Tampere University

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INVESTIGATION OF THE NEEDS FOR NATIONAL AND LOCAL BIOBANK SERVICES AND IMPROVEMENT OF BIOBANK AWARENESS

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PRO GRADU -TUTKIELMA

Paikka:	Tampereen Biopankki
Tekijä:	MAKKONEN, ENNI MARIA
Otsikko:	Kansallisten ja paikallisten biopankkipalveluiden tarpeiden kartoitus ja biopankkitietoisuuden lisääminen
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Ohjaajat:	FT Johanna Mäkelä, FT Kimmo Savinainen
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TIIVISTELMÄ

Tutkimuksen tausta ja tavoitteet: Biopankki kerää ja säilöö ihmisperäisiä näytteitä sekä niihin yhdistettäviä tietoja tulevia lääketieteellisiä tutkimustarpeita varten. Biopankeilla on merkittävä rooli lääketieteen kehityksessä oire- ja diagnoosikeskeisestä hoidosta ennakoivaan, ehkäisevään ja yksilöllistettyyn lääketieteeseen. Biopankkilaki tuli voimaan Suomessa vuonna 2013, jonka jälkeen Suomessa on rekisteröity kymmenen biopankkia. Tampereen Biopankki sai toimiluvan vuonna 2015. Suomalainen biopankkitoiminta on vielä suhteellisen uutta ja vaatii siksi kehittämistä vastatakseen käyttäjiensä tarpeisiin. Tämän tutkimuksen tavoitteena oli lisätä Tampereen Biopankin näkyvyyttä paikallisten akateemisten tutkijoiden keskuudessa sekä lisätä heidän biopankkitietoisuuttaan markkinoinnin avulla. Tutkimuksella pyrittiin myös selvittämään akateemisten tutkijoiden ja lääkeyritysten tarpeita biopankkipalveluiden suhteen.

Menetelmät: Tämä tutkimus koostui kahdesta osasta: paikallisesta, akateemisille tutkijoille suunnatusta osuudesta sekä kansallisesta, lääkeyrityksille suunnatusta osuudesta. Biopankki-tarpeiden selvittämiseksi sekä akateemisten tutkijoiden biopankkitietoisuuden tason kartoittamiseksi käytettiin sähköisiä kyselyitä. Paikallisessa osuudessa toteutettiin kaksi kyselykierrosta mahdollisten biopankkitietoisuudessa tapahtuneiden muutosten tutkimiseksi. Tietoisuuden lisäämiseksi kyselyiden välissä suunniteltiin ja toteutettiin rinnakkaiset markkinointimenetelmät: esitelmä, sähköposti ja esite. Ensimmäiselle kyselykierrokselle osallistuneet tutkijat jaettiin kolmeen verrokkiryhmään näiden markkinointimenetelmien tehokkuuden testaamiseksi. Toisen kyselyn jälkeen kunkin menetelmän yhteyttä biopankkitietoisuuteen analysoitiin tilastomenetelmin, jotta voitiin löytää tehokkain markkinointimenetelmä jatkokäyttöä varten.

Tulokset: Kasvotusten pidetty esitelmä osoittautui tehokkaimmaksi menetelmäksi lisätä sekä biopankin näkyvyyttä että tunnetta riittävästä määrästä biopankkitietoa. Sähköposti ja esite puolestaan eivät olleet näin tehokkaita menetelmiä. Tutkimukseen osallistujien määrä oli liian pieni sähköpostimarkkinoinnin onnistumiseksi. Esite ei yksinään ollut tehokas menetelmä, mutta yhdessä esitelmän kanssa se johti parhaisiin tuloksiin biopankkitietoisuuden lisäämisessä. Vaikka biopankkitietoisuus lisääntyi tutkimuksen aikana, on se edelleen matalalla tasolla tamperelaisten tutkijoiden keskuudessa. Siinä missä akateemiset tutkijat ovat kiinnostuneita laajasti erilaista biopankkinäytteistä ja -tiedoista, lääkeyritysten kiinnostus on kohdistunut pääasiassa tietoihin ja kansallisesti yhtenäistettyihin biopankkipalveluihin

Johtopäätökset: Paikallinen markkinointi, mieluiten henkilökohtaiset tapaamiset, sekä paikallisten palveluiden kehitys ovat etusijalla biopankin ja akateemisten tutkijoiden välisen yhteistyön lisäämisessä. Kohentunut yhteistyö mitä todennäköisimmin lisää tutkijoiden kiinnostusta biopankkeja kohtaan myös kansallisella tasolla. Kansallinen koordinointi on tarpeen suomalaisten biopakkipalveluiden yhtenäistämisessä. Tämä oletettavasti johtaisi lääkeyritysten lisääntyneeseen kiinnostukseen hyödyntää biopankkeja tutkimuksessaan.

MASTER'S THESIS

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ABSTRACT

Background and aims: Biobank is a repository where human-derived samples and associated data are collected and stored for future research purposes. Biobanks have an essential role in the development of medicine from the symptom- and diagnose-based cure to proactive, preventive and personalized medicine. In Finland, Biobank Law came into effect in 2013, after which ten biobanks have been registered. Finnish Clinical Biobank Tampere received its operating license in 2015. The Finnish biobank operations are still relatively new and require development to meet the biobank users' needs. This study aimed to increase the visibility of Finnish Clinical Biobank Tampere among the local academic researchers and to improve their biobank awareness by the means of marketing. Another aim of this study was to investigate the needs for biobank services among academic researchers and pharmaceutical companies.

Methods: This study composed of two parts: a local part for academic researchers and a national part for pharmaceutical companies. Online questionnaires were used to explore the needs for biobank services and to find out the level of academic researchers' level of biobank awareness. Two rounds of questionnaires were used in the local part to investigate the possible changes in biobank awareness. To increase the academic researchers' biobank awareness, different marketing methods were planned and implemented between the questionnaires: a presentation, an email, and a leaflet. The researchers on the first round were divided into three reference groups to test the effect of each marketing method. After the second questionnaire, the effect of each method was analyzed with statistical analyses to find out the most effective method(s) for further use.

Results: Presentation given face-to-face appeared to be the most effective marketing method in raising both biobank visibility and the sense of having received enough information about the biobank operations. Email and leaflet were not as effective methods. The number of study participants was too small for email marketing to succeed. Leaflet alone was not an efficient method, but together with presentation, led to best results in increasing biobank awareness. Although increased during this study, the biobank awareness among academic researchers in Tampere is still low. Academic researchers' interests towards different biobank sample and data types are widely distributed, whereas pharmaceutical companies are primarily interested in data and nationally unified biobank services.

Conclusion: Local marketing, preferably personal meetings, and local service development should be prioritized to increase collaboration between the biobank and academic researchers. Enhanced collaboration would probably lead to researchers' further interest towards biobanks in a national level as well. National coordination is needed to unify the Finnish biobank services. Presumably, that would increase the interest of pharmaceutical companies towards utilization of biobanks in their research.

Acknowledgements

This study was conducted in Finnish Clinical Biobank Tampere, in collaboration with the Finnish Biobank Cooperative, FINBB.

First, I would like to thank my supervisors Johanna Mäkelä and Kimmo Savinainen. Johanna, thank you for your help and support, for the ideas that formed this project into its eventual shape, and for your professional remarks that guided me into right direction time after another. Kimmo, thank you for your assistance, for trusting me right from our first meeting, and for the effort you made in enabling this project. I am endlessly thankful for this opportunity. I would also like to thank Professors Vesa Hytönen and Anne Kallioniemi for letting me follow my desire and push the limits with a thesis project quite different from the former ones in this degree program.

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Tampere, October 2019

Enni Makkonen

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Abbreviations

BBMRI-ERIC	Biobanking and BioMolecular resources Research and Infrastructure – European Research Infrastructure Consortium
BBMRI.fi	Finnish national node of BBMRI-ERIC
BRC	Biological Resource Center
BRISQ	Biospecimen Reporting for Improved Study Quality
FCBT	Finnish Clinical Biobank Tampere
FFPE	Formalin-fixed paraffin-embedded
FINBB	FinBioBank, the Finnish Biobank Cooperative
IARC	International Agency for Research on Cancer
ISBER	International Society for Biological and Environmental Repositories
ISO	The International Organization for Standardization
MIABIS	Minimum Information About BIobank data Sharing
NCI	National Cancer Institute
OECD	The Organization for Economic Co-operation and Development
SOP	Standard Operating Procedure
SPREC	Standard PREanalytical Code
STP	Segmenting–Targeting–Positioning

1 Introduction

The need for human biomaterials in medical research has increased significantly during the past two decades, as the interest in translational research and personalized medicine have evolved (Hainaut, Vaught, Zatloukal, & Pasterk, 2017, p. vi; Mackenzie, 2014). Moreover, the former use of animal models in biomedical research and drug discovery has increasingly shifted towards the use of human-derived materials (Mackenzie, 2014). The first consistently collected, processed, and stored collections of biospecimen were founded in the mid-1990s (Hainaut et al., 2017, p. vi), and since then their number has significantly increased throughout the world to answer to varying research needs. Studies utilizing human biomarkers, i.e. biological indicators of diseases or certain biological processes (Mackenzie, 2014), have improved the understanding and identifying of the molecular basis of diseases, and consequently, clinical decision-making (Mackenzie, 2014; Malm et al., 2013; Mohamadkhani & Poustchi, 2015). Therefore, the use of human samples has become a norm for majority of biomedical research areas (Mackenzie, 2014).

Biobank is a collection of biological material and related data stored for research purposes (Hewitt, 2011; Paskal, Paskal, Dębski, Gryziak, & Jaworowski, 2018; Shaw, Elger, & Colledge, 2014). In this study, the term biobank is considered as a repository for human biological samples and data that are stored for future medical research purposes. Biobanking and the research utilizing biobank samples and data provide an essential contribution to the development of medicine from the symptom- and diagnose-based cure to proactive, preventive and personalized medicine (Hood & Friend, 2011; Kinkorová, 2016; Lehtimaki, Helen, Snell, Eriksson, & Montonen, 2017). Biobanks collect samples from patients or other volunteers that have given a consent for it, store the samples, and release them and related data to high-quality research projects. These projects can be either national or international, academic or commercial. Every biobank may store samples from several sources, and every research project may use samples from several biobanks. To prevent the variability in sample quality and to ensure high-quality research, international standards and protocols for collecting, processing and storing the samples are required (Harris et al., 2012). Several biobank networks, such as the pan-European biobank infrastructure BBMRI-ERIC (defined more closely in the chapter 2.1.3 *Biobank networks*) have been established to facilitate the sharing of sample collections in regional, national and international level. These infrastructures also support the development of high-quality research by ensuring the efficient usage of sample collections.

Biobank operations are regulated by law to secure the ethical and open usage of human-derived samples. Finland is a pioneer in the legislation concerning biobanks, as we have a certain law for biobanking, whereas many countries have the requirements relevant for biobanking covered in several more general parts of legislation (Kaye et al., 2016). The Finnish Biobank Law came into effect in 2013 (https://www.biopankki.fi/biopankkilaki-ja-saately/, 24.4.2019). It ensures the citizens' privacy protection and right to self-determination regarding to their samples. For example, the possibility to obtain information about the research projects in which one's samples are used is decreed in the Biobank Law. (Biobank Law 30.11.2012/688)

The challenges of biobanking are commonly related to harmonization of operations, consistency of sample quality (Asslaber & Zatloukal, 2007; Hainaut et al., 2017; Malm et al., 2013; Watson et al., 2014), and ethical concerns when finding a balance between the demand for scientific development and individual's integrity (Staunton, Slokenberga, & Mascalzoni, 2019). From the researchers' point of view, the most common issues in biobanking are the scale of sample and data selection and accessibility to this material set, as well as the biobanks' responsiveness to requests (Capocasa et al., 2016; Watson et al., 2014). Additionally, and even paradoxically, the development of cancer diagnostics and treatments brings up challenges in biobanking, as the tumors are detected earlier, and neoadjuvant therapies are used before surgical procedures. Therefore, tumors are often too small to allow obtaining a part of them for research use, which impairs the gathering of large tumor tissue collections (Hewitt, 2011; Mackenzie, 2014). Biobanks face also financial challenges, such as inadequate resourcing and limited opportunities to secure long-term funding (Watson et al., 2014), which is even harder if a biobank suffers from a surprisingly common problem of underutilization of biobank collections (Cadigan, Juengst, Davis, & Henderson, 2014). Economic sustainability of a biobank may be challenging to achieve as the main products are human-derived samples and thus not commercial commodities (Ciaburri, Napolitano, & Bravo, 2016)

There are ten biobanks in Finland, six of them being hospital biobanks that operate regionally in the areas of hospital districts. The other four biobanks operate in the whole Finland. The focus of this study is on the operations of Finnish Clinical Biobank Tampere (FCBT). FCBT was established in 2015 and received its operating license from Valvira in the same year (https://www.tays.fi/biopankki, 24.4.2019). Sample and data releases began in June 2018 as the old diagnostical samples were transferred from the pathology and clinical genetics departments of Tampere University Hospital to the possession of FCBT. In addition to the old samples, FCBT collects prospective samples with donors' consent.

The operations of FCBT are still new and relatively unknown to academic researchers, pharmaceutical companies and other stakeholders. To ensure FCBT's optimal activities as a regional biobank in the Pirkanmaa Hospital District, and to contribute to the development of biomedical research, the amount of sample and data releases for research use should be increased. Therefore, one of the main aims of this study is to increase academic researchers' biobank awareness and thus bring the biobank closer to researchers. The expected outcome is an increased collaboration between FCBT and research groups in Tampere. To achieve this, researcher-targeted marketing is implemented as a part of this study. Alternative marketing methods are tested to find out the most effective method for further use. Additionally, the academic researchers' needs for biobank services are explored to give FCBT an overview of the local researchers' expectations. This will facilitate the FCBT's future service development.

Biobanks are essential partners for both academic and commercial groups that have focus on biomedical research and/or drug discovery. Therefore, it is reasonable that the needs and expectations for biobank services are examined within both of these groups. This study also aims to find out the pharmaceutical companies' needs for biobank services on a national level. The national part of this study is conducted in cooperation with the Finnish Biobank Cooperative, FINBB, and aims to provide FINBB with directions for their service development.

The literature review of this thesis gives an overview to biobanking both in national and international scale. The most popular research areas in biobank research are reviewed, as well as internationally proven standards and guidelines to standardize biobanking. Legal aspects and biobank sustainability are discussed as well. Gathering these and other related subjects together aims to provide FCBT with tools to develop their operations.

2 Literature Review

2.1 Biobanks in general

2.1.1 Meaning of biobanks

The variable purposes and designs of repositories storing biological material, as well as still evolving central control over them, make it difficult to define biobank in one sufficient way. The Organization for Economic Co-operation and Development (OECD) defines human biobanks as "structured resources that can be used for the purpose of genetic research and which include: (a) human biological materials and/or information generated from the analysis of the same; and (b) extensive associated information." (OECD, 2009) According to the Finnish Biobank Law, biobank is a unit maintained by a biobank practitioner, where human-derived samples are collected and stored for future research purposes (Biobank Law 30.11.2012/688). In Finland, the establishment of a biobank requires a license form Valvira, the National Supervisory Authority for Welfare and Health (https://www.biopankki.fi, 10.9.2019). Valvira maintains a national biobank register in Finland.

Biobanking benefits the field of medical research in several ways. For example, it prevents duplication of effort and resources, as sample collection is organized by biobanks, and researchers do not need to collect samples by themselves. The effort and resources are also saved because the results analyzed from the samples are returned to the biobank after using samples in research (Hainaut et al., 2017, p. 106). Therefore, the scientific value of the sample collection grows every time the samples are used in research as the next researchers do not need to do the same measurements again from the same donors' samples. The value of the collection can be seen to grow also because the possibilities for analyzing the samples that are harvested now will be extended as the techniques evolve through time. Biobanks facilitate medical research and enable the development new treatments for diseases, as drug and diagnostics development often require large, standardized and high-quality patient sample collection (Capocasa et al., 2016; Guerin et al., 2010; Malm et al., 2013). Biobanks also form important research infrastructures that enhance the collaboration between research consortiums nationally and internationally, both in academy and industry, as well as between them (Asslaber & Zatloukal, 2007; Morente & Alonso, 2005). The rest of this chapter describes the diverse nature of biobanks and biobank networks.

2.1.2 Classification of biobanks

Biobanks can be classified in several different ways and there is no unequivocal, generally accepted system. However, the classification of biobanks is important in order to help researchers to understand what type of biobank they need to have access to, to support the appreciation of diversity of biobanks, and to assist institutions and funding agencies to understand the varying requirements for support of different types of biobanks (Watson & Barnes, 2011). For example, the requirements for storage space differ between biobanks, as some need large storages and others no storage space at all (Watson et al., 2014). Similarly, the range and amount of data needed varies between biobanks and leads to varying requirements in digital storage and computing capacity.

A common way for biobank classification is categorizing biobanks according to their purposes. These categories include population biobanks and disease-oriented biobanks (Hewitt, 2011; Paskal et al., 2018; Riegman, Morente, Betsou, de Blasio, & Geary, 2008). Disease-oriented biobanks can be divided into classes of epidemiology-driven biobanks and tissue biobanks, also known as tumor banks (Paskal et al., 2018; Riegman et al., 2008). Disease-oriented biobanks are typically hospital-based, and the sample collections contain blood, tumors and other disease-specific samples, as well as healthy controls (Asslaber & Zatloukal, 2007). Epidemiology-driven biobanks aim to determine certain exposure factors for a disease (Paskal et al., 2018; Riegman et al., 2008). These biobanks also collect samples from patients suffering from infectious diseases. For example, biobanks for AIDS and Ebola have been established to increase the understanding of the diseases (Paskal et al., 2018). Tissue biobanks, i.e. tumor banks, aim to explore the molecular basis of the diseases by collecting and comparing neoplastic and unaffected tissue samples (Morente & Alonso, 2005; Paskal et al., 2018).

Population biobanks, however, are usually not established in connection with hospitals (Hewitt, 2011) but they rather are broad-scale biobank projects, such as UK Biobank, Estonian Genome Project, and Icelandic Biobank. THL Biobank is a Finnish example of a population biobank. The samples are donated by volunteers without specific inclusion or exclusion criteria and combined with epidemiological or clinical data. (Hewitt, 2011; Paskal et al., 2018; Swede, Stone, & Norwood, 2007) The goal of population biobanks is to understand the genetic identity of a population, and its contributions to health and disease risk among certain country, region, or ethnic cohort (Riegman et al., 2008; Swede et al., 2007; Zawati, Knoppers, & Thorogood, 2014). For instance, population biobanks provide valuable information about frequencies for disease-specific alleles in a certain population. However, in heterogenic populations such as in the UK and USA, it might be difficult to find gene variants

common in the whole population. Therefore, more targeted screening among ethnic groups or isolated populations might be more appropriate (Swede et al., 2007).

Many biobanks fall into more than one of these categories, which is important as research projects may require material from different types of biobanks. FCBT is an example of biobank combining all of these categories, as it has disease-specific sample collections including tissue collections and it participates in the population-based FinnGen project. However, this classification into population biobanks and disease-oriented biobanks is rather limited and do not depict the diversity of individual biobanks. For this reason, Watson and Barnes (2001) presented an optional solution for classifying biobanks. Their functional classification system is based on functional biobank elements such as biospecimens, donors/participants, design (e.g. data format), and brand (e.g. user type) (Watson & Barnes, 2011). These elements can be further classified into sub-elements. For example, biospecimen might be further categorized according to preservation method (frozen, fixed, desiccated, etc.). In turn, the brand or 'user type', that is the intended use of a biobank, can be further classified into mono-, oligo, and poly-users (Watson et al., 2014). These categories illustrate whether biobank collections are intended to support a single research project (mono-user), several research projects within a joint institution (oligo-users) or several users with undecided research projects (poly-users). Watson and Barnes (2011) stated that this system would capture the level of complexity, diversity, and specialization of biobanks more comprehensively than the former system of classifying biobanks into population, disease-oriented and tumor biobanks.

2.1.3 Biobank networks

Development of high-throughput technologies for broad spectrum of biomolecules over recent decades has increased the research needs for biological samples (Hainaut et al., 2017, p. 116). Single biobanks would not be able to deal with these needs alone, which has been one of the main factors driving biobanks towards cooperation with each other. Furthermore, research on rare diseases as well as understanding the medical diversity of certain diseases require sharing of sample collections from different biobanks (Asslaber & Zatloukal, 2007). Regional, national and international biobank networks have been established to meet these needs and to ensure the efficient usage of sample collections to support the development of high-quality research (Van Ommen et al., 2015). These networks coordinate the standardization of their policies and procedures so that the pooling of samples from different biobanks is possible without variation in sample quality (Hainaut et al., 2017, p. 116; Watson et al., 2014). Sharing of expertise in these networks enables economic benefits as well as higher quality of services compared to

single biobanks, since manpower costs can be reduced, and the service selection optimized within the network (Hainaut et al., 2017, p. 117). Therefore, the activities enabled by biobank networks increase the sustainability of biobanks either financially, operationally, or socially (Watson et al., 2014). These dimensions of biobank sustainability are discussed more closely in the chapter 2.6 *Biobank sustainability*.

A significant biobank network, both in European and in global scale, is BBMRI-ERIC (Biobanking and BioMolecular resources Research and Infrastructure – European Research Infrastructure Consortium). BBMRI-ERIC is a pan-European research infrastructure of biobanks and biomolecular resources. It brings together biobanks, researchers, industry, and patients with the aim of facilitating the access to resources and supporting high-quality medical and biomolecular research (Van Ommen et al., 2015). They provide biobanks and researchers with quality management services, ethical and legal support, and online tools with the ultimate goal of enhancing the development of medical research and new treatments (http://www.bbmri-eric.eu, 1.2.2019, Asslaber & Zatloukal, 2007; Chalmers et al., 2016; Van Ommen et al., 2015). BBMRI-ERIC currently consists of 20 member states and one international organization. BBMRI-ERIC can be seen as a network of networks, as the national nodes of it comprise national biobank networks (figure 1). The Finnish national node, BBMRI.fi is introduced in the next chapter. Currently, BBMRI-ERIC consists of 609 biobanks in total (BBMRI directory: https://directory.bbmri-eric.eu, 23.10.2019).

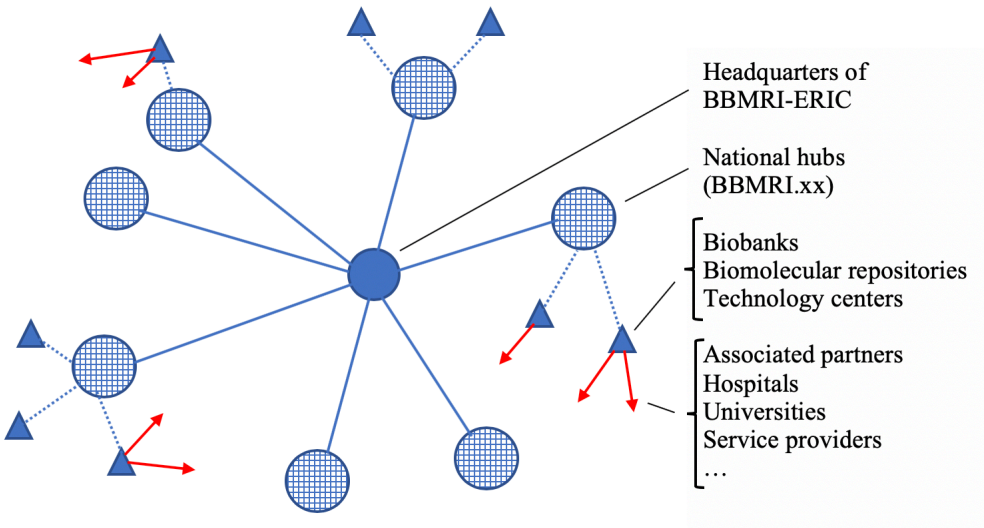

Figure 1 An illustration of the organizational structure of BBMRI-ERIC. The figure depicts the structure of BBMRI-ERIC that consists of the Headquarters and the national hubs consisting of biobanks, biomolecular repositories and technology centers, and their associated partners. (modified from Asslaber & Zatloukal, 2007*).*

Another kind of networks in the biobanking field are expertise networks. They are networks of individual people with shared interest and expertise in biobanking (Hainaut et al., 2017, p. 111). Expertise networks play an educational role and provide forums for networking with their conferences, where representatives of different biobank networks and organizations get together. A typical expertise network offers support in technical, managerial, legal, and ethical issues related to biobanking. A globally working example of expertise network providing these services is the International Society for Biological and Environmental Repositories (ISBER). ISBER is a global organization which provides networking opportunities, education, and innovations in the field of biobanking, and promotes high-quality standards and ethical principles in the management of biobanks (https://www.isber.org, 31.1.2019). The Finnish biobank cooperative, FinBioBank (FINBB) can be seen as a Finnish version of expertise network and is introduced in the next chapter.

