

RETT SYNDROME Communication Guidelines

Rettsyndrome.org

Rett Syndrome Communication Guidelines

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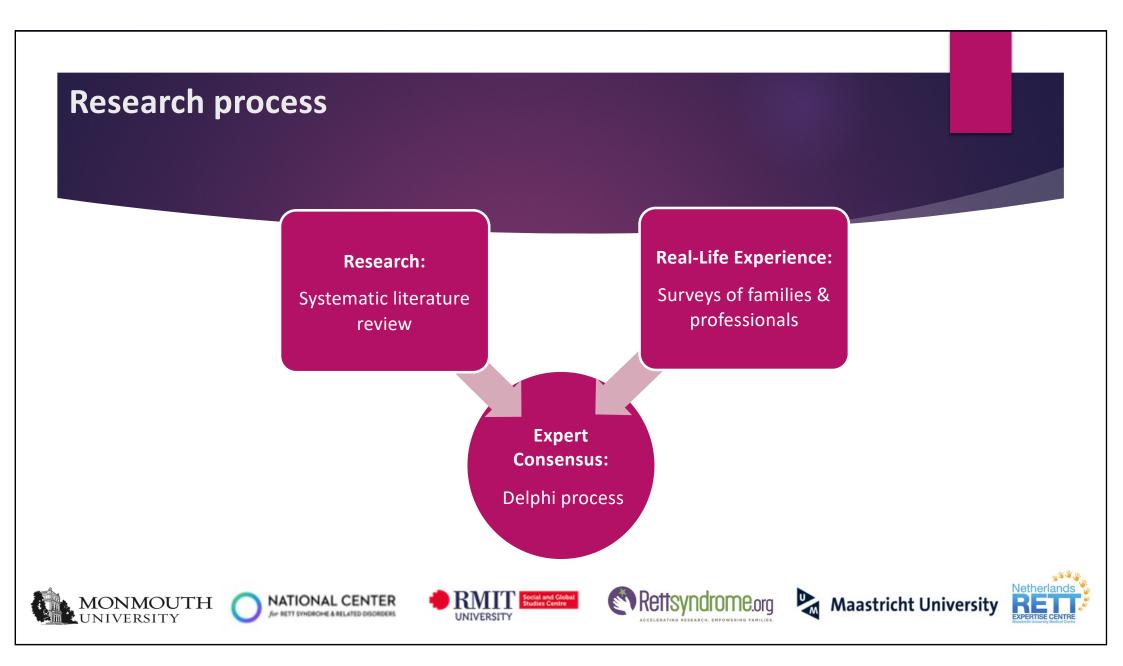
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Why are Guidelines needed?

- Knowledge and expertise within countries is fragmented and inconsistent
- Many countries lack Centres of Expertise or people with expert knowledge
- Access to services and supports is inequitable
- Individuals and their families struggle to find accurate, up to date information and guidance
- Professionals (doctors, therapists, teachers) struggle to access accurate, up to date information and advice
- Guidelines set a baseline share information build knowledge
- Guidelines (can) promote a minimum standard of care that can (should) be expected
- Guidelines (can) influence policy at local, regional, national, European, international level





