

## APPENDIX 6

### *Focus Group and Interview Topic Guides and Introductory Scripts*

#### **Focus Group Topic Guide and Introductory Script Parent Advisory Group Focus Group and Interview Questions**

##### **Explanation of background information**

- ❖ Purposes
  - “The purpose of this study is to do a needs assessment to gather information that will help develop a model of care coordination that enhances the quality of life for Department of Defense children with life-threatening conditions and their families. This information will help project staff understand how physicians and other healthcare providers and the Military Health System can better meet the needs of children with life-threatening illnesses and their families. It will help us plan for better care for families with children like yours.”
  - “The purpose of today’s group is to review focus group and interview questions for parents and healthcare providers.”
- ❖ Informed consent
  - “Before beginning the group, we will go over the informed consent form and ask each of you who has not previously signed this form to do so before participating in the group.”
  - Present and explain the consent form (and HIPAA form) for parent advisors.
  - Answer any questions.
  - Obtain signed consent form (and HIPAA form) for each group participant who has not previously consented.
- ❖ Confidentiality
  - “The information discussed in this group is confidential. Outside of this group, please do not discuss any information shared by anyone else in the group in any way that would enable anyone else to identify that person or his or her family. Please keep this information in this room.”
- ❖ Practical information about the group
  - Introduce project staff and advisors present.
  - “This group meeting will last about 2 hours. It will be audiotaped and later transcribed.”
  - “Please sign this sheet in order to receive the fee for participating as described in the consent form.”
  - Explain parking, restrooms, food as relevant to this group.

##### **Materials available for review**

- ❖ FACCT End-of-Life Survey
- ❖ Quality of Life of Caregivers of Children with Special Needs survey
- ❖ Medical Home Assessment Tools

- ❖ Tentative Schematic Diagram of Care
- ❖ Topic Guides for focus groups and interviews

### **Topics for discussion**

- ❖ Review topic guides for parent focus groups and interviews
- ❖ Review topic guides for healthcare provider focus groups and interviews
- ❖ Discuss ways to be sensitive to parent participants in future focus groups and interviews
- ❖ Obtain suggested wording for focus group and interview questions
- ❖ Discuss suggestions for incorporating surveys listed above in focus groups and interviews
- ❖ Review tentative schematic diagram of care
- ❖ Determine whether additional topics need to be added to focus group and interview guides

**Focus Group Topic Guide and Introductory Script**  
**Parent Advisory Group**  
**Quality of Life Survey**

**Explanation of background information**

- ❖ Purposes
  - “The purpose of this study is to do a needs assessment to gather information that will help develop a model of care coordination that enhances the quality of life for Department of Defense children with life-threatening conditions and their families. This information will help project staff understand how physicians and other healthcare providers and the Military Health System can better meet the needs of children with life-threatening illnesses and their families. It will help us plan for better care for families with children like yours.”
  - “The purpose of today’s group is to adapt a survey about Quality of Life for Caregivers of Children with Special Needs, so that it will effectively address the needs of parents of children with life-threatening illnesses.”
- ❖ Informed consent
  - “Before beginning the group, we will go over the informed consent form and ask each of you who has not previously signed this form to do so before participating in the group.”
  - Present and explain the consent form (and HIPAA form) for parent advisors.
  - Answer any questions.
  - Obtain signed consent form (and HIPAA form) for each group participant who has not previously consented.
- ❖ Confidentiality
  - “The information discussed in this group is confidential. Outside of this group, please do not discuss any information shared by anyone else in the group in any way that would enable anyone else to identify that person or his or her family. Please keep this information in this room.”
- ❖ Practical information about the group
  - Introduce project staff and advisors present.
  - “This group meeting will last about 2 hours. It will be audiotaped and later transcribed.”
  - “Please sign this sheet in order to receive the fee for participating as described in the consent form.”
  - Explain parking, restrooms, food as relevant to this group.

