Biobanking: from vision to reality

Jennifer R. Harris, Anita Haugan and Isabelle Budin-Ljøsne

Division of Epidemiology, The Norwegian Institute of Public Health, Oslo, Norway

Correspondence: jennifer.harris@fhi.no

Biobanks are well-organized collections of human biological samples and associated research and clinical data; they are providing the essential ingredients for contemporary biomedical research and transformative approaches in personalized medicine. The last decade has witnessed enormous progress in the science of biobanking; it has emerged as a field in its own right and is becoming increasingly grounded in a growing evidence base. Likewise, biobanks are fuelling great advancements in our scientific knowledge, particularly in genetics and systems biology, as novel analytic techniques are brought to bear on a wealth of data and samples held in biobanks worldwide. However, this is just the tip of the iceberg. Biobanks, if properly managed and coordinated, hold great promise to unravel disease aetiology, improve diagnostics and prevention, translate findings, accelerate personalized medicine and improve public health.

In recognition of this promise, researchers, funders and governmental bodies have shared a vision to establish an internationally interoperable network of biobanks to accelerate science and innovation through enhanced data integration and the secure sharing of data and biospecimens. The agenda is both huge and ambitious. It has been accelerated in Europe through several interrelated initiatives funded by the European Commission and also through close collaborations with projects outside of Europe. Primary among these are harmonization projects (1-4) and the preparatory phase of the "Biobanking and Biomolecular Resources Research Infrastructure" (BBMRI) (5) – which is a critical component of the European Strategy Forum for Research Infrastructures (ESFRI). Many other projects, too numerous to reference here, have also contributed. Together, they have begun to address the essential and practical issues required to realize the vision of international biobanking. Spanning population- and disease-based biobanks, harmonization platforms are being developed for biospecimen handling, ethical legal and social issues (ELSI), phenotype harmonization, biomolecular technologies, databasing, biostatistics and bioinformatics. An impressive set of resources has been generated including prototypes, tools, guidelines, information cataloguing, compatible bioinformatics and standard operating procedures (SOPs). This work continues to develop as new frontiers emerge in biobanking and as biobanking becomes increasingly global.

Today, the foundations of modern biobanking have been laid and many countries around the world are now investing heavily in national biobanks. Europe has been particularly well placed to lead and profit scientifically from these activities due to its rich array of human research biobanks and large cohort studies, well organised public health care systems, and the ability to link data from national registries in many countries. Progress thus far is enormous; the preparatory phase of the BBMRI has ended and plans are in effect to implement a BBMRI-ERIC (European Research Infrastructure Consortium), a European legal entity characterised by a distributed research infrastructure and operational units – the BBMRI national hubs. Several of these hubs are already active in countries such as Sweden, Italy, The Netherlands, Norway, Finland, France and Denmark.

This special issue is timely in that it provides the opportunity to glimpse at the hands-on activities now taking place, nationally and internationally, that are helping to move international biobanking from a vision to reality. The compilation of 20 articles herein provides input from experts working in diverse aspects of the biobanking enterprise. The thematic content includes a gamut of biobanking activities spanning the establishment of nascent biobank infrastructures, building cross-walks between different types of collections, harmonisation, the development of special analytical models and tools to help optimize the use of the data, biospecimen quality control and the engagement of stakeholders. Many of these topics are enveloped in ethical, legal and social issues (ELSI) that are articulated throughout, not only as challenges but also with foresight to build workable solutions that can accommodate the dynamic nature of contemporary biobanking.

NATIONAL BIOBANKS – TOWARDS A EUROPEAN BIOBANKING INFRASTRUCTURE

The first set of articles report about the process and experiences associated with the establishment and enrichment of national biobank infrastructures. All countries face the dual challenges of maintaining national momentum while maximizing synergies internationally. However, the specific strategies employed will vary based on national differences in the requirements, starting points, and the ethico-legal frameworks of each country. The opening article ***From Biobanks for health to Biobank Norway*** by Stoltenberg and colleagues epitomizes the steps taken to pave the way for developing a national biobanking structure (6). Already in 2002 Norway launched BioHealth, a consortium of population-based biobank studies. It played a critical role in laying the groundwork for establishing a national biobank infrastructure by articulating the value of existing collections and the scientific and economic

