

BPSU PPI Guidance for Researchers

By Rachel Winch

The British Paediatric Surveillance Unit (BPSU) undertakes national epidemiological surveillance of rare diseases of childhood. Unlike many research projects, patients or their parents are not approached, so its studies are undertaken without consent and have to obtain approval from the National Information Governance Board for Health and Adult Social Care (NIGB) as well as a Multicentre Research Ethics Committee (MREC). Patient and public involvement (PPI) is especially important in research which does not involve individual consent, to ensure openness, transparency and accountability to the public.

After an extensive review of the impact of PPI on its research activity, the BPSU has produced a guidance document for researchers on how to involve patients and the public in their research. This document has been designed to be an accessible and practical guide for researchers carrying out research through the BPSU, but we also hope it will be useful to a wider audience who are grappling with PPI in similar types of epidemiological surveillance. It offers practical advice on how to involve people, and provides examples of where PPI has been effective in BPSU studies. The guidance was developed by TwoCan Associates in collaboration with a steering group of BPSU Scientific Committee members, including its lay representatives.

www.rcpch.ac.uk/bpsu/ppi

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