# Appendix

# Appendix 1: Key Informant Survey

Qualtrics Link: <https://dartmouth.co1.qualtrics.com/SE/?SID=SV_4T8NAl2bDzp7gW1>

**Brief Questionnaire Concerning Decision Aids for Life-Sustaining Treatment**

I am a researcher at The Dartmouth Institute in Lebanon, N.H. trying to identify all tools that help patients understand and articulate their choices concerning life-sustaining treatment(s) if they may be approaching the end-of-life.

I am very grateful for any information you can provide. I appreciate your support as I work to understand and improve the body of resources available for patients and families facing difficult decisions.

These tools may be videos or booklets or any other type of information for patients and/or their families. Sometimes these tools are called patient decision aids.

We are looking to uncover these types of tools to inventory them. We also plan to evaluate the strength of those resources.

I am contacting organizations and individuals who may be aware of decision aids for patients or families considering life-sustaining treatment(s).

**I would be very grateful if you would please complete the following brief questionnaire. It should take less than 5 minutes.**

If you have any questions or comments, please feel free to reach out: 603-653-0868; catherine.h.saunders.gr@dartmouth.edu.

This project has been exempt by the Dartmouth College Committee for the Protection of Human Subjects. The next page will ask for your consent to participate in this brief questionnaire.

All the best,

Katie

Catherine Hylas Saunders, MPH

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**CONSENT TO TAKE PART IN RESEARCH**
The Dartmouth Institute for Health Policy and Clinical Practice

Decisions About Life-Sustaining Treatment
Catherine Hylas Saunders (principal investigator)

You are being asked to take part in a research study.  Taking part in research is voluntary.

**What is the purpose of this study?**
I want to identify, categorize and assess the quality of patient decision aids for life-sustaining treatments. I also want to understand how they are used.

**Will you benefit from taking part in this study?**
There is little chance you will personally benefit from completing this questionnaire, but we hope to gather information that will help people in the future. We also hope to share our results broadly so that the information we uncover will be available for patients and families facing decisions concerning life-sustaining care. We will also add to the knowledge base, and to develop an inventory.

**What does this study involve?**
Your participation in this study will include completion of a questionnaire; this task should take roughly 5 minutes. The questionnaire will ask about your awareness of decision aids for life-sustaining treatments.

**What are the risks involved with being enrolled in this study?**
There are no obvious risks to participating in this research study.

**Other important items you should know:**

**• Leaving the study:**  You may choose to stop taking part in this study at any time.
• **Funding:**There is no outside funding for this research project.

**How will your privacy be protected?**
Questionnaire responses will be retained. Respondent names will be masked. Names of patient decision aid developers will not be masked and will likely be published. The data collected will be confidentially and securely stored for three years after study completion in a password-protected computer file, only accessible to the research team.

The information collected for this study will be used only for purposes of research as stated earlier in this form.

**Will you be paid to take part in this study?**
No.

**Whom should you call with questions about this study?**
If you have questions or concerns about this study o, you can call the principal investigator, Catherine Hylas Saunders at 603-653-0868 or reach out via email Catherine.h.saunders.gr@dartmouth.edu.

If you have questions, concerns, complaints, or suggestions about human research at Dartmouth, you may call the Office of the Committee for the Protection of Human Subjects at Dartmouth College (603) 646-6482 during normal business hours.

**1.** Do you consent to participate in this study?

 [Yes]

 [No]

**2.** Are you aware of any tool(s) that patients or families can use to help make decisions about life-sustaining treatments? These may include tools for cardiopulmonary resuscitation, ventilation, hydration, nutrition, antibiotics or other life-sustaining treatment decisions.

 [Yes] [Please type name of tool(s) here.]

 [No]

**[Skip logic will apply.]**

**4.** Do you have any information about any hospitals or health organizations that use the tool(s)?

 [Yes] [Please share the name of the organization using the tool(s).]

 [No]

**5.** If you have access to the tool and permission to share it, are you willing to share with us for research purposes?

 [Yes]

 [No]

**5.** If you do not have permission to share the tool, are you willing to put us in touch with someone who does? If so, could you please provide his or her email address below.

[Please type response here.]