Guidelines development

Literature Review

- 222 peer-reviewed
- 53 grey literature
- 37 extra AAC articles
- 312 in total

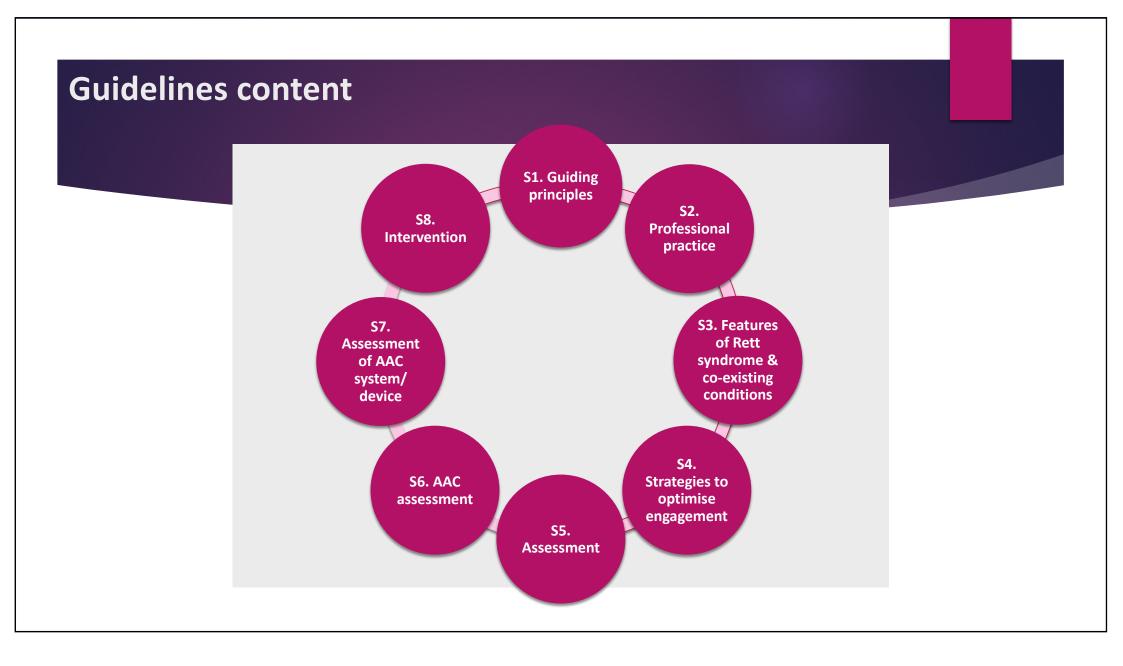
Surveys

- 120 professionals
- 490 caregivers
- 43 countries
- 16 languages

Expert Panel

• 36 members

650 people in total



S1. Guiding principles

For any individual with Rett syndrome, their level of receptive language (understanding) is usually better than their ability to express themselves

Communication partners should have an open mind to the communication potential of the individual with Rett syndrome

The potential to communicate is frequently underestimated in individuals with Rett syndrome

Communication partners should believe that, given the opportunity, individuals with Rett syndrome will be able to communicate using AAC

FIGURE 1: NJC COMMUNICATION BILL OF RIGHTS³

National Joint Committee for the Communication Needs of Persons With Severe Disabilities (NJC)

COMMUNICATION BILL OF RIGHTS

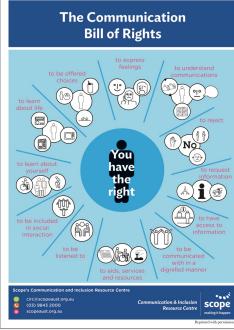
All people with a disability of any extent or severity have a basic right to affect, through communication, the conditions of their existence. Beyond this general right, a number of specific communication rights should be ensured in all daily interactions and interventions involving persons who have severe disabilities. To participate fully in communication interactions, each person has these fundamental communication rights:

- 1. The right to interact socially, maintain social closeness, and build relationships
- 2. The right to request desired objects, actions, events, and people
- 3. The right to refuse or reject undesired objects, actions, events, or choices
- 4. The right to express personal preferences and feelings
- 5. The right to make choices from meaningful alternatives
- 6. The right to make comments and share opinions
- The right to ask for and give information, including information about changes in routine and environment
- 8. The right to be informed about people and events in one's life
- 9. The right to access interventions and supports that improve communication
- The right to have communication acts acknowledged and responded to even when the desired outcome cannot be realized
- The right to have access to functioning AAC (augmentative and alternative communication) and other AT (assistive technology) services and devices at all times
- The right to access environmental contexts, interactions, and opportunities that promote participation as full communication partners with other people, including peers
- 13. The right to be treated with dignity and addressed with respect and courtesy
- The right to be addressed directly and not be spoken for or talked about in the third person while present
- The right to have clear, meaningful, and culturally and linguistically appropriate communications