advantages to be gained by unifying biobank holdings under a common unified infrastructure. Moving from BioHealth Norway to a national biobank infrastructure plan required communication, cooperation and negotiation between a diverse set of stakeholders including universities, researchers, funders, health and government agencies. The transition is now well on its way, The Research Council of Norway recently granted funds to establish the Norwegian biobanking infrastructure – Biobank Norway – which officially started during the fall of 2011, and will become a hub in the BBMRI EU. This infrastructure development will be greatly bolstered by a new funding programme to promote the use of Norwegian biobanks nationally and internationally. In her statement entitled ***Biobanks in Norway – funding by the Research Council***, Johne (7) describes a new research solicitation for studies that use Norwegian biobanks in conjunction with the many Norwegian health registries, health surveys and the health services. Importantly, Johne also emphasises that international collaboration must occur on many levels if we are to develop biobanks as sustainable and vibrant infrastructures for national and international research. To this end, the Norwegian Research Council encourages international collaboration, and Johne also highlights the need for strategic cooperation between funding bodies.

The article by Brandsma and van Ommen entitled ***How to kickstart a national biobanking infrastructure – experiences and prospects of BBMRI-NL*** (8) describes four main pillars of the BBMRI-NL: harmonisation, enrichment, data management and analysis and ELSI (Ethical, Legal and Societal Issues). Their infrastructure goals are to enhance and enrich existing biobanks through harmonisation. While these goals mirror those in other national hubs, BBMRI-NL has adopted quite a different strategy to achieve them by establishing unique within-project funding opportunities. These have proven to be an effective and creative solution to kick-start their infrastructure and strengthen their biobank network. Their article describes the specific strategies put in place, results thus far and lessons learned in this process.

The article ***Adapting research to the 21st century – The Swedish Biobank Registry*** by Norlin and colleagues (9) emphasises that the ability to share information between biobanks significantly increases the power of biobank research. They describe several additions and extensions to the Swedish BBMRI biobanking structure that greatly enhances the ability to track, use and share data in epidemiological and clinical research settings. This includes the Swedish Biobank Registry (SBR) (10), a national register for biobank samples that will be extended using an information system that includes a research catalogue. Importantly, BBMRI.se (11) is the first national hub to implement the BBMRI EU minimum data set (12) designed to describe biobanks and their objects. The information infrastructure developed in conjunction with BBMRI.se demonstrates the key principles and steps involved in moving towards a universal information e-infrastructure.

As noted above, BBMRI EU is gaining momentum as more national hubs come on board. In 2011, the Norwegian initiative Biobank Norway and the Strategic Integration and Co-ordination work package of BioSHaRE-EU[1] organized a meeting of ELSI experts and representatives from national hubs to discuss the most pressing ELSI challenges the BBMRI hubs were facing on their respective national fronts. The results from those discussions, including potential solutions, are reported in the paper entitled ***ELSI challenges and strategies of national biobank infrastructures***, by Budin-Ljøsne and colleagues (13). Generally, there is great overlap in the challenges reported, but some national differences do exist. It is critical to address these issues as a community and, where feasible, develop common ways forward. To this end a highly interactive and strong ELSI community, networked through multiple projects, is articulating critical ELSI considerations and organising dissemination activities to support the biobank agenda to meet national requirements while optimizing opportunities for international collaborations.

In contrast to the experiences in many countries where biobanks may fall under a highly restrictive or a complexly constructed legal framework, the situation in Denmark is quite simple and works well. In her article entitled ***Danish biobank legislation, a simple approach***, Kyvik (14) explains that there is no specific biobank act in Denmark. Rather the creation and use of biobanks for research are regulated by existing legislation. Inter-country comparisons not only highlight the relative ease or burden by which biobank legislation can foster use of the data, but can be highly useful for guiding ways forward to formulate legally compliant approaches to support new types of biobanks. Questions about the development of biobank governance models are raised in the next article by Knoppers and colleagues (15) entitled ***Newborn screening programmes: Emerging Biobanks?*** The management and secondary use of dried blood spots left over from newborn screening programmes (NBS) is highly relevant for many countries worldwide. However, there is no consensus on how to handle these. The authors explore whether policies on storage and research used to govern contemporary biobanks can serve as a basis to guide the development of policies for the 'inadvertent' newborn biobanks that derive from blood spots. Issues of informed consent, privacy and misrepresentation, are examined to determine the types of changes that would need to be undertaken to ensure a robust ethical framework for the secondary use of the dried blood spot samples from NBS. The authors stress that when