**Materials available for review**

- ❖ Quality of Life of Caregivers of Children with Special Needs survey
- ❖ Tentative Schematic Diagram of Care

**Topics for discussion**

- ❖ Review current version of Quality of Life of Caregivers of Children with Special Needs survey
- ❖ Review categories of questions in the survey

- ❖ Discuss the categories of questions in the survey, whether any categories should be eliminated, and whether additional categories of questions are needed to address the circumstances of children with life-threatening illnesses
- ❖ Discuss whether the wording of existing questions should be changed for this group of parents
- ❖ Draft wording for any questions that the advisors think should be added to the survey

**Focus Group Topic Guide and Introductory Script**  
**Parent Advisory Group**  
**Assistance with Data Interpretation and Needs Assessment Template**

**Explanation of background information**

- ❖ Purposes
  - “The purpose of this study is to do a needs assessment to gather information that will help develop a model of care coordination that enhances the quality of life for Department of Defense children with life-threatening conditions and their families. This information will help project staff understand how physicians and other healthcare providers and the Military Health System can better meet the needs of children with life-threatening illnesses and their families. It will help us plan for better care for families with children like yours.”
  - “The purpose of today’s group is to assist with interpretation of data for the needs assessment and to develop or modify a needs assessment template.”
- ❖ Informed consent
  - “Before beginning the group, we will go over the informed consent form and ask each of you who has not previously signed this form to do so before participating in the group.”
  - Present and explain the consent form (and HIPAA form) for parent advisors.
  - Answer any questions.
  - Obtain signed consent form (and HIPAA form) for each group participant who has not previously consented.
- ❖ Confidentiality
  - “The information discussed in this group is confidential. Outside of this group, please do not discuss any information shared by anyone else in the group in any way that would enable anyone else to identify that person or his or her family. Please keep this information in this room.”
- ❖ Practical information about the group
  - Introduce project staff and advisors present.
  - “This group meeting will last about 2 hours. It will be audiotaped and later transcribed.”
  - “Please sign this sheet in order to receive the fee for participating as described in the consent form.”
  - Explain parking, restrooms, food as relevant to this group.

**Materials available for review**

- ❖ Tentative themes from focus groups and interviews completed to date (no identifying information)
- ❖ Summary presentations of survey data (no identifying information)
- ❖ List of items for a needs assessment template
- ❖ Tentative schematic diagram of care

**Topics for discussion**

- ❖ Review tentative themes and discuss clarity of descriptions of the themes

- ❖ Review available survey data and discuss clarity of its presentation
- ❖ Discuss additional information that needs to be collected
- ❖ Discuss implications of themes and survey results to date
- ❖ Edit needs assessment template as needed
- ❖ Review tentative schematic diagram of care and modify as needed to reflect data to date

**Focus Group Topic Guide and Introductory Script**  
**Parent Advisory Group**  
**Editing Study Reports and Making Recommendations for a Model of Care**

**Explanation of background information**

- ❖ Purposes
  - “The purpose of this study is to do a needs assessment to gather information that will help develop a model of care coordination that enhances the quality of life for Department of Defense children with life-threatening conditions and their families. This information will help project staff understand how physicians and other healthcare providers and the Military Health System can better meet the needs of children with life-threatening illnesses and their families. It will help us plan for better care for families with children like yours.”
  - “The purpose of today’s group is to edit one or more draft study reports and make recommendations for a proposed model of care.”
- ❖ Informed consent
  - “Before beginning the group, we will go over the informed consent form and ask each of you who has not previously signed this form to do so before participating in the group.”
  - Present and explain the consent form (and HIPAA form) for parent advisors.
  - Answer any questions.
  - Obtain signed consent form (and HIPAA form) for each group participant who has not previously consented.
- ❖ Confidentiality
  - “The information discussed in this group is confidential. Outside of this group, please do not discuss any information shared by anyone else in the group in any way that would enable anyone else to identify that person or his or her family. Please keep this information in this room.”
- ❖ Practical information about the group
  - Introduce project staff and advisors present.
  - “This group meeting will last about 2 hours. It will be audiotaped and later transcribed.”
  - “Please sign this sheet in order to receive the fee for participating as described in the consent form.”
  - Explain parking, restrooms, food as relevant to this group.

