**Development of a common core dataset for rare diabetes syndromes registry: the EURO-WABB registry for Wolfram, Alström and Bardet-Biedl syndromes**


**INTRODUCTION**
Rare diabetes syndromes affecting less than 1:100,000 children are under-recognised; delayed diagnosis is common; treatable complications may not be identified, and it is challenging to recruit sufficient patients to clinical trials.

**OBJECTIVES**
We aimed to develop a common core dataset for notifying children with Wolfram, Alström, Bardet-Biedl, Wolcott-Rallison, Thiamine-responsive Megaloblastic Anaemia, Deafness and Diabetes, and other rare diabetes syndromes, to an international European registry.

**METHODS**
We convened two meetings of international researchers in rare diabetes syndromes (French Wolfram syndrome association 2010; EURO-WABB meeting 2011); we reviewed the case records of patients attending the national specialist commission Alström and Bardet-Biedl services during 2010 (UK); and published clinical descriptions of rare diabetes syndromes to April 2010.

We developed a consensus core and extended dataset. The core dataset includes 44 data fields of which 5 relate to referring physician and consent data; 18 define the clinical and molecular genetic features and differentiate between syndromes; and 10 relate to age of onset of symptoms, and optional free text. The extended dataset comprises 370 fields of detailed phenotyping information. The core dataset can be completed in less than 15 minutes.

If you would like to participate in this registry project and have affected patients, please register at [www.euro-wabb.org](http://www.euro-wabb.org).

**CONCLUSION**
Agreement on a common core dataset for very rare diabetes syndromes is essential in order to compare data between national registries, link registries and identify subgroups of patients that may be eligible for clinical trials or to prioritise genes for mutation searches. We have developed a common core dataset for European Union states that can be shared between national rare disease registries as they are developed; and will allow linkage with other international disease registries. The core dataset can be found at: [www.euro-wabb.org](http://www.euro-wabb.org).