[1] The goal of the Strategic Integration and Co-ordination work package of BioSHaRE-EU is to interface with relevant initiatives to help ensure that complementarities are developed across projects and to conduct strategic horizon scanning so that key developments can be integrated into inter-project dialogues.

biobanks are established through an interface with public health programmes it is essential that participation rates in the screening programmes are not affected.

BRIDGING BIOBANKS

Maximizing the research potential in our biobanks means that we should be able to draw on biospecimens and data from diverse and heterogeneous biobanks, spanning clinical and non-clinical collections. Science continues to drive towards a greater convergence of population- and clinical-based designs; this is reflected, for example, in the need to develop seamless systems for extracting and sharing samples and data across research milieus and in the increasing recognition of the advantages of integrating biobanks into health care. In her article entitled ***Embedding biobanks as tools for personalised medicine***, Kaye's synthesis stresses that the bidirectional flow of information between the clinic and research setting is essential to enable translational medicine (16). Simultaneously she focuses on issues of how to best utilise biobanks for translational research and sustainability. One solution is to embed biobanks in healthcare structures in such a way that healthcare and research purposes are best served. This paper describes how the CURATATA model of the Netherlands, in conjunction with the EnCoRe dynamic consent 'patient interface' might provide an appropriate model to embed a biobank within a university research hospital setting. Critical issues are framed and focus placed on implementation needs. This article highlights how important shifts and repositioning of the structures underpinning clinical and research activities will help to maximize the use of our biobanks for translation.

The next three articles describe important bridging activities that have enhanced the research value and potential of Norwegian biobanks. "One biobank, many collections" is the central tenet around which the regional research biobank of central Norway is built. In their article entitled ***The regional research biobank of central Norway – "One biobank, many collections"***, Halgunset et al. (17) explain why one clinical research biobank, dedicated to enhancing biobank based research in a hospital setting, is established to serve the entire region. The Regional Research Biobank of Central Norway is an organizational framework. Its primary mission is to facilitate the collection and use of clinical data by providing guidance and support to researchers who want to utilize biospecimens and data from patients in their research projects. The background and underlying principles that guided its development are described and results thus far presented.

The advantages of integrating between data sources is the topic of the article entitled ***Scientific scope of integrating activities in the Janus Serum Biobank and Cancer Registry of Norway*** by Langseth and colleagues (18). The population-based Janus Serum Bank was originally established in the 1970s to examine pre-morbid sera for biological indicators of early cancer development. Linking the biospecimens in the Janus Bank with data from the National Cancer Registry has created an exceptional cancer research resource containing high quality clinical data and samples to investigate biomarkers and causal pathways underlying various cancers. It also demonstrates the value of long-term banking of blood samples from healthy individuals prior to illness. Numerous studies have already been published based on this repository, it figures prominently in the cancer literature, and continues to develop to support international research.

The recurrent theme that fragmentation between clinical and research structures impedes progress is also addressed by Reed et al. in their article entitled ***How can clinical biobanks and patient information be adapted for research – establishing a hospital based data warehouse solution*** (19). They focus on two specific issues. First, is the importance of making clinical data and biological samples readily available for research; and second, is the need for an efficient and secure crosswalk system enabling access and combined use of data and samples derived from clinical and non-clinical sources. They propose the establishment of a data warehouse, based on a patient-centred solution, which takes into account the different legal requirements that apply in Norway when data/biospecimens derive from health care settings versus from participation in population studies. The basic principles underlying this approach are presented and illustrated by an example of an information model for a data warehouse that was developed between collaborating hospitals in Norway.