**Materials available for review**

- ❖ Draft study reports as ready
  - Report of parent focus groups and interviews
  - Report of healthcare provider focus groups and interviews
  - Case study reports
  - Military Health System Analysis report
  - Research reports for submission to journals
- ❖ Tentative schematic diagram of care

## **Topics for discussion**

- ❖ Review one draft report
- ❖ Discuss recommended editing of that report
- ❖ Repeat for one or more additional reports if available and time permits
- ❖ Discuss recommended editing of additional report(s)
- ❖ Review tentative schematic diagram of care and modify as needed to reflect information in reports
- ❖ Discuss implications of reviewed reports for a recommended model of care



**Interview Topic Guide and Introductory Script**  
**Parent Advisory Group**  
**Focus Group and Interview Questions**

**Explanation of background information**

- ❖ Purposes
  - “The purpose of this study is to do a needs assessment to gather information that will help develop a model of care coordination that enhances the quality of life for Department of Defense children with life-threatening conditions and their families. This information will help project staff understand how physicians and other healthcare providers and the Military Health System can better meet the needs of children with life-threatening illnesses and their families. It will help us plan for better care for families with children like yours.”
  - “The purpose of today’s interview is to review focus group and interview questions for parents and healthcare providers.”
- ❖ Informed consent
  - “Before beginning the interview, we will go over the informed consent form and I will ask you to sign it.” (if this participant has not previously signed this form)
  - Present and explain the consent form (and HIPAA form) for parent advisors.
  - Answer any questions.
  - Obtain signed consent form (and HIPAA form).
- ❖ Confidentiality
  - “The information discussed in this interview is confidential. I will not share any information outside of this interview in any way that would identify you or your family.”
- ❖ Practical information about the interview
  - “This interview will last about (1 hour). It will be audiotaped and later transcribed.”
  - “If applicable to you, you will receive the fee for participating as described in the consent form.”

**Materials available for review**

- ❖ FACCT End-of-Life Survey
- ❖ Quality of Life of Caregivers of Children with Special Needs survey
- ❖ Medical Home Assessment Tools
- ❖ Tentative Schematic Diagram of Care
- ❖ Topic Guides for focus groups and interviews

**Topics for discussion**

- ❖ Review topic guides for parent focus groups and interviews
- ❖ Review topic guides for healthcare provider focus groups and interviews
- ❖ Discuss ways to be sensitive to parent participants in future focus groups and interviews
- ❖ Obtain suggested wording for focus group and interview questions
- ❖ Discuss suggestions for incorporating surveys listed above in focus groups and interviews

- ❖ Review tentative schematic diagram of care
- ❖ Determine whether additional topics need to be added to focus group and interview guides

**Interview Group Topic Guide and Introductory Script**  
**Parent Advisory Group**  
**Quality of Life Survey**

**Explanation of background information**

- ❖ Purposes
  - “The purpose of this study is to do a needs assessment to gather information that will help develop a model of care coordination that enhances the quality of life for Department of Defense children with life-threatening conditions and their families. This information will help project staff understand how physicians and other healthcare providers and the Military Health System can better meet the needs of children with life-threatening illnesses and their families. It will help us plan for better care for families with children like yours.”
  - “The purpose of today’s group is to adapt a survey about Quality of Life for Caregivers of Children with Special Needs, so that it will effectively address the needs of parents of children with life-threatening illnesses.”
- ❖ Informed consent
  - “Before beginning the interview, we will go over the informed consent form and I will ask you to sign it.” (if this participant has not previously signed this form)
  - Present and explain the consent form (and HIPAA form) for parent advisors.
  - Answer any questions.
  - Obtain signed consent form (and HIPAA form).
- ❖ Confidentiality
  - “The information discussed in this interview is confidential. I will not share any information outside of this interview in any way that would identify you or your family.”
- ❖ Practical information about the interview
  - “This interview will last about (1 hour). It will be audiotaped and later transcribed.”
  - “If applicable to you, you will receive the fee for participating as described in the consent form.”