2.2 Biobank operations in Finland

2.2.1 Finnish biobanks

The very first moments of Finnish biobanking were experienced in 2012 when the first clinical biobank in Finland, Auria Biobank in Turku, was founded (Lehtimaki et al., 2017). The Finnish Biobank Law came into action in September 2013, and six months later, Auria Biobank received its operating license from Valvira in March 2014 (https://www.biopankki.fi, 16.10.2019). Today, there are ten biobanks in Finland (figure 2). Six of them operate regionally in the areas of hospital districts and are established by universities and the hospital districts. Since they operate in connection with university hospitals, they are commonly called hospital biobanks. These biobanks are Auria Biobank, Biobank of Eastern Finland, Central Finland Biobank, Finnish Clinical Biobank Tampere, Helsinki Biobank, and Northern Finland Biobank Borealis. The other four are national biobanks that make country-wide collections. The national biobanks are run by the National Institute for Health and Welfare (THL), Blood Service, and Terveystalo Oyj. Finnish Red Cross' Blood Service runs two biobanks: Blood Service Biobank for all blood donors and Hematological Biobank (FHRB Biobank) for patients with hematological diseases (https://www.veripalvelu.fi, 18.10.2019). Terveystalo Biobank Finland is the only commercial biobank in Finland and collects samples from the consent given clients of the healthcare service company Terveystalo. Every biobank in Finland has to obtain a license from Valvira and operate under the instructions and supervision of Valvira. (https://www.biopankki.fi, 10.9.2019)

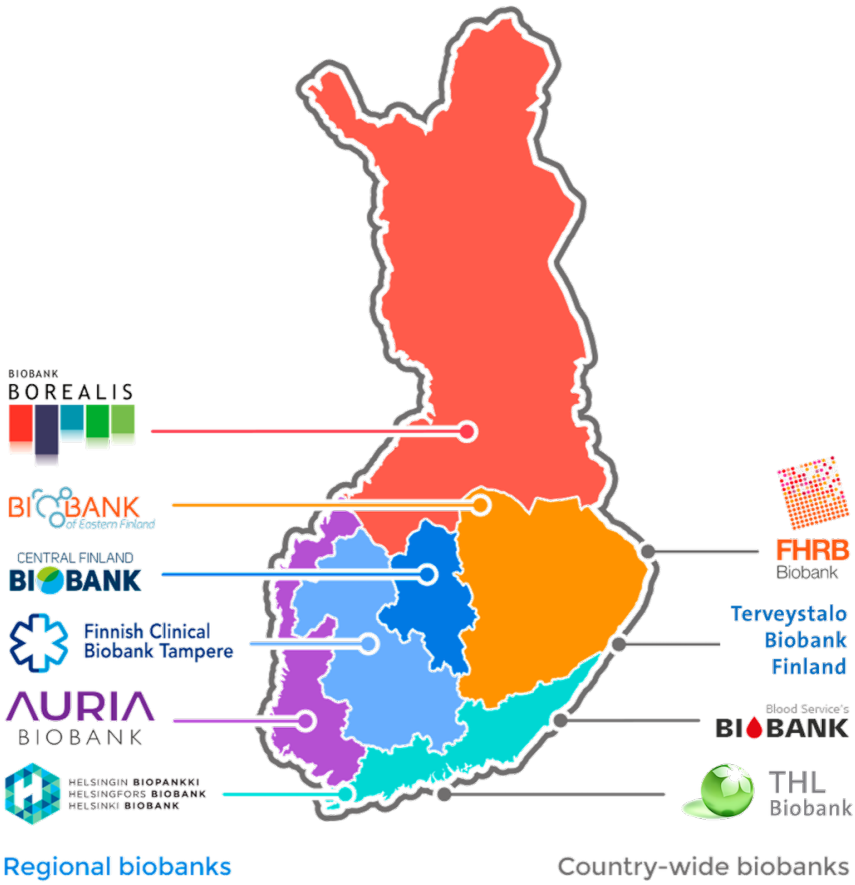

Figure 2 Finnish biobanks. There are ten biobanks in Finland; six of them collect samples regionally in the area of hospital districts, and the other four make country-wide collections (source and photo credits: Suomen Biopankit; https://www.biopankki.fi, 10.9.2019).

As described above, biobank networks are essential for efficient utilization of biobank collections, services and expertise. In Finland, the national-level biobank networks are formed by BBMRI.fi and FINBB. BBMRI.fi is the Finnish national node of BBMRI-ERIC and thus connects the Finnish biobanks to the European-wide infrastructure. The main goal of BBMRI.fi, as well as of FINBB (introduced shortly), is to build an internationally advanced biobank infrastructure in Finland to promote biomedical research and the development of personalized medicine. BBMRI.fi network consists of nine Finnish biobanks, Terveystalo Biobank Finland being only an observer. THL works as a host organization for BBMRI.fi. (http://www.bbmri.fi, 8.4.2019)

The Finnish biobank co-operative FINBB was established in 2017 by six Finnish universities and the six biggest hospital districts. All Finnish hospital biobanks are members of

FINBB. FINBB aims to build an advanced biobank infrastructure in which every Finnish biobank is involved by providing biobanks with communicational, legal, business, and data processing support, allowing biobanks to focus on their actual mission, that is, collecting, storing and enriching samples. (http://www.bbmri.fi, 8.4.2019) Furthermore, FINBB aims to improve citizen's awareness in biobank research and its significance in health care development (https://finbb.fi, 8.4.2019). In April 2019, FINBB launched a one-stop access to all Finnish hospital biobank materials for academic and industrial researchers' use. This nationally coordinated service, called Fingenious, facilitates biobank research as a researcher can access all six Finnish hospital biobanks through one service, instead of the former need to contact them separately. Through Fingenious, a researcher can submit feasibility and access requests to all participating biobanks with one application. (https://finbb.fi/access-finbb-biobanks-fingenious/, 2.8.2019)

2.2.2 Finnish Clinical Biobank Tampere

Finnish Clinical Biobank Tampere (FCBT) operates under Tampere University Hospital and was established in 2015 by the University of Tampere, Pirkanmaa Hospital District, Etelä-Pohjanmaa Hospital District, and Kanta-Häme Hospital District. FCBT received its license to operate from Valvira on September 8, 2015 (https://www.biopankki.fi, 3.4.2019). FCBT follows the research strategy delineated by Tampere University and Pirkanmaa Hospital District, the focus being in the research of cardiovascular diseases, cancer, autoimmune diseases and type 1 diabetes. The aim of FCBT is to support the research related to preventing, diagnosing, and treating the diseases, and facilitate the research utilizing pathological findings. (https://www.tays.fi/biopankki, https://www.biopankki.fi, 3.4.2019)

Like other hospital biobanks, FCBT collects and stores samples from the local patients, but these collections may be used in medical research globally through the above-mentioned biobank networks. The sample collection consists of diagnostic pathology tissue samples (e.g. cancer tumors) in formalin-fixed paraffin-embedded (FFPE) blocks, clinical genetics samples (blood, cells and tissues), and prospective blood and tissue samples. The prospective blood samples are divided into aliquots for serum, plasma and DNA extraction. In October 2019, the FCBT's sample collection contained approximately ~3.4 million diagnostic pathology samples, ~30 000 clinical genetics samples, and prospective samples from ~13 000 persons. However, the number of prospective samples is growing continuously, approximately by 1000 new donors' samples monthly. The samples are enriched with hospital register data

(e.g. patient's gender, age and diagnosis) before releasing them for research use as pseudonymized to protect the patients' privacy.

FCBT started their sample and data releases in June 2018 when the old diagnostical samples were transferred to FCBT's possession from the pathology and clinical genetics departments of Tampere University Hospital. The projects started since then are related to different types of cancers, celiac disease, fibrotic dysplasia, rheumatoid arthritis, and inflammatory bowel disease (IBD), among others.

2.2.3 The FinnGen project

All Finnish biobanks, except for Terveystalo Biobank Finland, participate in the FinnGen project which began in the autumn 2017. The goal of this project is to collect samples from 500 000 Finnish people, meaning ten percent of the Finnish population, and produce genome information from these samples. An original aim was to achieve the 500 000 participants by the year 2023 (https://www.finngen.fi, 9.4.2019). However, the project has proceeded faster than expected and now the estimated time of reaching that goal is by the year 2021 (Palotie et al., 2019). The estimated duration of the entire project is ten years. The responsible organization for the project is University of Helsinki, and the sample collection is coordinated by Helsinki Biobank (https://www.finngen.fi, 9.4.2019). However, the actual collections are performed by the participating biobanks. Besides the new samples, old sample cohorts from THL biobank are used. (Palotie et al., 2019) FinnGen is the first shared project between Finnish biobanks on a broad scale (https://www.finngen.fi, 9.4.2019).

The idea of the study is to combine genome information with digital health care data from national health registers, and this way enable medical innovations and supporting Finland to become a pioneer in biomedicine and personalized healthcare. Naturally, all the donors' personal data is secured, and only pseudonymized and encoded data is handled and stored within the FinnGen project. An access for the possible healthcare innovations and personalized treatments will be provided for all Finns as soon as possible. After the study has been completed, the genomic data will be owned by the Finnish biobanks, and thus remain available for further research use for both academia and companies. (https://www.finngen.fi, 9.4.2019)

FinnGen is a collaborative study between Finnish universities, hospital districts and hospitals, Finnish biobanks, THL, Blood Service, international pharmaceutical companies, and Finnish citizens. The project is funded by Business Finland and the nine participating

pharmaceutical companies (Abbvie, AstraZeneca, Biogen, Celgene, Genentech, GSK, MSD, Pfizer, and Sanofi). FinnGen is an exceptional project even in global level, as it is one of the first personalized medicine projects at this scale, and a public-private collaboration of this kind is rare among other ongoing studies. Therefore, one of the main aims of FinnGen is to create a co-operation model between public sector and healthcare industry. The ideal success of the project would benefit all the parties: biobanks, as the sample collections are expanded and enriched with genetic data; medical research, since the data generated in the study will remain in Finland and be available for further research purposes; pharmaceutical companies participating in the project, as they get an access to genetic data from Finnish population which enhances their possibilities to develop new drugs; and lastly, the Finnish citizens, as new solutions for predict, prevent and treat the disease are identified. Eventually, FinnGen will benefit the entire world. (https://www.finngen.fi, 9.4.2019)

FinnGen is not the first population-wide biobank study in the world, but it has several advantages compared to other equivalent studies such as UK Biobank. Firstly, the conditions for genetic research covering the whole population are exceptional in Finland, as the biobank network covers the whole country and the collections are available for all researchers (https://www.finngen.fi, 9.4.2019). Secondly, the Nordic countries have a long history in gathering medical information into population-wide registers (Graham, McDonald, Wasiak, Lees, & Ramagopalan, 2018) and therefore, the Finnish health registers and digital medical records are very comprehensive and easily accessible (Lehtimaki et al., 2017). Thirdly, Finns are a genetically isolated population, which makes the analyzing of genetic data faster and the probability to find compatible results is higher than in genetically heterogenic populations (Swede et al., 2007). Already now some genetic variants enriched in the Finnish population have been found from the FinnGen materials. For example, preliminary findings for variants that are rare elsewhere have been made in type 2 diabetes, glaucoma, sleep apnea, and asthma and more is expected as the participant number grows (Palotie et al., 2019). Furthermore, to develop the medical research, it is crucial that there are several diseases among the project participants. In Finland, the biobank samples are given mainly during the hospital procedures, thus the proportion of donors that are suffering from some diseases is greater than in the UK Biobank that collected samples primarily from healthy citizens. (Palotie et al., 2019) The significance and magnitude of the FinnGen project has been noticed world-wide. It was listed among the ten largest biobank projects in the world by the global biobanking industry portal Biobanking.com in May 2018 (https://www.biobanking.com/10-largest-biobanks-in-the-world/, 10.4.2019).

2.3 Standardization of biobanking

2.3.1 International guidelines

Already in 1999, OECD recommended that national governments, the scientific community and the private sector should work together to "support the development of an accreditation system for BRCs [biological resource centers] based upon scientifically acceptable objective international criteria for quality, expertise and financial stability" (OECD, 2001). Several guidelines by different international organizations were developed before the International Organization for Standardization (ISO) published the first international biobank standard in August 2018. However, the former guidelines are still applicable and recommended to use. For example, BBMRI requires its members to implement their operations in compliance with the European and international standards, but also with OECD Best Practice Guidelines for Global Biological Resource Centers Networks, and WHO/IARC Common Minimum Technical Standards by International Agency for Research on Cancer (IARC) operating under the World Health Organization (WHO) (http://www.bbmri-eric.eu/services/standardisation/, 11.3.2019). Other guidelines have been published, for example, by the US National Cancer Institute (NCI), the European Council, and the ISBER. These standards and guidelines will be overviewed next.

The international biobanking standard published by ISO, the *ISO 20387:2018 Biotechnology – Biobanking – General requirements for biobanking,* is a standard applicable to all organizations performing biobanking. The ISO20387:2018 document defines the general requirements for competent, impartial and consistent biobank operation that follows the quality control requirements to ensure the high quality of sample and data collections (ISO, 2018; http://www.bbmri-eric.eu/services/standardisation/, 11.3.2019). The aim of this standard is to unify the policies and processes used with biological materials and their related data, and facilitate collaboration, exchange and harmonization of the biobank and research practices (ISO, 2018).

OECD published the *Best Practice Guidelines for Biological Resource Centers* in 2007 and the *Guidelines on Human Biobanks and Genetic Research Databases* in 2009 (OECD, 2007, 2009; Staunton et al., 2019). The first published best practice guideline contains procedures that deal with general quality aspects, biosecurity issues, instructions for biological resource centers holding and supplying micro-organisms, and instructions for biological resource centers holding and supplying human-derived materials (OECD, 2007). The second set of guidelines published in 2009 aims to "provide guidance for the establishment, governance, management, operation, access, use and discontinuation of human biobanks and

genetic research databases" (OECD, 2009). Additionally, OECD published the *Recommendation on Health Data Governance* in 2017 that provides a framework for processing and greater availability of health data and minimizing the risks related to privacy and data security (OECD, 2017).

The National Cancer Institute (NCI) published their *Best Practices for Biospecimen Resources* in 2016. This guideline focuses on technical and operational best practices, as well as on ethical, legal and policy best practices. These aim to ensure the uniformity and standardization of biospecimen resources. Furthermore, NCI Best Practices give instructions for data protection and intellectual property issues (National Cancer Institute, 2016). This guideline is proposed to be applicable to all biospecimen resources but the implementation of it is voluntary.

The European Council published their newest recommendation set in 2016 (Staunton et al., 2019). This *Recommendation CM/Rec(2016)6 of the Committee of Ministers to member states for research on biological materials of human origin* was an update to the *Recommendation (2006)4* published in 2006. The Recommendation (2006)4 was planned to ensure the ethical aspects of using biological material of human origin in research. The updated version takes into account the advancements in biobanking, such as the increased diversity in biological material stored in biobanks and privacy protection issues (https://www.coe.int/en/web/bioethics/biobanks, 8.3.2019).

The ISBER has published a comprehensive set of best practices for biological repositories. The first edition of the ISBER Best Practices was published in 2005, and it has been revised in 2008, 2012, and 2018. *The ISBER Best Practices: Recommendations for Repositories Fourth Edition* (2018) defines the best practices for the collection, long-term storage, retrieval and distribution of biospecimens in collections and repositories (Campbell et al., 2018). This supports the future research by ensuring the availability of high-quality specimens. The ISBER Best Practices document is freely available on the ISBER website (https://www.isber.org, 12.7.2019).

IARC that operates under the WHO has published the *Common Minimum Technical Standards and Protocols for Biobanks Dedicated to Cancer Research* in 2017 (Mendy, Caboux, Lawlor, Wright, & Wild, 2017). This set of standards includes guidelines and recommendations related to sample sharing, ethical, legal and social issues, biobank governance, and harmonization of collaborative research works that use biological materials. Additionally, this standard contains protocols for selected sample processing procedures. Although addressed primarily for cancer research, IARC's standard is broadly applicable to other research areas as

well. The Common Minimum Technical Standards by IARC bring together the most important standardization tools in biobanking, such as Standard Preanalytical Code (SPREC), Biospecimen Reporting for Improved Study Quality (BRISQ) protocol, and the Minimum Information About Biobank Data Sharing (MIABIS) model. The IARC guideline gives also a description for the recommended contents of standard operating procedures (SOPs) that guide the workflow of every biobank. The above-mentioned tools and SOPs in general will be introduced in the next sections.

2.3.2 Standard operating procedures

As mentioned in the previous chapter, biobank protocols need standardization in order to ensure the stable quality of samples between biobanks. This enables the use of samples from several biobanks in one research project and the (international) sharing of biobank collections. To maintain biobank protocols standardized and replicable, biobank networks and other authorities have established standard operating procedures (SOPs) for biobanks (Zhou, Sahin, & Myers, 2015). IARC Common Minimum Technical Standards point out that "biobanks should develop, document, and regularly update policies and procedures in a standardized written format into an SOP manual" (Mendy et al., 2017). The SOP manual must be available to all laboratory personnel all the time and it is a key part of the quality management of the biobank.

SOPs cover the whole process of sample acquisition, starting from obtaining the consent from the donor and collection of the material, followed by sample processing and storage, and procedures for sharing and transferring the samples (Guerin et al., 2010; Mendy et al., 2017; Zhou et al., 2015). Guerin et al. (2010) classified SOPs into three categories in their *Guidelines for Standardized Biobanking*, which have been published by Molecular Medicine Ireland. These categories are pre-clinical, clinical, and laboratory SOPs. Pre-clinical SOPs include the assessment of the research participant, safety guidelines, specimen identification and labeling, whereas clinical SOPs are guidelines for sample collection, and laboratory SOPs give instructions to the use of protective laboratory equipment, and the processing of each sample type (Guerin et al., 2010; Paskal et al., 2018).

2.3.3 SPREC (Standard PREanalytical Code)

Sample management requires systematic documentation of the collection, processing and storage conditions to ensure the high quality of the samples and their suitability for specific purposes (Ellervik & Vaught, 2015; Hainaut et al., 2017, p. 33). The requirements for quality management and documentation differ between prospective and historical collections. The uniformity of sample quality in prospective collections can be ensured by exact documentation of preanalytical steps, whereas historical collections need quality control assays and diagnostics for sample's previously made preanalytical steps and for its fitness-for-purpose (Hainaut et al., 2017, p. 33).

The ISBER Biospecimen Science working group developed a coding system for classifying and documenting preanalytical variables that can have an impact on the integrity of samples during their collection, processing and storage. Practically, in biobanking, the term preanalytical refers to all the processes a sample goes through before it is used in a research (Ellervik & Vaught, 2015). This coding system is called Standard PREanalytical Code (SPREC) and its first version was published in 2009 (Fotini Betsou et al., 2010; Lehmann et al., 2012). After that, updates have been made in 2012 and 2018 (Fay Betsou et al., 2018).

The SPREC is a 7-element code, each element referring to a crucial preanalytical variable of collecting, processing or storing biospecimen. This labeling system provides a universal format for recording details of sample processing and storage. It also increases the focus on accurate and standardized sample handling throughout the pre-analytic process and thus reduces deviations in sample quality. (Lehmann et al., 2012) Therefore, the SPREC facilitates sample comparison and the collaboration between laboratories and institutions using similar samples. The SPREC is easily applicable in any laboratory or sample collecting unit because of its simplicity and easy usage as it requires only strict recording practices and no special knowledge. There is also a free online tool available for SPREC users (Hainaut et al., 2017, p. 33). The seven SPREC elements for fluid and solid biospecimen with example codes are presented in table 1. The full list of preanalytical variables with their codes are listed in the SPREC Version 3.0. (Fay Betsou et al., 2018).

Table 1 SPREC elements for fluid and solid samples. The example code for fluid sample (SER-SST-B-F-N-C-G) corresponds to a serum specimen (SER) collected from a serum separator tube (SST). The pre-centrifugation delay between collection and processing has been <2 hours at 2°C to 10°C (B), and the centrifugation has been done at 2°C to 10°C and 3,000 to 6,000 g with braking for 10 min (F). Centrifugation has been done only once (N), and the delay between centrifugation and freezing was 1-2 hours at 2°C to 10°C (C). The sample was stored in straws at -85°C to -60°C (G). The example code for solid sample (TIS-BPS-A-C-NAA-B-J) corresponds to a solid tissue specimen (TIS) collected as a biopsy (BPS), with warm ischemia time <2 minutes (A) and cold ischemia time at room temperature 10-20 minutes (C). The sample has been fixed in nonaldehyde without acetic acid (NAA) for 15 to 60 minutes (B) and stored in ≥5 mL polypropylene tube at -85°C to -60°C (J). (Modified from Fay Betsou et al., 2018)

Code element	**Fluid sample**	**Example code**	**Solid sample**	**Example code**
First	type of sample	SER	type of sample	TIS
Second	type of primary container	SST	type of collection	BPS
Third	pre-centrifugation	B	warm ischemia time	A
Fourth	centrifugation	F	cold ischemia time	C
Fifth	second centrifugation	N	fixation type	NAA
Sixth	post-centrifugation	C	fixation time	B
Seventh	storage condition	G	storage condition	J

2.3.4 BRISQ (Biospecimen Reporting for Improved Study Quality) protocol

Another international standard for biobanking is called BRISQ (Biospecimen Reporting for Improved Study Quality) protocol. This list of recommendations was developed by the members of ISBER and (Moore et al., 2011). The purpose of BRISQ recommendations is to form a standardized reporting manner for data elements of human biospecimens. These recommendations aim to provide researchers with consistent and standardized information about sample preanalytical factors. The purpose of the BRISQ recommendations is to offer better facilities to decipher, evaluate, compare and reproduce the results derived from the experiments using human biospecimens (Ellervik & Vaught, 2015; Moore et al., 2011). They are planned to apply to any research using human biospecimens (Moore et al., 2011).

The BRISQ list contains data elements that are likely to influence biospecimen quality, molecular composition or consistency and thus should be recorded. The BRISQ elements are prioritized into three tiers according to their importance of being reported. These tiers are called “Items recommended to report” (Tier 1), “Items beneficial to report” (Tier 2) and “Additional items to report” (Tier 3). Tier 1 consists of 15 elements of necessary data, such as sample types and collection and storage manners. This set of information is required for publication in several journals (Mendy et al., 2017; Watson et al., 2014). Tier 2 comprises of 19 elements. This beneficial data covers patient demographic information, and times and temperatures, for example. The 16 elements of Tier 3 are less important, “nice-to-have” information such as exposures, storage containers and shipping parameters. (Mendy et al., 2017) The elements are also organized according to the life-cycle step of biospecimen, starting from pre-acquisition, followed by acquisition, stabilization/preservation, storage/transport, and quality assurance measures. Examples of each tier and life-cycle step are presented in table 2, and the full BRISQ list can be found from the article by Moore et al. (2011).

Table 2 BRISQ recommendations. Examples of data elements recommended to be recorded according to BRISQ recommendations. The elements are classified according to biospecimen life-cycle step and their importance of being recorded, Tier 1 being the most important group to report. Elements in Tier 2 are beneficial to report, and Tier 3 elements are additional information to report. One example data element of each tier in each biospecimen life-cycle step is presented here (if applicable). (Modified from Moore et al., 2011)

Biospecimen life-cycle step	**Tier #**	**Data element**	**Example / explanation**
Pre-acquisition	1	Biospecimen disease status	Diabetes
	2	Patient demographic information	Age
	3	Exposures	Smoking status
Acquisition	1	Collection mechanism and parameters	Fine needle aspiration
	2	Time from biospecimen excision/acquisition to stabilization	Time between blood drawn and stabilization
	3	Time from cessation of blood flow in vivo to biospecimen excision/acquisition	Ischemic time in the body
Stabilization / Preservation	1	Mechanism of stabilization	EDTA
	2	Aliquot volume / Specimen size	The amount of liquid sample / the size or weight of solid sample
Storage / Transport	1	Storage temperature	-80°C to -65°C
	2	Shipping duration	<1 hour
	3	Shipping parameters	Packing material
Quality assurance measures	1	Composition assessment and selection	Parameters used for choosing biospecimens in the study
	2	Method of enrichment for relevant component(s)	Centrifugation of blood
	3	Embedding reagent/medium	Paraffin

2.3.5 MIABIS (The Minimum Information About Biobank Data Sharing)

The Minimum Information About Biobank Data Sharing (MIABIS) is a list of the information required to share when starting the collaboration between two or more biobanks. The newest version of MIABIS, the MIABIS 2.0 Core was formulated by BBMRI-ERIC in 2016. It describes detailed guidelines for minimum information required when sharing data between biobanks and aims to standardize data elements used in describing biobanks, their samples and associated data. (https://github.com/MIABIS/miabis/wiki, 1.3.2019)

Originally, the first version of MIABIS was developed in 2012 by the Swedish node of BBMRI, BBMRI.se (Merino-Martinez et al., 2016). The broad acceptance of this version led to the development of more systematized and descriptive standard by BBMRI-ERIC. Eventually, MIABIS 2.0 Core standard was formed through multi-country collaboration. The MIABIS 2.0 Core guideline consists of 22-element instructions for describing biobanks, sample collections and studies and is formulated into a modular structure (presented in the table 3) (Merino-Martinez et al., 2016). Additionally, data describing sample and sample donor are served but still under development (https://github.com/MIABIS/miabis/wiki, 18.10.2019). MIABIS is the only standard that gives instructions for this type of collective information and is useful when creating catalogues for biobank resource availabilities (Mendy et al., 2017). This standard contributes to the more efficient use of bioresources in biobank collections and therefore promotes the research on human diseases.

By applying SPREC, BRISQ and MIABIS data items into biobank sample collections, the value of a collection for end users increases, since biological samples and their related clinical and pre-analytical data should not be separated (Hainaut et al., 2017, p. 33). These standards are partly overlapping and support each other. Combining them with SOPs, biobanking becomes internationally compatible.