Although not directly related to the bridging of biobanks, the issues surrounding return of results from incidental findings brings into sharp relief the contextual factors that differentiate clinical and non-clinical research. What are the implications of these differences for biobank research? A question of outmost relevance for biobank studies is whether participants in non-clinical studies should receive feedback of incidental findings. This is hotly debated within ELSI circles and, as of yet, there is no clear consensus. Although incidental findings occur in many areas of research, this issue has strongly re-emerged in the wake of whole genome sequencing, which is rapidly becoming a method of choice in many biobank studies. It illustrates how new technologies are forcing us to revisit the ELSI frameworks that were developed in a different scientific era. For example, issues surrounding the return of incidental findings have blurred the boundary between researcher and clinician, and engender a recontextualisation of the ethical considerations pertaining to the 'right to know'. An analysis of these and related factors is presented in the paper entitled ***Managing incidental findings in population based biobank research***, by Solberg and Steinsbekk (20) who compare clinical with population-based research regarding the management and return of incidental findings.

Using a case study from Norway, they illustrate potential pitfalls that could be encountered if the research milieu is not taken into account. They argue that fundamental differences between clinical and population-based research mean that the ethically responsible approach to incidental findings is not uniform across all research settings.

THE BIGGER PICTURE

Our ability to use the data and samples across different biobanks and borders is at the crux of our biobanking endeavours; this is a dynamic issue that evolves with the science and is so important that it will either accelerate or retard research. The confluence of factors affecting our ability to utilize the data – and novel solutions to address these factors, are the focus of the article entitled ***Navigating the perfect [data] storm*** by Murtagh and colleagues (21). They describe four main areas that must be addressed for biobanking to serve bioscience optimally. Many of these areas represent the specific substantive focus of articles comprising this special issue and include the creation of robust frameworks, spanning political, ELSI and governance considerations, incentivizing the field as we move from the model of individual researchers or research groups to a community reliant on a global data platform, optimal solutions for dealing with the data along the full pipeline from data collection to analysis, and the importance of engaging stakeholders in such a way that the larger agenda is developed within the context of relevant social considerations and translational goals. The solutions they describe illustrate how the needs to manage and share data on a large scale have catalysed new tools and approaches.

The magnitude of the data is also central to Hoeyer's (22) analysis; although he focuses from a very different angle, his conclusions echo key points made by Murtagh and colleagues (21). His paper entitled ***Size matters: the ethical, legal and social implications of large-scale biobank initiatives***, addresses how the transition to large-scale biobanking interacts with qualitative change to recast a host of issues including ELSI considerations that span social, legal and ethical arenas. The magnitude of these effects and their consequences are so great that the development of biobanks within society should be viewed as civic projects. Accordingly, problems cannot be neatly classified along traditional boundaries as being solely an ethical, a legal or a social issue. Solutions must derive from constructive dialogue and negotiation between multiple stakeholders connected through a variety of ways to the large scale biobanking enterprise.

HARMONISATION, DATA SHARING AND BEYOND

Harmonisation, and sometimes standardisation, must occur at many levels of the biobanking process in order to enable the secure sharing and analysis of high quality data and biospecimens. A wide array of tools, technologies, (SOPs and other resources have been developed to facilitate harmonisation and sharing across the full gamut of biobank activities. Guided by the general principles of resource and knowledge sharing, these resources are widely available to the scientific community. The article entitled ***Facilitating collaborative research: Implementing a platform to support data harmonization and pooling*** by Doiron and colleagues outlines key approaches to phenotypic data harmonisation and describes a framework for harmonising retrospective data (23). This work builds upon and extends the exceptional programme for harmonisation developed under the Public Population Project in Genomics (P^3G) and its partner projects. Methods and an entire suite of open-source web-based software are being developed to facilitate each step in the harmonisation process. These methods are already being used by several consortia and will continue to be developed in response to the needs of the scientific community that is employing them.

