

ICTS ATR-HLQ Abstracts

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Title: The Australian Twin Registry Health and Lifestyle Questionnaire

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Aims: In 2014 the Australian Twin Registry (ATR) began administering an online Health and Lifestyle Questionnaire (HLQ) to ATR members. The questionnaire contained demographic questions and covered a broad range of health conditions and risk factors. The questionnaire aimed to enable research and provide improvements to the ATR member experience by (1) allowing the ATR to better describe its membership; (2) enabling identification of potential participants for specific research studies to reduce costs to researchers and reduce unnecessary approaches to ineligible ATR members; and (3) fast-tracking research by providing de-identified data to researchers for ethically approved research analyses.

Methods: The design of the HLQ incorporated advice from twin researchers and validated questionnaires were used where possible. Many of the demographic and health questions were selected to enable comparison with Australian Bureau of Statistics data. All parents of twin pairs aged 1 to 18 and twins aged 18 or above were eligible to participate in the HLQ and were invited to complete the questionnaire. The email invitation contained a link to the online questionnaire which would take approximately 20 minutes to complete. New members and existing members who provide an email or reach the eligible age will continue to be approached indefinitely.

Results: Over 6,100 adult twins, including over 1,500 pairs and over 3,000 parents of twin children have completed the HLQ. The responses to the survey have provided information on the zygosity of each pair from three sources; self-report, DNA test result and validated zygosity questionnaire. The results include lifestyle factors and current medical conditions for each twin which allowed analysis of the incidence as well as concordance within pairs. Examples of information obtained included self-reported health rating, diabetes, asthma, epilepsy, psychological wellbeing, mental illness, cancer, vision problems, smoking and alcohol consumption.

Conclusions: Responses to the HLQ have allowed identification of over 700 twin pairs with specific medical conditions to meet the eligibility requirements of four studies currently recruiting through the ATR. With this information, the ATR has been able to use targeted approach methods to invite participants, allowing more participants to be recruited in less time. Identification of appropriate twin pairs has also provided important information for funding applications, both in Australia and internationally.

Data from the HLQ is available for use in twin health research either as de-identified data or to be linked with ATR or other datasets. Data from the HLQ has already been provided to researchers for three national projects and one international project either as unaccompanied de-identified data or as a linked dataset for analyses. The ATR has been collaborating with the recently established Brazilian Twin Registry (BTR) to implement a HLQ to BTR members.