

Rare Disease Registries - Perception Of Parents & Young People

Arundathi Jayasena, Miriam Muscarella, Faisal Ahmed

Developmental Endocrinology Research Group, Yorkhill, Glasgow, UK

Background

Rare-disease registries are considered to be the key for improving patient care through research and audit.

In the field of paediatric endocrinology the views of parents and affected young people about such registries are unclear.

Objective

To conduct a survey to understand the views of parents and young people with rare conditions.

Method

A structured questionnaire was completed by two groups of clinic attendees, those who were participating in the I-DSD Registry (www.i-dsd.org) and those who had a rare condition other than DSD. I-DSD participants were also asked about their recollection of the information sheet received and non-I-DSD participants were provided with generic rare disease registry information.

Results

Of 28 people approached, 25(89%) completed the questionnaire. The DSD and non DSD groups comprised of 11 and 14 participants respectively. Each group included one young person.

7/11(64%) participants had already joined the I-DSD registry, all had received the information sheet and found it informative. None of the non-DSD group had joined a registry, but 9/14(64%) found the information sheet informative (Figure 1).

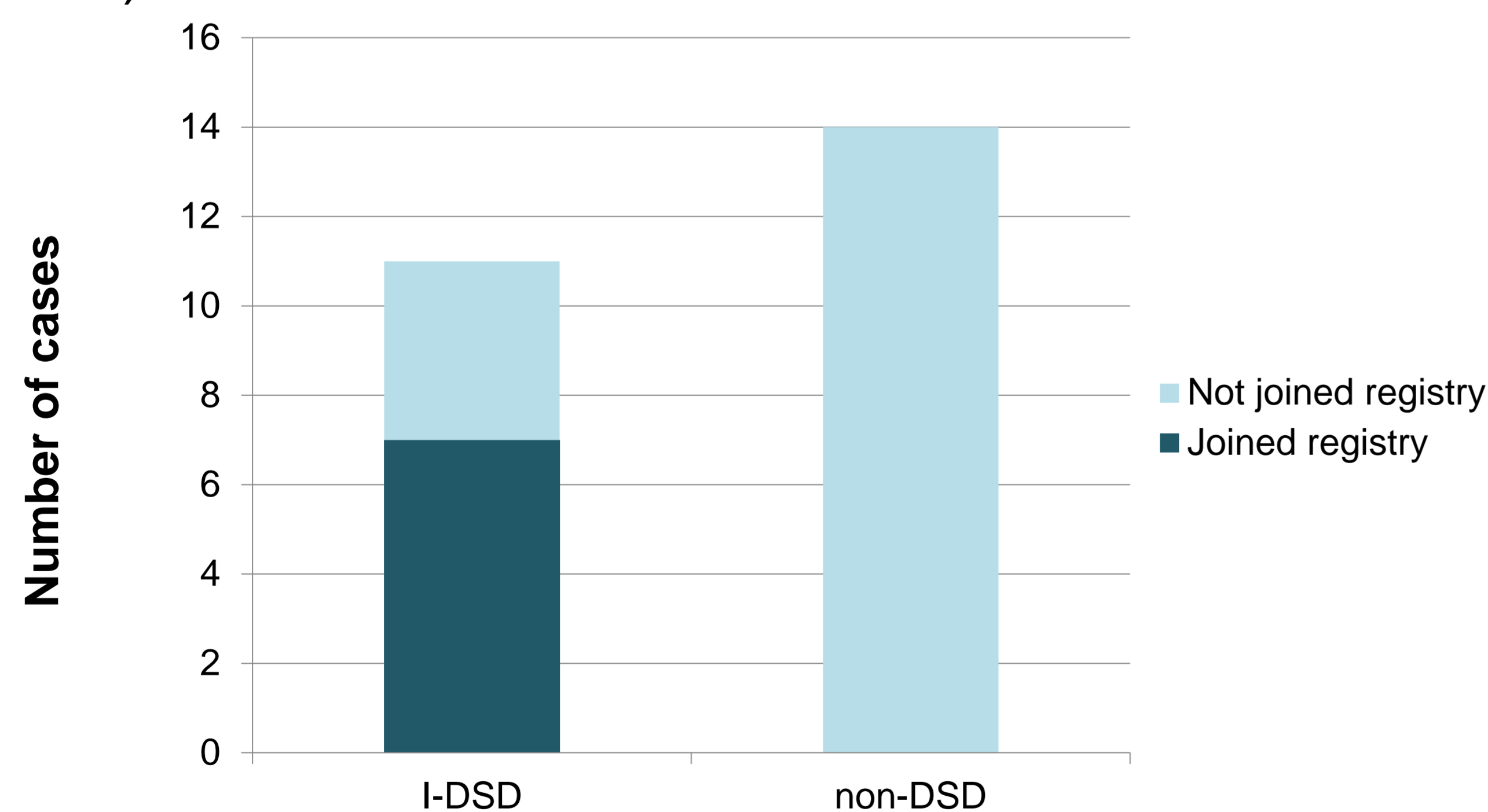


Figure 1: Classification according to the state of joining the registry

There were no differences between the responses from the DSD and the non-DSD participants. All agreed that the registry's goal was to improve care and that the internet was the best medium to access information.

More than 90% of the respondents wanted to use the registry to access information regarding diagnosis, surgery, investigations, genetics and medication.

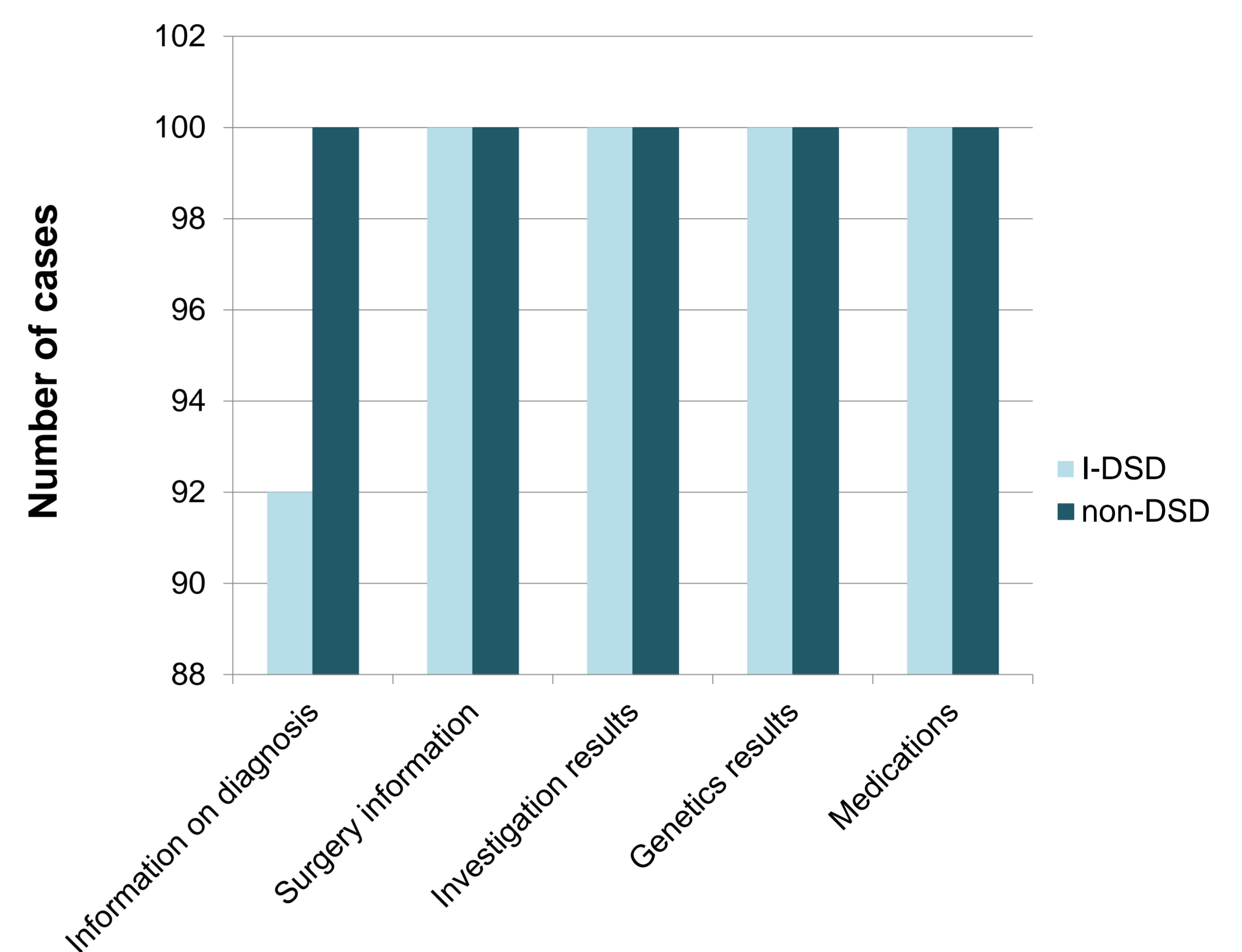


Figure 2: Access of information from the registry-(Percentages)

23/25(92%) respondents agreed that accessing information regarding the tools for talking about the condition with others and the child, parenting strategies, connecting with support organizations would be useful.