Harmonisation and standardisation protocols are also crucial for sample handling. Ensuring that the assay values derived from biospecimens are reliable and valid reflections of the bioanalytes of interest is pivotal to all biomedical research. Furthermore, the well-known issue of lab-specific effects introducing extra experimental noise into studies can have significant implications for research based on samples from multiple biobanks. Biospecimen quality programs, quality assurance and quality control are critical to operations of biobanks and considerable effort has been dedicated to developing SOPs and evidence-based protocols for the handling of biospecimens. Many biobanks represent an amalgamation of studies that have collected different types of samples for different research purposes and the protocols for handling and storage must be tailored to the specific study needs. Processing samples in ways that maximize their usability for multiple purposes unknown at the time of sample handling is another important challenge. The article entitled ***Biospecimen Quality Program in the Biobank of the Norwegian Institute of Public Health*** by Paltiel and colleagues (24) addresses these issues by describing the biospecimen quality programme used by the Biobank at the Norwegian Institute of Public Health (NIPH). This program was established to minimize pre-analytical variation that arises in the lifetime of a sample along the pipeline from collection through processing and storage for analysis. Biobanking of samples is a dynamic science that is constantly being updated and improved as new evidence-based knowledge becomes available. Tools to evaluate and improve the NIPH biobank are presented and the authors emphasise that the science of biobanking can now provide information, based on pre-analytic factors, which will help to determine which samples to use for specific analyses and studies.

The next article demonstrates how the challenges of data sharing helped spark a novel solution,

DataSHIELD (Data Aggregation Through Anonymous Summary-statistics from Harmonised Individual levEL Databases), which is a biostatistical tool that coordinates analyses of data. In their article entitled ***DataSHIELD – shared individual-level analysis without sharing the data: a biostatistical perspective***, Jones and colleagues (25) highlight the fundamental conflict that arises between research reliant on conducting individual-level analysis and ethico-legal and data security constraints surrounding data sharing. DataSHIELD was developed so that individual level meta-analysis can be conducted without physically sharing the data. At the core, modern distributed computing methods are used to perform a parallelised analysis using a remote access analysis server. This paper describes the biostatistical basis for the congruencies between the DataSHIELD approach and results generated from an individual level meta-analysis using generalised linear models. The IT requirements and ELSI challenges that have to be taken into consideration are also discussed. By bypassing some of the typical ELSI concerns and hindrances encountered in manipulating and sharing large data files, DataSHIELD also helps to ensure rapid access to research data. Its development and refinement will continue through pilot projects and in tandem with new analytical needs that arise in particular projects that want to tailor the DataSHIELD solution to address ever more complex research questions and data.

The next two articles represent work from a research team that uses data from biobank studies and develop analytical models to investigate the genetic and environmental basis of facial clefts. These articles showcase the advantages of parent-offspring triad design. The triad structure is the basic design of the one of the largest Norwegian biobank studies, the Norwegian Mother and Child Cohort Study (MoBa) (26), but, as indicated in their paper, triads can also be generated from other sources such as registries. They have developed statistical models to exploit the triad data and also developed analytical tools and software to analyze those models. This reflects a trend we see throughout biobanking science where the structure of the data encourages the development of new methods and approaches. The first article by Jugessur and colleagues (27), ***Assessing the impact of nicotine dependence genes on the risk of facial clefts: An example of the use of national registry and biobank data***, demonstrates the use of registry and biobank data to investigate important question in genetic epidemiology. Case-parent triads were recruited from a nationwide case-control study while control-parent triads were recruited form the Norwegian Medical Birth Registry. They report findings from investigations asking whether genetic variants that influence maternal smoking also impact the risk for facial clefts. In the next paper Jugessur et al. (28) note that many of the approaches developed to analyse high-throughput genomic data have focused on traditional case-control designs. Less common are methods that explain how to capitalize on the triad configuration. Therefore, they provide a solid tutorial in their article entitled ***Using offspring-parents triads to study complex traits: A tutorial based on orofacial clefts***. This tutorial covers models to test for various types of genetic effects. It introduces design basics, including the novel and statistically more powerful hybrid design, and the Haplin (29) software programme – which was specifically designed for analyzing genetic and environmental exposures in offspring-parent triads and case-control collections. It then walks the reader through several sets of examples that test for different types of genetic influence including fetal genes, maternal genes, gene by environment interactions plus several more.

