

North Cumbria Genetics Project 1994: Fate/Future of Samples

EHSC relayed CORE's questions about this project to Newcastle Biomedicine Biobank. The following replies were kindly supplied by Professor John Burn.

The Westlakes Research Institute stored infant blood samples and infant DNA but ceased trading earlier this year.

1. What is the fate of these samples and who is responsible for them?

All DNA and tissue samples collected as part of the NCCGP were transferred to the Newcastle University Biobank when Westlakes closed. It was always made clear that overriding responsibility for the NCCGP samples was held by Professor J Burn as Chief Investigator

All identifiers were held by the academic clinical team from the start.

2. Where are they stored?

The data are held at the Institute of Genetic Medicine under the stewardship of Dr Caroline Relton. The samples are held in the Biobank which is housed in the Newcastle Medical faculty at Framlington Place.

3. What are the plans regarding their future?

The samples have been used in a number of important studies which have led to significant contributions to the medical literature.

We have over the years made a number of bids for funding to develop the NCCGP without success. We are currently negotiating with new funders and hope to have a response in the next few weeks

4. Will participants be informed of any changes?

The study was not set up to allow routine contact with the donors. It was agreed that we would contact potential participants in research through their GPs. We were successful in getting funds for research into the genetic basis of eczema. Our dermatology research fellow contacted all families through the junior school network in 2007 and achieved excellent support in collecting information on the pattern of skin problems which we were able to link to the genetic resource. This work reminded most participants of the existence of the NCCGP as did the significant newspaper and TV coverage. The Research Ethics Committee were made aware of the plan to transfer the tissue and DNA samples into the Newcastle biobank. It was agreed that this did not represent a substantive reason to attempt to contact the donor community. It is worthy of note that formal Biobanks did not exist when NCCGP was collecting samples. Had the Newcastle Biobank been established at that time, we would probably have considered using them from the outset, though a factor in our discussions was to continue to involve Westlakes Research Institute wherever possible in order to help them develop a research presence and support local employment.

5. Are there any plans to write to some of the children who will now be approaching their 16th birthday and to ask for their permission to continue storing their sample, rather than relying on the mother's original consent?

Our consent clearly states that we are not permitted to retain identifiable samples on any child beyond the age of 16 years without renewed consent. We have had extensive dialogue with the ethics committee on this issue. This begins to be an issue in 2012. If our current efforts to raise funds are successful, we will design a new project to re-consent the participants and extend the remit and scope of the project to take account of the rapidly developing field of genomics.

NB Human Tissue Act 2004, if applicable, requires appropriate consent for storage of human tissue samples. The Human Tissue Act 2004 does not apply to stored DNA

John Haywood
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