Table 3 MIABIS 2.0 Core elements. MIABIS 2.0 consists of 22 elements describing biobank, sample collection and study. According to BBMRI-ERIC, this is the minimum set of information recommended to share when starting a collaboration between biobanks. (Modified from https://github.com/MIABIS/miabis/wiki, 1.3.2019)

Attribute Code	Attribute Name	Description	Applicable to data describing:		
			Biobank	Sample Collection	Study
MIABIS-2.0-01	ID	ID of each MIABIS component. A generic attribute name used with several MIABIS components.	✓	✓	✓
MIABIS-2.0-02	Acronym	Short name in use for biobank / sample collection.	✓	✓	
MIABIS-2.0-03	Name	The name of the biobank / sample collection / study in English.	✓	✓	✓
MIABIS-2.0-04	URL	Complete http-address for the biobank.	✓		
MIABIS-2.0-05	Juristic Person	The juristic person, e.g. a university, for the biobank.	✓		
MIABIS-2.0-06	Country	Two-letter code for the country of the biobank.	✓		
MIABIS-2.0-07	Contact Information	Contact information for the contact person of the biobank / sample collection / study.	✓	✓	✓
MIABIS-2.0-08	Description	A description about the biobank / sample collection / study in English.	✓	✓	✓
MIABIS-2.0-09	Sex	The sex of the individuals in the sample collection / study participants.		✓	✓
MIABIS-2.0-10	Age Low	Age of the youngest donor / participant.		✓	✓
MIABIS-2.0-11	Age High	Age of the oldest donor / participant.		✓	✓

MIABIS-2.0-12	Age Unit	Unit defining Age Low and Age High (years, months, weeks, or days).		✓	✓
MIABIS-2.0-13	Data categories	Types of data that are available or associated with the samples.		✓	✓
MIABIS-2.0-14	Material type	The biospecimen saved from a biological entity for propagation e.g. diagnostics or research purposes.		✓	✓
MIABIS-2.0-15	Storage temperature	The long-term storage temperature at which the samples are stored after preparation.		✓	
MIABIS-2.0-16	Collection type	The type of the sample collection.		✓	
MIABIS-2.0-17	Disease	The disease of main interest in the sample collection, if any.		✓	
MIABIS-2.0-18	Principal Investigator	The name of the person responsible for the study, e.g. the principal investigator.			✓
MIABIS-2.0-19	Study design	The design of the study.			✓
MIABIS-2.0-20	Total number of participants	Total number of individuals recruited to the study.			✓
MIABIS-2.0-21	Total number of sample donors	Total number of individuals with biological samples in the study.			✓
MIABIS-2.0-22	Inclusion criteria	Information on type of parameters that determine which individuals will become study participants.			✓

2.3.6 IT systems and data standardization

Samples and their processing are not the only aspects of biobanking that should be standardized. Moreover, the obtaining and processing of data must be guided with standards to enable harmonious data sharing. The huge amount of digital data requires powerful and optimized IT systems that serve databases in a real-time manner with an easy access (Paskal et al., 2018). Some clinical datasets, such as genetic information, needs further processing, which requires bioinformatics solutions and computing capacity. The data is mainly sensitive as it contains personal health information, so privacy protection and pseudonymization have to be carefully organized. Hospital-based biobanks handle fully identified patient data including personal, clinical and laboratory data which can only be stored in hospital databases (Malm et al., 2013). These databases and servers are carefully protected to keep the medical information is safe. The design of data sharing from biobanks should be cooperative with these national healthcare information systems to ensure efficient and controlled share of data (Harris et al., 2012). Naturally, the formats for sharing need to be standardized across biobanks as well.

Additionally, the form and extent of information that is listed about the available samples and data should also be standardized to facilitate efficient sharing (e.g. MIABIS). The availability information should also be easily accessible by potential biobank users. That is, the available samples and data of every biobank should be described in an electronic catalogue available for possible clients. Standardization of the information in these catalogues enable merging them into network-wide catalogues. The lack of such catalogues has been considered as an essential factor when biobanks face the problem of under-use of their biological sample collections (Chalmers et al., 2016; Paradiso, Daidone, Canzonieri, & Zito, 2018).

2.3.7 Biobank standardization in Finland

In Finland, the legal and ethical aspects of biobanking are regulated by the Biobank Law, which will be introduced in the next chapter focused on the legal aspects. Additionally, Valvira (the National Supervisory Authority for Welfare and Health) guides and supervises the operations of Finnish biobanks.

As mentioned earlier, BBMRI requires that their members follow the OECD guidelines and other international standards. Therefore, all Finnish biobanks obviously obey these guidelines at least to some extent. However, Auria Biobank is the only Finnish biobank telling on their website that their quality management system is based on the OECD guidelines for biobanking (https://www.auria.fi/biopankki/en/quality, 10.9.2019). Other biobanks only tell that they operate under the supervision of Valvira and obey the Biobank Law. Furthermore,

Auria Biobank is also the first biobank in Finland that has started the work towards accreditation of ISO Biobank standard (*ISO 20387:2018 Biotechnology – Biobanking – General requirements for biobanking*) published in 2018. In practice, this means that they have self-evaluated their operations and listed the requisites in the standard that require remedial actions from them. Aulikki Santavuori, the Quality Manager from Auria Biobank stated (personal communication, September 6, 2019) that the work towards fulfilling the requisites has begun. For example, updates have been made into existing operating procedures, some new procedures have been composed, still missing procedures have been recognized, and training of the personnel is ongoing. Applying accreditation is possible after fulfilling the ISO standard requisites and self-evaluating the operations after the applied changes. According to Santavuori (personal communication, September 11, 2019), Auria Biobank will most likely be ready to apply accreditation in the year 2020.

Applying international standards into their operations might explain the fact that unlike other Finnish biobanks, Auria Biobank has done several national and international industry-based project collaborations (www.auria.fi/biopankki/biopankkitutkimukset, 12.3.2019) (look also figure 3). In the near future, the accreditation of ISO biobank standard will be ahead of FCBT and other Finnish biobanks as well.

2.4 Laws and authorities directing biobanks

A key concern in biobanking is data protection. It is a prerequisite that donors' privacy is protected from the sample acquisition to their eventual use in research (Malm et al., 2013). Currently, there is no single, European-wide regulation system for biomedical research that would apply to both human-derived samples and data (Kaye et al., 2016). Kaye et al. (2016) compared the legislation of BioSHaRE-EU project (a project aiming to harmonize biobanking across Europe) participant countries: Finland, France, Norway, Germany, the Netherlands and the United Kingdom. They came into conclusion that although each member country has directives for sample and data use in research purposes, the source of these directives differs between the countries. Only Finland and Norway have a specific legislation for biobanking, whereas the others have these requirements covered in a few more general pieces of legislation (Kaye et al., 2016). The width of administrative and legal regulatory framework concerning particularly biobanks is one reason why Finland is one of the most advanced countries in biobanking globally (Lehtimaki et al., 2017).

The General Data Protection Regulation (GDPR) that came into effect in Europe in May 2018 have harmonized the data protection across Europe and increased transparency. However, GDPR has also evolved incoherencies in scientific research as a research following the legal steps of GDPR and the national (biobank) laws, may not be in line with the ethical standards required by research ethics committees (Staunton et al., 2019). Therefore, biobanks need to have clear and transparent governance procedures and policies publicly available. The national legislation should work as a basis for these local procedures for processing of personal data and oversee the use of data in research. This would ensure the protection of personal data and also be analogical with the GDPR's transparency requirements (Staunton et al., 2019).

In Finland, the biobank operations are regulated primarily by the Biobank Law, but also by a bunch other of laws, including the Law on the medical use of human organs, tissues and cells, the Law on the status and rights of the patient, the Medical research law, and the Data Privacy Act (https://www.biopankki.fi, 27.8.2019). Additionally, the recently approved Act on the Secondary Use of Health and Social Data as well as the forthcoming Genome Law will have an effect on the regulation of Finnish Biobanking.

The Biobank Law came into effect in Finland on September 1, 2013. It ensures the citizens' possibilities to obtain information about the research projects in which their samples are used. The law also decrees about the requirements on establishing and running a biobank, collecting, storing, and processing samples and data in a biobank, and the registers used in biobank studies. According to the Biobank Law, a broad and informed consent given by the donor is required for a biobank to have a right to collect, process and use their samples (Biobank Law 30.11.2012/688, Kaye et al., 2016) The law made a change in the research usage of biobank samples, as it enables collection of samples for research projects that are not formulated in advance. Previously, the details for the use of donor's samples should be explained to them when they were giving the consent. The Biobank Law also enabled the transfer of samples collected in the past to biobanks. (https://www.biopankki.fi/biopankkilaki-ja-saately/, 24.4.2019)

A new biobank law is currently under development (https://valtioneuvosto.fi/, https://www.lausuntopalvelu.fi, 28.8.2019). This new law will replace the former Biobank Law and is set up to relate to the new European data protection requirements mentioned above. This law will also highlight the biobank practitioner's responsibility to fulfill the legality of their operations. Another significant change in the new law in relation to the former Biobank Law is that the samples derived from healthcare operations would be utilizable in research by the terms of law. Thus, a patient particularly needs to deny the use of their samples and data in research

instead of the former requirement of a consent given by the donor (https://stm.fi/artikkeli/-/asset_publisher/esitys-biopankkilain-kokonaisuudistukseksi-lausunnoille, 28.8.2019).

Another change in the legal aspects concerning biobanks came into effect in the spring 2019. The Act on the Secondary Use of Health and Social Data was approved by the Finnish Parliament on March 13, 2019 and verified by the president on April 26, 2019. The secondary use of data means that data in registers is used for different purposes than it was originally stored. The goal of the act is to facilitate the safe and efficient use, processing, and access to the social welfare and health data in different registers. The act is expected to benefit research, statistics, teaching, knowledge-based management, development and innovations in health and social sector, and ensures the individual's privacy and rights when processing personal data. The act includes the establishment of a centralized data permit authority that aims to accelerate the granting of permits for research and other secondary use of health and social data. (https://stm.fi/sote-tiedon-hyodyntaminen, 2.9.2019; Secondary Use Act 26.4.2019/552)

Although the Secondary Use Act does not directly involve biobanks and their own registers, researchers doing biobank research often need data from other registers as well. The Secondary Use Act comes into question when a researcher applies material from two or more biobanks and needs patient register data from registers of several hospital districts. Grants for individual hospital registers are still applied locally but accessing data from several hospital registers is granted by the data permit authority. (Tom Southerington, General Counsel, FINBB, unpublished seminar presentation, Tampere, 12.4.2019; T. Southerington, personal communication, 3.9.2019).

Additionally, the forthcoming Genome Law will be in close relation to biobank operations. This law is still in a draft phase and statements by Finnish healthcare and medical research field were given in the summer 2019. The Genome Law is supposed to come into effect in the beginning of the year 2020 (https://www.eduskunta.fi, 27.8.2019), and support the data-secure, equal and responsible use of genome information for the benefit of citizens' health. This law proposes the establishment of the Genome Center that would be a national authority handling the genome information derived from healthcare and biobank operations (https://stm.fi, 27.8.2019).

Furthermore, two authorities guide and monitor the Finnish biobanks. These are the National Supervisory Authority for Welfare and Health (Valvira) and the National Committee on Medical Research Ethics (TUKIJA). Valvira supervises and directs Finnish biobank operations, and TUKIJA's supportive statement is required when a new biobank is

established. (https://www.biopankki.fi/biopankkilaki-ja-saately/, 24.4.2019) Regional ethical committees might also participate in monitoring biobanking in local level.

2.5 Characteristics of national and international biobank research

2.5.1 Biobank research

Biobank research is defined as a research project utilizing samples and/or data from one or more biobank(s). Biobank research projects can be classified into academic and commercial researches based on the type of a customer; a customer can be an academic researcher or a research group, or a commercial company. Majority of the biobank studies conducted in Finland are academic studies. Auria Biobank was the only biobank performing commercial studies for a long time, and still 85 % of the biobank studies conducted in Finland has been performed by Auria. They got an advance in being the first clinical biobank in Finland, and therefore being ahead of other Finnish biobanks in their service development. Furthermore, they have invested in commercializing of biobank data and marketing biobank services to medical industry (Lehtimaki et al., 2017). Figure 3 shows how the Finnish biobank research projects have distributed between academic and commercial studies. Additionally, a group for biobanks' internal projects is shown, including only one study performed by the Blood Service Biobank.

Same procedures regarding to sample and data collection and release processes, and feasibility analyses to explore the availability of suitable material at biobanks apply to both academic and commercial research projects. One remarkable difference between these two types of biobank customers is the cost structure for reaching biobank materials and services. Typically, a minimal fee is charged from academic researchers as the universities and hospital districts are funders of hospital biobanks and therefore participate in the costs of running a biobank in other ways. For example, in FCBT, the fee for an academic researcher to reach the biobank materials is basically the hourly cost based on the time that each sample collection takes from the biobank personnel. No additional service fees or sample-specific costs are charged. Conversely, it is typical that considerably higher fee is charged from researchers working for commercial departments (Chalmers et al., 2016).

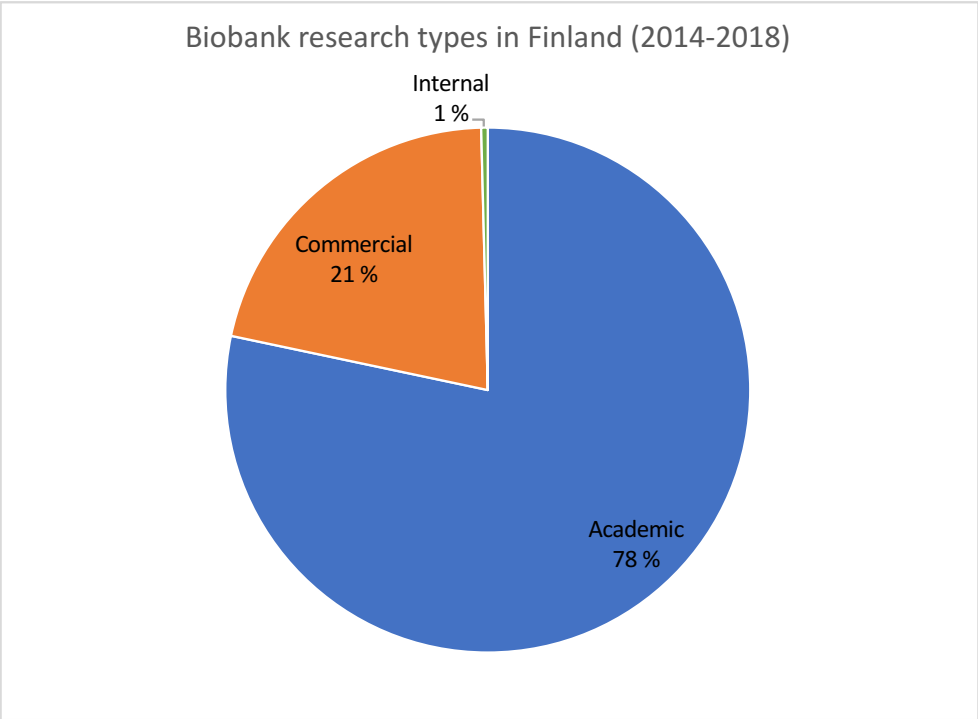

Figure 3 Finnish biobank research types during the years 2014-2018. Majority of the Finnish biobank researches are conducted by academic researchers. Furthermore, it should be noted that 85 % of the commercial, industry-based projects has been performed by Auria Biobank. Biobanks' internal projects listed on their websites are presented as well, but only one project (by Blood Service Biobank) was mentioned. Numbers have been counted from the research projects listed on the websites of the Finnish biobanks. The research project information of seven out of ten biobanks was available in July 2019. (Source: the websites of the Finnish biobanks)

2.5.2 The popularity of research areas

As stated above in the section 2.1.2 *Classification of biobanks*, biobanks can be classified into population biobanks and disease-oriented biobanks. In Finland, there is only one clearly disease-oriented biobank, Hematological Biobank (FHRB Biobank). It is focused on the hematological diseases. In this classification system, the six Finnish hospital biobanks do not fall clearly into either of these classes, but they have some features of disease-oriented biobanks. They collect samples from many areas of medical interest and typically have their own main focus areas that follow the local research strategy. For example, FCBT is focused primarily on the research in cardiovascular disease, cancer, immunology, and type 1 diabetes (https://www.tays.fi/biopankki, 19.2.2019). THL Biobank, however, has features of both population and disease-oriented biobanks. Because of their exceptional collection of population-wide samples and registers, THL Biobank enables a broad scale of research projects concerning population health. They also have disease-specific collections, including migraine, diabetes and psychiatric diseases (https://directory.bbmri-eric.eu, 20.2.2019).

Because of the variable interest areas of the Finnish biobanks and the research projects using their samples, it is interesting to explore if some area of research is significantly more popular than others in biobank research. This would also give a clue of what type of samples should be prioritized in the future when gathering biobank collections. For this, the lists of research projects in each Finnish biobank were examined and the research projects classified according to their focus area or areas. Some research projects fell into several categories if several research areas were clearly indicated. Seven out of ten biobanks (FCBT, Auria Biobank, Helsinki Biobank, THL Biobank, Biobank of Eastern Finland, Northern Finland Biobank Borealis, and Blood Service Biobank) had their research projects listed on their website in summer 2019. The relative proportions of research areas in these seven Finnish biobanks are presented in the figure 4. According to the listed projects, the most popular area in the Finnish biobank research is cancer. Genetics-related researches is the second most popular area in the statistics, which is explained by the involvement of genetics in several different disease-specific research projects. THL biobank has also conducted several population-wide research projects concerning primarily genetics, such as exploring rare sequence variants enriched in Finnish population (https://thl.fi/fi/web/thl-biopankki, 29.7.2019).

Internationally, there are several disease specific biobanks. However, universal trends in the sample needs for specific disease areas have not always been considered when establishing these biobanks (Mackenzie, 2014). To compare the distribution of international biobank studies with the above-mentioned Finnish biobank studies, the numbers of submitted access applications in UK Biobank between 2012 and 2019 were used. The UK Biobank's samples and data are used in research projects around the world: from UK to USA, and from Australia to China and France, just to name few (https://www.ukbiobank.ac.uk/approved-research/, 25.4.2019). Therefore, it gives a broad image of how biobank studies have distributed into different research areas internationally. The research areas analogous to the Finnish ones presented above are shown in the figure 5. The categorizing of these areas used by UK Biobank itself differs from the one used with the Finnish studies. Therefore, to avoid misleading numbers, neurological diseases are left in their original groups of dementia and cognition, and psychiatric diseases are considered as equal with the original group named as mental health. Cancer and cardiovascular diseases are the most popular of the given disease areas. Almost half of the UK Biobank's research projects are related to genetics. The massive number is explained by the involvement of genetics and genotyping in the projects of several disease areas.

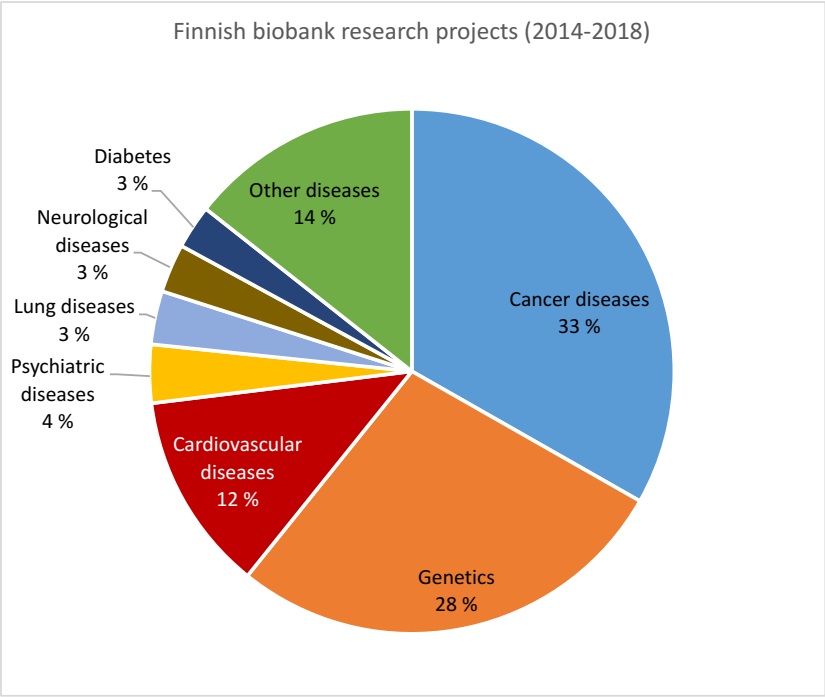

Figure 4 The relative proportions of research areas in the Finnish biobank research projects during the years 2014–2018. The projects of seven out of ten Finnish biobanks were available and are listed here. 249 projects in total were listed during this time period. (Source: the websites of the Finnish biobanks)

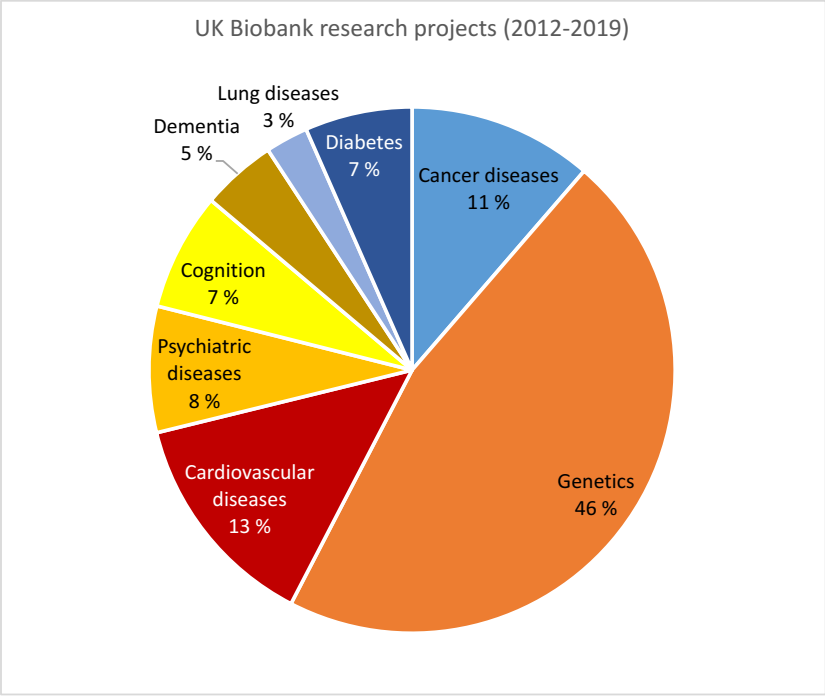

Figure 5 The relative proportions of research areas of submitted access applications in UK Biobank between March 2012 and January 2019 in the chosen disease groups. Many groups in the original chart were left out of this chart as only the ones comparable to Finnish biobank studies were chosen. Totally 1463 applications were received during the given time period. One application may be counted in more than one group.
(Source: https://www.ukbiobank.ac.uk/approved-research/, 25.4.2019)

2.5.3 Sample and service needs

Needs for biobank samples and services differ between different stakeholders. In a survey conducted by Fiona Mackenzie (Mackenzie, 2014), these needs were identified by surveying different types of biobanks in the UK, France, Germany, and USA. The stakeholders were divided into four groups: academic researchers, pharmaceutical companies, research-based biotechnology companies (often spin-offs from universities), and clinical research companies. According to the survey, academic needs are mainly related to very specific or hard to collect samples or disease data, but also the samples from healthy donors to compare them with the diseased samples. Pharmaceutical industry use biobank samples in early-stage drug discoveries and clinical trials to test the effectiveness of potential new drugs and to identify their possible side effects. Their sample requests are typically broad and for large number of samples, often requiring very detailed donor information. Research-based biotechnology companies, in turn, typically require less detailed donor information for their drug and diagnostics development. By contrast, clinical research companies that undertake clients' research projects typically require very highly annotated samples to fulfil the end-users' demands. (Mackenzie, 2014)

The demand for formalin-fixed paraffin-embedded (FFPE) blocks samples has increased and probably will increase because of their high and constant quality due to their standardized processing methods (Asslaber & Zatloukal, 2007; Mackenzie, 2014). Additionally, they usually are easily available in biobanks since they are easy to collect and store, even in biobanks with low resources (Hainaut et al., 2017, p. 189). This enables large collections, typically comprising samples even from several decades. In addition to FFPE blocks, the need for fresh-frozen tissue samples have increased (Asslaber & Zatloukal, 2007; Mackenzie, 2014) and they are typically used for biomarker studies and genomic profiling to understand the molecular basis of diseases (Mackenzie, 2014).

2.6 Biobank sustainability

One of the biggest challenges for biobanking is long-term sustainability (Harris et al., 2012). The focus of biobanking has evolved through years from the collection size -based focus in the early days to biospecimen quality -centered thinking, and eventually, to customer-focused and evidence-based orientation. The latest stage will allow biobank sustainability in a long run (Simeon-Dubach & Watson, 2014). However, the planning of sustainability models for biobanks is challenging, even controversial, as the main products are human-derived samples and thus not commercial commodities (Ciaburri et al., 2016). Other challenges in modeling

biobank sustainability arise from the diversity of biobanks and their purposes, as well as from the lack of universally approved value metrics for the biobank stakeholders, such as funders (Watson et al., 2014). The term sustainable is commonly referred to self-sustainability, but biobanks are rarely self-sustaining as they widely rely on external funding (Chalmers et al., 2016; Watson et al., 2014). Therefore, Watson et al. (2014) have formed a framework for biobank sustainability, consisting of three dimensions: financial, operational, and social sustainability (figure 6). This framework is presented next and intrinsically sums up this literature review.

