

APPENDIX B

OUTREACH LANGUAGE

Boilerplate Email

Dear <Name/Entity>:

The National Institute of Nursing Research (NINR), part of the National Institutes of Health, has created a survey to gather feedback from parents and families of children with serious illnesses. NINR developed *Palliative Care: Conversations Matter*[®] to increase awareness and use of palliative care for children, and this campaign survey will inform upcoming efforts to provide families with information and resources they deem valuable. NINR hopes to learn what might be helpful in supporting their journeys—and those of many other families who have, or will, experience similar situations when caring for children with serious illnesses.

To this end, NINR invites families to share their thoughts through a brief 10-question survey. The questions are short, and the survey should take 10 minutes or less to complete. All responses are anonymous and no personal information is collected.

Given your work with <insert entity's focus area (palliative care/family support/parents)>, we greatly appreciate any assistance in reaching families who would like to participate. A direct link to the survey follows and sample social media posts are provided in the attachment to this email. The survey will remain open through <insert cutoff date>.

<Insert link to survey>

Please feel free to contact me with any questions.

Sincerely,

<Insert signature block>

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Prepared Tweets

- We are seeking responses to a brief #NINRCAMPAIGN survey for parents and families of #seriouslyillchildren. <link>
- Parents: Support #NINRCAMPAIGN by sharing your thoughts to help families of #seriouslyillchildren: <link>
- #NINR seeks input from families of #seriouslyillchildren to inform #NINRCAMPAIGN. Take or share this short survey: <link>
- Families of #seriouslyillchildren: #NINRCAMPAIGN needs your input! Answer 10 questions to help -families like yours. <link>
- Are you the parent of a #seriouslyillchild? #NINRCAMPAIGN needs your insights about #palliativecare <link>
- Are you the parent of a #seriouslyillchild? Help shape the next phase of #NINRCAMPAIGN <link>
- Has your child received #palliativecare? Consider sharing your experience w. #NINRCAMPAIGN <link>

Prepared Facebook Posts

- The National Institute of Nursing Research (NINR), part of NIH, seeks input from parents and families of children with serious illnesses. This 10-question anonymous survey will help NINR provide families with helpful information and resources to support them on their journeys. <Embed link>
- Parents and families of children with serious illnesses: the National Institute of Nursing Research needs your input. This anonymous survey takes less than 10 minutes and will help give families like yours the information and resources they need and deserve. <Embed link>