**7.** Are you aware of any other individuals or organizations who might have information about tools for life-sustaining treatment decisions? If so, will you please share contact information for the individual or organization?

[Individual/organization.]

[Email address.]

[Phone.]

[Additional information.]

Thank you so much for your time and participation. If you have any questions, please do not hesitate to reach out to me: Catherine Hylas Saunders at 603-653-0868; Catherine.h.saunders.gr@dartmouth.edu.

# Appendix 2. Additional Tables

# Table 1: MEDLINE (PubMed) Search Terms

|  |  |
| --- | --- |
| **Concept** | **Search Terms** |
| **Decision aid** | "Decision Support Techniques"[Mesh:NoExp] AND ("Patient Participation"[Mesh] OR "Patient-Centered Care"[Mesh] OR "Patient Preference"[Mesh])) OR decision aid\* |
| **End of life** | Terminal Care[Mesh:Exp] |
| **Life sustaining treatments** | Life Support Systems[Mesh:Exp] |
| **CPR** | Cardiopulmonary Resuscitation[Mesh:Exp] |
| **Ventilation** | Respiration, Artificial[Mesh:Exp] |
| **LVAD** | Heart-Assist Devices[Mesh:Exp] |
| **Dialysis** | Renal dialysis[Mesh:Exp] |
| **Hydration** | Fluid Therapy[Mesh:Exp]  |
| **Nutrition** | Enteral Nutrition[Mesh:Exp] OR Nutritional Support[Mesh:Exp] |
| **Antibiotics** | Anti-Bacterial Agents[Mesh:Exp] |

# Table 2: Google and App Store Search Terms

|  |  |
| --- | --- |
| **Construct** | **Search Terms** |
| **Decision aid** | (“decision support tool” OR “Patient decision aid” OR “Patient decision aids”) |
| **End of life** | “end of life” |
| **Life sustaining treatments** | ((“life sustaining therapies” OR “life sustaining treatment”) AND (withdrawal OR withhold OR withholding) AND (terminal OR “end of life”)) |
| **CPR** | (“Cardiopulmonary resuscitation” OR CPR OR Resuscitation) |
| **Ventilation** | ((Ventilation OR “artificial respiration” OR Ventilator) AND (withdrawal OR withhold OR withholding)) |
| **LVAD** | ((“Heart-Assist Devices” OR “Heart assist devices” OR “left ventricular assist device” OR LVAD) AND (withdrawal OR withhold OR withholding)) |
| **Dialysis** | ((dialysis OR “renal dialysis”) AND (withdrawal OR withhold OR withholding)) |
| **Hydration** | ((hydration OR fluid OR liquid) AND (withdrawal OR withhold OR withholding)) |
| **Nutrition** | ((nutrition OR “artificial nutrition” OR “nutritional support”) AND (withdrawal OR withhold OR withholding)) |
| **Antibiotics** | ((antibiotics OR “antimicrobial agents”) AND (withdrawal OR withhold OR withholding) AND (terminal OR “end of life”)) |

# Table 3: Decision Aid Data Collection Form

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Name** | **Description** | **Developer** | **Primary Decision** | **Other Decisions** | **Disease/****Condition** | **Availability** | **Use** | **Notes** |
| Name of patient decision aid. | Description of decision aid format, layout and content | Developer of patient decision aid.  | Primary decision under consideration.  | Secondary decisions under consideration.  | Specific disease or condition, if applicable.  | Whether the tool is publicly available or proprietary.  | Whether anything is known about the use of the patient decision aid, including location. |  |

# Table 4: Decision Aid Screening and Quality Review (Draft National Standards for the Certification of Patient Decision Aids)