The financial dimension of the Watson's model is analogous to economy and focused on identifying stakeholders' needs and creating value for them, communicating the value of investment in biobank to all stakeholders, and developing and maintaining strategic plans (Watson et al., 2014). Marketing is a crucial point in communicating the value to the customers. Generally, marketing is considered as a set of actions aiming to build a relationship with the existing and new customers (Ciaburri et al., 2016; Kotler & Keller, 2016). Marketing strategies, in turn, include the approaches to be implemented in order to inform the stakeholders and to advertise the activities offered by a biobank (Ciaburri et al., 2016). Marketing strategies may increase the sustainability of a biobank as they possibly, and preferably, lead to better funding. However, applying commercial marketing strategies into biobanking might lead biobanks to reach better and better results to fulfill the metrics for funding, and at the same time, lose the focus from their initial reason of existence: providing public benefit and better health (Chalmers et al., 2016). Consequently, this may have a negative impact on public trust. Therefore, in this study, the marketing strategy presented in the chapter 4.1 *Marketing strategy* is focused on the actions to be made to reach the customers, not to the financial aspect.

Operational dimension in the Watson's model is analogous to environment and relates to efficiency of biobank in terms of input, internal, and output components. Input efficiency refers to activities like optimizing the process of obtaining donor consent and using common, standardized obtaining mechanisms for biospecimens. Internal efficiency can be achieved, for example, by optimizing the processing of biospecimens and retaining relevant stock for possible retrospective questions. Output efficiency may be improved by enhancing response time to requests and offering more products and services. (Watson et al., 2014)

The standardization frameworks introduced above, such as SPREC, BRISQ and MIABIS, as well as SOPs, are efficient tools to enhance operational sustainability of biobanking. However, they are important also for social dimension, which includes the aspects of acceptability and obeying good, standardized practices. The acceptability refers to the

ethicalness and transparency around the biobanking operations to promote trust towards these activities among the donors and other stakeholders. The commitment to accepted standards in biobanking practice promotes the high quality of biospecimen and enables value measuring. (Watson et al., 2014) In addition to the internationally accepted biobank standards, the national laws, authorities and ethical committees are essential when building the social dimension of biobank sustainability.

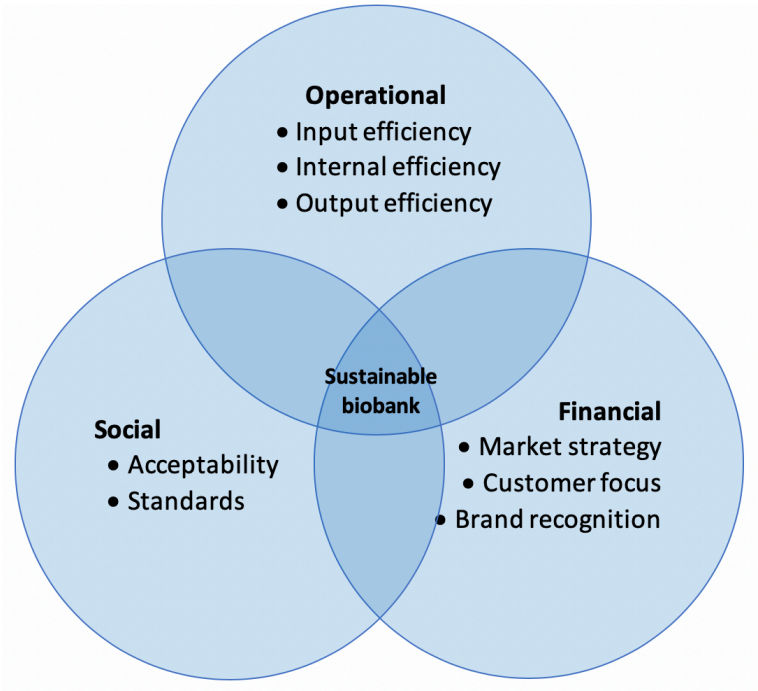

Figure 6 Three dimensions of biobank sustainability, according to Watson et al (2014).

3 Objectives

This study focuses on the Finnish biobank operations in national and local levels and academic researchers' biobank awareness. The aim is to find out how the local and national biobank services should be developed. The study is divided into two parts:

1. Local part targeted to academic researchers, focused on local biobank services and improvement of biobank awareness.
2. National part targeted to pharmaceutical companies, focused on national biobank services.

The local part focuses on the operations of FCBT. The operations are still new and expected to be unknown among local academic researchers. This study aims to improve the visibility of FCBT and the researchers' biobank awareness to increase the cooperation between researchers and the biobank. This, in turn, is expected to increase the number of sample and data releases from FCBT and thus enable efficient usage of the materials. Researchers' needs concerning to biobanks services are explored to enable optimal service development in the future.

The national part of this study is conducted in cooperation with FINBB and targeted to pharmaceutical companies participating in the FinnGen project. This part is focused on the national biobank services offered by FINBB. The needs and expectations concerning these services are explored among the pharmaceutical companies. Finding out these needs will help FINBB to develop their services.

The objectives of the study are the following:

The local part of the study

1. Investigate the level of biobank awareness among academic researchers and explore their expectations and needs concerning biobank operations.
2. Create a researcher-targeted marketing strategy and marketing material for FCBT in a form easily applicable in other hospital biobanks as well.
3. Increase biobank awareness among academic researchers in Tampere.
4. Analyse the factors affecting the biobank awareness by using statistical analyses.

The national part of the study

5. Explore the needs and expectations related to national biobank services among pharmaceutical companies.

The literature review

6. Provide FCBT with tools for service development by investigating and comparing national and international biobank procedures.

4 Materials and Methods

4.1 Marketing strategy

One of the aims of this study is to build a marketing strategy for FCBT. Marketing strategy defines the methods planned to be used to inform the stakeholders of the activities and products provided by the firm, in this case the biobank, with the aim of creating value to the customer (Ciaburri et al., 2016). Before building a marketing strategy, a market analysis is needed to identify the customers, to understand their needs, and to indicate the best channels to reach them. In this study, the market analysis was implemented with questionnaires targeted to researchers (introduced later). A widely used model for marketing strategy, Segmentation–Targeting–Positioning (STP) process, is used here as a baseline for the marketing strategy.

4.1.1 Segmentation–Targeting–Positioning – The STP model

The elements of the STP process include segmentation, targeting and positioning (figure 7). Segmentation defines which kinds of customers exist, targeting describes which customer segments are the most attractive ones and thus selected as target segments, and finally, positioning refers to the process of optimizing the products and services for the selected segment(s). Positioning aims to create a competitive advantage and to communicate it to locate the business into customers' minds. The positioning stage also defines the desired state of the business at the market. (Kotler & Keller, 2016; Lilien, Rangaswamy, & De Bruyn, 2013; Whalley, 2010)

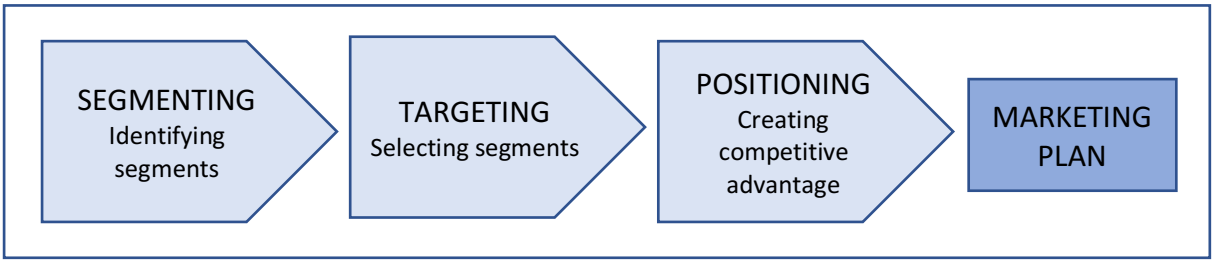

Figure 7 STP process. (Modified from Lilien et al., 2013)

4.1.2 The STP model and FCBT

Now the STP process is used as a model for building a marketing strategy for FCBT.

Segmenting: Customer segments of a biobank, here FCBT, include academic researchers, pharmaceutical and biotech companies, and public and private healthcare. These segments are the customers who use the biobank services. Another side of biobank operation is the collection of samples. Therefore, patients and other donors can be considered as customers, too. From the biobank's point of view, the donor's role as a customer is completely different from the service user's role. They are not the end-users of biobank services, but rather the initial material providers. However, marketing needs to be targeted to potential donors as well to raise their awareness and trust towards biobank operations, and eventually, to acquire a comprehensive sample collection.

Targeting: To achieve the aims of this thesis, that is, to raise the biobank awareness among academic researchers, the target segment obviously is academic researchers. Above this thesis project, other segments are interesting targets as well, but at this stage where FCBT's operations are still relatively new, the primary aim for FCBT is to raise their visibility among local academic researchers. This segment is the key target as the primary focus of FCBT's research projects follows the research strategy of Tampere University and Tampere University Hospital, and Tampere University is one of the funders of FCBT (www.tays.fi/biopankki, 12.7.2019). Therefore, the operations of FCBT are primarily planned to serve local researchers. Furthermore, a close collaboration with local academic researchers is easy to implement and would mutually benefit both FCBT and the researchers.

Positioning: As described in *targeting*, FCBT's products and services are already planned to serve local academic researchers. To optimize them even further, the researchers' needs regarding to biobank services and sample/data collection must be investigated. Here, it was done by sending an online questionnaire to local academic researchers asking about this aspect. The same questionnaire was used to find out what channels are preferred by researchers to obtain information about biobank. This information helps in planning the best marketing channels. Here, three different marketing methods were tested: face-to-face marketing, email marketing, and an information leaflet (described more closely in the next chapter). A control questionnaire was sent to researchers to test the effect of these marketing methods. This helped in finding the most effective marketing methods and channels, and therefore, enabled giving guidelines for FCBT's future marketing.

These approaches aimed to develop the offerings of FCBT to answer to the needs of the key segment, local academic researchers, and to communicate the possibilities to this

segment in a best possible manner. Eventually, this is hoped to increase the collaboration of FCBT and academic researchers so that the use of biobank services would become a natural part of academic research.

4.2 Local study targeted to academic researchers

4.2.1 Questionnaires

The aims of the study were to find out 1) how familiar the academic researchers of Tampere University and Tampere University Hospital (Tays) are with the operations of FCBT and 2) what their expectations and needs are concerning biobank operations. These aspects were examined with two online questionnaires (appendices 1 and 2), implemented with E-lomake platform (version 3, Eduix Oy). The first one of them measured the initial level of researchers' biobank awareness and the second one was a control questionnaire that measured the possible change in biobank awareness.

The first questionnaire was sent in the autumn 2018 to the group leaders of the research groups in the Faculty of Medicine and Health Technology at Tampere University and Tays (n = 92). The group leaders were asked to share the questionnaire to their research groups. However, this objective did not work well, and sharing was ineffective. Therefore, other channels were used as well. These additional channels were the Tays Twitter account, and the Facebook group of the biotechnology student association involving several current and former students working in research groups in Tampere. Eventually, 33 answers returned from this questionnaire.

The second questionnaire was sent six months after the first one. During these six months, different marketing methods (introduced shortly) were taken into action. This questionnaire worked as a control questionnaire to test the effect of marketing. This time, the questionnaire form was shared via the email list of all the employees in the Faculty of Medicine and Health Technology, since the earlier sharing via group leaders was not as effective as hoped. In addition to this, also the above-mentioned Facebook group was used again to reach an equivalent answerer group in relation to the first questionnaire. This questionnaire gained 37 answers. To encourage researchers to participate on the both rounds, movie tickets were raffled between those who answered to the both questionnaires.

4.2.2 Reference groups for marketing

After collecting the answers, the answerers were divided into three reference groups to test different marketing methods. Obviously, it was impossible to reach all of the answerers in these reference groups again on the second questionnaire round to compare the whole reference groups. However, the grouping ensured that there were differences in the marketing methods that answerers on the second questionnaire round had encountered.

The first group experienced face-to-face marketing, that is, a presentation given in a research group meeting. The second group received an information package (appendix 3) sent by email, and the third group was a control group for which no targeted marketing was directed. They might only see the leaflets (appendix 4) shared around the university building, telling about the services of FCBT directed to researchers. The grouping was made partially according to the answers given in the questionnaire. The first group was formed of the six answerers hoping to be contacted to settle a meeting for a biobank presentation. Meetings were arranged with their research groups. The group members of these groups were also asked to answer to the questionnaire before the meeting, and these answerers formed the first group of 12 answerers together with the original six answerers. Email marketing was sent to six answerers that choose personal contact as one of the information channels where they would like to receive more information about biobank operations (appendix 1, question 3). The other five email receivers were selected randomly from those who had given their email addresses and were not involved in the first group. The third group was formed of the remaining 10 answerers. The groups and the background of answerers in them are presented in the table 4.

Table 4 Reference groups for marketing.

Background		**Group 1, presentation**	**Group 2, email**	**Group 3, no targeted marketing**
		n = 12	**n = 11**	**n = 10**
Primary site of work	**Kauppi**	33 %	64 %	60 %
	Hervanta	58 %	27 %	40 %
	Tays	8 %	0 %	0 %
	Other	0 %	9 %	0%
	Total	100 %	100 %	100 %
Role	**Group leader**	17 %	46 %	20 %
	Researcher	8 %	0 %	0 %
	Postdoc	8 %	0 %	0 %
	Doctoral student	50 %	18 %	30 %
	Assistant/ trainee/student	8 %	36 %	50 %
	Other	8 %	0 %	0 %
	Total	100 %	100 %	100 %

4.2.3 Marketing methods

Three different marketing methods were tested. The reference group 1 was given a biobank presentation at their own research group meetings. The presentation defined the main aspects of biobanking in general and biobank operations in Finland, but the main focus of it, however, was in the operations of FCBT and its sample collection. Presentations were given by myself and my supervisors, quality coordinator Johanna Mäkelä and/or director Kimmo Savinainen from FCBT. A great part of all the six, approximately one-hour-meetings was left for general discussion and questions, which enabled the researchers to get all the relevant information they needed. It should be noted, that the presentations were seen by much more people than the actual number of answerers in this reference group, since the audience of each meeting ranged from three to approximately thirty people, including research group leaders and researchers at varying stage of their careers. One presentation was given for the doctors of the Tays Cancer Center.

The email marketing was implemented by sending an information package to the participants in the reference group 2. This set of information was planned to give all the relevant information a researcher would need to become interested in using FCBT's samples, data, and services in their research. The email included the description of FCBT's sample collection, what researchers need to do to access it, and how they would benefit from using the biobank samples and data (appendix 3).

The group 3 did not receive any targeted marketing, but they might have encountered general marketing in the form of leaflets. The leaflet was planned as a part of this study and targeted especially for researchers (appendix 4). Approximately one hundred copies of it were shared around two campuses of Tampere University (Kauppi and Hervanta).

Also, an additional method for sharing biobank information was implemented during this study, although not officially as a part of this study. That was a biobank seminar organized on the April 12, 2019 at the shared campus (Kauppi) of Tampere University and Tampere University Hospital. The seminar was targeted to clinicians, researchers, and students interested in research and involved speakers from the top of Finnish biobanking, the FinnGen project, a pharmaceutical company collaborating with biobanks, and research groups conducting biobank-related studies. To see the effect of this kind of an event for biobank awareness and visibility, this seminar was taken into account in the second questionnaire when asking what kind of marketing or share of information the answerers had encountered. Another additional marketing method was a roll-up exhibition at the researcher- and student-targeted seminar organized by SPARK Finland in December 2018 at Kauppi Campus.

4.2.4 Statistical analyses

The results of the two questionnaires were analyzed by using SPSS Statistics program (IBM, version 25, 64-bit edition). The small N in the questionnaires limited the analysis methods that were possible to use. Therefore, mainly descriptive statistics and nonparametric tests were used to avoid the requirements for assumptions of normality and large sample size.

It was necessary to test what kind of effects the implemented marketing had between the two questionnaire rounds. The samples were not related between the rounds as a partly different researcher group participated in the first round than in the second round. However, the samples were not completely independent either, as twelve researchers answered on the both rounds. Still, the samples of the first and second questionnaire rounds were thought here as random samples of researchers at a given time point. Therefore, the differences explored between the two questionnaires were thought as the differences in the random researchers' answers between the timepoints before and after implemented marketing. The twelve researchers who answered on the both rounds were counted in these comparisons as a part of the random researcher groups, but later they were handled also separately as related samples between the questionnaires.

The statistical significance of arisen differences was explored with Mann-Whitney U test for several studied aspects. This test is used in testing the statistical significance of the difference between independent samples. It is a nonparametric counterpart to Student's T-test. Mann-Whitney test also works better for samples with opinion scale and was therefore suitable to compare, for example, how the researchers' own perceptions of biobank awareness changed between the questionnaires and how the opinions about the sample and data collection and quality differed between the questionnaires. Mann-Whitney U test was used also to test the significance of differences in the channels in which researchers had encountered FCBT, the channels they would like to get more biobank information, and the number of researchers that had used the samples or services from FCBT.

The comparison of medians, the median test, was used to compare the results in perceived biobank awareness between the two questionnaires. Two factors were used to measure this; opinions about the sufficiency of received biobank information and the visibility of FCBT. Median is here a better statistic for comparison than mean, as the questions had opinion scales for which it is not sensible to count means. The five-point Likert-scale was converted into 1 – 5 scale, and the medians of given grades was used to depict the differences that the marketing possibly caused to these factors of biobank awareness. Medians were also used to depict the changes in of the twice-answered researchers' biobank awareness.

Another way to see how the marketing had worked was to explore the correlations of different marketing methods to the development of the factors of biobank awareness. For the data derived from the questions with opinion scales, the Spearman rank-order correlation was the best choice. It is a nonparametric test that can be used for ordinal data and is thus suitable for the data in question. It defines the strength and direction of the association between two variables. Furthermore, crosstabulation and Fisher's exact test were used to test the statistical significance of the effect of each marketing method to a given factor of biobank awareness. To avoid too small values in single crosstabulation cells and to simplify the analysis, the answers were grouped by transferring the five-point Likert-scale (*Strongly disagree – Strongly agree*) into three-point scale (1 = *Strongly disagree / Disagree*, 2 = *Neither agree nor disagree*, 3 = *Agree / Strongly Agree*). The *Do not know* answers were not included in the calculation. Fisher's test was chosen instead of chi-square test as the expected values of several cells were < 5 and the sample size was so small.

As mentioned above, twelve researchers participated in the both questionnaire rounds and formed a group of relative samples between the rounds. The answerers were asked to give their date of birth to enable the identification between the two questionnaire rounds. Therefore, it was possible to form related groups from these two questionnaires and compare the results between them. For example, the effect of marketing was tested by using Wilcoxon signed-rank test. This test was chosen because it does not assume the normal distribution and is suitable for small sample size unlike its parametric counterpart paired sample T-test. Wilcoxon test can be used to define the difference in the distribution of populations where the dependent samples have been selected. Therefore, it was applicable for testing the effect of each marketing method.

The comparison for related samples that had binomial variables (two possible outcomes) was conducted with McNemar test. It is suitable for related nominal data, in this case yes/no answers to the question asking if researchers had encountered FCBT on a given university campus or not. This information was connected to the primary workplaces of the twice-answered researchers to see if the campus visibility had changed significantly because of marketing.

4.3 National study targeted to pharmaceutical companies

The national and company-targeted study aimed to find out the needs and expectations for national-level biobank services among pharmaceutical companies. An online questionnaire (appendix 5), implemented with E-lomake platform (version 3, Eduix Oy), was sent in April 2019 to nine pharmaceutical companies participating in the FinnGen project. This target group was chosen because FINBB, the collaborating partner of this study, already had contacts in these companies from the FinnGen-related co-operation. Furthermore, these nine companies, AbbVie, AstraZeneca, Biogen, Celgene, Genentech (a part of the Roche Group), GSK, MSD, Pfizer, and Sanofi, have significant roles in the pharmaceutical industry both internationally and in Finland and therefore, are excellent examples of biobank users in the industrial field.

The focus of the questionnaire sent to these pharmaceutical companies was on the national biobank services. The questions were partially similar with the questions used in a questionnaire sent to the headquarters of the above-mentioned companies whose Finnish departments are participating in the FinnGen project. This enabled the comparison between global and national results and lead to maximum benefit for FINBB. However, the global questionnaire is not a part of this thesis. Additionally, questions related to sample and data use were added to be able to compare the results of this national questionnaire targeted to companies with the results of the local questionnaire targeted to academic researchers.

The original idea was that in every company, as many people working with biobanks studies as possible would give their answers. Answers from the people working in different roles, such as in leading positions and in laboratory work would have given interesting viewpoints to needs regarding to biobank services. In reality, this was too much to ask, and companies hoped that only one representative from a company could give an answer on behalf of a whole company. This was agreed.

The results of the company questionnaire were presented to the participating companies and FCBT, Helsinki Biobank, and THL Biobank in a meeting organized with FINBB in June 2019 in Helsinki. The purpose of this meeting was to discuss further about the topics arisen in this questionnaire as biobanks, FINBB, and pharmaceutical companies were present at the same time.

5 Results

5.1 Local study targeted to academic researchers

5.1.1 Background information

The survey consisted of two rounds of questionnaires: the first one was implemented in the autumn 2018 and the control questionnaire was sent in the spring 2019. The first round resulted in 33 answers and the second round 37 answers. The answerer profiles, that is, the relative proportions of the answerers' primary sites of work, their current roles at the time of answering and the areas of research are described in table 5.

Table 5 Answerer profiles. All the answerers did not tell their site of work in the spring 2019 and areas of research on either round.

Primary site of work	**Autumn 2018 (n = 33)**	**Spring 2019 (n = 37)**
Kauppi	52 %	76 %
Hervanta	42 %	22 %
Tays	3 %	0 %
Other	3 %	0 %
Total	100 %	98 %
Role		
Assistant / Trainee / Student	30 %	8 %
Doctoral student	33 %	32 %
Postdoc	3 %	19 %
Researcher	3 %	19 %
Group leader	27 %	14 %
Other	3 %	8 %
Total	100 %	100 %
Area of research		
Cancer-related	15 %	24 %
Cell technology / Tissue engineering	27 %	19 %
Biomedical signals (neuronal)	3 %	5 %
Ophthalmology	0 %	3 %
Vaccinology	6 %	3 %
Bioimage analysis	3 %	3 %
Bioinformatics	9 %	0 %
Total	64 %	57 %

5.1.2 The visibility of FCBT and biobank awareness

The initial level of academic researchers' biobank awareness and their preferences for receiving biobank information were explored by four questions in the first questionnaire (appendix 1, questions 1–4). These same questions were asked on the second round as well to investigate the effect of marketing (appendix 2, questions 1, 2A, 3, 4). Two questions (appendix 2, questions 2B & 2C) were added to explore what marketing methods, if any, the answerers had encountered between the two questionnaires. Answerers had also a possibility to give feedback about the marketing.

Figure 8 shows that majority of answerers had heard about FCBT during the last three years, that is, after the establishment of the biobank in 2015, and more than one year ago. Only 12 % of the answerers on the first round had never heard of it, and that proportion decreased to 8 % until the second round. There was also a difference of eight percentage points in the proportion of researchers that had heard of FCBT during the last six months (from 6 % to 14 %). The ones that answered in the second questionnaire that they had first heard about FCBT during the last six months, probably encountered it via marketing related to this study. Additionally, the growth in this *Last six months* section might have caused the decrease in the *Never* section as the marketing reached researchers who had never heard of FCBT before. However, it should be noted that partly different group of researchers participated on the first questionnaire round compared to the second round, which might cause some misleading variation in the results.

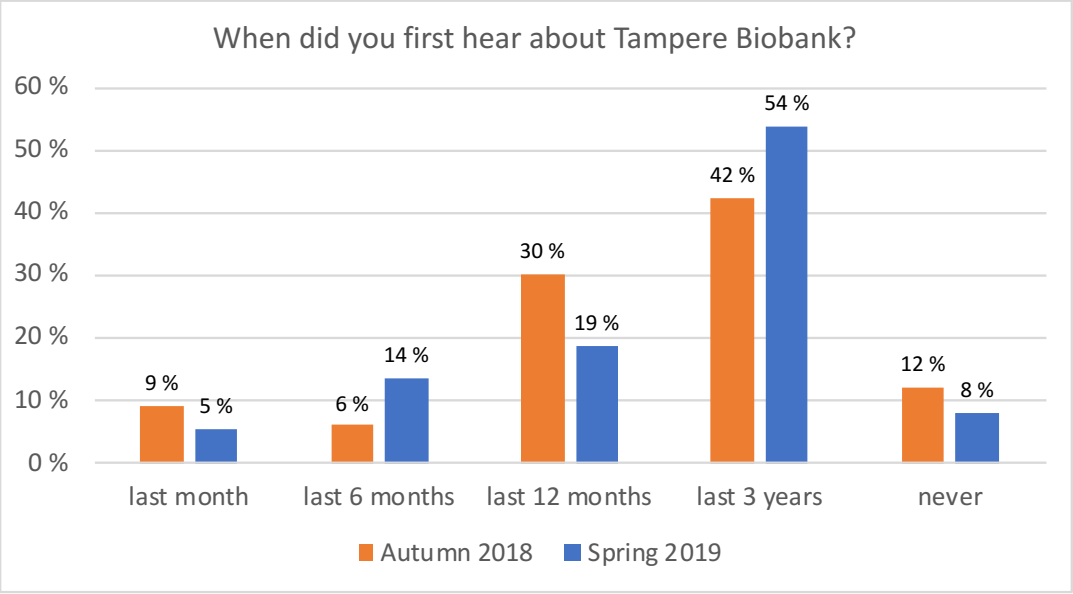

Figure 8 The time of first hearing about FCBT.

