other medical conditions and how serious these are; and the patient's ability to recover from this acute illness with a quality of life that is worthwhile to them. Information is also needed on what the patient wants regarding treatment and what is important to them in terms of the outcome of their treatment. This information should ideally be gathered from the patient themselves but if this is not possible because the patient is too sick then it may be gained from a patient's family or someone with a Welfare Lasting Power of Attorney, or from an advance directive or a ReSPECT form.

C. *Deciding on the best treatment and where it should be given*

A specific requirement in the decision support framework is to clearly describe how the clinician has balanced the burdens and benefits of intensive care for this patient. This balancing of benefits and

burdens should be done with reference to the information gathered in the previous section. This should be followed by a statement setting out the combination of therapies the clinician recommends to provide care that is in the best interests of the patient. The clinician should also state where this care should be given. Our observation study has shown that some patients may be admitted to ICU because of a lack of resources on the general ward.

D. Communication of decision and planning for future care

Whether or not the patient is admitted to ICU, the intensive care team should give recommendations for their further care including the aims of care, specific treatment options, and plans for review. The decision should be communicated both to the referring team and to the patient or their family.

Questions for the focus groups:

1. This part of the Decision Support Framework – does it make sense. Will it provide what is needed to support decision making?
2. Will it work in practice?

Affix patient sticker here

Admission date _____/_____/_____

Date of assessment _____/_____/_____

Time of assessment _____

Assessment number_____*(for repeat assessments)*

Decision-making for ICU admission: Deliberation and Decision form

This form is designed to guide and record the process of decision-making for ICU admission. It should be completed by the person making the decision whether or not to admit. It is meant to facilitate the best possible decision-making, but not to determine who should and should not be admitted. This remains the responsibility of the clinical teams looking after the patient

Context *(to allow planning of service and prompt reflection on needs of patients)*

Current patient ward…… Is patient being appropriately monitored……..

Outlier ward ……(yes/no) Number ICU beds available at time of decision……..

Background *(brief background of facts surrounding case and reasons for potential ICU admission)*

Acute illness *(nature, severity and prognosis)* **Current NEWS……**

ABG

Chronic conditions *(nature, severity and prognosis)*

Evidence regarding ability to recover from critical illness (*functional reserve, trajectory of illness, exercise capacity, dependence, self-reported QoL)*

Patient values and wishes *(, what are the patients values and views about escalation of care; what is important to the patient with regard to their treatment and the potential outcomes (priority is to get better/to achieve balance between getting better and a good quality of life/remaining comfortable)please note ReSPECT form/advance directive if available*

Balancing of burdens and benefits of escalating care (based on the information in section one)

Benefits of escalation of care *(what good may be achieved and what harms may be avoided, and what are the chances of this happening)*

Harms of escalation of care *(what harms are likely to occur, and what benefits may be missed due to escalating care)*

What combination of therapies are recommended to optimise care?

Can this care safely be delivered outside ICU *(if resources not available to deliver required care outside ICU consider admission on grounds of patient safety and escalate concern to management team)*

☐ Care required can only be delivered on ICU

☐ Care required can be delivered outside ICU and resources are available to do this safely

☐ Care required can be delivered outside ICU but resources are not available to do this safely

Outcome of decision-making process **Initials**

The potential benefits of all therapy on ICU outweigh the harms. This patient should be admitted to ICU

The potential for benefit from any treatment on ICU is so low that burdens of therapy outweigh them. This patient should not be admitted to ICU.

This person may benefit from ICU care but does not require this immediately. This patient should be reassessed after further therapy.

This patient may benefit from some care on ICU but not unlimited organ support. They should be admitted to ICU with a limited ceiling of care *(please document below)*

Individuals contributing to decision-making

ICU team

Name

Role

Referring team

Name

Role

Patient *(please state if no involvement and reason for this)*

Family

Name

Relationship to patient

Ongoing care and review plan *(Please document what care the patient should receive on ICU and any limitations to this. For those patients not transferred to ICU please document what the focus of care should be, and any specific recommendations for treatmentand follow up)*

Once a decision on future care has been made this must be communicated to both the referring team and the patient's family. *(The communication to a patient's family is the responsibility of both clinical teams and the most appropriate person to do this will depend on the individual situation)*

Intensive care clinician *(registrar or consultant)*

Name (PRINT)_____

Signature_____

Registration number_____

Handover to:_____ *(doctor).* Date:_____ Time:_____

Referring specialty team *(person making referral. If they are not present please document telephone hand-over of decision outcome)*

Name (PRINT)_____

Signature_____

Registration number_____

Focus group handout 3

Referral and workload tracking system

In order to learn from decisions made regarding ICU referrals a tracking system should be used to record all referrals to the intensive care team. If hospitals are using an electronic referral and decision form this process may be automated, but a paper-based format should be developed where this is not possible.

Information on ICU bed availability should be collected so that referrals and admissions can be mapped against limited resources.

Mortality outcomes (number of deaths), both for patients who have and have not been admitted to ICU, should also be collected so that patterns can be identified and reflected on.

Questions for stakeholder conference:

1. Referral and Work load tracking – does it make sense. Will it provide what is needed to support decision making?
2. Will it work in practice?

Focus group handout 4

Educational package

An education package will be delivered to clinicians who refer patients to intensive care and to intensive care clinicians. The aim is to give clinicians the knowledge and skills to make clinically and ethically justifiable decisions related to referral and admission to ICU that achieve the best care possible for the individual patient. The learning outcomes and teaching materials, including hypothetical cases, have been developed from our observational study (work package one). The education intervention will include specific guidance on using the Decision Support Framework.

Learning outcomes:

After this educational session attending clinicians will be able to

1. Make an ethically justifiable patient centered decision regarding escalation of care to ICU.
2. Describe the potential harms and benefits of organ support on ICU and how to balance harm versus benefit in individual cases
3. Recognise non-medical patient factors that are relevant to decision-making related to referral and admission of a patient to ICU, and those that are not relevant, in individual cases.
4. Recognise the organisational and situational factors that are relevant to a decision regarding referral and admission of a patient to ICU, and those that are not relevant, in individual cases.
5. Recognise how a clinician's personal characteristics, relationships and situation can influence their decision-making, and reflect on this in their own practice
6. Recognise uncertainty in clinical decision-making and describe how to manage this to maintain patient safety.
7. Identify conflict arising in the process of decision making and facilitate its resolution
8. Describe the elements of good communication between referring and ICU teams, the barriers to good communication, and the risks to patient safety of poor communication.
9. Understand the role and responsibility of ICU in maintaining patient safety throughout the hospital

Questions to focus groups:

1. Education package – does it make sense. Will it provide what is needed to support decision making?
2. Will it work in practice?

Focus group handout 5

Support materials for patients and families

It is important that patients and their families are aware of the process of decision-making for intensive care admission, and that they are able to participate as much as they wish to in the process. We have developed an information leaflet which describes the process and provides some information on where further help and advice can be gained.

Questions to focus groups:

1. Support materials for patients and families – does it make sense. Will it provide what is needed to support decision making?

2. Will it work in practice?