**Materials available for review**

- ❖ Quality of Life of Caregivers of Children with Special Needs survey
- ❖ Tentative Schematic Diagram of Care

**Topics for discussion**

- ❖ Review current version of Quality of Life of Caregivers of Children with Special Needs survey
- ❖ Review categories of questions in the survey
- ❖ Discuss the categories of questions in the survey, whether any categories should be eliminated, and whether additional categories of questions are needed to address the circumstances of children with life-threatening illnesses

- ❖ Discuss whether the wording of existing questions should be changed for this group of parents
- ❖ Draft wording for any questions that the advisor thinks should be added to the survey

**Interview Group Topic Guide and Introductory Script**  
**Parent Advisory Group**  
**Assistance with Data Interpretation and Needs Assessment Template**

**Explanation of background information**

- ❖ Purposes
  - “The purpose of this study is to do a needs assessment to gather information that will help develop a model of care coordination that enhances the quality of life for Department of Defense children with life-threatening conditions and their families. This information will help project staff understand how physicians and other healthcare providers and the Military Health System can better meet the needs of children with life-threatening illnesses and their families. It will help us plan for better care for families with children like yours.”
  - “The purpose of today’s group is to assist with interpretation of data for the needs assessment and to develop or modify a needs assessment template.”
- ❖ Informed consent
  - “Before beginning the interview, we will go over the informed consent form and I will ask you to sign it.” (if this participant has not previously signed this form)
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  - Answer any questions.
  - Obtain signed consent form (and HIPAA form).
- ❖ Confidentiality
  - “The information discussed in this interview is confidential. I will not share any information outside of this interview in any way that would identify you or your family.”
- ❖ Practical information about the interview
  - “This interview will last about (1 hour). It will be audiotaped and later transcribed.”
  - “If applicable to you, you will receive the fee for participating as described in the consent form.”

**Materials available for review**

- ❖ Tentative themes from focus groups and interviews completed to date (no identifying information)
- ❖ Summary presentations of survey data (no identifying information)
- ❖ List of items for a needs assessment template
- ❖ Tentative schematic diagram of care

**Topics for discussion**

- ❖ Review tentative themes and discuss clarity of descriptions of the themes
- ❖ Review available survey data and discuss clarity of its presentation
- ❖ Discuss additional information that needs to be collected
- ❖ Discuss implications of themes and survey results to date
- ❖ Edit needs assessment template as needed
- ❖ Review tentative schematic diagram of care and modify as needed to reflect data to date

**Interview Group Topic Guide and Introductory Script**  
**Parent Advisory Group**  
**Editing Study Reports and Making Recommendations for a Model of Care**

**Explanation of background information**

- ❖ Purposes
  - “The purpose of this study is to do a needs assessment to gather information that will help develop a model of care coordination that enhances the quality of life for Department of Defense children with life-threatening conditions and their families. This information will help project staff understand how physicians and other healthcare providers and the Military Health System can better meet the needs of children with life-threatening illnesses and their families. It will help us plan for better care for families with children like yours.”
  - “The purpose of today’s group is to edit one or more draft study reports and make recommendations for a proposed model of care.”
- ❖ Informed consent
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  - Present and explain the consent form (and HIPAA form) for parent advisors.
  - Answer any questions.
  - Obtain signed consent form (and HIPAA form).
- ❖ Confidentiality
  - “The information discussed in this interview is confidential. I will not share any information outside of this interview in any way that would identify you or your family.”
- ❖ Practical information about the interview
  - “This interview will last about (1 hour). It will be audiotaped and later transcribed.”
  - “If applicable to you, you will receive the fee for participating as described in the consent form.”

