

Childhood Disability Research Priority Setting Partnership Form A: Interim prioritisation ranking form

The James Lind Alliance Childhood Disability Research Priority Setting Partnership has produced a 'long list' of unanswered questions about the effectiveness of interventions for children and young people affected by neurodisability. These are on Form B. These have been taken from the survey completed in 2013 by families, professionals and members of the public.

We now need to develop a 'shortlist' of these questions for consideration at the final priority setting stage. We are asking **young people with a neurodisability, their families, relevant professionals, and organisations supporting families** to do this exercise and tell us which of the unanswered questions they think should be prioritised for research, and should therefore appear in the shortlist.

How you do this is up to you. For example, you might simply respond as an individual based on your own experience or expertise. Or you might consult with friends or family, or collaborate with colleagues to identify your priorities. There is space at the end of this form to describe how you did it. Please also let us know whether you are responding as a young person with a neurodisability, family member or carer, or a healthcare professional.

Please can you do the following:

- Choose up to 10 questions from Form B that you would like to go forward for consideration at the final priority setting stage.
- In the second column on the next page, put the Question Number (1-53) from the long list in ranked order from 1 to 10, starting with 1 (most important), through to 10 (slightly less important).
- If you would like to, please tell us why you made these choices. This is **optional** but interesting to us.
- Fill in your details. All information will be kept confidential.

Please turn over

| Priority 1 = most important | Chosen ten uncertainties | Comments about my choices (optional) We are interested in the reasons for your choices - please tell us here |
|------------------------------------------|-----------------------------|-----------------------------------------------------------------------------------------------------------------|
| 10 = less | Enter question | |
| important | number here | |
| 1 | | |
| 2 | | |
| 3 | | |
| 4 | | |
| 5 | | |
| 6 | | |
| 7 | | |
| 8 | | |
| 9 | | |
| 10 | | |

Are you responding as: (required – tick all that apply)

A young person with a neurodisability

A parent, carer or relative of someone with a neurodisability

A health professional

Part of an organisation representing young people with a neurodisability

Other: Please describe.....

Your name: (optional)

Your organisation (if applicable):

Did you do this exercise on your own? Yes / No

If you involved other people in the exercise please describe this briefly:

Please return your completed form by **25 April 2014** by email to <u>PenCRU@exeter.ac.uk</u> or by post to Freepost-RSUT-KTJT-LAKJ PenCRU Veysey Building Salmon Pool Lane Exeter EX2 4SG