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## **Europaforum Northern Sweden - views on Horizon 2020 and biobanks**

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Europaforum Northern Sweden (EFNS) is a partnership and network for councillors at local and regional level covering the four northernmost regions in Sweden: Norrbotten, Västerbotten, Västernorrland and Jämtland.

The objective is to increase knowledge and awareness of policies at EU level – above all to increase involvement in shaping EU policies on matters regarding northern Sweden.

Our views represent the positions of elected officials in the four northernmost regions in Sweden. The viewpoints have been formed in close cooperation between the regions.

According to the general [positioning paper](#) that EFNS adopted on 30 March 2012 with focus on Horizon 2020, the region has specifically strong research and business areas of strategic significance to NSPA (Northern Sparsely Populated Areas in northern Europe), and to Europe in a wider perspective.

One area is research and innovation in the field of biobanks, where the counties in the region collaborate closely also on concrete research projects and findings that can be implemented through cooperation between the county councils.

Health promoting initiatives, both from the community and citizens, are a decisive factor in health and life quality. Access to research findings from epidemiological studies and biobank research are crucial as a basis for preventive work. The EFNS area thereby provides both a national and international model, since the region has a research infrastructure that is among the global leaders, and collaborates both in the European and the international arena.

Within Horizon 2020, primarily in “societal challenges” concerning “health, demographic change and well-being”, the EFNS region can provide a strong European environment for research and innovation. In addition the region can be a demonstration and pilot environment in the field of healthcare, public health, demographic development, well-being and food.

### **EFNS and biobanks**

Like many countries and regions in Europe and the world, the EFNS region has an ageing population and therefore increased costs for medical and healthcare. This leads to a need for long-term data for follow-up and preventive measures, as well as research and innovation to meet these challenges.



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The region has unique population-based biobank material with very long follow-up times and repeated testing. There is nothing internationally that covers the entire population of a whole region. New fields of disease mean greater challenges, for example the neurodegenerative field (Alzheimer, Parkinson's disease, MS, ALS). Researchers in the northern region have achieved a leading position internationally thanks to the material that has been built up, which in certain fields covers practically the whole population. This unique structure is the result of cooperation between researchers, university and medical administrators: cooperation which is continuing and developing.

The human biological environmental sample bank (linked to the "MONICA" project), in a way that cannot be done in other parts of the world, gives additional possibilities to study environmental factors, including food consumption, that affect an entire population. The project also concerns monitoring the status of immunity to infectious diseases and the development of risk factors for major endemic diseases such as cardiovascular disease, diabetes and cancer.

Linking blood biobank material with tumour biobanks is another area in which the EFNS region is successful, and in many respects an international leader through collaboration in the whole region.

One recently started project is "the NORTHPOP infrastructure: A new concept for population-based multigenerational studies of human health, disease and living conditions." The purpose of NorthPop is to build up a new national research infrastructure that integrates data from biobanks and different forms of register and expositional data covering many generations. In the field of biomedical research, the multigenerational perspective creates new opportunities to understand how heritage, environment and life conditions affect our health.

Multigenerational studies that include biobank samples and expositional data have previously been very difficult to carry out on a large scale for lack of reliable and easily available genealogical information at demographic level. An important part of infrastructure construction is therefore a longitudinal demographic database.

Digitisation and linking of individual-based data is carried out by the demographic database using well developed systems and stringent quality requirements. At the same time, long-term gathering of new samples and health data from two selected population groups is being carried out, on the one hand from elderly individuals, and on the other hand children and their mothers. The project involving children will increase our knowledge of how conditions during childhood affect the risk of developing disease later in life, and how the different conditions of the parent generation and perhaps even earlier generations influence children's health. The project complements existing biobanks which already today cover 90% of the age group 45-89 (in the Västerbotten County).



With complete genealogies, expositional data and biobanks of a homogenous population, NORTHPOP will be a globally unique resource for groundbreaking research which will be accessible to the entire international research community, and an important and in many ways unique complement to other population-based initiatives in the biomedical field. Thanks to the unique structure, scientific breakthroughs can be achieved if the infrastructure is utilised in a good and innovative way. The region and Umeå University also possess advanced skills in data storage, access and security, facilitating these initiatives.

The biobank field is internationally competitive. The unique infrastructure and collaboration in the EFNS region mean that we have a competitive edge on the international market. There is a demand today from international pharmaceutical companies for the type of resources that are now in place in Northern Sweden, giving access to research material which the industry cannot build up through its own resources.

### **Horizon 2020 and biobanks**

The EFNS region already has established collaboration between research in the University and the University Hospital, as well as follow-up and implementation of findings through collaboration between the four counties (which geographically constitute more than half of Sweden) and the county councils in the region. The universities and companies in the region are also highly skilled at the international level in secure storage of large quantities of data.

The proposed priorities (COM 811 final, 2011/042) in Horizon 2020 are thereby highly relevant to the EFNS region in “**societal challenges**”, primarily within “**health, demographic change and well-being**” with focus on e.g.:

*“Effective health promotion, supported by a robust evidence base, prevents disease, improves wellbeing and is cost effective. For efforts to prevent, manage, treat and cure disease, disability and reduced functionality to be successful, there is a need for fundamental understanding of their causes, processes and effects, as well as factors underlying good health and wellbeing. Effective sharing of data and the linkage of these data with large-scale cohort studies is also essential, as is the translation of research findings into clinical application, in particular through the conduct of clinical trials.”*

Priority areas of particular relevance include.

#### **Better understanding of disease**

*“Underpinning basic research will encompass and encourage development and use of new tools and work methods for the generation of biomedical data. These activities will demand close links between fundamental and clinical research. Close links with research and medical work (databases, biobanks etc.) are also required, for standardisation, storage, sharing of*



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*and access to data, which are all essential for maximising data utility and for stimulating more innovative and effective ways to analyse and combine datasets.”*

### **Better use of health data**

*“The integration of infrastructures and information structures and sources as well as the standardisation, interoperability, storage, sharing of and access to data to enable such data to be properly used. Special attention should be given to data processing, knowledge management, modelling and visualisation.”*

### **Improved scientific tools and methods to support policy making and regulation**

*“There is a need to support the development of scientific tools, methods and statistics for rapid, accurate and predictive assessment of the safety, efficiency and quality of health technologies.”*

The H2020 prioritisation of **international collaboration** is of great relevance to EFNS also in these areas. The EFNS region and the field of biobank research collaborates closely with nearby counties/county councils in NSPA (such as Trondheim in Norway), and within the EU and internationally with e.g. the USA and China.

The high ICT competence in the region - research and innovation (e.g. within BigData) and successful companies and implementations in the public sector – are also relevant in the field of biobanks and **“industrial leadership”** in Horizon 2020, e.g. within priorities such as:

- *“Next-generation data management: advanced computer systems and computer technologies*
- *Future internet: infrastructure, engineering and services*
- *Content technologies and information management”*

## **EFNS in the European Agenda**

EFNS therefore proposes:

- That the region shall form a node in the European biobank initiative and a research and innovation, demonstration and pilot environment available to and collaborating with the whole of Europe.