**Materials available for review**

- ❖ Draft study reports as ready
  - Report of parent focus groups and interviews
  - Report of healthcare provider focus groups and interviews
  - Case study reports
  - Military Health System Analysis report
  - Research reports for submission to journals
- ❖ Tentative schematic diagram of care

**Topics for discussion**

- ❖ Review one draft report
- ❖ Discuss recommended editing of that report
- ❖ Repeat for one or more additional reports if available and time permits

- ❖ Discuss recommended editing of additional report(s)
- ❖ Review tentative schematic diagram of care and modify as needed to reflect information in reports
- ❖ Discuss implications of reviewed reports for a recommended model of care

## **Focus Group Topic Guide and Introductory Script Parents**

### **Explanation of Background Information**

- ❖ Purposes
  - “The purpose of this study is to do a needs assessment to gather information that will help develop a model of care coordination that enhances the quality of life for Department of Defense children with life-threatening conditions and their families. This information will help project staff understand how physicians and other healthcare providers and the Military Health System can better meet the needs of children with life-threatening illnesses and their families. It will help us plan for better care for families with children like yours.”
  - “The purpose of today’s group is to learn about your child’s needs, your family’s needs, and your experiences in seeking, finding and using services to meet those needs.”
- ❖ Informed consent
  - “Before beginning the group, we will go over the informed consent form and ask each of you who has not previously signed this form to do so before participating in the group.”
  - Present and explain the consent form (and HIPAA form) for parent advisors.
  - Answer any questions.
  - Obtain signed consent form (and HIPAA form) for each group participant who has not previously consented.
- ❖ Confidentiality
  - “The information discussed in this group is confidential. Outside of this group, please do not discuss any information shared by anyone else in the group in any way that would enable anyone else to identify that person or his or her family. Please keep this information in this room.”
- ❖ Practical information about the group
  - Introduce project staff and advisors present.
  - “This group meeting will last about 2 hours. It will be audiotaped and later transcribed.”
  - “Please sign this sheet in order to receive the fee for participating as described in the consent form.”
  - Explain parking, restrooms, food as relevant to this group.

### **Materials needed**

- ❖ FACCT End-of-Life Survey
- ❖ Quality of Life of Caregivers of Children with Special Needs survey as adapted by advisory group
- ❖ Medical Home Family Index
- ❖ Topic guide for parent focus groups and interviews as adapted by advisory group

### **Topics for discussion**

- ❖ Discuss how parents define the needs of children and families when a child has a life-threatening illness



- ❖ Discuss the experience of children and families with the MHS (direct care system and TRICARE) in meeting those needs
- ❖ Discuss the experience of children and families in finding and using services in their communities (both military and civilian communities)
- ❖ Discuss education and information necessary to enable them to find and access the health care and services that they need
- ❖ Discuss the degree to which the children's care has been coordinated and what the mechanisms of coordination have been.

## **Focus Group Topic Guide and Introductory Script Healthcare Providers**

### **Explanation of background information**

- ❖ Purposes
  - “The purpose of this study is to do a needs assessment to gather information that will help develop a model of care coordination that enhances the quality of life for Department of Defense children with life-threatening conditions and their families. This information will help project staff understand how physicians and other healthcare providers and the Military Health System can better meet the needs of children with life-threatening illnesses and their families. It will help us plan for better care for families with children like yours.”
  - “The purpose of today’s group to gather your perspectives as a healthcare provider about the needs of children with life-threatening illnesses and their families, the care and services available to address those needs, and your need for education about these topics.”
- ❖ Informed consent
  - “Before beginning the group, we will go over the informed consent form and ask each of you who has not previously signed this form to do so before participating in the group.”
  - Present and explain the consent form (and HIPAA form) for healthcare providers.
  - Answer any questions.
  - Obtain signed consent form (and HIPAA form) for each group participant who has not previously consented.
- ❖ Confidentiality
  - “The information discussed in this group is confidential. Outside of this group, please do not discuss any information shared by anyone else in the group in any way that would enable anyone else to identify that person. Please keep this information in this room.”
- ❖ Practical information about the group
  - Introduce project staff and healthcare providers present.
  - “This group meeting will last about 1 hour. It will be audiotaped and later transcribed.”

