

Response ID ANON-BS5M-HV8F-K

Submitted to **Proposed changes to the National Health Index (NHI) system and HISO 10046, the Consumer Health Identity Standard**
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9. Disability status

Feedback on 9. Disability status

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IHC comment: National Health Index System – 9 - Disability Status

IHC strongly supports high priority being given to including disability status in the National Health Index (NHI) system.

We recommend, however, that several changes are made to the proposed means of data collection. We have two main concerns.

Firstly, without modification, the Washington Group Short Set (WGSS) of questions does not adequately identify people with intellectual disability. Yet people with intellectual disability experience some of the poorest health outcomes of any population group in New Zealand. It is critical that this population group are made visible within the NHI and health system. Data needs to be captured in reliable and valid ways that can be disaggregated to identify those with intellectual disability.

Secondly, the most common impairments types for children with disabilities are learning, speaking and psychological/psychiatric impairments, none of which are captured well by the WGSS. If the proposed questions are used without modification information about the disability status of children will be largely absent from the NHI.

We acknowledge the difficulty in getting the questions right and that this is an area that is fraught with both methodological and ideological challenges, including the range of terms used. For robust official national data definitions must be used consistently, especially given the implications for tracking progress and monitoring the wellbeing of and outcomes for people with intellectual disability across their lifespan.

We recommend that in developing these proposals further the Ministry of Health and Statistics New Zealand explore ways to ensure accurate identification of disability status for people with intellectual disability and children with disabilities.

