

# **Development of a patient-centered conceptual model of the impact of living with autism spectrum disorder**

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This research was undertaken to help researchers identify what they should measure in clinical trials involving individuals with autism.

We interviewed 10 individuals with autism and 26 parents/caregivers of individuals with autism. We asked them about the symptoms and impacts of autism and which experiences were most bothersome. The interview findings were combined with previously published research to produce a list of relevant symptoms and impacts. These were grouped together into domains (related groups) to build a picture of what it is like to have autism. This picture is referred to in the article as a conceptual model. The conceptual model describes core symptoms that are considered central to having autism (communication, social aspects and restrictive, repetitive behaviors). It also describes other symptoms that are common in autism such as physical symptoms, emotional problems and cognitive (thinking) problems. Finally, we have included impacts that autism can have on day-to-day life (e.g. around the home, school or work, and social life). The interview participants highlighted socialization- and communication-related symptoms as particularly bothersome areas that they would like to see improvement in. The conceptual model provides a view on the experience of living with autism that is centred on individuals with autism and their caregivers. It also provides a framework for researchers to identify appropriate measures to assess experiences and outcomes that are important to individuals with ASD and their families.