### **Materials needed**

- ❖ Medical Home Index
- ❖ Medical Home Assessment Questionnaire—Health Care Professional version

### **Topics for discussion**

- ❖ Discuss how residents, pediatricians, family medicine physicians and other healthcare providers define the needs of the children with life-threatening conditions and their families for whom they provide care
- ❖ Discuss participants’ experiences with the Military Health System (direct care system and TRICARE) in meeting those needs
- ❖ Discuss education and information necessary to help them provide comprehensive care in a Medical Home model for children with life-threatening illnesses and their families.

## **Interview Topic Guide and Introductory Script Parents**

### **Explanation of Background Information**

- ❖ Purposes
  - “The purpose of this study is to do a needs assessment to gather information that will help develop a model of care coordination that enhances the quality of life for Department of Defense children with life-threatening conditions and their families. This information will help project staff understand how physicians and other healthcare providers and the Military Health System can better meet the needs of children with life-threatening illnesses and their families. It will help us plan for better care for families with children like yours.”
  - “The purpose of today’s interview is to learn about your child’s needs, your family’s needs, and your experiences in seeking, finding and using services to meet those needs.”
- ❖ Informed consent
  - “Before beginning the interview, we will go over the informed consent form and I will ask you to sign it.” (if this participant has not previously signed this form)
  - Present and explain the consent form (and HIPAA form) for parent advisors.
  - Answer any questions.
  - Obtain signed consent form (and HIPAA form).
- ❖ Confidentiality
  - “The information discussed in this interview is confidential. I will not share any information outside of this interview in any way that would identify you or your family.”
- ❖ Practical information about the interview
  - “This interview will last about (2 hours). It will be audiotaped and later transcribed.”
  - “If applicable to you, you will receive the fee for participating as described in the consent form.”

### **Materials needed**

- ❖ FACCT End-of-Life Survey
- ❖ Quality of Life of Caregivers of Children with Special Needs survey as adapted by advisory group
- ❖ Medical Home Family Index
- ❖ Topic guide for parent focus groups and interviews as adapted by advisory group

### **Topics for discussion**

- ❖ Discuss how parents define the needs of children and families when a child has a life-threatening illness
- ❖ Discuss the experience of children and families with the MHS (direct care system and TRICARE) in meeting those needs
- ❖ Discuss the experience of children and families in finding and using services in their communities (both military and civilian communities)

- ❖ Discuss education and information necessary to enable them to find and access the health care and services that they need
- ❖ Discuss the degree to which the children's care has been coordinated and what the mechanisms of coordination have been.

## **Interview Topic Guide and Introductory Script Healthcare Providers**

### **Explanation of background information**

- ❖ Purposes
  - “The purpose of this study is to do a needs assessment to gather information that will help develop a model of care coordination that enhances the quality of life for Department of Defense children with life-threatening conditions and their families. This information will help project staff understand how physicians and other healthcare providers and the Military Health System can better meet the needs of children with life-threatening illnesses and their families. It will help us plan for better care for families with children like yours.”
  - “The purpose of today’s interview is to gather your perspectives as a healthcare provider about the needs of children with life-threatening illnesses and their families, the care and services available to address those needs, and your need for education about these topics.”
- ❖ Informed consent
  - “Before beginning the interview, we will go over the informed consent form and I will ask you to sign it.” (if this participant has not previously signed this form)
  - Present and explain the consent form (and HIPAA form) for healthcare providers.
  - Answer any questions.
  - Obtain signed consent form (and HIPAA form).
- ❖ Confidentiality
  - “The information discussed in this interview is confidential. I will not share any information outside of this interview in any way that would identify you”
- ❖ Practical information about the interview
  - “This interview will last about (1hour). It will be audiotaped and later transcribed.”

### **Materials needed**

- ❖ Medical Home Index
- ❖ Medical Home Assessment Questionnaire—Health Care Professional version

### **Topics for discussion**

- ❖ Discuss how residents, pediatricians, family medicine physicians and other healthcare providers define the needs of the children with life-threatening conditions and their families for whom they provide care
- ❖ Discuss participants’ experiences with the Military Health System (direct care system and TRICARE) in meeting those needs
- ❖ Discuss education and information necessary to help them provide comprehensive care in a Medical Home model for children with life-threatening illnesses and their families.