

## SUMMARY OF RESULTS



Psychological Wellbeing in people with conditions such as Congenital Adrenal Hyperplasia and Androgen Insensitivity Syndrome.

Many thanks for your involvement in the research project. We are pleased with the number of people who responded. It is much appreciated and will help doctors and psychologists know more about what helps or harms people. The following information provided a summary of the main findings.

Although limited, previous research has suggested that whilst psychological difficulties are not inevitable for people with conditions such as AIS and CAH, they may struggle with emotional consequences.

As it turned out, we did find a higher level of psychological distress and relationship difficulties than would be seen for the general population. The overall level of distress was higher than that found in non-patients (this would be expected of any random sample of the population too), but less than that in psychological outpatients. Overall it seems that about 40% of people with conditions such as AIS and CAH may meet criteria for clinical levels of psychological distress.

The areas respondents reported to have found most difficult tended to centre on feelings of inferiority in comparison with others, difficulty trusting others, feelings of anger and finding it hard to be sociable.

It is likely that experiences of people with conditions such as CAH and AIS will have contributed to these feelings. Such experiences may have included fitting in within society and treatment in the health care setting. It may also be the case that these difficulties are part of a healing process, for example, feelings of anger replacing those of shame.

This information has allowed us to suggest ways in which health professionals may be able to help. In brief, these include the following: (i) provision of ongoing support; (ii) clear, honest information; (iii) opportunities to talk (e.g. support groups, clinical psychology etc); (iv) more general awareness raising.

We hope that this information has been useful to you. The Androgen Insensitivity Syndrome Support Group UK and Adrenal Hyperplasia Network will be informed of any subsequent publication.

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