
**Background**
Loss of hand function is one of the characteristic features of Rett syndrome. In this study, we developed a measure of hand function and then investigated the relationships between hand function, type of MECP2 mutation, age and severity of symptoms.

**What we did**
Families who were participating in the Australian Rett Syndrome Study provided us with video of their daughter participating in daily functional activities. We observed the video footage of their hand use and developed an 8 level scale to describe the level of hand function. We then examined how factors such as age, the type of mutation and general severity were related to the level of hand function.

**What we found**
Some of the girls and women were not able to grasp objects although approximately two thirds of the girls and women did demonstrate purposeful hand function ranging from simple grasping skills to picking up and manipulating small objects.

In general, the younger girls, those who could walk and those with generally less severe symptoms had higher levels of hand function. Also, those with a p.R133C or p.R294X mutation tended to have better hand function whereas those with a p.R168X or p.R270X mutation tended to have lower levels of hand function.

**What does it mean**
This study has allowed us to understand more clearly what the range of hand function is in Rett syndrome. The measurement scale that we developed can potentially be used in both clinical and research settings.