For more information, go to the NJC website at: www.asha.org/njc

Brady, N. C., Bruce, S., Goldman, A., Erickson, K., Mineo, B., Ogletree, B. T., Paul, D., Romski, M., Sevcik, R., Siegel, E., Schoonover, J., Snell, M., Sylvester, I., & Wilkinson, K. (2016). Communication services and supports for individuals with severe disabilities: Guidance for assessment intervention. *American Journal on Intellectual and Developmental Disabilities*. 17(1): 13–138.



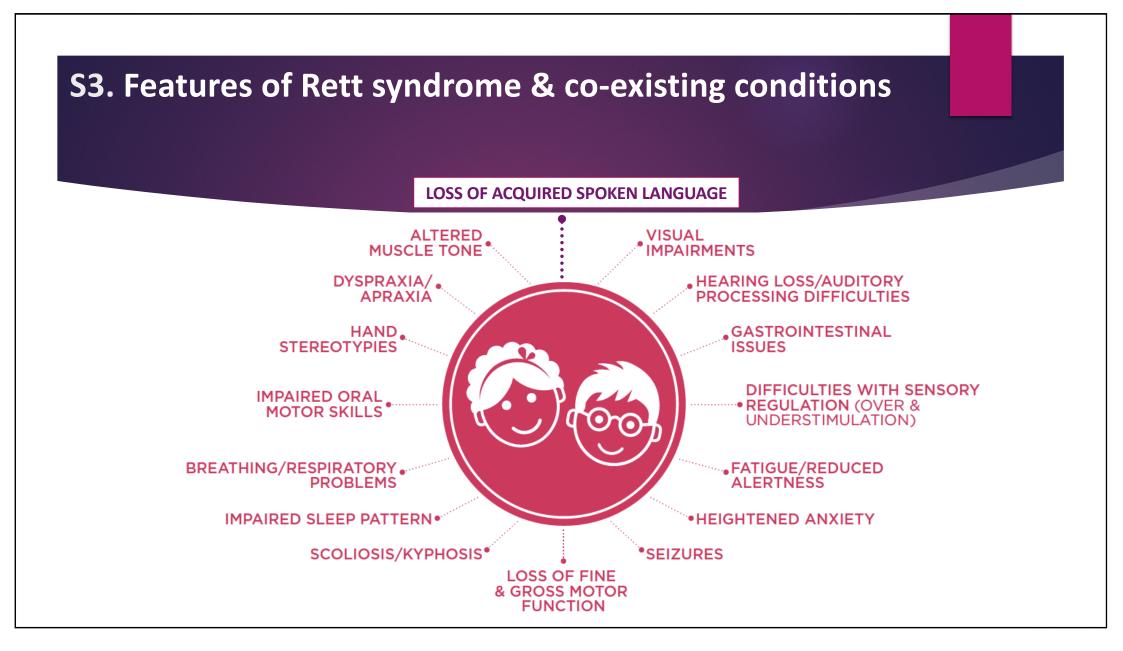


S2. Professional practice

Every individual with Rett syndrome should be supported by a multidisciplinary team

The team should share a common vision and work collaboratively to define and agree communication goals and support plans One person in the team should be identified as the "key person" with responsibility for monitoring communication goals Organizations employing new or inexperienced professionals to work with individuals with Rett syndrome have a duty to enable those professionals to receive training in relevant topics

> Professionals who are inexperienced in working with individuals with Rett syndrome should seek training in relevant topics as well as advice and support from colleagues with more specialist knowledge and expertise in the area



S4. Strategies to optimise engagement "Communication partners should..."