The final article presents results from a qualitatively different type of biobank study. ***Peeking into the box of privacy – biobank participants on the importance of recognition,*** uses focus group methodology to generate data on one of the most critical issues of biobanking – privacy (30). Although much has been written on privacy in biobanking, data representing the perspectives of the participants are scarce. But, as emphasised in several pieces in this special issue, it is essential to engage participants to generate a knowledge base that will help guide the development of ethical frameworks. Ursin & Steinsbekk have done just that in their study based on focus groups of HUNT participants, one of the world's biggest prospective population-based research cohort studies. They examine how participants articulate the nature of privacy issues in biobanking. Their findings provide new insights into the complex nature of privacy and identify dimensions of privacy that the participants view as most important.

There is now no doubt that progress in both the pace and face of biomedicine is fully related to our ability to mobilize and harmonize biobank data on a global scale. The works comprising this special issue represent a wide range of topics and perspectives; yet provide only a glimpse into the activities underpinning the large endeavour of translating our biobanking vision into a reality. They highlight the considerable progress already made and that significant challenges must still be tackled. The common thread throughout, however, is that the reality of biobanking is only achievable through continued collaboration and coordination, and that this will, indeed, transform biomedicine.

ACKNOWLEDGEMENTS

The guest editors gratefully acknowledge Biobank Norway, funded by the Norwegian Research Council (NFR 197443/F50), the ENGAGE Consortium (grant agreement HEALTH-F4-2007-201413) and BioSHaRE-EU (grant agreement HEALTH-F4-2010-261433), both funded by the European Union's Seventh Framework Programme (FP7/2007-2013) for valuable support to their work in producing this special issue.

