About the National Autism Registry and Biobank Stakeholder Consultation:
This is a consultation process that is being undertaken by three partner organizations, namely the National University of Ireland, Galway (NUIG), Trinity College Dublin (TCD) and Autism Speaks. The aim of the consultation is to engage with stakeholders affected by or involved in service provision to people with autism or other related neurodevelopmental disorders. Specifically we would like to learn more about the needs of the community and what kinds of information is most helpful to record in a clinical registry. Additionally we would like community feedback on the development of a biobank to support biomedical research. At the end of this process we plan to produce a report that will be provided to the stakeholders summarizing the outcomes and recommendations for next steps.

What is a clinical registry?
Clinical registries gather clinical information and other data on patients to inform the development of clinical practice, services and future research. Some of the best-known examples of registries are those that exist in Scandinavian countries where there are well-established patient registries for a variety of physical and mental illnesses and disabilities for many years. These well-organised registries provide critical data that are useful for the development of services and to identify critical research questions to be further investigated.

Why do we need a registry for ASD and related neurodevelopmental disorders?
To address critical questions concerning ASD and related conditions in Ireland there is an urgent need for a comprehensive registry. This registry will serve as a national resource for research in the areas of health, education and social services and to inform policy development. In March 2013, a private members bill, The Autism Bill, was brought forward to government to require the development of a national strategy for autism, including the development of a national registry providing an accurate estimate of the number of people with ASD in Ireland.

The development of a registry can address a range of research topics that may include:

- The scale of autism in Ireland across the lifespan
- The behavioral health and medical needs of the Irish autism community
- The impact of early intervention on later outcomes
- Factors that influence successful school placement
- Factors that influence improved quality of life among adolescents and adults with autism
- Planning for transitions in service delivery, e.g. from pre-school to school, from school to adult services

In Ireland the National Intellectual Disability Database (NIDD) is gathering information on individuals with intellectual disabilities nationally to provide information to government and policy makers regarding the service needs of the ID population. There is no ASD-specific registry gathering this type of data. Individuals with ASD and an intellectual disability may have been included in the NIDD but since many people diagnosed with autism today do not have an intellectual disability, it is likely that their needs are not captured in the NIDD. This may also be true for rare neuro-genetic syndromes such as Fragile X, Prader Willi syndrome and Velocardiofacial syndrome (VCFS), among others, which are also associated with specific behavioural features but not necessarily with intellectual disability.
We are proposing the development of a national registry that will record information about people in Ireland living with ASD and other related neurodevelopmental disorders. The aim of this registry would be to collect information that is vital to service planning in all areas of the lives of people with such disabilities, e.g. healthcare, social care, education and occupation. The proposed registry will record information about people anonymously and will not affect the rights or access of individuals to services.

What is a biobank?
A biobank is a type of repository that stores biological materials, such as blood and saliva that can be used in research. Biobanks have become a key resource to support medical research particularly in the fields of genetics and personalized medicine and for the development of biomarkers for various human conditions. Biobanks typically include samples from people affected by the same condition. In the future it is hoped that by combining genetic information (e.g. DNA or RNA) with other information, e.g. regarding physical symptoms or environmental factors, it will be possible to better understand how genes and environment interact to cause autism and to find better ways to prevent and treat the condition.

Why do we need an autism biobank?
Large collections of biomaterials from individuals affected by autism and their families have previously been assembled in the United States and have provided researchers with essential information to investigate the genetic factors that may contribute to autism. Many Irish families have previously participated in a biobank known as The AGP Simplex Collection (TASC) through Trinity College, which provided almost 2000 samples from 13 different centres internationally for research in autism genetics. This collection has been used widely in recent research that has shown that in some cases autism is caused by rare genetic changes. To progress research of this nature many more samples are likely to be required. In many fields of medical research, scientists are coming together to share samples globally so that studies have enough power to find some of the answers for complex conditions. It is proposed therefore to develop a biobank in Ireland that would collect DNA samples from people with ASD, willing to contribute, and their families. This would provide more samples to Irish researchers and to large-scale international studies to conduct genetic studies in autism. Biobanks are also increasingly used by private companies such as pharmaceutical companies to help research to develop new treatments for many conditions such as cancer and other common conditions like diabetes. Such a biobank might also be useful for pharmaceutical companies interested in researching new treatments for these conditions.

Are there any issues in relation to sharing personal information or biological samples?
The most important concern with registries and biobanks is to protect the privacy of the individuals included. Information is usually stored as coded information that does not contain any personally identifying information. There are also strict controls about who can access the data to ensure that certain groups do not get unauthorized access to the data. This is important to prevent any person or agency from using the data in a way that might discriminate against a person because they have a particular condition.

Genetic data also needs to be handled carefully as researchers might identify information that shows that someone is more at risk of a particular condition. It is important to maintain the persons right to privacy over this information. It is also important to know if this information might be important people such as family members who are also at an increased risk of getting the condition. Usually when people
consent to take part in a biobank these questions are discussed with them so that they can decide what way this information should be shared with them and their relatives. People may also want to opt for the right not to know if they have an increased risk for a given condition and this also needs to be respected.

**How do we make sure that the views of the community are heard?**

The Irish Centre for Autism and Neurodevelopment Research (ICAN) and the Centre for Studies in Autism and Related Disorders Trinity College Dublin, and Autism Speaks are engaging in a consultation process with the community in Ireland about the development of a national registry and biobank for autism and related neurodevelopmental disorders. The process of establishing these resources should take account of the needs, perspectives and wishes of people with ASD and related disorders and their families. It should also take account of the information required by service providers to provide optimal resources for service users. The community can best advise on the type of data that might be informative and to identify critical issues that need to be highlighted. They will also be best placed to share their perspectives on important considerations such as privacy and data protection and other concerns that they might have about this type of development. The development of a biobank is also likely to create many questions for the community affected by autism and related neurodevelopmental disorders such as who will access the biological material and how will it be used.

We launched this consultation process at the 2nd conference on autism and related neurodevelopmental disorders at NUIG in June 2013, where we had a roundtable discussion and conducted a pilot survey. The next phase of the consultation process involves engagement with the community through town hall meetings, meetings with service providers and policy makers and an online survey.

**Who we are:**

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**Website will launch shortly at** [www.iarb.ie](http://www.iarb.ie)

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