...address and talk directly to the individual with Rett syndrome rather than talking about them in their presence ...adapt natural situations & activities so that opportunities for communication are created

...make the individual's AAC system(s)/device(s) available at all times ...model vocabulary as they talk to an individual throughout the day

...be responsive in their interactions, acknowledging & reinforcing all communication attempts

...be consistent (in approach, language, & vocabulary used) ...keep communication in the here & now

...follow the

individual's lead

...give feedback & attribute meaning

...make sure vocabulary, topics, & activities are appropriate to the interests of the individual

...use multimodal communication

...be aware of delayed response time

URE 4: SENSORY REGUL	LATION CHA	RT		
OVERSTIMULATED Agitated/sensory overload	Level 3	 Needs strong sensory input from sensory diet to assist in calming down; overwhelmed by sensory input. Will take longer to return to Level 1 when sensory system moves into Level 3 or "red zone." 		
OVER RESPONSIVE Needs to be "calmed down"	Level 2	 Needs sensory input or a sensory break based on sensory diet to help return to Level 1; snack or drink; music can help re-engage; change of activity; movement and/or change of position 	Pay attention to behaviors that indicate the need for a change in position or a change/break in activity The "traffic light system" developed by Judy Lariviere can be helpful for	
FUNCTIONAL STATE OF AROUSAL "Regulated state"	Level 1	 Ready to learn, communicate, and actively participate Calm; body supported and relaxed Sitting upright and/or remaining seated Establishing eye contact; smiling; giggling Interactive; easily looking between different things Communicating with communication partner(s) Engaged, playing, having fun Does not seem anxious or tired 		
UNDER RESPONSIVE Needs to be "revved up"	Level 2	 Needs sensory input based on sensory diet to help return to Level 1; typically needs a break involving movement/change of position or snack to re-energize and/or listening to favorite music; change of activity. 	training caregivers to recognise leve of sensory arousal and to develop t strategies needed to adjust them. It also helps individuals with Rett	
UNDERSTIMULATED Falling asleep/ shutdown	Level 3	 Needs strong sensory input from sensory diet with extended break to assist in "waking up" or "revving up" sensory system. 	syndrome to recognise their own internal state.	

A personal communication passport can be...

an invaluable resource for sharing information about an individual's communication style, strategies that are most appropriate to use, and any personal/health-related factors that may affect their behavior and the choice of strategies/ communication methods

S5. Assessment (general)

Assessment should not take place at a single moment in time; it should be ongoing and dynamic

Standardized assessments may be adapted to obtain information on certain specific skills

Assessment should include identification of the most appropriate access method for an individual (e.g., eyes and hands)

Assessment should be part of a team process

Standardized assessments may not accurately reflect an individual's underlying ability nor their communicative and learning potentials Adapted standardized assessments can be used to assess expressive language, receptive vocabulary, and cognition

Adaptions to standardised assessments can include modifying presentation of test materials (e.g., mounting test items on a board, use of partner-assisted scanning, eye gaze, or other AAC strategies as response modalities) Eye gaze is the best access method for assessment of cognition

Eye gaze is the best access method for assessment of receptive and expressive language skills

S6. AAC assessment (specific)

No prerequisite skills must be demonstrated before aided AAC should be considered

> An individual does not have to 'pass' assessment at an early level of screen use (e.g., demonstrate cause-effect understanding) before their response to more advanced levels of eye-gaze technology use can be assessed (e.g., introducing them to grids for communication)

Assessments of readiness to use eye-gaze technology are best conducted through informal activities

S7. Assessment of AAC system/device

Trial periods are essential for assessing whether any AAC system or device is appropriate for an individual. This applies to both low- and high-tech systems or devices

Trial periods should be for a minimum of 8 weeks

During trial periods, the individual and their key communication partners should be well-supported by knowledgeable and experienced professionals who are familiar with/trained to use the system/device on trial

> During trial periods, the system/device should be used in multiple environments and with multiple communication partners.

