

Biobanks in Norway – funding by the Research Council

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The Norwegian biobanks encompass population based health survey-studies and hospital based clinical biobanks. Together with health registers and other population surveys they constitute a world class research resource (1,2). Norway's public health system, unique personal ID numbers, national health registers, a population positive to medical research and the ability to track the health of individuals throughout life provide an excellent basis for long term epidemiological and clinical research (3-5).

The Research Council of Norway (RCN) is funding close to one third of the public research in Norway, and is a key research policy adviser to the government. A number of programs for funding research related to health and medicine have been established. These programs, in conjunction with open funding opportunities in arenas for basic research and innovation are relevant for biobank research (6). However, significant efforts on developing biobank infrastructure must be complemented by programs that promote the use of these biobanks. Thus we have a new program (7) dedicated to the development of research-based knowledge about human health and disease through better use of human biobanks and health data as unique resources.

INFRASTRUCTURE AND INTERNATIONAL COOPERATION

A significant biobank infrastructure effort is being implemented in Norway (8) and Europe (9). Nationally, the focus is to build capacity at the Norwegian Institute of Public Health (10) (NIPH), Oslo, and in Levanger for the *Nord-Trøndelag Health Study (HUNT)* (11). The project *Biobank Norway* (12) has received 80 million NOK from the Research Council. A consortium has been established, consisting of the four medical faculties at the four comprehensive universities (University of Oslo, Norwegian University of Science and Technology, University of Bergen, and University of Tromsø), the four regional health authorities in Norway and the Norwegian Institute of Public Health (NIPH). The project has coordinated Norway's cooperation with the European biobank effort *Biobanking and Biomolecular Resources Research Infrastructure* (www.BBMRI.eu), aiming at the establishment of a *European Research Infrastructure Consortium* (BBMRI-ERIC). There is also a close Nordic cooperation regarding biobank infrastructure and research, with activities funded by NordForsk (www.nordforsk.org).

The population based health surveys and research biobanks in Norway are attractive for international researchers, and projects have received substantial exter-

nal funding. The National Institutes of Health (NIH) in the USA is an active co-funder of the Norwegian *Mother and Child Cohort Study (MoBa)*. MoBa is a unique collection of data and biological material from more than 100 000 mothers, their children and a large number of fathers.

HUNT is one of the largest and most complete population based health surveys, also internationally. Altogether, the three HUNT surveys contain health data from close to 120 000 persons and biological material from 100 000 participants. HUNT-data have been used over a number of years by international research groups, such as the USA, the Netherlands and France, in collaboration with Norwegian researchers. HUNT is coordinated with the other Norwegian health surveys in Troms, Finnmark, Hordaland, Oslo, Oppland and Hedmark, into the *Cohort of Norway (CONOR)*, a valuable multiregional biobank which will contain health data from 200 000 subjects.

Other Norwegian population based biobanks are the *Janus Serum Bank*, where blood reserved for cancer research was collected through the *National Health Screening Services* (more than 300 000 persons) and the *Norwegian Women and Cancer (NOWAC)* cohort study, which includes 170 000 women and blood samples from 50 000.

A DEDICATED RESEARCH PROGRAM

A new research program, *Human Biobanks and Health Data*, was launched by the Research Council in February 2012 with a total budget of 110 million NOK (7). The main purpose of this program is to take advantage of the potential for research on human biological material in biobanks, by exploiting the ability in Norway to link data derived from biobank analyses with data from health surveys, health registers (13) and the health services. The primary goal for the program is thus to establish research-based new knowledge aiming at prevention, detection, diagnosis, treatment and survival of somatic and psychiatric diseases.

This program is broad and relevant for research of all hypotheses and questions related to human health and disease; it is not limited to particular topics or methods. Projects may cover basic biomedical, clinical, epidemiological or societal health questions. The research shall be based on the use of human biobanks, in combination with data from health surveys, health registers and the health services, as well as other relevant registers. Research projects should use the full potential of the large biobanks and registers, unless there are scientific reasons for a smaller study sample

or population. Furthermore, the use of analysis capacity and competencies built up through national infrastructure programs, such as the biobank infrastructure (Biobank Norway) and the large scale Functional Genomics program (FUGE)-supported technology platforms, is encouraged.

There is considerable international interest in biobanks as a research resource, and the new program also aims at strengthening Norwegian researchers' ability to participate in international cooperation. Thus it is essential that the ethical, legal and societal aspects of this research are treated as an integral part of the program and of the individual projects, and for the program to stimulate and participate in public dialogues. Through effective and optimal use of data from the population based health surveys and biobanks, society shows respect for the participants and motivates for continued high compliance and participation in the health surveys. It is a fundamental premise that the research has the trust of the population.

STRATEGIC WORK BETWEEN FUNDING BODIES

Cooperation and coordination within and across borders extend beyond the reach of technical exchange of data to include legal, societal and funding issues. Funding agencies must work strategically at national

and international levels, in order to maximize the potentials for international collaborations based on national biobanks, to ensure high quality research output and to reduce duplication of effort. The European Strategy Forum on Research Infrastructures (14) (ESFRI) and the European Research Area Joint Programming Initiatives (15) (JPIs) are examples of such strategic collaborations.

Strategic dialogues outside Europe are also essential. For the medical sciences the National Institutes of Health (NIH) in the US are the world's largest funder of basic biomedical science and other countries and regions are gaining importance fast. Biobanks are at the core of the Research Council's strategic dialogues with NIH, with reference to a letter of intent signed in 2010 (16). Sessions on biobanks have been featured at Norway's Transatlantic Science Week; at NIH in 2008 and at Georgetown University in 2010 (17). This annual event in North America promotes research cooperation and policy dialogues between Norway and the US and Canada.

Finally, it is of utmost importance that scientists and funding agencies work closely together in these strategic dialogues; in formal fora, but also in a more open and *ad hoc* manner. Such versatile coordination processes are creating new models for necessary strategic dialogues in order to achieve optimal funding for biomedical science.

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13. Health registers in Norway, coordinated by NIPH (see www.fhi.no).
14. The European Strategy Forum on Research Infrastructures (ESFRI), see http://ec.europa.eu/research/infrastructures/index_en.cfm?pg=esfri.
15. European Research Area, Joint Programming, http://ec.europa.eu/research/era/areas/programming/joint_programming_en.htm.
16. Letter of intent between NIH and Norway, signed in 2010 (www.rcn.no/international).
17. Transatlantic Science Week, an annual event organized by the Norwegian Embassy in Washington DC, see <http://www.norway.org/scienceweek>.