Figure 9 depicts the channels and places where academic researchers have encountered FCBT (appendix 1, question 2; appendix 2, question 2A). The word of mouth and Tampere University's Kauppi campus were the most common channels for academic researchers to encounter FCBT on both questionnaire rounds (52 % and 59 % of the answerers, respectively). Also, more than half of the answerers on the first round said to have seen FCBT at the Kauppi campus, where majority of the participating researchers primarily then worked (table 5). The visibility at the Kauppi campus increased in the second questionnaire as 68 % of the answerers had seen FCBT there. However, also the proportion of researchers working primarily at Kauppi campus increased from 52 % to 76 % between the two questionnaires, so marketing was not the only factor growing the perceived campus visibility. On the other hand, visibility at Hervanta campus increased from 12 % to 19 % between the two questionnaires although the proportion of researchers working there was lower in the second questionnaire (22 %) compared to the first round (42 %).

The other channels were more or less web based. Figure 9 shows that the proportion of the answerers who had visited on the FCBT's own website increased notably between the questionnaires. This was the most remarkable difference between the questionnaire by looking at the p-values. Additionally, BBMRI.fi, FINBB, and medical journal were mentioned only in the spring questionnaire.

The significances of differences between the first and second questionnaires were calculated with Mann-Whitney U test, and the p-values are presented in the figure 9. Despite the positive results in the visibility in several channels, none of the changes was statistically significant on a significance level 0,05.

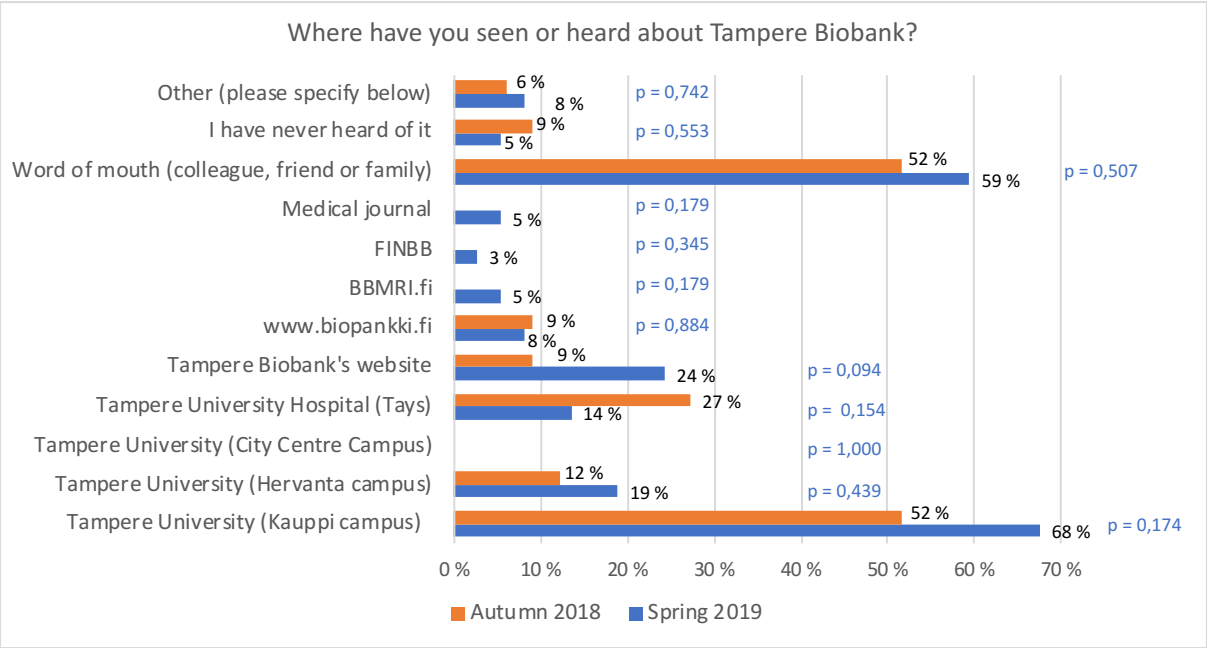

Figure 9 Places and channels to encounter FCBT. P-values (calculated with Mann-Whitney U test) refer to the statistical significance of the change between the two questionnaires. On the significance level 0,05, none of the changes was statistically significant.

To see how the visibility changed on these two university campuses without the effect of different answerer profiles of the two questionnaires, it is possible to look at the group of twelve answerers who answered on the both rounds of the survey. As the answerers were the same individuals on both rounds, the actual change can be seen. The table 6 shows how the encountered campus visibility changed among these twelve answerers from the first until the second questionnaire. Also, the p-values for the changes are given. The visibility in both campuses increased by 33 percentage points and the exact 2-sided p-values from McNemar test were 0,125 for both changes. Therefore, the visibility increased equally in both campuses, but the change was not statistically significant on a 0,05-significance level.

Table 6 The campus visibility encountered by the group of 12 answerers who answered on the both questionnaire rounds.

	n	Seen FCBT at the campus		Primary site of work	
		Kauppi	Hervanta	Kauppi	Hervanta
Autumn 2018	12	42 % (5)	0 % (0)	75 % (9)	25 % (3)
Spring 2019	12	75 % (9)	33 % (4)		
p-values for change (McNemar test)		0,125	0,125		

On the second round of the questionnaire, in the spring 2019, researchers were asked what marketing or share of information they had encountered during the last six months, that is, between the two questionnaires (figure 10). Almost half of the answerers (49 %; n_{total} = 37) told that they had seen the leaflets made for this study (appendix 4). The second most common answer was a biobank presentation at a group meeting; 30 % of the answerers had seen our presentation, although we gave only six presentations. 14 %, that is, five persons, of the answerers on the second questionnaire round said to have received an information package sent by email. Similarly, 14 % of the answerers had attended to the Biobank Seminar in April. As discussed in the chapter *4.2.3 Marketing methods*, the seminar was not officially a part of this study but was taken into this questionnaire to see the effect of such a seminar. Three answerers (8 %) mentioned that they had seen other marketing as well. These answers included Tays screens, a booth on the corridor at Kauppi campus [at the event organized by SPARK Finland], and a word of mouth form a colleague. 30 % of the answerers had not seen marketing at all.

The next question about the researchers' preferred ways to get more information related to biobank operations (appendices 1 & 2, question 3) gained quite similar results on both rounds (p-values for differences 0,382 – 1,000, calculated with Mann-Whitney U test), and the popularity order of the options remained the same (figure 11). Therefore, it is not sensible to investigate closer the differences between the questionnaires. Instead, the means of the percentages on both questionnaire rounds are shown in the figure 11 to illustrate the overall popularity of different options. For academic researchers, the most important channel to receive biobank information is biobank's own website targeted to researchers. Another option that stands out from the results is education and science events with 60 % of interested answerers, whereas the events organized by biobanks gained notably less interest (38 %). Internal communication in researchers' own organization and personal contacts were the least popular options.

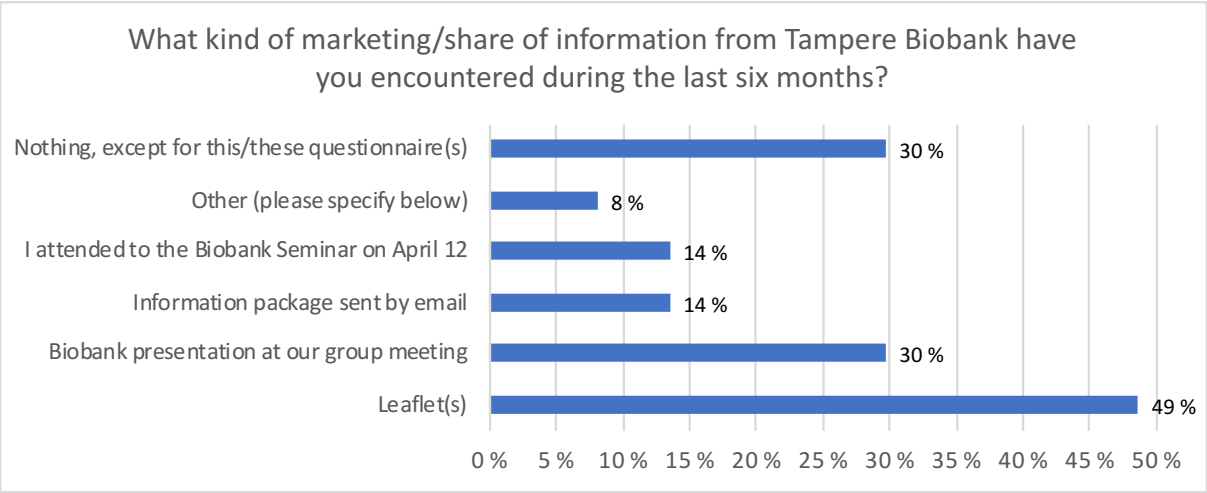

Figure 10 Encountered marketing. This question was asked only on the second questionnaire round after testing different marketing methods.

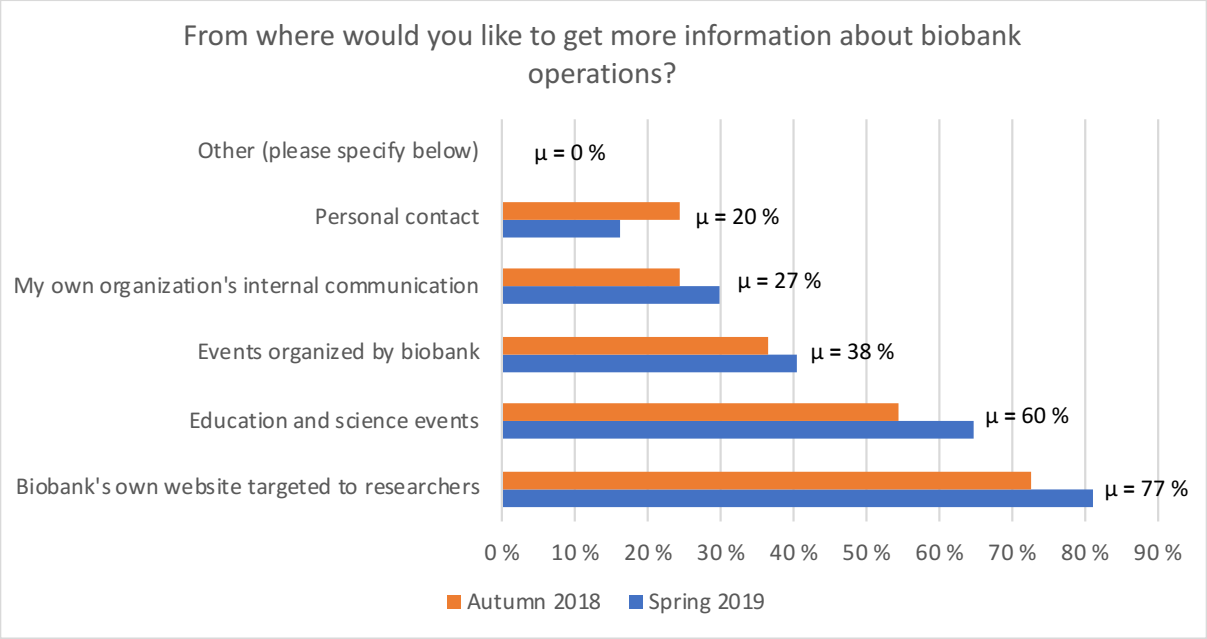

Figure 11 The most popular ways to obtain biobank information. The means (μ) of the percentages on both questionnaire rounds are shown.

The question pair about the sufficiency of received information and the visibility of FCBT (appendices 1 & 2, question 4) describes best the level of researchers' biobank awareness before and after the implemented marketing. The researchers were asked if they have received enough information about FCBT and if the visibility of FCBT is good enough in their opinion. Both parts of this pair of questions had a five-point Likert scale with options *Strongly disagree – Disagree – Neither agree nor disagree – Agree – Strongly agree (*and *Do not know)*.

Figure 12 shows what the researchers thought of the amount of the information they had received concerning FCBT. The positive effect of the marketing can be seen from these results, as the number of answerers strongly disagreeing and disagreeing to have received enough information have reduced from the first until the second questionnaire. Moreover, the number of answerers agreeing and strongly agreeing have increased, as well as the neutral opinions. Consequently, researchers felt that they have received enough information about FCBT more likely in the spring after marketing than they did in the autumn. The difference is statistically significant (p = 0,007, calculated with two-tailed Mann-Withney U test). The median of the questionnaire answers (transferred to 1 – 5 scale) also differed between the questionnaires. It changed from 2 to 3 but the difference in the medians was not statistically significant (p = 0,161) (figure 13).

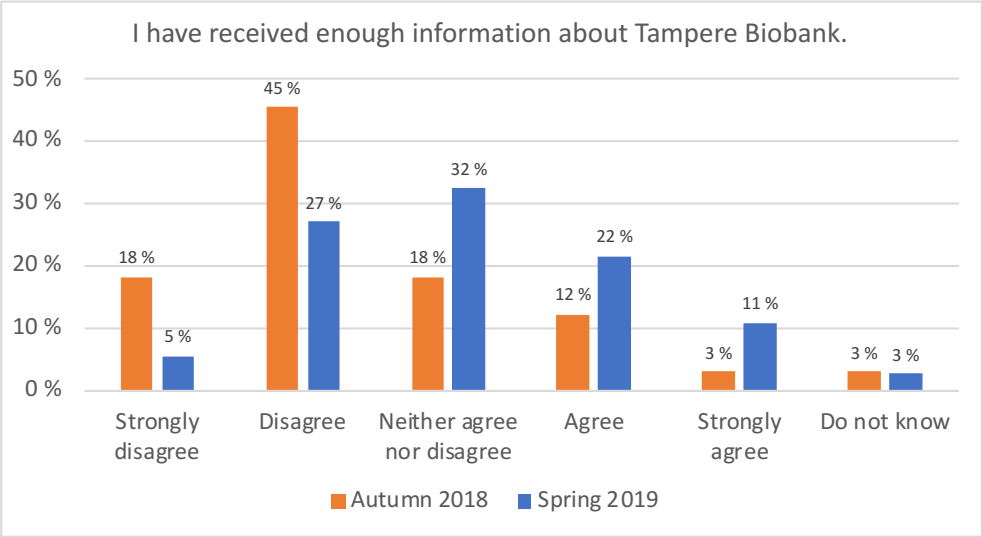

Figure 12 Answers to the argument "I have received enough information about Tampere Biobank" from the both questionnaire rounds.

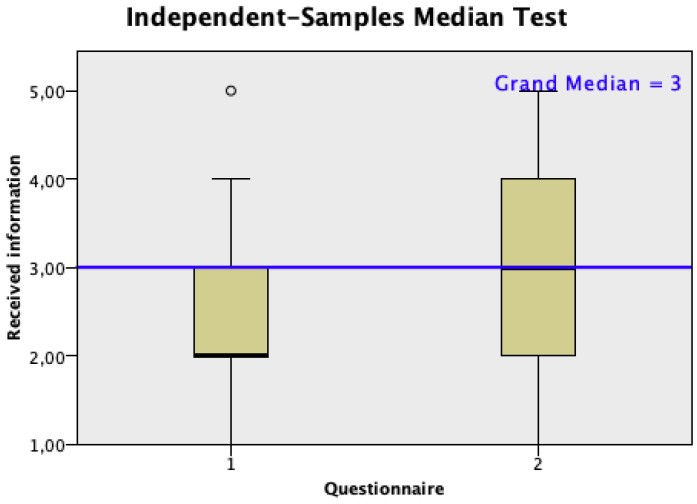

Figure 13 Medians for the "received information". 1 = Strongly disagree ... 5 = Strongly agree.

To see how the tested marketing methods affected to the experienced sufficiency of received information, the answers of encountered marketing and the answers of the argument about received information (from the second questionnaire) were applied into one graph (figure 14). In figure 14, the different colors represent the level of agreement and the bars represent different marketing methods; the greener the bar, the better the marketing method worked in sharing information. This figure shows that the presentations at group meetings led to the best results when it comes to the researchers' experience of receiving enough information about FCBT. The second most successful marketing method in sharing information was the information a package sent by email as 40 % of those who received the email agreed to have received enough information. However, there were only five answerers in this group and the rest 60 % neither agreed nor disagreed. Both the leaflet and the biobank seminar led to answers of strong agreement (22 % and 20 %, respectively), but they also received *Disagree* answers (44 % and 40 %, respectively). The answerers that had not encountered any marketing were the only group giving *Strongly disagree* answers, which also tells that all marketing methods had at least some effect to the experienced sufficiency of received information.

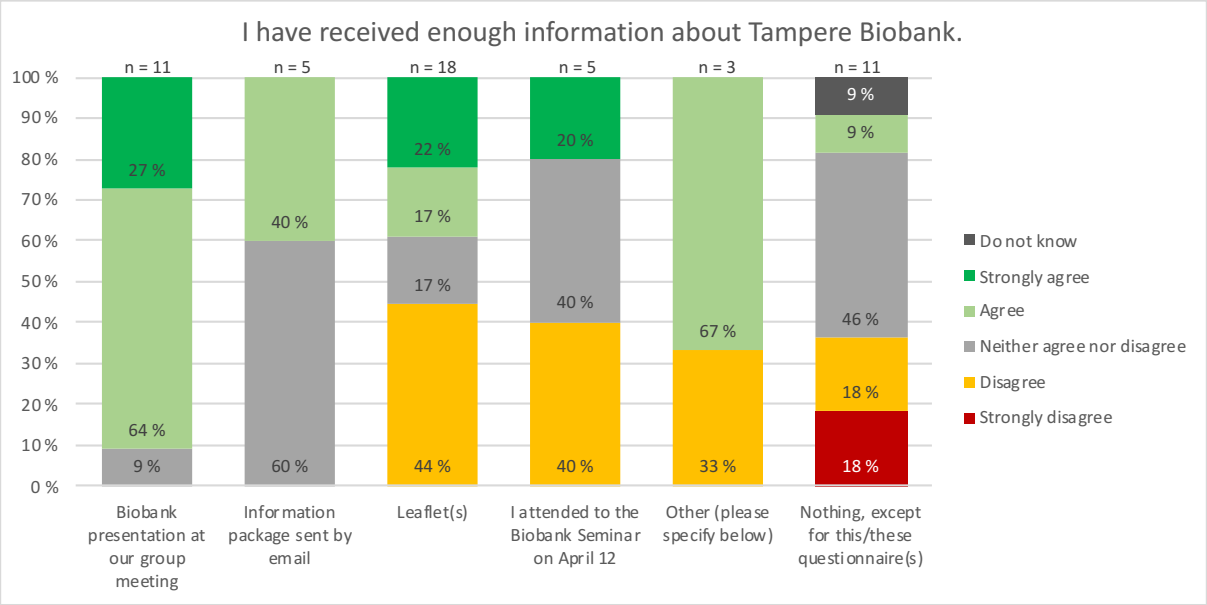

Figure 14 The effect of encountered marketing on the sufficiency of received information. One answerer might be counted into more than one marketing method group.

Figure 15 shows the distribution of the answers to the argument "The visibility of Tampere Biobank is good enough" and how it differed between the two questionnaire rounds. The main results referring to the improvement of the visibility of FCBT among academic researchers are that the *Strongly disagree* answers reduced from 15 % to 3 % and the *Agree* answers increased from 3 % to 16 %. The improvement in visibility is statistically significant on a 0,05-significance level (p = 0,023, calculated with two-tailed Mann-Whitney U test). When comparing the medians of the answers of both questionnaires (on 1–5 scale), the median was 2 (*Disagree*) in both questionnaires, and the difference in the medians was not statistically significant (p = 0,184) (figure 16).

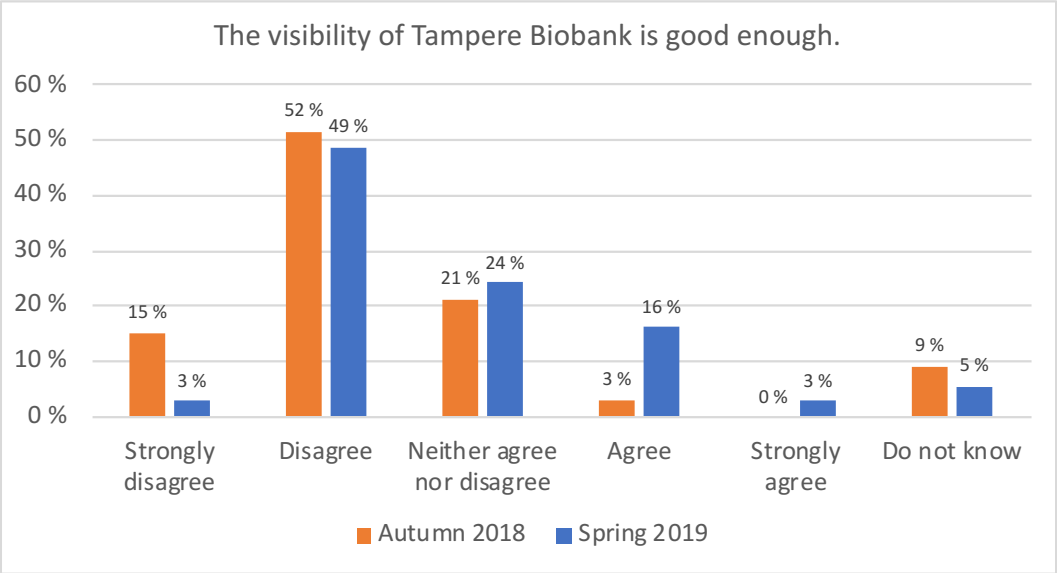

Figure 15 Answers to the argument "The visibility of Tampere Biobank is good enough" from the both questionnaire rounds.

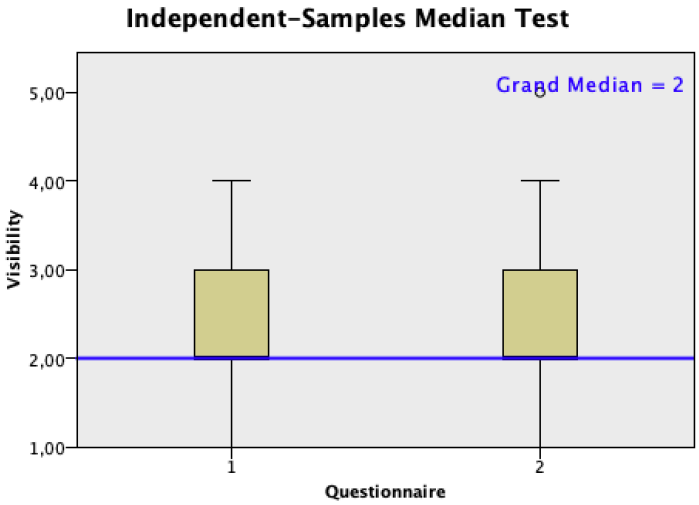

Figure 16 Medians for the argument about visibility. 1 = Strongly disagree ... 5 = Strongly agree.

Again, the connection between different marketing methods and the experienced visibility of FCBT are presented in a graph combining these answers (figure 17). The presentation shows up with the greenest bar once again with 55 % of the answerers strongly agreeing or agreeing that the visibility of FCBT is good enough. The bar for the marketing method "other" is even greener with 33 % of strongly agreeing and 33 % of agreeing answerers. However, there were only three answerers in this group. Leaflets gained also a couple of *Strongly agree* answers, but otherwise the differences between marketing methods were minor, and most of the researchers still think that the visibility of FCBT is not good enough.

The effect of each marketing method was explored by using Fisher's exact test. The p-values of this test are presented in table 7. On a significance level 0,05, only the effect of presentation was statistically significant for the perceived sufficiency of received information (p = 0,000) as well as for the visibility of FCBT (p = 0,001). Other methods gave no statistically significant results.

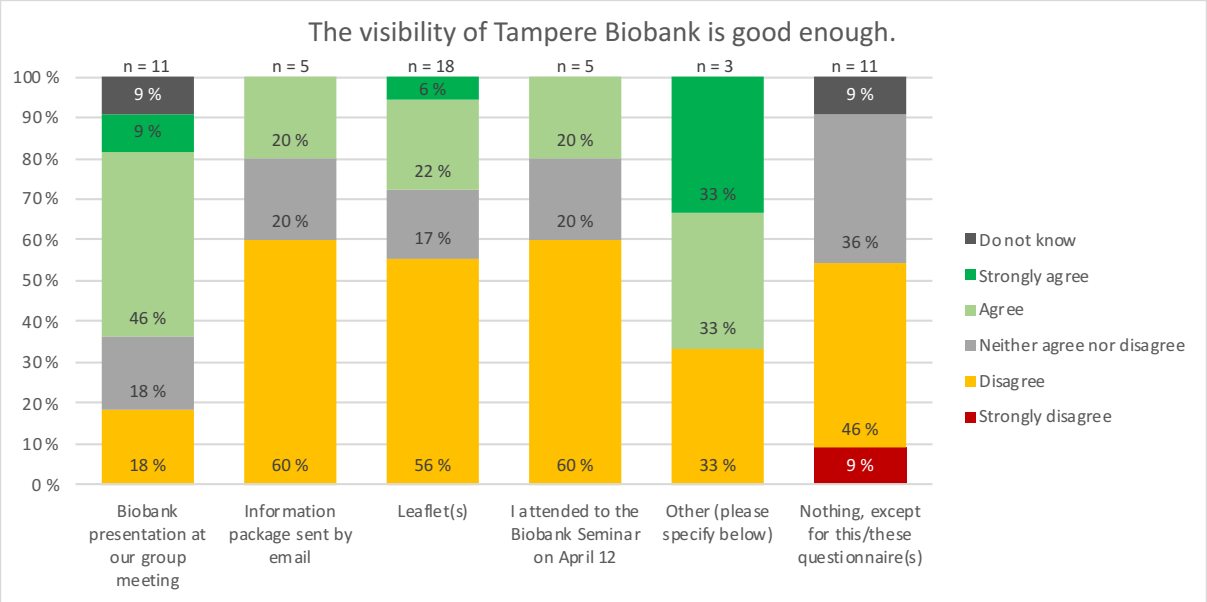

Figure 17 The effect of encountered marketing on the visibility of FCBT. One answerer might be counted into more than one marketing method group.