S8. Intervention

Communication should be developed across multiple modalities

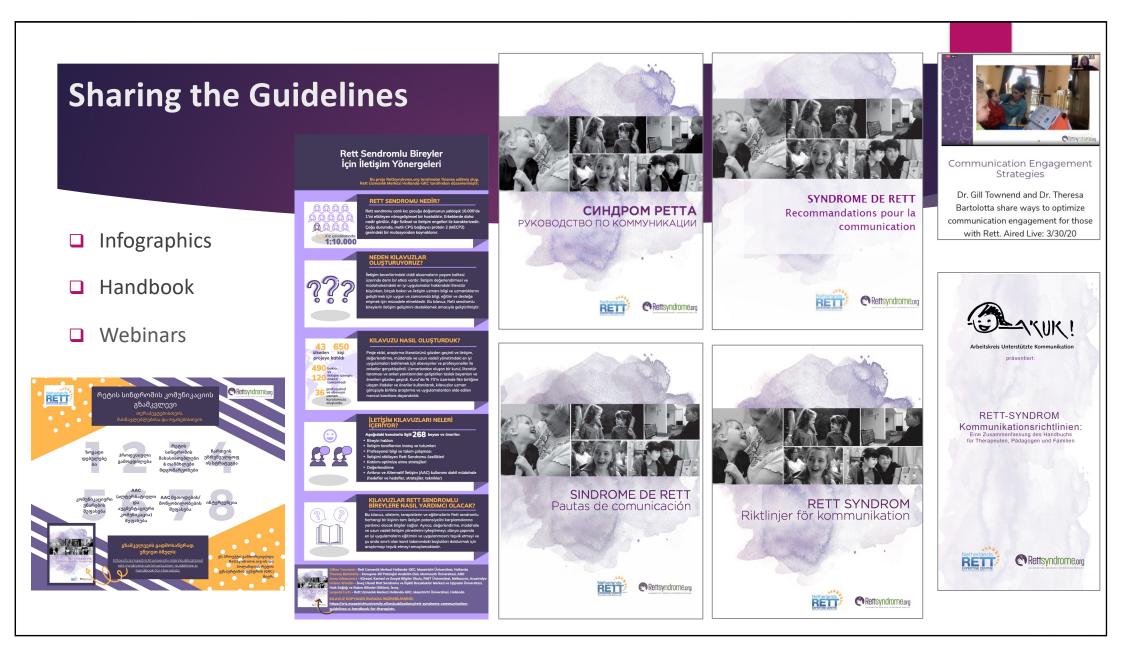
An individual should have more than one AAC system/device for use in different situations/settings

A low-tech system should always be available as a back-up for a high-tech system

Language intervention should begin with exposure to a robust vocabulary so that potential for communication is	Vocabulary in an AAC system should allow for change & flexibility	Aided AAC can be introduced & used successfully in adulthood	Communication intervention and management should start early and be lifelong
A robust vocabulary can be used in conjunction with a smaller set of	Developing a yes/no response is important for all individuals with Rett syndrome	Aided AAC can be used by individuals who are ambulatory	Goals to expand the range of communication functions should be included
choices that are appropriate for specific situations	Partner-assisted scanning can be used once a yes/ner response has been established	o Commu help th	unication intervention will le individual to become more omous as a communicator

