

NEWS

# Large U.K. study reports stable rates of autism

BY LAURA GEGGEL

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The prevalence of autism among 8-year-old children remained relatively stable from 2004 to 2010 in the U.K., reports a study published 16 October in *BMJ Open*<sup>1</sup>. But experts say the study may be underestimating autism's rates in the general population.

The stability in prevalence follows a period of rising autism diagnoses in the U.K. The number of 8-year-old children with an autism diagnosis increased fivefold between 1996 and 2003 but plateaued later that decade<sup>2</sup>.

In the new study, researchers found that among 8-year-olds, approximately 0.38 percent of boys and 0.08 percent of girls have an autism diagnosis. The annual incidence — the rate of new cases — also stayed steady at 0.12 percent of boys and 0.02 percent of girls.

"Our study goes from Northern Ireland to the southeast of England, so this is a broad sample of the U.K. population," says principal investigator **Hershel Jick**, associate professor of medicine at Boston University School of Medicine.

However, the numbers don't fit the trends reported in other parts of the world, where autism rates are on the rise, prompting experts to question the results. The **prevalence** is at **1.2 percent** in Iceland, **1.1 percent** in the U.S. and **2.65 percent** in South Korea.

What's more, other U.K. studies also report a higher prevalence of autism, albeit based on different methods. A 2006 study in the South Thames region of the U.K. reported a 1.1 percent prevalence in 9- and 10-year-old children, and a 2009 study in Cambridgeshire County found a prevalence of 1.57 percent in children aged 5 to 9 years<sup>3, 4</sup>.

"It's an interesting study because it shows there is a plateau in the rates of prevalence in this particular dataset in the U.K.," says **Eric Fombonne**, professor of psychiatry at Oregon Health and Science University in Portland, Oregon, who was not involved in the study. "Why they have these low rates, I don't know. It has to be queried."

## Database mining:

In 1990, Jick launched an electronic network called the **General Practice Research Database** (GPRD) that tracks medical diagnoses, including autism, in the U.K. By 1996, more than 1,000 general practitioners from 300 practices were using the database, accounting for about 5 percent of the U.K. population, according to the study.

Last year, the **Centers for Disease Control and Prevention** (CDC) announced that autism prevalence among 8-year-old children in the U.S. had risen to 1.1 percent, a **23 percent increase** from its 2009 rates. Prompted by this report, Jick and his colleagues set out to record rates in the U.K., using data from their database for the same time period and age group<sup>5</sup>.

"[The CDC] had to go back to records and spend endless amounts of time and money to get this done over a ten-year period," Jick says. "But all we had to do was go over to the computer and identify these cases, validate them and then put them into the analysis."

The GPRD has medical records from about 140,000 boys and 130,000 girls each year during the seven-year period ending in 2010. Overall, 1,190 boys and 217 girls received autism diagnoses during that time.

One reason these stats diverge so sharply from reported rates in the U.S. may be that the CDC's data are not accurate, Jick says. For instance, the CDC numbers vary from state to state, ranging from 0.4 percent in Alabama to 2.1 percent in Utah, suggesting **inconsistencies in the collection methods**. "I thought [it] had lots of limitations and problems," Jick says.

Researchers who don't use **standard autism evaluations** may inflate the number of autism cases with incorrect diagnoses. Rising **awareness of autism**, among both doctors and the general public, and a **broadening of autism's definition** may also account for the rising prevalence in many parts of the world.

"We still don't know what autism is," says **Mayada Elsabbagh**, assistant professor of psychiatry at McGill University in Montreal, Canada, who was not involved in the new study. "We change our minds about it every once in awhile."

Prevalence that varies by study is best understood as a **number on a spectrum**, she adds.

"There isn't a single accurate prevalence figure that could reflect prevalence for the whole world or

for any specific country,” Elsabbagh says. “We just have to think about the ranges instead.”

## Network challenges:

The GPRD network reported steady numbers throughout the study, most likely because the doctors using the database, and presumably their diagnosis techniques, remained the same. But researchers are still cautious about its findings.

“Before we jump ahead, we need to seek replication, and preferably in other datasets, and of course in other cities or countries,” Fombonne says.

Fombonne and his colleagues have used the GPRD database for their own research, and he calls it a valuable tool<sup>6</sup>. It has data from large numbers of children, and an independent group examined the medical records and found the autism diagnoses to be reliable.

However, the database has limitations. It relies on medical records for diagnosis rather than finding children through special education records or conducting a population-based survey. Also, some children with less severe symptoms or limited healthcare access may not seek clinical help, particularly if there is a long wait to see a specialist.

“We leave out a lot of children with autism in the community who cannot seek medical service,” says **Young-Shin Kim**, associate professor at the Child Study Center at Yale University School of Medicine in New Haven, Connecticut. “So it’s going to be an underestimation and we need to understand that.”

Kim, an epidemiologist who was not involved in the study, found a higher prevalence of autism in South Korea when she and her colleagues **extended their search beyond clinical samples**. There are many children in the general population who have less severe cases of autism and do not seek medical attention, she says.

Jick concedes that the GPRD database isn't perfect, but says that with a national healthcare system, almost all children in the U.K. are able to access healthcare if needed.

"We might have missed some children who really were autistic but for some reason were never referred and never diagnosed," he says. Even so, "our rates have been much lower than those in the U.S."

## References:

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