|  |  |  |
| --- | --- | --- |
| **Category** | **NQF Criteria** | **Modifications and notes on operationalization** |
| **Screening criteria**  |
| Describes condition | Describes health condition or problem for which a decision is required. | Given the variable experiences and disease courses of seriously ill individuals, if the decision aid does not identify the user but instead offers an opportunity for customization, that will suffice.  |
| Identifies user | Identifies the target user. | Given the variable experiences and disease courses of seriously ill individuals, if the decision aid does not identify the user but instead offers an opportunity for customization, that will suffice. |
| States decision | Explicitly states the decision under consideration. | Given the variable experiences and disease courses of seriously ill individuals, if the decision aid does not identify the user but instead offers an opportunity for customization, that will suffice. |
| Describes options | Describes the options available for the decision, including nontreatment when appropriate. | Given the variable experiences and disease courses of seriously ill individuals, if the decision aid does not identify the user but instead offers an opportunity for customization, that will suffice. |
| Describes positive | Describes the positive features of each option. | Given the variable experiences and disease courses of seriously ill individuals, if the decision aid does not identify the user but instead offers an opportunity for customization, that will suffice. |
| Describes negative | Describes the negative features of each option. | Given the variable experiences and disease courses of seriously ill individuals, if the decision aid does not identify the user but instead offers an opportunity for customization, that will suffice. |
| Clarifies values | Clarifies patient values for outcomes of options by asking patients to consider or rate which positive and negative features matter most to them and/or describing the features of options to help patients imagine the physical and/or social and/or psychological effects. | Given the variable experiences and disease courses of seriously ill individuals, if the decision aid does not identify the user but instead offers an opportunity for customization, that will suffice. |

|  |
| --- |
| **Certifying criteria** |
| Balanced | The DA provides a balanced presentation of options.  | Inclusion of all reasonable options and language that does not suggest one option is superior to another.  |
| Rigorous | The patient decision aid content is based on a rigorous and documented evidence synthesis method.  | Decision aid must report that information about outcomes was derived from a systematic review or some other clearly-articulated evidence-synthesis process. If the decision aid itself is clearly linked to this information, that will suffice. If the supplementary information is not clearly linked to the decision aid, however, the decision aid will not meet this criterion.  |
| Evidence sources | The patient decision aid or supporting document provides information about the evidence sources used | References must be in-text in the decision aid content or listed at the end of the decision aid.  |
| Outcome probabilities | The patient decision aid or supporting document provides key outcome probabilities, adopting risk communication principles.  | Outcomes must be reported quantitatively. Additionally, the decision aid must employ one of the following risk-communication principles: 1. Positive or negative framing i.e. 30 people who have the procedure will live; 70 will die
2. Graphic representation of outcome probabilities i.e 30% of individuals will die plus a picture
3. Natural frequencies i.e. 10 in 100 people will die
 |
| Publication date | The patient decision aid provides a publication date.  | If the decision aid itself is clearly linked to this information, that will suffice. If the supplementary information is not clearly linked to the decision aid, however, the decision aid will not meet this criterion.  |
| Update policy | The patient decision aid or supporting document provides information about the update policy and next expected update.  | If the decision aid itself is clearly linked to this information, that will suffice. If the supplementary information is not clearly linked to the decision aid, however, the decision aid will not meet this criterion.  |
| Funding sources | The patient decision aid provides information about the funding sources used for development.  | Explicit language about funding, as well as corporate logos must be present. If the decision aid itself is clearly linked to this information, that will suffice. If the supplementary information is not clearly linked to the decision aid, however, the decision aid will not meet this criterion.  |
| Competing interests | The patient decision aid or supporting document provides information about competing interests and/or policy | Explicit language about competing interests and/or policy. If the decision aid itself is clearly linked to this information, that will suffice. If the supplementary information is not clearly linked to the decision aid, however, the decision aid will not meet this criterion.  |
| Plain language | There is evidence that the patient decision aid follows plain language guidelines to ensure understanding of people with low literacy and/or low health literacy skills | Flesch-Kincaid readability scores under a 7th grade reading level will be considered plain language.  |
| **Excluded from quality assessment**  |
| Development process | The DA or supporting document provides information about the evidence sources used. | We plan to exclude this criterion from our review because this information is rarely reported in detail on the decision aids themselves. And we do not reliably have access to the supplementary material.  |
| User testing | The DA or supporting document provides information about the update policy and next expected update. | We plan to exclude this criterion from our review because this information is rarely reported in detail on the decision aids themselves. And we do not reliably have access to the supplementary material. |
| Readability levels | The DA or supporting document provides information about competing interests and/or policy. | We plan to exclude this criterion from our review because this information is rarely reported in detail on the decision aids themselves. And we do not reliably have access to the supplementary material. |