Cohort Profile

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Pocket Profile for SDRNT1BIO

Title: Cohort Profile: Scottish Diabetes Research Network Type 1 Bioresource Study (SDRNT1BIO)

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Cohort purpose: Type 1 diabetes (T1DM) causes substantial morbidity and loss of life expectancy from both acute metabolic complications and chronic complications. The causal pathways of T1DM and its complications are only partially understood. The Scottish Diabetes Research Network Type 1 Bioresource (SDRNT1BIO) is a collection of biosamples and data from adults with T1DM, Latent Autoimmune Diabetes of Adults (LADA) and Maturity Onset Diabetes of the Young (MODY) resident in Scotland. It was established: to facilitate research into the genetic determinants of T1DM and its related complications; to enable discovery of predictive and surrogate biomarkers of complications yielding insight into pathogenesis; to enable stratification of apparent T1DM into monogenic and polygenic diabetes; and to discover environmental determinants of T1DM. The ultimate aim is to drive forward the prevention of T1DM and its complications.

Cohort Basics: Between 2010 and 2013, 6,127 participants aged 16 years and older with a clinical diagnosis of T1DM, MODY, or LADA were recruited. They comprised consecutive attendees at routine hospital and primary care annual diabetes review visits in 10 of the 13 NHS Board areas in Scotland. A questionnaire was completed, physical measurements made and samples stored. Participants gave consent for follow-up in person (93%) and through their electronic health care records (100%). They are representative of the total adult population with T1DM in Scotland in their clinical history and clinical and demographic characteristics.

Follow-up and attrition: Prospective data linkage will also provide follow-up data and a process of prospectively collecting serial samples using spare blood from clinical encounters has been established.

Design and Measures: The SDRNT1BIO is a prospective cohort study. The baseline data set comprises biological samples including serum, plasma, whole blood and urine; physical measurements including anthropometry, bioimpedance, and blood pressure; and questionnaire data including sociodemographics, details of diabetes diagnosis and treatment, history of complications, and lifestyle assessment e.g. physical activity, smoking and alcohol. Linkage to extensive retrospective and prospective e-health record data has

captured all hospital admissions, annual diabetes clinical reviews, laboratory data, retinopathy screening, renal replacement register data, prescribing and death data.

Unique features: The SDRNT1BIO is one of the largest and most comprehensive collections of biomaterials and data from people with T1DM worldwide and 93% of participants have consented to future re-contact for additional studies. Unique features include harnessing the common health care identifier used in all health records in Scotland to collect comprehensive retrospective and prospective data at minimal cost and automated capture of future blood samples from routine clinical encounters.

Reasons to be cautious: Only a subset of SDRNT1BIO participants have follow-up biosamples as yet though almost all have follow-up data.

Collaboration and data access: Data are accessed through supported collaboration with the study investigators. Interested collaborators should contact the study coordinator in the first instance (Helen.Colhoun@igmm.ed.ac.uk).

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