

**INVITATION TO PARENTS AND FAMILIES: WE NEED YOUR HELP....**  
**Communication services and support for individuals with Rett syndrome:**

- What are your experiences of communication services?
- What support for communication do you receive?
- What are the communication goals you are working towards with your child?
- What works for you?
- What could help you more?

As a parent/caregiver of someone with Rett syndrome, you can answer all of these questions and more in our survey for families. The survey is part of a larger project, funded by Rettsyndrome.org, to develop clinical guidelines for the assessment, intervention and longer-term management of communication in individuals with Rett syndrome. To make the guidelines truly international we need input from everyone affected by Rett syndrome, in as many countries as possible. This survey is for parents/caregivers. By working together and listening to everyone's experiences we hope that communication services for all individuals with Rett syndrome will be improved. We can't do it without you.

The survey has been online in English since October. It is now available in other languages, including: Chinese (Mandarin), Danish, Dutch, Finnish, French, German, Hebrew, Italian, Lithuanian, Russian, Polish, Portuguese, Swedish.

If you speak another language and would find it easier to complete the survey in your own language, please contact the project coordinator to see whether we can make arrangements for this.

The survey can be completed on your computer or mobile device. It can be accessed via this link or by scanning the QR code:

[https://maastrichtuniversity.eu.qualtrics.com/SE/?SID=SV\\_1HxpRW1GBQ2yCBn](https://maastrichtuniversity.eu.qualtrics.com/SE/?SID=SV_1HxpRW1GBQ2yCBn)



If you have any queries, please contact:  
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The survey will remain active until the **end of January 2017**.  
Please take time to add your voice and share your experiences with us.

Thank you,  
The project team.