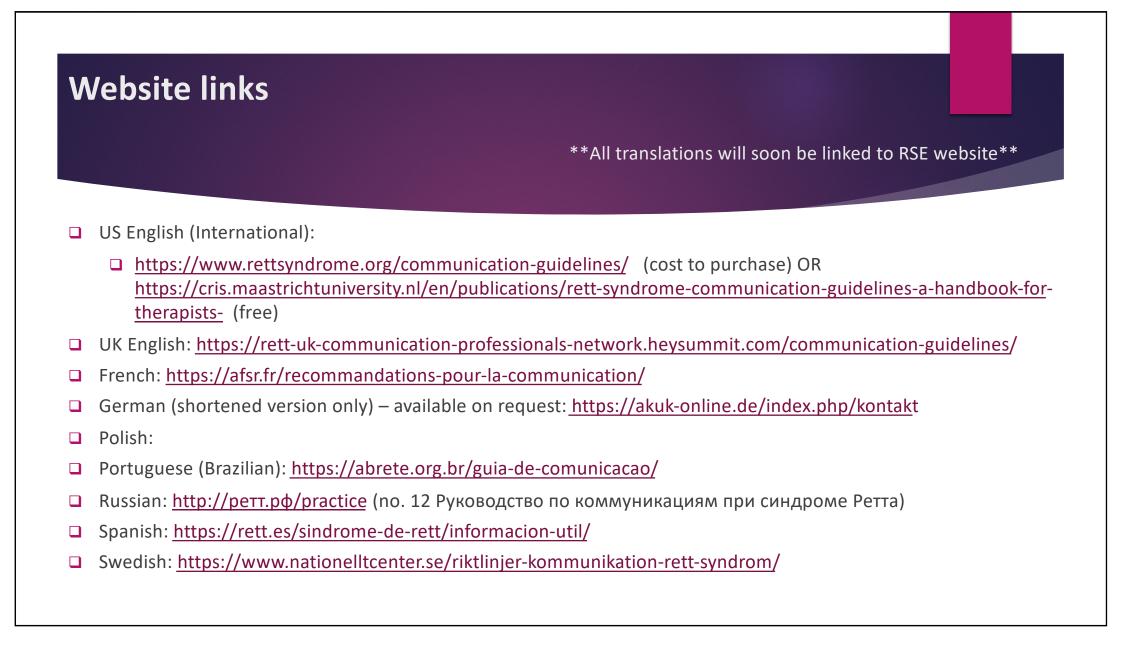
Key messages

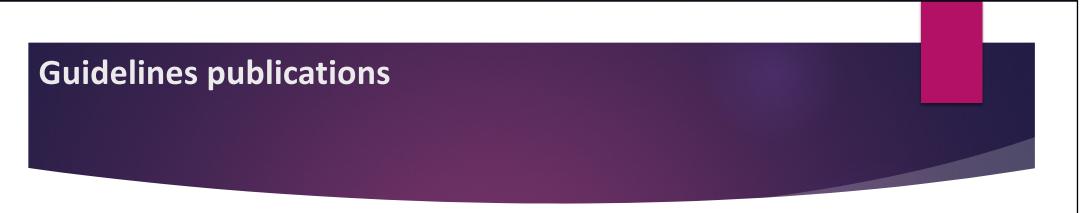
- The team must share a common vision
- Communication should be multimodal
- □ An individual should have more than one system (e.g. low tech & high tech)
- □ An individual's AAC system/device should always be available
- No prerequisites before aided AAC should be considered
- Ultimate goal is to increase autonomy
- □ Important starting points = develop yes/no response, exposure to robust vocabulary
- □ Important strategies = modelling, use of Partner Assisted Scanning
- Expect inconsistency
- Never too young nor too old



Available languages

- □ English (US and UK versions)
- **French**
- German (shortened version only)
- Polish
- Portuguese (Brazilian)
- Russian
- Spanish
- Swedish
- □ Soon to be published Dutch, Georgian, Hungarian, Turkish, (Chinese)





- Townend GS, Bartolotta TE, Urbanowicz A, Wandin H, Curfs LMG. (2020). Rett syndrome communication guidelines: a handbook for therapists, educators and families. Rett Expertise Centre Netherlands-GKC, Maastricht, NL, and Rettsyndrome.org, Cincinatti, OH.
- Townend GS, Bartolotta TE, Urbanowicz A, Wandin H, Curfs LMG. (2020). Development of consensusbased guidelines for managing communication in individuals with Rett syndrome. Augmentative and Alternative Communication. 36(2), 71-81.



Would you like to translate the Guidelines into your language?

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