REFERENCES

1. Promoting Harmonisation of Epidemiological Biobanks in Europe (PHOEBE). URL: http://www.fhi.no/eway/default.aspx?pid=233&trg=MainArea_5661&MainArea_5661=5631:0:15,4380:1:0:0:::0:0.
2. Public Population Project in Genomics (P³G). URL: http://www.p3g.org/secretariat/index.shtml.
3. Biobank Standardisation and Harmonisation for Research Excellence in the European Union (BioSHaRE-EU). URL: http://www.p3g.org/bioshare/.
4. International Society for Biological and Environmental Repositories (ISBER). URL: http://www.isber.org/.
5. Biobanking and Biomolecular Resources Research Infrastructure (BBMRI). URL: http://www.bbmri.eu/index.php?option=com_content&view=frontpage&Itemid=27.
6. Stoltenberg C, Budin-Ljøsne I, Harris JR, Hveem K. From Biobanks for health to Biobank Norway. *Norsk Epidemiologi* 2012; **21** (2): 127-132.
7. Johne B. Biobanks in Norway – funding by the Research Council. *Norsk Epidemiologi* 2012; **21** (2): 141-142.
8. Brandsma M, Baas F, de Bakker PIW, Beem EP, Boomsma DI, Bovenberg J, et al. How to kickstart a national biobanking infrastructure – experiences and prospects of BBMRI-NL. *Norsk Epidemiologi* 2012; **21** (2): 143-148.
9. Norlin L, Fransson M, Eaker S, Elinder G, Litton J-E. Adapting research to the 21st century – the Swedish Biobank Register. *Norsk Epidemiologi* 2012; **21** (2): 149-153.
10. Swedish Biobank Registry (SBR). Nationellt biobanksregister klart att införas. URL: http://www.cehis.se/nyhetsarkiv/nationellt_biobanksregister_klart_att_inforas (In Swedish).
11. BBMRI.se. URL: http://bbmri.se/.
12. BBMRI Sweden Newsletter, Issue no 2. URL: http://www.bbmri.se/Global/Nyheter/issue%202_2011_biobank_Sweden.pdf.
13. Budin-Ljøsne I, Harris JR, Kaye J, Knoppers BM, Tassé AM, Bravo E, et al. ELSI challenges and strategies of national biobank infrastructures. *Norsk Epidemiologi* 2012; **21** (2): 155-160.
14. Kyvik KO. Danish biobank legislation, a simple approach? *Norsk Epidemiologi* 2012; **21** (2): 161-162.
15. Knoppers BM, Avard D, Sénécal K. Newborn screening programmes: Emerging biobanks? *Norsk Epidemiologi* 2012; **21** (2): 163-168.
16. Kaye J. Embedding biobanks as tools for personalised medicine. *Norsk Epidemiologi* 2012; **21** (2): 169-175.
17. Halgunset J, Mikkelsen ØL, Skogseth H. The Regional Research Biobank of Central Norway – "One biobank, many collections". *Norsk Epidemiologi* 2012; **21** (2): 177-184.
18. Langseth H, Gislefoss R, Martinsen JI, Tretli S. Scientific scope of integrating research activities in the Janus Serum Bank and Cancer Registry of Norway. *Norsk Epidemiologi* 2012; **21** (2): 185-190.
19. Reed W, Jor S, Bjugn R. How can clinical biobanks and patient information be adapted for research – Establishing a hospital based data warehouse solution. *Norsk Epidemiologi* 2012; **21** (2): 191-194.
20. Solberg B, Steinsbekk KS. Managing incidental findings in population based biobank research. *Norsk Epidemiologi* 2012; **21** (2): 195-201.
21. Murtagh MJ, Thorisson GA, Wallace SE, Kaye J, Demir I, Fortier I, et al. Navigating the perfect [data] storm. *Norsk Epidemiologi* 2012; **21** (2): 203-209.
22. Hoeyer KL. Size matters: the ethical, legal, and social issues surrounding large-scale genetic biobank initiatives. *Norsk Epidemiologi* 2012; **21** (2): 211-220.
23. Doiron D, Raina P, Ferretti V, L'Heureux F, Fortier I. Facilitating collaborative research: Implementing a platform supporting data harmonization and pooling. *Norsk Epidemiologi* 2012; **21** (2): 221-224.
24. Paltiel L, Aarem J, Bækken S, Stensrud NK, Harbak K. Biospecimen quality program in the biobank of the Norwegian Institute of Public Health. *Norsk Epidemiologi* 2012; **21** (2): 225-229.
25. Jones EM, Sheehan NA, Masca N, Wallace SE, Murtagh MJ, Burton PR. DataSHIELD – shared individual-level analysis without sharing the data: a biostatistical perspective. *Norsk Epidemiologi* 2012; **21** (2): 231-239.
26. Magnus P, Irgens LM, Haug K, Nystad W, Skjaerven R, Stoltenberg C and the MoBa Study Group. Cohort profile: The Norwegian Mother and Child Cohort Study (MoBa). *Int J Epidemiol* 2006; **35**: 1146-1150.
27. Jugessur A, Gjessing HK, Wilcox AJ, Nguyen TT, Nilsen RM, Murray JC, Lie RT. Assessing the impact of nicotine dependence genes on the risk of facial clefts: An example of the use of national registry and biobank data. *Norsk Epidemiologi* 2012; **21** (2): 241-250.
28. Jugessur A, Skare Ø, Harris JR, Lie RT, Gjessing HK. Using offspring-parent triads to study complex traits: A tutorial based on orofacial clefts. *Norsk Epidemiologi* 2012; **21** (2): 251-267.
29. HAPLIN. URL: http://www.uib.no/smis/gjessing/genetics/software/haplin/.
30. Ursin LØ, Steinsbekk KS. Peeking into the black box of privacy – biobank participants on the importance of recognition. *Norsk Epidemiologi* 2012; **21** (2): 269-276.

The guest editors

Jennifer R. Harris
Norwegian Institute of Public Health
Div. of Epidemiology
Dept. of Genes and Environment
P.O. Box 4404 Nydalen
NO-0403 Oslo
Norway

jennifer.harris@fhi.no

Isabelle Budin-Ljøsne
Norwegian Institute of Public Health
Div. of Epidemiology
Dept. of Genes and Environment
P.O. Box 4404 Nydalen
NO-0403 Oslo
Norway

isabelle.budin.ljosne@fhi.no

Anita Haugan
Norwegian Institute of Public Health
Div. of Epidemiology
Dept. of Management and Staff
P.O. Box 4404 Nydalen
NO-0403 Oslo
Norway

anita.haugan@fhi.no