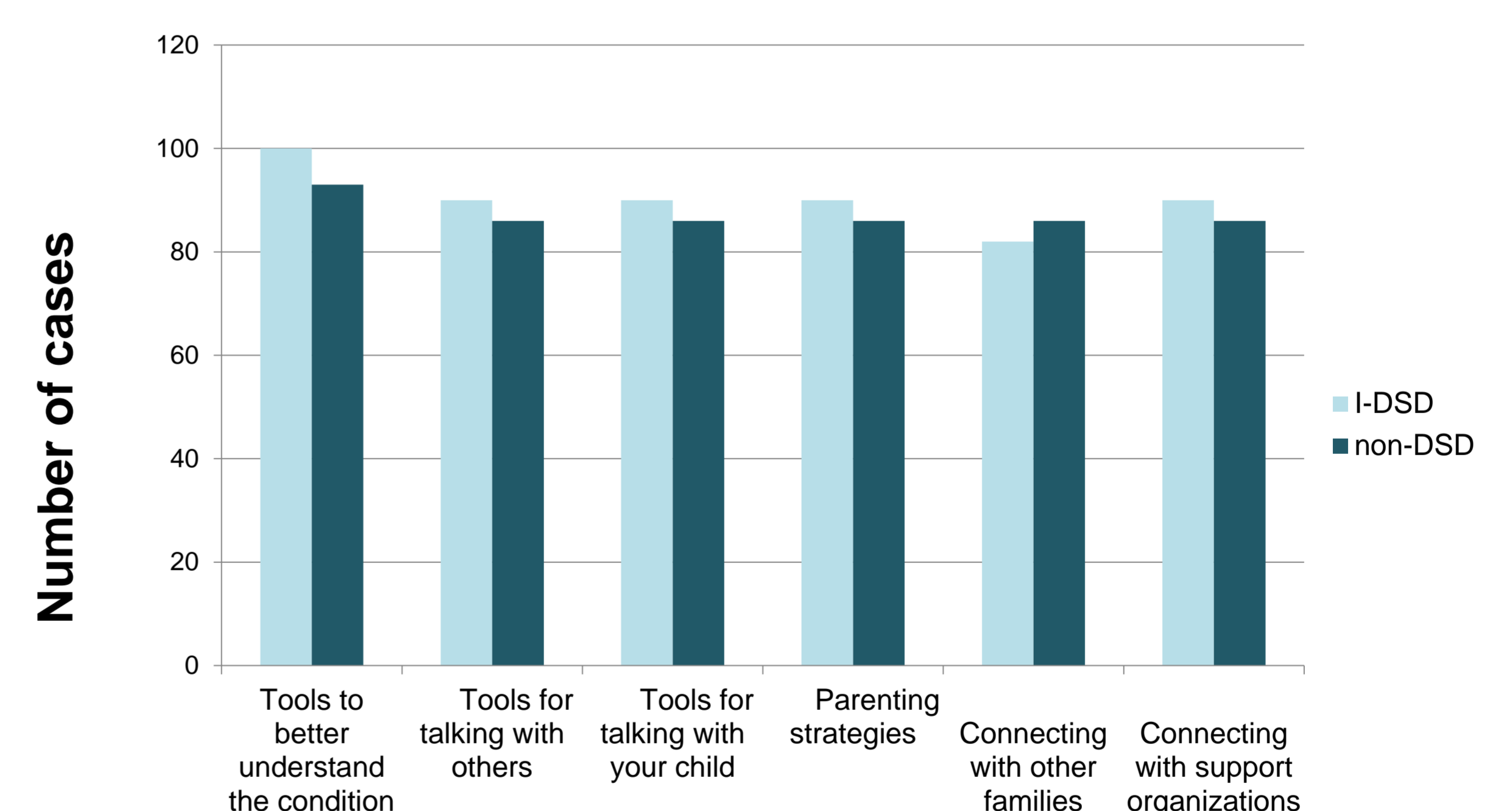


Figure 2: Access of information from the registry-(Percentages)

Of 25 respondents, 1 stated concerns of security.

Conclusion

Parents of children with rare conditions generally have a positive outlook on internet-based rare-disease registries and are keen to use such resources for more information.

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