Table 7 P-values for the significance of the effect of each marketing method for received information and visibility. Calculated with Fisher's exact test.

	Presentation	Email	Leaflet	Seminar	Other	Nothing
Received information	**0,000**	0,332	0,175	1,000	0,758	0,255
Visibility	**0,001**	1,000	0,357	1,000	0,147	0,150

Additionally, the Spearman's correlations were calculated for the answers of the arguments about received information and visibility (changed to grades 1–5, from *Strongly disagree* to *Strongly agree*, respectively) and different marketing methods. The correlation coefficients and their p-values are presented in table 8. Again, only the presentations given in research group meetings gave a statistically significant positive correlation with the experienced sufficiency of received information (correlation coefficient 0,739 and p = 0,000) as well as with the visibility of FCBT (0,555 and p = 0,001).

Researchers had a possibility to give feedback on the marketing methods they had encountered. The feedback for each method is presented in table 9. All the methods except for email received some feedback. The feedback was mostly positive for every method.

Table 8 Spearman's correlations for marketing methods and the experienced sufficiency of received information and the visibility of FCBT in the spring 2019.

		Presentation	**Email**	**Leaflet**	**Seminar**	**Other**	**Nothing**
Received information	Correlation coefficient	**0,739**	0,197	-0,068	-0,098	0,123	-0,228
	p-value	**0,000**	0,389	0,841	0,775	0,727	0,262
Visibility	Correlation coefficient	**0,555**	-0,036	0,050	-0,036	0,224	-0,166
	p-value	**0,001**	0,956	0,821	0,956	0,282	0,336

Table 9 Feedback on the marketing.

Method	Feedback
Presentation	• Presentation was a good package about the Biobank and how it works. • The presentation was very useful to attend. • I found the presentation given at our group meeting informative and useful even though most of the audience were not very likely customers at their current positions. • Before the meeting with biobank, we thought that for dealing with biobank and getting clinical samples, we would need ethical permits to work with the samples, which put us off. • Very clear information. Straightforward. It worked very well as a marketing method for the biobank because I believe the information was transmitted face to face, in the informal environment of our group meeting. We could ask questions, which was very useful. • Biobank presentation at our group meeting was very informative.
Email	-
Leaflet	• The leaflet was well-constructed and probably tempted some people to the website. • The leaflet I found first got me interested and I looked up Biobank on the web. • I saw some kind of leaflet in Arvo building's cafeteria but have to admit that I didn't really read it. • It was a very informative and easy-to-follow leaflet. • I did not actually read the leaflets.
Seminar	• The seminar was really helpful to understand what it is and how it works. • The seminar was really good. I learned many things about the Biobanks and the possibilities they offer. I saw that many steps are being taken to improve practical aspects of utilizing Biobanks. • Seminar was informative and clarified some preconceptions.
Other	• I've seen marking related to patients. That was informative (although long). • Booth encounter was quite informative.
General	• Advertisements look professional. • Good marketing!
Nothing	• I don't remember seeing any marketing material lately.

5.1.3 Twice-answered researchers

Twelve answerers of the first questionnaire (36 %) answered to the second round as well. These answerers were given answerer-IDs A1–A12. Their answers could be used to analyze the differences in the effectiveness of the used marketing methods. The arguments exploring researchers' opinions about receiving enough information about FCBT and the visibility of FCBT were the most useful for this matter. To analyze the answers, the five-point Likert scale (*Strongly disagree – Disagree – Neither agree nor disagree – Agree – Strongly agree*) was again converted into grades 1–5. The grades of both questionnaire rounds were compared to see the change in the answerers' opinions after marketing. Figure 18 shows the changes in these grades between the first and the second round for each answerer A1–A12. The *Do not know* answers were not included in the comparison. Therefore, A10 and A11 have a red cross marking for impossible change calculation (A10 gave a *Do not know* answer to both arguments on the first round and *Disagree* answers on the second round, whereas A11 answered *Do not know* to the argument about visibility on both rounds).

The significances of the changes for both arguments measuring the level of biobank awareness were analyzed with Wilcoxon Signed rank test. The change in the perceived sufficiency of received information, as well as the visibility of FCBT, was statistically significant on a 0,05-significance level; p-values for changes were 0,010 and 0,016, respectively (table 10).

To analyze the effect of different marketing methods, the answerers A1–A12 were grouped by the marketing methods they told that they had perceived. Furthermore, the changes in the grades of received information and visibility shown in figure 18 were summed to get an overall effect of marketing. The overall changes of each answerer's own perception of biobank awareness are depicted in the figure 19 and organized into groups of perceived marketing. Again, the *Do not know* answers were not included, and therefore A10 is marked with a red cross. The best effect on biobank awareness was clearly with the presentation combined with leaflets (mean of the change: 5), whereas the seminar combined with leaflets lead to the poorest results (mean of the change: 1).

Table 10 Significances of the changes in the arguments measuring the level of biobank awareness for twice-answered researchers. "Do not know" answers were not included.

	n	**p-value for change between the questionnaires (Wilcoxon signed rank test)**
Received information	11	0,010
Visibility	10	0,016

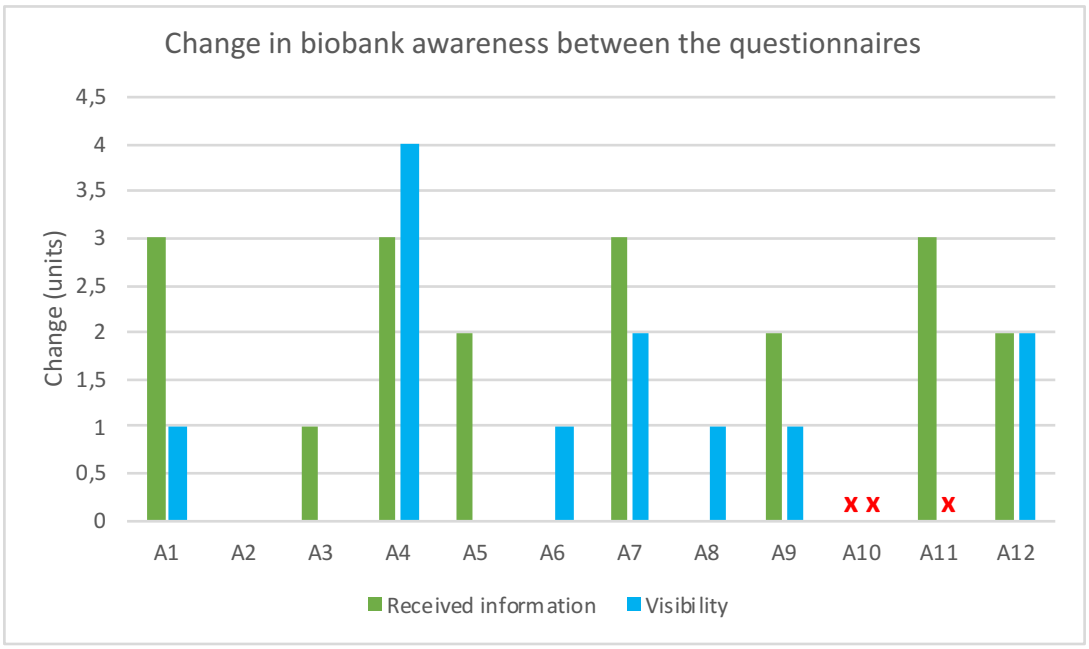

Figure 18 Changes in the opinions of the twice-answered researchers. Green bars represent the change in the opinion about receiving enough information and the blue bars the change in the opinion about the visibility of FCBT. All changes were either positive or zero. The "Do not know" answers are not included and no change have been counted for these answerers (marked with red crosses).

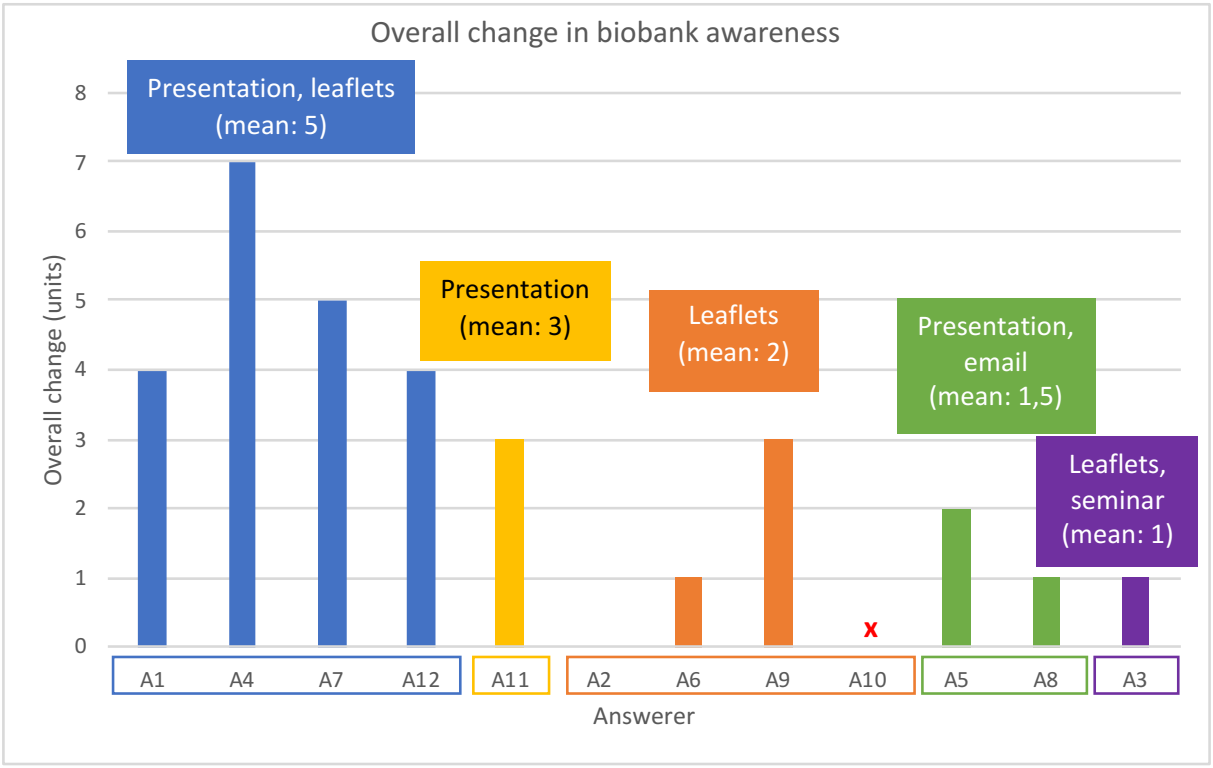

Figure 19 The overall changes in biobank awareness of twice answered researchers. The bars represent the sums of green and blue bars in the figure 18 and are grouped by the marketing methods that these answerers had perceived. A10 gave a "Do not know" answer to both arguments on the first round, and therefore is not included in the calculation (marked with a red cross).

Additionally, the medians of changes of each marketing method were compared separately. Table 11 shows these medians for received information, visibility and overall change; the higher the median, the bigger the change and the effect of a marketing method was. The effect of presentation was the greatest on both received information and visibility, and therefore also on the overall change. Email was the least effective method of the actual study methods (presentation, leaflet and email). The seminar that was taken into this comparison just for curiosity, did not lead to notable improvements either in received information or visibility. However, only one of the twice-answered researchers participated in the seminar, so the result for seminar should be interpreted cautiously. All the methods were more effective in sharing information than increasing visibility.

Table 11 The medians of changes within marketing methods. The higher the median, the greater the effect of marketing was. These are the medians for twice-answered researchers.

	Presentation	**Email**	**Leaflet**	**Seminar**
Received information	2,50	1,00	2,00	1,00
Visibility	1,50	0,50	1,20	0,00
Overall	3,67	1,50	3,33	1,00

5.1.4 Biobank samples and services

Only one of the answerers (3 %) on the first round had used biobank samples and/or services before this study (appendices 1 & 2, question 5). The number raised to six researchers (16 %) until the second questionnaire (table 12). Somewhat different answerer group might explain this change, but at least one project started after the given biobank presentation. The change was not statistically significant on a significance level 0,05 ($p = 0,068$, calculated with Mann-Whitney test).

Table 12 Have you used samples or services from FCBT?

	n	**Have used the samples / services**
Autumn 2018	33	3 % (1)
Spring 2019	37	16 % (6)
p-value for difference (Mann-Whitney U test)		0,068

The next two questions aimed to find out the researchers' interest and needs for biobank sample, data and service selection. The first one asked about their interest in currently available biobank samples and/or services (appendices 1 & 2, question 6; figure 20). The second one explored their expectations on what biobank sample and data collection should look like (appendices 1 & 2, question 7; figure 21). Only the results of the spring 2019 questionnaire are shown here as the distributions of the answers were similar on both questionnaire rounds and comparison between the questionnaires therefore irrelevant.

The answer options for the question asking about the interest in the FCBT's current collection were *Very interested – Slightly interested – Not interested*. The results are presented in the order of popularity of the samples and services. To alleviate comparison, each sample and service choice was given a score that is a result from multiplying the *Very interested* answers by two and adding the number of *Slightly interested* answers. The exact numbers of given answers are used in this comparison as all the questionnaire participants did not answer to this question or answered only to a part of it, so the percentages might be misleading. Figure 20 shows that the researchers in Tampere are most interested in tissue samples. The next most interesting samples are DNA, plasma, and serum. The most interesting service is sampling, and the sample and data release services follow right after that. The least interesting services were preliminary report requests and other inquiries.

Figure 21 shows how the researchers' expectations and needs concerning biobank sample (dark blue) and data (light blue) collection are distributed. Again, tissue samples stand out as the most popular samples and are followed by cells and whole blood samples. The data types given as examples, diagnoses and health data, both received interest form approximately half of the answerers. The specifications for disease-specific samples included the following sample types:

- cardiac tissue from cardiac disorder patients
- brain tissue and other neural tissue samples from neural disorder patients
- cancer tissue
- gastrointestinal disorder samples (e.g. inflammatory bowel disease and celiac disease)
- samples from the patients with confirmed / suspected infective disease (e.g. influenza); sample taken at the time of infection

The answers to the option "Other" included the following data and sample types:

- clinical data (e.g. survival information)
- EEG & EKG data

- imaging data
- fresh living samples
- ctDNA
- matched tissue and blood samples
- tissue samples for mechanical testing
- healthy and diseased cells for disease modeling cell cultures

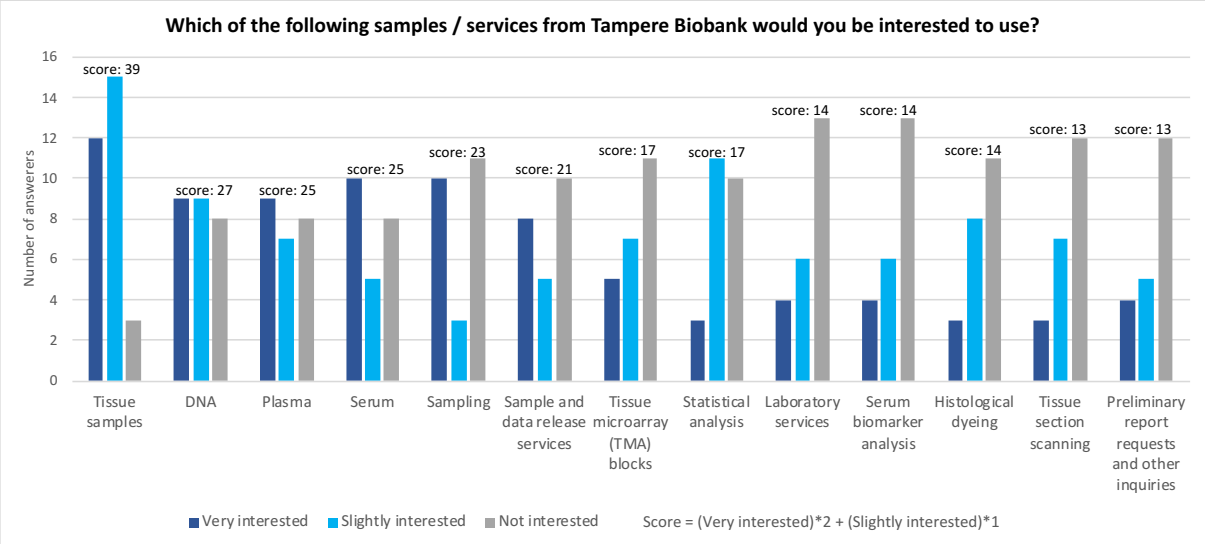

Figure 20 The popularity of samples and services that FCBT can currently offer. Answers are from the spring 2019.

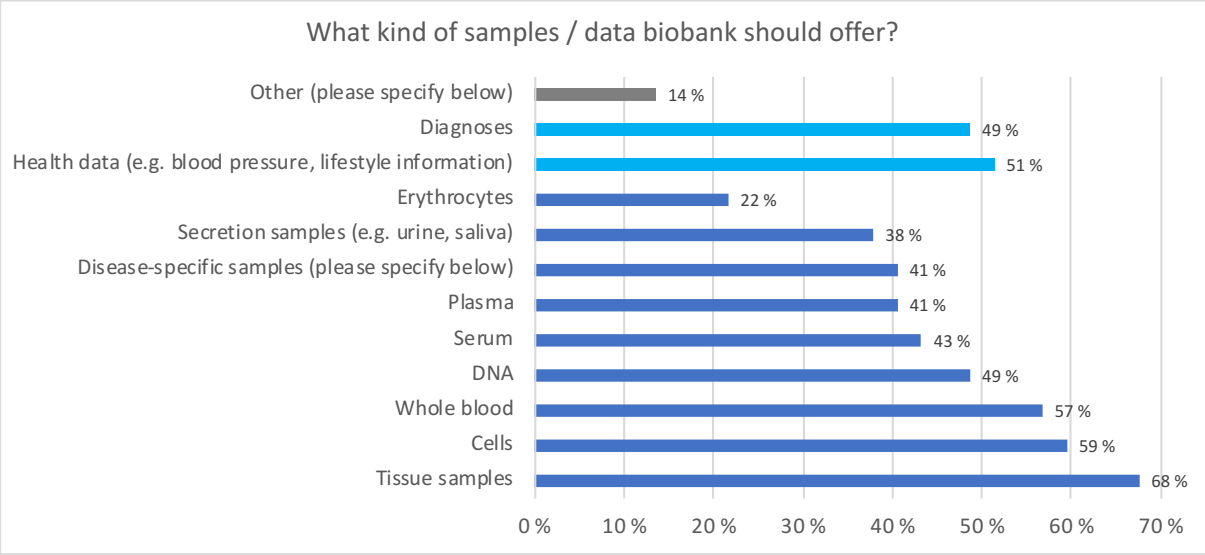

Figure 21 An ideal biobank collection. Dark blue bars represent different sample types and light blue bars represent data. Answers are from the spring 2019.

The opinions on the arguments about the sample and data collection and quality, as well as the service selection and quality of FCBT remained approximately the same during this study (appendices 1 & 2, question 8; figure 22). The differences between the two questionnaires were not statistically significant on the significance level 0,05: $p = 0{,}386$ for sample and data collection, $p = 0{,}363$ for sample and data quality, $p = 0{,}232$ for service selection, and $p = 0{,}566$ for service quality (calculated with Mann-Whitney U test). Majority of the researchers gave a *Do not know* answer to each of these arguments, which is in line with the above-listed (table 12) numbers of researchers who had used the samples or services from FCBT.

Same trend in the answers continued with the next arguments about the accessibility of FCBT's samples and services and the researchers' willingness to recommend FCBT to their colleagues (appendices 1 & 2, question 9; figure 23). Again, the differences in the opinions for these arguments were not statistically significant on the 0,05-significance level: $p = 0{,}381$ for "It is easy to take use of Tampere Biobank's services and sample collection", and $p = 0{,}967$ for "I could recommend Tampere Biobank to my colleagues" (calculated with Mann-Whitney U test). A positive note from the willinges to recommend FCBT is that the percentage of the combined number of *Agree* and *Strongly agree* answers raised from 18 % to 25 %, and only the *Strongly agree* answers raised from 3 % to 11 % of the researchers.

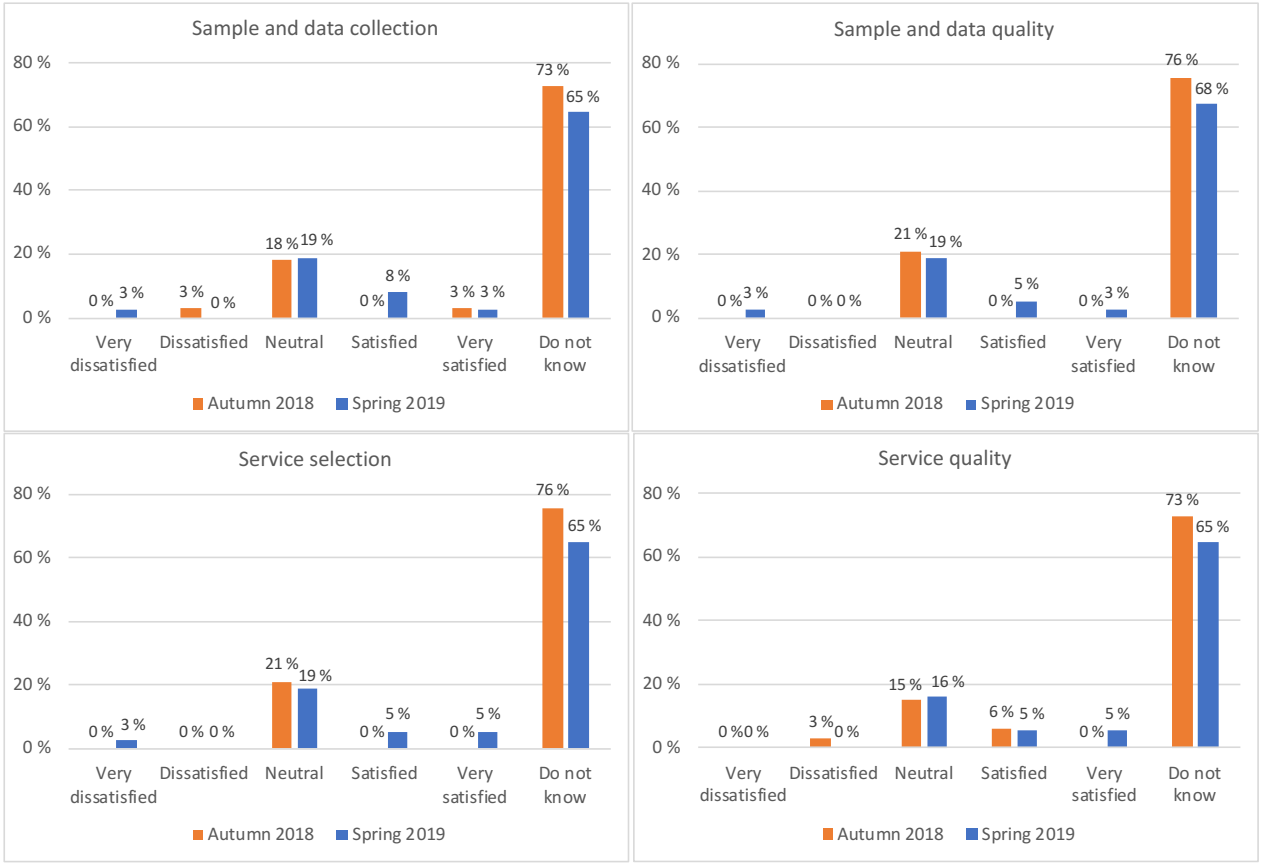

Figure 22 Satisfaction to sample and data collection and quality, and to service selection and quality.

