



Checklist for Researchers Partnering with the Spina Bifida Association

1. Have you included IRB Approval? YES NO NOT APPLICABLE IRB Approval Date ___/___/___
2. Have you included all informed consent materials? YES NO
3. Does the study involve specific medical tests or interventions? YES NO
4. If you responded “yes” to question 3 above, have you included this information in the informed consent materials and in your marketing content. YES NO
5. Does the study involve mental health assessments? YES NO

If you responded “yes” to question 5 above, please describe your protocol to address the possibility of participants who may need immediate or urgent mental health intervention (such as for severe depression or suicidal ideation.) _____

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6. Have you included the abstract / detailed description of the study? YES NO
 7. Have you included a downloadable copy of the actual survey/questionnaire created for this study and the link? YES NO
 8. If your study is using a survey/questionnaire that has already been published, please provide the original citation. _____
 9. How many participants do you need? _____ by what target date? ___/___/___?
 10. Who is the target population and age range (e.g., parents of children with Spina Bifida ages 5 – 10; young adults ages 18 – 25)?
 11. If the survey/questionnaire will also be given in Spanish, have you included the Spanish version? YES NO
 8. Have you included all promotional materials to be used for recruitment of participants? YES NO
 9. Have you included promotional materials in Spanish? YES NO N/A
 10. Do you agree to share study/questionnaire outcomes with SBA? YES NO

11. Please include an explanation or example of the implications of your findings on the SBA community (e.g., study informs SBA Research Agenda; results inform SB community)?

12. Please describe how you have included the SB community during the development stages of your proposal

13. If it was not possible to include the SB community during the development stages of your proposal, please include a brief explanation.

14. What is the project deadline date? ___/___/_____?

Please send the requisite materials **and this completed checklist** to research@sbaa.org

Timeline: Please allow 5 – 10 business days for review and approval. After approval, our Marketing Department will determine when to schedule promotional content about your study. You will be notified of the tentative dates for which the promotional content for your study will be posted.

Thank you for partnering with the Spina Bifida Association.

September 2024