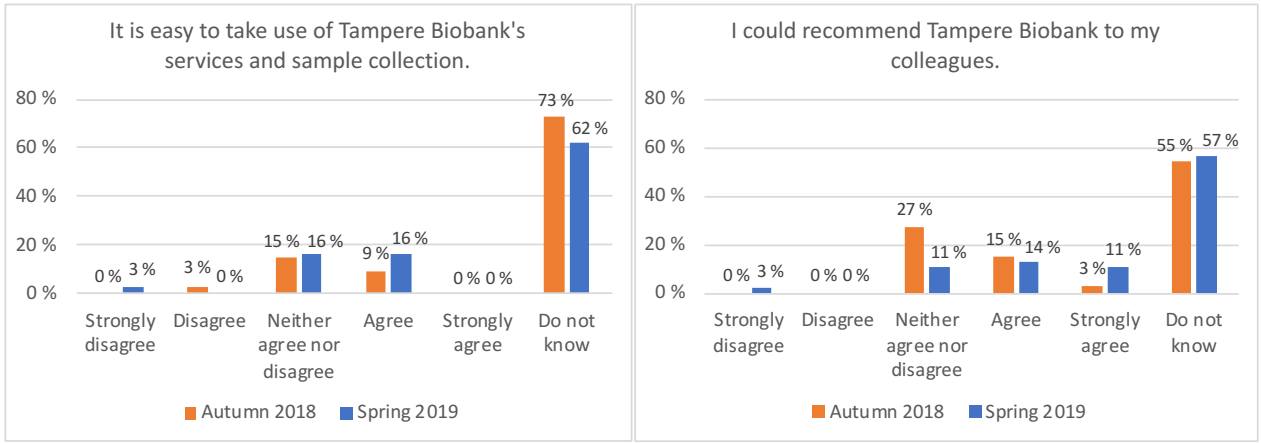

Figure 23 Arguments about the accessibility of FCBT's services and sample collection and researchers' willingness to recommend FCBT to their colleagues.

The last question (appendices 1 & 2, question 10) was an open question where researchers might suggest improvements to operations of FCBT. The following aspects are picked up from the two questionnaire rounds:

- More information about what is available, how to get it and where it is useful.
- The data pick up is too complicated (M codes needed instead of ICD codes).
- It is good that Tampere Biobank is increasing their visibility.
- More aggressive advertising and informing.
- Clear pricing list for samples.
- The process to receive information about sample-availability is preliminary and only later on you are informed about that costs that are all too high.
- The basic services (e.g. development of the processes) should be covered by someone else than the researcher who pays for the samples. Costs should be as low as possible.

To sum up the results of the local study for academic researchers, table 13 shows the numbers of inquiries, received preliminary requests, and received sample and data access requests that had arrived before the first questionnaire round until the end of September 2018 and before the second questionnaire round until the end of March 2019.

Table 13 The numbers of received inquiries, preliminary requests, and sample and data access requests until the end of September 2018 and until the end of March 2019. The numbers are from before the first questionnaire and before the second questionnaire after marketing.

	Count until September 2018	**Count until March 2019**
Inquiries (emails, calls, meetings)	10	43
Received preliminary requests	5	30
Received sample and data access requests	1	9

5.2 National study targeted to pharmaceutical companies

5.2.1 Background information

The questionnaire for pharmaceutical companies was sent in April 2019 to nine pharmaceutical companies participating in the FinnGen project. Seven out of nine (78 %) companies gave their answers. Due to small sample size, the results are presented with the exact numbers of answerers instead of percentages used in the section 5.1. Percentages are given in the results where they offer reasonable additional information. Part of the questions were meant for FINBB's internal use and therefore are not presented here.

To understand better the results, answerers' relationship to the FinnGen project was asked (appendix 5, question 2), and if they are decision-makers in the initiation of biobank studies in their organization (appendix 5, question 3). The answerers' relationships to FinnGen were related only to the company partnership with FinnGen, and most of them told that they are not directly involved with the project. This was asked only for curiosity, and to give a clue of the answerers' involvement in biobank operations. However, five out of seven company representatives told that they are decision-makers in the initiation of biobank studies in their company and thus directly involved in biobank collaboration. All the connections this questionnaire was sent to were FINBB's already existing contacts, and therefore involved in the collaboration between biobanks and pharmaceutical industry at least to some extent.

Compared to the researcher questionnaires, biobank awareness was only in a minor role in this questionnaire. It was explored by asking "How well do you know Finnish biobanks?" (appendix 5, question 4). Five out of seven (71 %) companies said that biobanks are *Familiar, and we have used their services*, whereas the remaining two companies (29 %) told that biobanks are *Familiar, but we have not used their services*. None of the companies told that biobanks are *Not familiar at all*.

5.2.2 Research projects

A multiple-choice question about the therapeutic areas of interest was given to these pharmaceutical companies to understand their scale of research (appendix 5, question 6). The areas of interest were distributed quite widely among these companies. Table 14 shows how many companies (out of seven) chose the given therapeutic area in the multiple-choice question consisting of all of these answering options. All relevant options were chosen. The most common areas of interest (five out of seven companies) were non-hereditary cancer, immunology, memory disorders, neurological disorders (other than memory disorders,

specified by the companies as ALS, Parkinson's disease, MS, and other neuroimmunological disorders). The next most common (four out of seven answers) were hereditary cancer and dermatology.

The distribution of different study types in pharmaceutical companies within the last year was explored to understand what kind of studies they mostly conduct and what is the proportion of biobank studies of them (appendix 5, question 5). Figure 24 shows that majority of the research projects that pharmaceutical companies conduct are clinical studies. Register studies are a bit more common than biobank studies. The total number of studies within the last year varied between 5 to 35, and the number of biobank studies ranged from 0 to 2, comprising 0 % to 20 % of all the studies these companies had conducted within the last year.

Table 14 The popularity of therapeutic areas of interest. The results of a multiple-choice question are presented in the order of popularity: the number of companies out of seven that chose a given area of interest. The companies were asked to choose all the relevant options.

Companies out of 7	Therapeutic area
5	• Cancer (non-hereditary) • Immunology • Memory disorders • Other neurological disorders (please specify below) o ALS, Parkinson's disease, MS, neuroimmunological disorders • Rheumatology
4	• Cancer (hereditary) • Dermatology
3	• Pulmonology • Rare diseases
2	• Cardiovascular diseases • Diabetes • Gastroenterology
1	• Arthritis • Medical devices • Obesity • Ophthalmology • Psychiatry • Ultra-rare diseases • Other (please specify below) o Vaccines
0	• Imaging • Osteoporosis

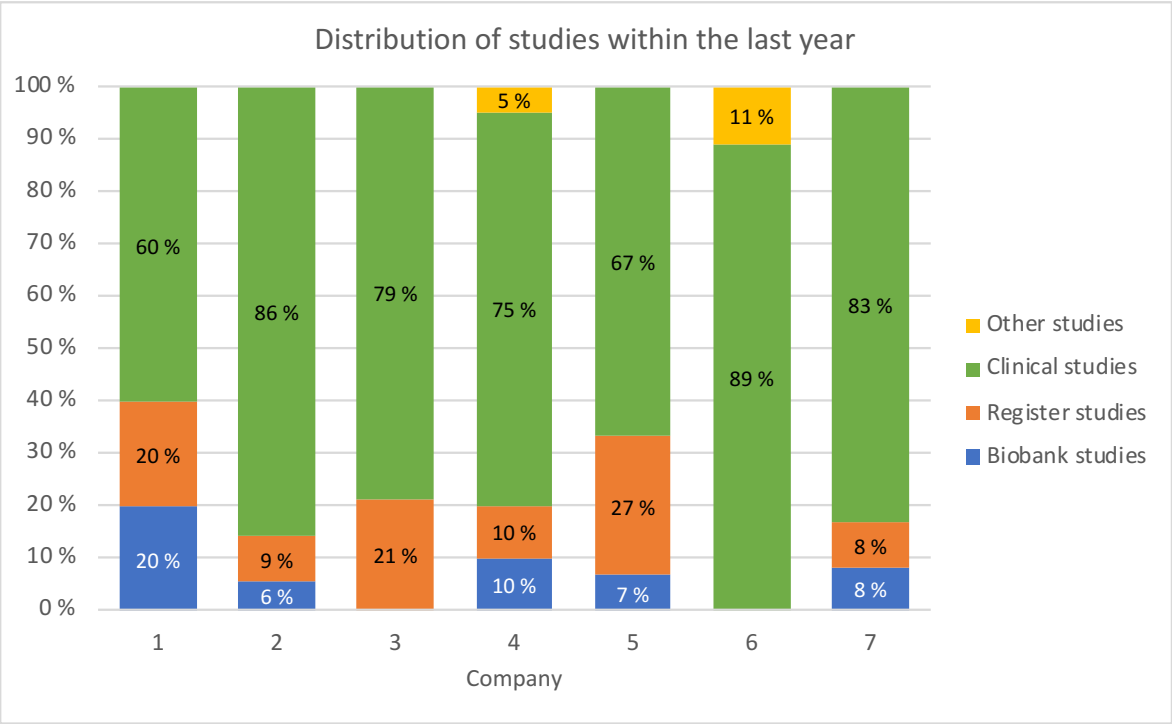

Figure 24 Distribution of different study types within the last year. The companies were asked to fill in the approximate number of each study type within the last year. Here the numbers have been changed to percentages to simplify comparison. The number of biobank studies ranged from 0 to 2. The "Other studies" were specified as FinnGen.

5.2.3 Biobank and biodata studies

The purposes for which these companies primarily conduct biobank or biodata studies were relatively similar among the participating companies (appendix 5, question 8; figure 25). The main reasons were to understand the real-world efficacy of treatments (seven out of seven answers) and understanding the burden of disease (six out of seven answers). Understanding disease mechanisms and identification and developing drugs and better diagnostics appeared to be important purposes for at least some of the companies. To summarize, the main aim behind the biobank studies of these companies is the deeper understanding of the diseases and their treatments. Biodata studies were mentioned separately here and in the forthcoming questions to ensure that the companies did not see biobank studies only as studies using biobank sample collections but also biological data from biobanks and registers.

When asked about a successful biobank or biodata study (appendix 5, question 12; figure 26), pharmaceutical companies most commonly appreciated high-quality data and samples and staying on an agreed schedule. However, conducting a study within a budget or less, as well as receiving expected results were not the kind of aspects that many would use to

define a successful study. Publishing the results in a top-tier journal makes a study successful only to two out of seven companies.

The companies were also asked when they would be willing to pay a service fee (appendix 5, question 16; figure 27). The fee was no further specified as this question was only meant to explore what the companies value the most in biobank or biodata studies. The time aspect stood out again as hitting the milestones earlier than targeted would be a reason to pay a service fee for four out of seven companies. The most probable condition (five out of seven answers), however, would be that the pricing or reimbursements would be negotiated according to the study results. Thus, the companies would be interested to have a money-saving incentive to end up in beneficial results. The money-saving aspect was also visible in the other end of the answers: none of the companies would be interested to pay a fee to ensure the financial and scientific benefitting of the Finnish hospitals and universities that enable the biobank studies.

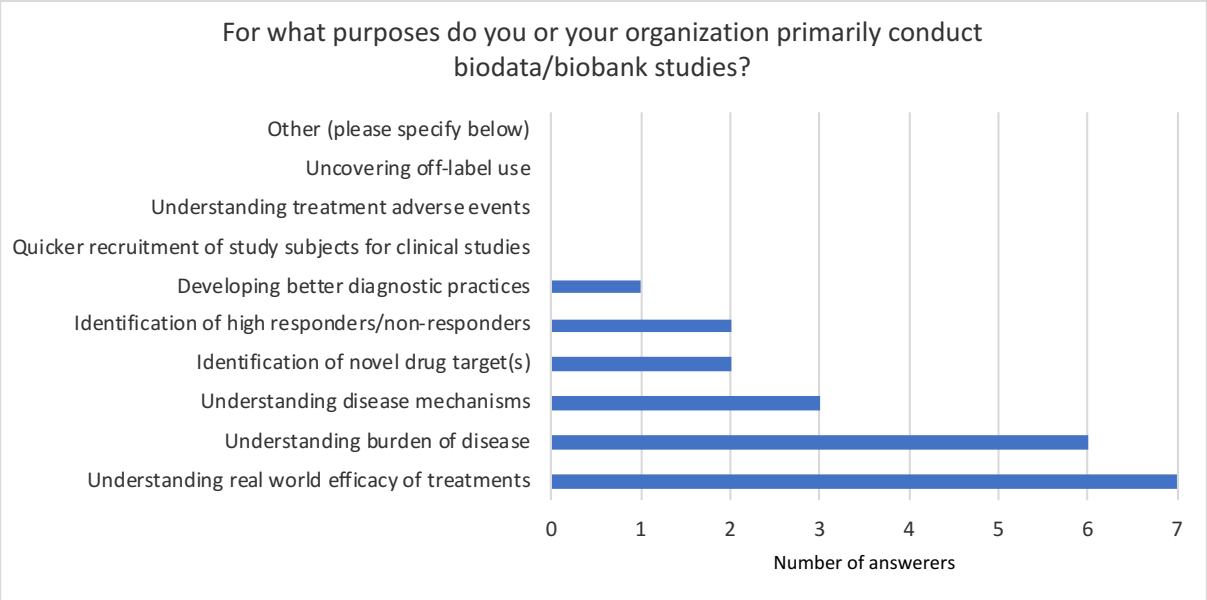

Figure 25 Primary purposes to conduct biodata/biobank studies. The companies were asked to choose three most important options.

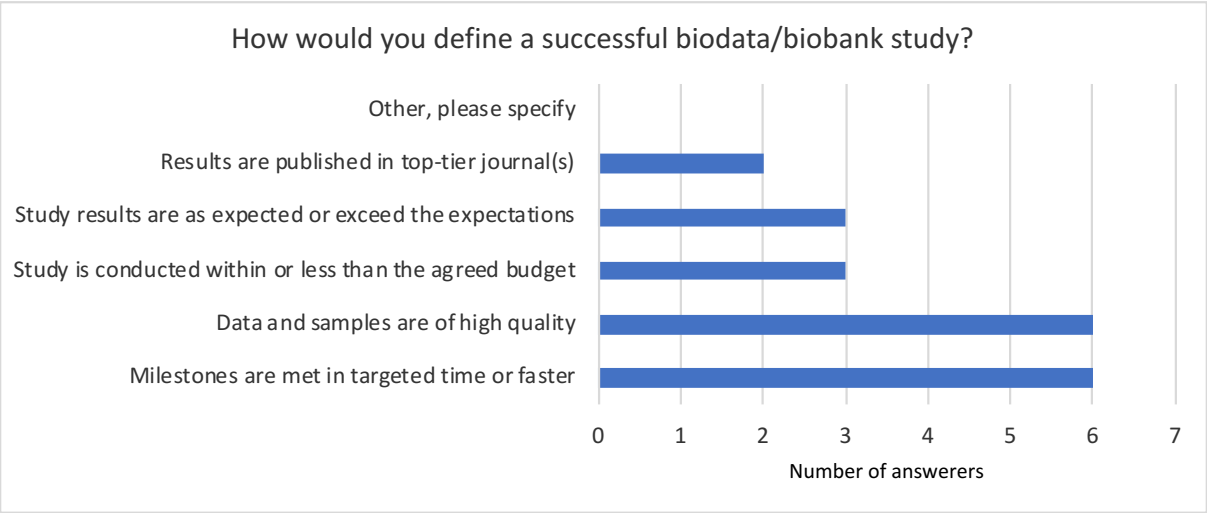

Figure 26 Successful biobank/biodata study. The companies were asked to choose three most important options.

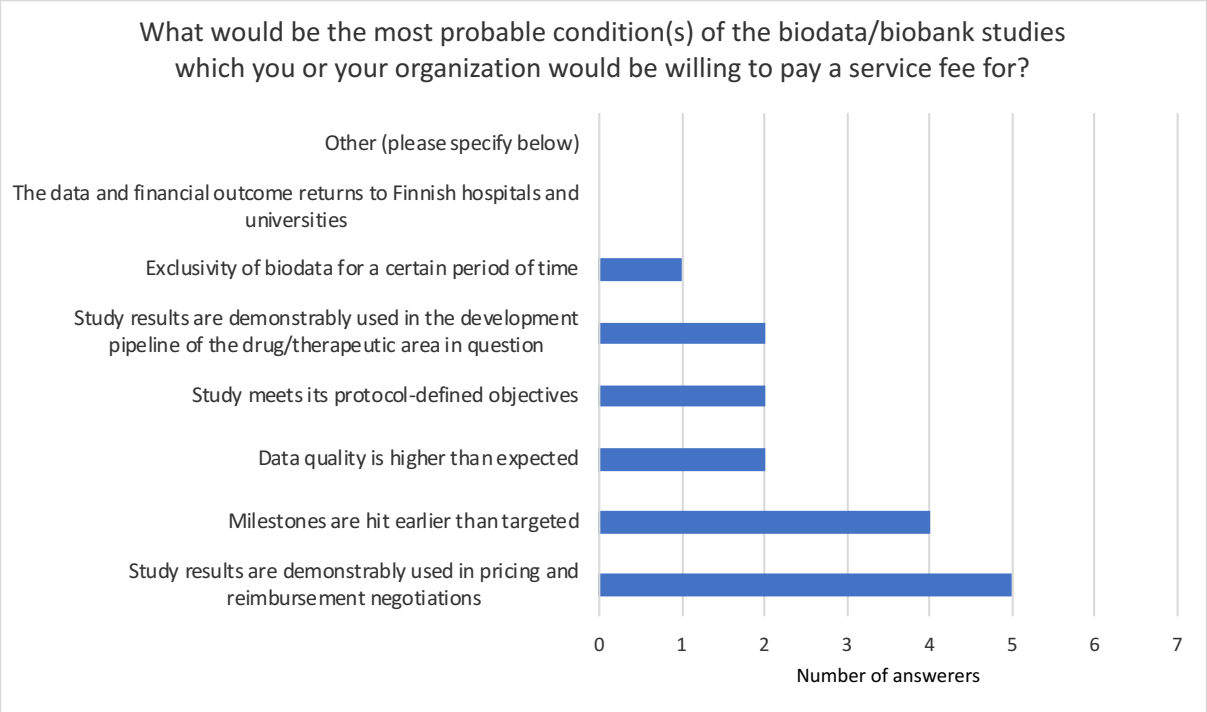

Figure 27 Probable conditions to pay a service fee when conducting biodata or biobank studies. The companies were asked to choose 1 to 3 most likely options.

5.2.4 Biobank samples and services

The question about the importance of different sample and data types was asked from the pharmaceutical companies as well as from the researchers. Accordingly, the researchers were asked what samples and data biobanks should offer (appendices 1 & 2, question 7; figure 21), whereas the pharmaceutical companies were asked to choose all the biobank sample and data types that are relevant for their research (appendix 5, question 10). Both of these questions had the same answering options except for the option *Medical records* that was added to the company questionnaire to clarify the options. Figure 28 combines the results from the company questionnaire with the researchers' answers. Data and samples are separated here with an orange dashed line. Pharmaceutical companies are much more interested in data than samples, whereas the researchers' needs are more evenly distributed.

The importance of biobank services, both nationally and locally coordinated, was explored with the question where the companies were asked to evaluate how important the following services are (or would be) for them on a scale 1 to 5 (1 = Not important, 5 = Very important) (appendix 5, question 9). Figure 29 shows how the companies rated the given list of services. All the companies rated the feasibility coordination and accessing to all Finnish hospital biobanks with one contract as important or very important (grade 4 or 5). An electronic portal to follow the study progress as well as to submit sample and data access request were widely seen important or very important. As researchers, also the pharmaceutical companies think that electronic catalogue for available sample and data selection would be important; all of the companies rated it from neutral to very important (grades 3–5). Less important services for pharmaceutical companies were the laboratory services and techniques that are organized locally in individual biobanks. That is a logical consequence to the perception in the question 10 (figure 28) that pharmaceutical companies are typically not very interested in the biobank samples. The overall observation concerning to the importance of biobank services is that pharmaceutical companies are more interested in nationally coordinated services than local services offered by individual biobanks. The appreciation for the nationally coordinated services was asked also separately and the result strengthens this observation. Five out of seven companies (71 %) told that nationally coordinated services are extremely valuable (grade 5 on a 1–5 scale) for them and the remaining two companies (21 %) told them to be valuable (grade 4) (figure 30).

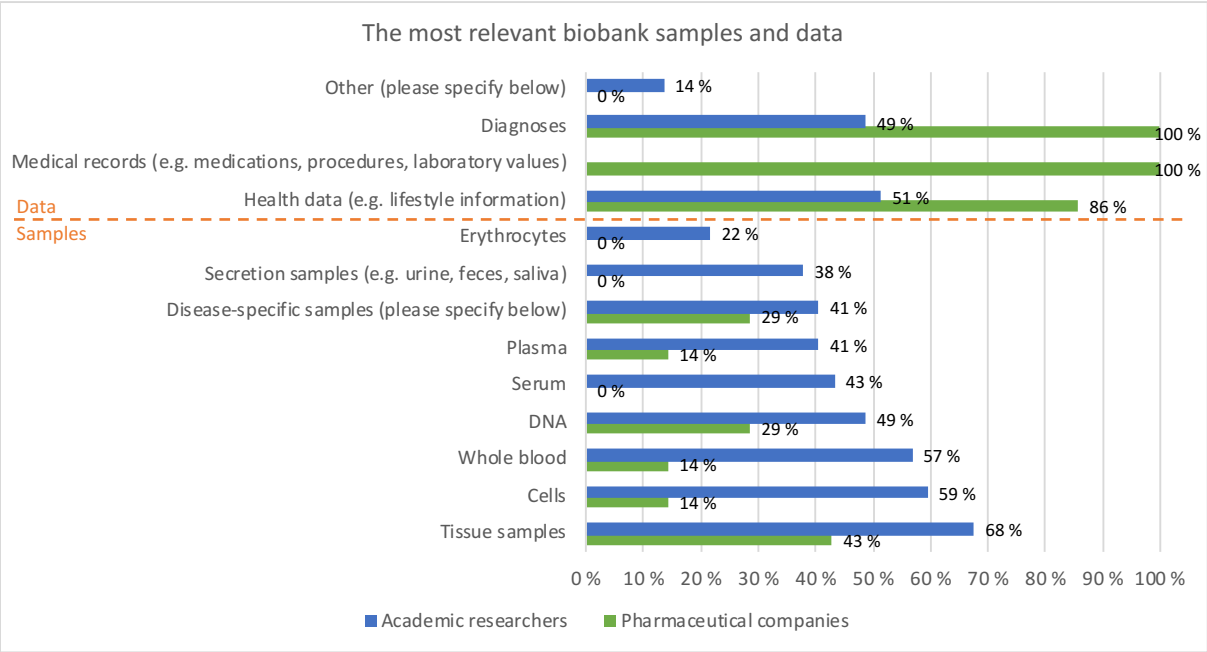

Figure 28 The most relevant biobank samples and data for pharmaceutical companies. The option "Medical records" was asked only from the pharmaceutical companies. The answerers were asked to choose all the relevant options.

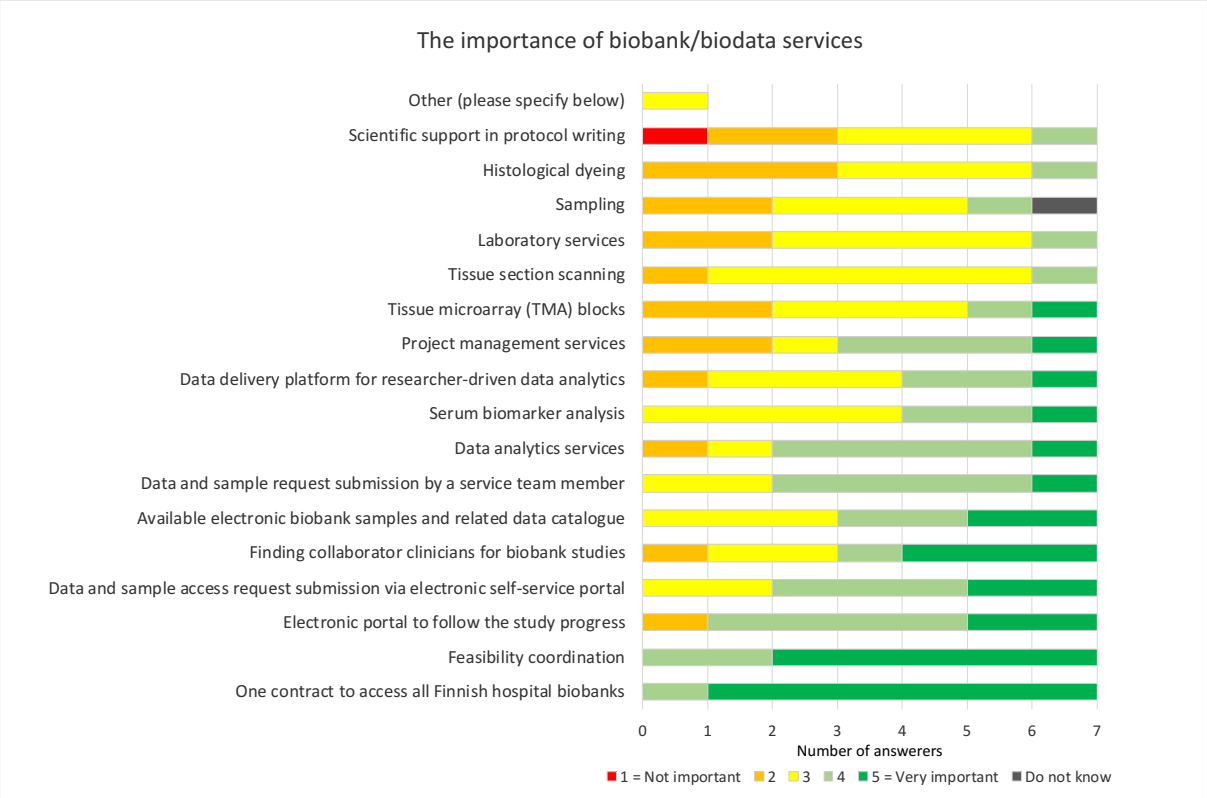

Figure 29 The importance of biobank or biodata services to pharmaceutical companies. The importance of each service was rated from 1 to 5 (1 = Not important, 5 = Very important.) The one "Other" answer was not specified more closely.

Key challenges in conducting biobank or biodata studies in Finland were explored for FINBB to be able to offer better national biobank services (appendix 5, question 13; figure 31). A common factor in almost all the most prevalent challenges is the lack of nationally consolidated requirements and services for accessing biobank materials. This questionnaire was sent before the Fingenious portal was launched, and therefore some of the given challenges have already been solved. Still, it is interesting to see that Fingenious really filled the gaps in the Finnish biobanking field. All the challenges that Fingenious has solved or aims to solve have been marked as green in figure 31. A positive note from this question is that the quality of Finnish biobank samples and data seems to be good. Only one company told the poor quality of samples to be a challenge, but without further specification it is impossible to know if this company has had only bad luck with one sample set or more serious problems with sample quality.

In an open question, the companies could wish for improvements to the Finnish biobank operations (appendix 5, question 17). These answers included roughly four themes:

- Nationally coordinated one-stop access for all biobanks (including registry data).
- Electronic catalogue of available samples and data (including additional information about available related data and longitudinal samples).
- Identical contracting in all biobanks.
- Predictable process with timeframes for all biobank projects.

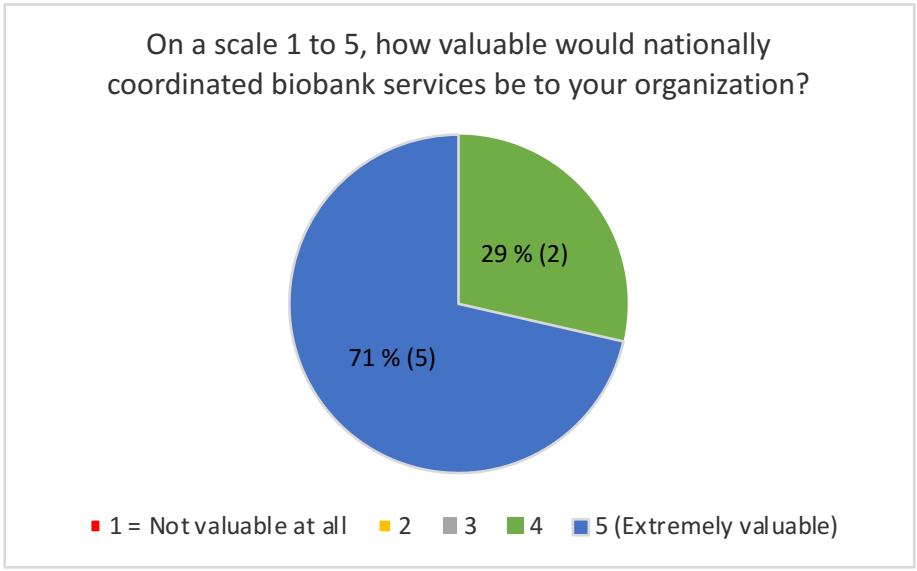

Figure 30 The value of the nationally coordinated biobanks services for pharmaceutical companies.

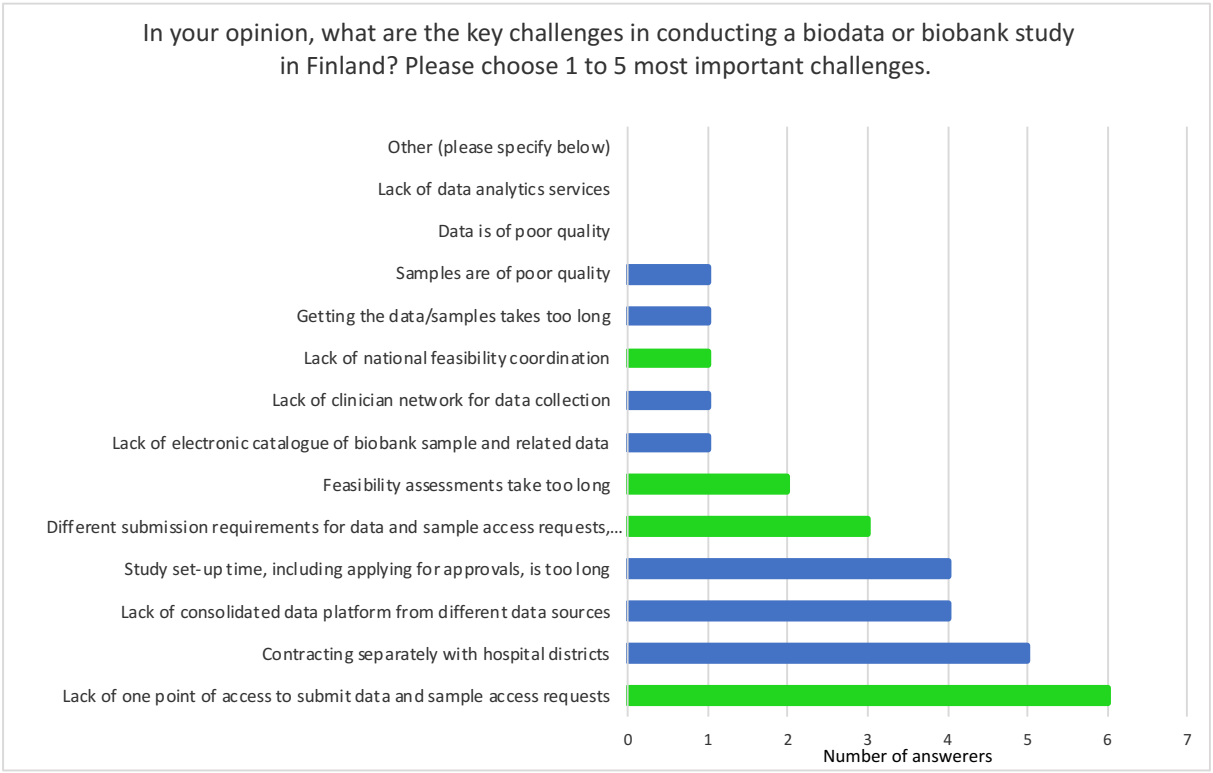

Figure 31 Challenges in conducting a biodata/biobank study in Finland. The green bars represent the challenges for which the Fingenious portal offers a solution. The companies were asked to choose 1 to 5 most important options.

6 Discussion

6.1 Local study targeted to academic researchers

6.1.1 Marketing methods

The aims of this study were to make researchers more familiar with the FCBT's services and to test which are the best methods to accomplish this. The idea was to test different marketing methods to see what kind of marketing works the best in increasing the biobank awareness of academic researchers. A study like this is presumably first of a kind in the Finnish biobanking field, possibly internationally as well. Therefore, the used methods were chosen so that it would be possible to conduct the marketing and to study its effectiveness in a relatively short time. The marketing methods should also be reasonable to use in the future and by other hospital biobanks as well.

The timing for implementing the marketing targeted to academic researchers was precise. Now that the sample collection of FCBT is wide enough to answer many kinds of research needs (https://www.tays.fi/biopankki, 23.10.2019), it is important to find users for it. In the beginning of this study, academic researchers at Tampere University were still quite unaware of FCBT; 12 % of them had never heard of it before, and their own estimations about the sufficiency of received information about FCBT referred to low level of knowledge. Fortunately, the marketing tested in this study led to positive results in several areas. Firstly, FCBT was noticed more often and in more channels until the second questionnaire compared to the first one. Although the differences were not statistically significant, some improvements were observable. The campus visibility increased (figure 9 and table 6) as well as noticing FCBT at the web-based channels (figure 9). The internet visibility was not improved as a part of this study, but still the biggest difference was in noticing FCBT at their own website. Here the effect of marketing was indirect; the researchers' increased interest towards biobanks led them to visit at FCBT's website and possibly also at the websites of FINBB and BBMRI.fi that appeared in the answers only on the second round. Secondly, the researchers more likely felt that they had received enough information when asked on the second round than on the first round. Also, the visibility of FCBT increased from the researchers' point of view during this study. Both differences between the questionnaires were statistically significant which tells about the effectiveness of marketing. Lastly, the numbers of inquiries, sample release requests and actual research projects increased notably during this study (table 13). It should be noted, however, that the marketing related to this study was not the only thing affecting to these

numbers, as aiming towards higher number of sample releases belongs to the normal workflow at the biobank. Nevertheless, the change in the numbers during these six months was remarkable, and this study may have had an implication to it.

So, what enabled these improvements? Three different marketing methods were tested, and these methods led to very different results. The presentation given in research group meetings was the only method that led into statistically significant results in raising biobank awareness. The increase was significant both in the sense of having received enough information about FCBT and in the visibility of FCBT. An interesting note is that only six presentations were given, and still 30 % (11 persons) of the answerers on the second round had seen it. This indicates researchers' strong involvement to the subject after a personal meeting. This in turn might relate to further communication and trust between the researchers and biobank in the future. Furthermore, the feedback about the presentations was only positive. The researchers were thankful for the informativeness of the presentation and for having had a possibility to ask questions face to face (table 9). Therefore, presentations or personal meetings in general would be beneficial ways to share information with researchers also after this study.

The other methods, leaflets and an information package sent by email, led into incoherent results. The correlation coefficients between these methods and both received information and visibility were close to zero and not even close to statistical significance. Email led even slightly negative correlation with visibility, as did the leaflet with sharing information. The problem with the leaflets as tools to share information is that people seeing them randomly at a cafeteria or a hallway might not actually read them. When it comes to visibility, the effect of leaflets was not statistically significant, although almost half of the answerers (49 %) on the second round had seen them. This tells about the potential ability of leaflets to raise the visibility, but apparently researchers do not think it is enough. Also, the feedback about leaflets was controversial; some said they had seen a leaflet but had not actually read it, some in turn mentioned that it was informative and had even led them to visit at FCBT's website (table 9).

Email marketing did not receive feedback at all and was not a successful marketing method in this study after all. In general, email is a challenging channel for marketing as the daily flood of emails may easily lead the receivers to ignore the message or consider them as a spam. This was proven also by the survey conducted by Adobe (https://theblog.adobe.com/email/, 23.10.2019). In this study, it was also problematic that the group of email receivers included only 11 persons. The size of this group was expectedly too small and led even unexpected problems that eventually made the results for email marketing unusable. On the second round, five researchers told that they had seen the information package

sent by email, whereas only two of them were among the twelve twice-answered researchers. This should not have been possible, as all the email receivers were picked from the first round and therefore on the second round, everyone who said to have received the email should have been among the twice-answered group. Additionally, these two email receivers told that they had seen also the presentation, which neither is plausible as these reference groups did not overlap with each other. Probably these two remembered receiving emails related to settling up the presentation. The email that the rest three researchers had received remains as a mystery. Possibly they thought that the emails about the questionnaire(s) of this study were the emails in question. This misconception was tried to avoid by asking if the researchers had seen an "information package sent by email" instead of "email marketing". Additionally, as the answerers within the group of twice-answered researchers were identifiable between the questionnaires, it was possible to notice that actually three of them were among the reference group of email receivers but did not mention email on the questionnaire form. This strengthens the proposition of easiness to ignore emails.

Accordingly, the study set up did not work with this small answering group in testing the email marketing. On the other hand, the reference group this small (one third of the answerers on the first round) was required to compare the methods. If the same email would have been sent to all the researchers, that is, with the same distribution as the whole survey, it would have been impossible to compare the effect of each marketing method individually. Afterwards, an option to send the email to a bigger, random group of researchers might have been more effective method as a great part of the receivers probably had ignored it anyway. Although this study failed in testing the email as a marketing method, it does not mean that email would not work in real life. Therefore, it should not be excluded from the possible marketing methods for future use in biobank marketing, as it is very easy, fast and cheap to implement and at its best also an effective marketing method (Yasmin, Tasneem, & Fatema, 2015). As noticed, ignoring advertisement emails is very easy, even probable, so the distribution of such an email should be as wide as possible.

The biobank seminar was not officially one of the marketing methods of this study, but it was taken along to see the effects of this kind of events to biobank awareness. The feedback about the seminar was solely positive; it was said to be very informative, but that was not visible in the results, though. The seminar led to the poorest results of all the studied methods in both received information and visibility. However, the number of answerers who had been in the seminar was only five. As a matter of fact, seminars like this are what the researchers hope for. When asking about the channels where the researchers would like to get

more information about biobank operations, a majority of them answered that in education and science events, and almost half of them answered that in the events organized by biobank (figure 11). An interpretation of these results is that academic researchers hope that biobanks would participate in seminars, conferences and exhibitions where probably other topics are presented besides biobanking, and where the researchers would most likely participate anyway. Although the events organized by biobank itself were not as popular, the proportion of interested researchers was remarkable anyway and most likely grows as the biobank awareness keeps increasing. Therefore, biobanks should be active in organizing events of their own and participate actively in other events as well to raise the visibility and to share information.

A common feature for all the studied marketing methods was that they were more effective in sharing information than increasing visibility. Obviously, the measures for receiving enough information and FCBT being visible enough were only people's own perceptions and opinions. Therefore, increasing visibility on the scale used in this study might be more challenging, since the visibility is not as easy to evaluate as the personal amount of enough received information.

Although different marketing methods were targeted to three reference groups, in reality it was impossible to avoid an individual researcher from encountering nothing else than the targeted marketing. Naturally, it was possible to choose the email receivers and presentation audiences, but leaflets and seminar were no targeted marketing and thus partly overlapped with other methods. This might have caused inaccuracy in the results. Therefore, it was sensible to also look how the combinations of marketing methods resulted in increasing biobank awareness. The overall changes (received information and visibility summed) between the questionnaires were counted for those researchers that participated in the both rounds (figure 19). A combination of marketing methods that led to best results in this calculation was presentation and leaflets. That is, the perceptions of both having received enough information about FCBT and the visibility of FCBT being good enough improved most with those who had seen both the presentation and leaflets. Therefore, although the leaflets themselves did not result in clear improvement of biobank awareness, they combined with other methods, preferably the presentation, might be the most effective mix to use in the future.

Another challenge from the marketing point of view was the timeframe within this study was conducted. For more prominent results in increasing biobank awareness, a longer time would have been needed to implement the marketing. The presentations were given between January and early March 2019, the email marketing was sent in February, the leaflets were distributed in March, and the seminar was arranged in April. The second questionnaire

was sent right after the seminar in April. Therefore, researchers had only a limited time to encounter and assimilate the marketing.

The biggest challenge in this study, however, was the number of answerers in the questionnaires. 33 answerers on the first round, 37 on the second round, and 12 same answerers on the both rounds were only a minor proportion of researchers in more than 90 research groups at Tampere University and Tays. It was also challenging to reach the answerers from the first round to participate on the second round as well to compare the reference groups. The small number of answerers made the results less generalizable and prevented running more advanced statistical analyses. On the other hand, having statistically significant results with this small sample size in at least some of the studied features, relates to successful marketing. It would be interesting to see what kind of effects all the studied marketing methods would generate in longer time and with a possibility to hear the views of a bigger proportion of researchers.

6.1.2 Samples, data and services

From the sample and service point of view, the timing of the study was both challenging and precise at the same time. A problem was the novelty of biobank operations in Tampere as well as in the whole Finland. FCBT was established in 2015, that is, three years before the beginning of this study. The process of starting biobank operations is time-consuming, involving several steps from applying a permission to establish a biobank, to actually start systematically collecting the samples and finally having a collection that researchers can utilize (https://www.valvira.fi/terveydenhuolto/toimintaluvat/biopankit, 23.10.2019). Therefore, it was too early for a questionnaire asking for researchers' opinions about FCBT's sample collection and services, the first sample releases having been realized only in the previous summer, in June 2018. This could be noticed from the results to the questions about sample and service use (table 12), the opinions about the sample or service collection and quality (figure 22), the accessibility of the samples and services and willingness to recommend FCBT to colleagues (figure 23). As researchers had not had enough time to use FCBT's samples and services, they barely knew the extent of the selection, not to mention its quality. However, the number of researchers who had used the samples or services raised from 3 % to 16 % until the second questionnaire. Although the difference was not statistically significant ($p = 0,068$), the achieved change promises good. The process of starting a research project takes time, and therefore the actual effect of this study is possible to see later. As researchers become more familiar with the biobank operations, they more likely use biobank in their forthcoming studies.

On the other hand, at this stage when the FCBT's sample collection still seeks for its shape and extent, it was very sensible to hear researchers' hopes and needs regarding to the sample and service selection. The most popular samples were tissue samples, and DNA, plasma and serum followed after that (figure 20). The set of DNA, plasma and serum is the basic set of samples collected from every biobank donor. Therefore, the collection of them is already comprehensive and is growing continuously. When asked about what samples and data the biobank should offer, tissue samples were again the most popular option (figure 21). However, cells and whole blood were the second and third most popular sample types, respectively. Luckily, FCBT's collection of old diagnostic pathological samples contains a wide collection of tissue samples, and the collection of clinical genetics samples contains both whole blood and cells in addition to extracted DNA. However, tissue samples and other cells than blood cells are collected only as a part of clinical treatments, so the collections of these samples do not grow as frequently as the DNA, plasma and serum collections. Finnish biobanks typically have large collections of old pathological tissue samples and large collections of prospective blood samples (https://www.auria.fi/biopankki, https://www.helsinginbiopankki.fi, https://www.ppshp.fi, 13.10.2019), which often meet the researchers needs. Currently, all the FCBT's prospective samples are used in research, as they are included in the FinnGen project. However, sometimes researchers need tissue samples from recent years or as mentioned in the open questions of this survey, tissue samples matched with blood samples from the same patient. Finding a comprehensive collection of these samples might be difficult. For this, utilizing the network of biobanks enables wider research material (Asslaber & Zatloukal, 2007). Fortunately, the Fingenious portal has made applying samples from several biobanks easier.

Since the tissue samples raised so much interest, the collection of them should be highlighted in FCBT, as well as in other hospital biobanks. This requires close collaboration with, for example, cancer clinics. The frequencies of previously conducted cancer-related biobank studies in Finland (figure 4) and internationally (figure 5) support this suggestion as well. However, the collecting of tumor tissue samples is nowadays harder than in the past, as the new cancer diagnostics allow earlier detection of the cancers and neoadjuvant therapies before surgeries make the tumors smaller. Therefore, the tumors are often too small to allow gathering of samples for research use (Hewitt, 2011; Mackenzie, 2014). Still, focusing on cancer samples, both tissue and blood, is important for FCBT as cancer was mentioned repeatedly in the survey answers about interesting sample types. This is not surprising, as cancer research is one of the most important areas of the research strategy of Tampere University and Pirkanmaa Hospital District (https://www.tays.fi/biopankki, 11.10.2019) and there are several

cancer research groups at Tampere University. FCBT has already started to collect circulating tumor DNA (ctDNA) samples from cancer patients. Also, a special collection of ctDNA samples from healthy donors was made in the summer 2019 as a part of a research project (https://www.tays.fi/biopankki, 23.10.2019).

As mentioned above, whole blood samples were also among the most popular sample types in this survey. This is interesting as no preliminary requests for whole blood samples has been received in FCBT, whereas plasma and serum are regularly requested. However, researchers may think that whole blood would enable more versatile studies, and thus give more possibilities for them as they obviously are capable of extracting serum, plasma and DNA by themselves. Typically, whole blood samples requested from biobanks are used, for example, to study interactions between genes and proteins or membrane proteomics from red blood cells (Mohamadkhani & Poustchi, 2015). According to BBMRI directory (https://directory.bbmri-eric.eu, 11.10.2019), four biobanks in Finland (Biobank of Eastern Finland, Central Finland Biobank, Helsinki Biobank, and THL Biobank) have whole blood in their collections. However, this directory does not describe completely the collections of biobanks and may offer defective information. Currently, all the whole blood FCBT stores from the prospective blood samples is used for DNA extraction. However, the wide interest towards it would encourage saving a part of the derived blood samples outside of the DNA, plasma and serum extraction. This might be a thing to consider in the future for FCBT, as well as for other biobanks, at least if their popularity is observable also in the forthcoming preliminary requests.

Academic researchers were also interested in data related to samples. FCBT can currently offer all the data types mentioned in this survey. Also, the other data types defined in the answers, that is, imaging data, clinical data (e.g. survival information), and EEG and EKG data are already widely available through FCBT.

Academic researchers were most interested in those samples, data, and/or services that they already expect to be available (figure 20). It is possibly not very broadly known that biobanks offer also services such as histological dyeing and tissue section scanning. Therefore, they did not receive notable interest in this survey. It is curious that preliminary report requests and other inquiries were the least interesting services, considering that they are the most common ways of making a first contact to biobank in order to start a biobank study and to check the sample availability. This was also the most common option that was skipped, probably because the answerers did not understand term “preliminary report request” and what it is used for.

Although not a clear biobank service, the website of a biobank could be thought as a preliminary service that potential customers of a biobank use. The channel where academic researchers most likely apply information about biobanks and their offerings is their websites (figure 11). Every hospital biobank in Finland has a section targeted to researchers on their website. This section typically includes, as a minimum, a description of the sample collection and instructions for how to reach the samples. Often, also the research projects in which a biobank has been involved in is included in this section. Researchers seem to appreciate this section very much and therefore, updating of the website should be prioritized in biobanks. The content of this site should also be broader than it currently is in many biobanks. For example, a clear pricing list for samples was hoped in the open questions as well as in the discussions with researchers after the presentations. Also, more information about sample-availability was wished.

The pricing of biobank samples is not very straightforward in the Finnish hospital biobanks as it is based not only on the samples' actual costs, but also on the working hours spent in collecting the samples (https://www.helsinginbiopankki.fi, 23.10.2019). A problem that stood out from the survey was the lack of informing the researchers about the prices early enough. A researcher stated that researchers are informed about the (possibly too high) costs of reaching the samples only after the process of checking the sample availability. This process itself might be time-consuming and probably even for nothing if the samples are not available or having them is too expensive. This researcher suggested that the initial services for accessing the samples should be free for researchers to enable as low costs as possible. That is, these services should be covered by someone else than the researcher who pays for the samples. This and the other comments about clear pricing list refer to researchers' preference for a sample-based pricing instead of costs based on working hours. However, it is challenging, even impossible, to build a comprehensive pricing list as the prices of different samples vary so widely. Therefore, at least descriptions of where the prices come from, what they include, and examples of the pricing of certain projects would be beneficial at the biobanks' websites. High prices should not put researchers into inequal positions with pharmaceutical companies and research groups with better resources, but as long as the funding of biobanks is partly external, the samples will cost something for researchers.

Additionally, more information about the sample availability was on the researchers' hope list. A catalogue of available samples would fill this need, and such a catalogue for prospective blood samples is currently under development in FCBT. Additionally, FINBB is currently developing a national, aggregate level catalogue of biobank samples. This

meets the researchers' needs even better as they might be interested samples stored in several biobanks. This and other national services are discussed more closely in the chapter 6.2.

6.1.3 The work continues

Many effects of this study are possible to see only later. As already discussed above, the increased biobank awareness makes researchers more likely to use the biobank later in their studies. Therefore, the number of sample releases from FCBT is expected to grow during the forthcoming years. Naturally, this requires continuing active marketing. Researchers commented in the survey that it is good that FCBT is increasing its visibility and even more aggressive advertising and informing was hoped. This implicates about researchers' great interest towards biobanking. This study was only as a starting engine for further advances in the collaboration between researchers and FCBT.

It would be reasonable to use the same questionnaire as here also later to see how the researchers' views have changed. For example, whether the biobank awareness has improved after continuing researcher-targeted biobank marketing for a year or two, or if sample, data and service preferences have changed. A continuous dialogue between academic researchers and the biobank is important to enable the development of the facilities into the right direction. The questionnaire planned for this study offers a tool to follow the progress of FCBT's operations in researchers' eyes and to see the achievements that further collaboration enables.

6.2 National study targeted to pharmaceutical companies

6.2.1 The companies and their studies

The idea of the questionnaire targeted to pharmaceutical companies was to explore the views of these companies regarding to national biobank services in Finland. This study was conducted in collaboration with FINBB, which nationally coordinates these services. Pharmaceutical companies chosen as a target group for this study were all involved in the FinnGen project and therefore at least somehow connected with biobank operations. For a wider view among the field of pharmaceutical industry in Finland, it would have been beneficial to let more companies participate. However, this restricting of answerers was clear and reasonable, as FINBB had conducted a comparable questionnaire with the international headquarters of these same companies earlier the same year. Seven out of nine (78 %) companies answered to the

questionnaire, which was a satisfactory participation and gave a wide enough vision of the needs of these FinnGen companies.

The therapeutic areas of interest of these companies were very widely distributed (table 14). Only two of the given answering options (imaging and osteoporosis) did not gain any answers, but all the other 18 options were the areas of interest at least for some of the companies. The wide interest of pharmaceutical companies for cancer, memory disorders and other neurological disorders refers to extensive needs of treatments for these disorders. These disorders, as well as diabetes and cardiovascular diseases (both were interest areas for two out of seven companies), are the most important chronic diseases affecting to national health and also significant killers among the Finnish nation (https://thl.fi/en/web/chronic-diseases, 12.10.2019). According to the WHO's Global Action Plan for the Prevention and Control of NCDs [noncommunicable diseases] 2013-2020 (WHO, 2013), these are the biggest causes of death also worldwide. Therefore, it is only logical that pharmaceutical companies respond to the high demand of medicinal treatments for these diseases.

Currently, biobank studies play only a minor role in the studies that these companies conduct (figure 24). This refers to the novelty of biobank operations in Finland; the customary ways of doing research probably stick quite strongly and companies might not know all the possibilities biobanks can offer. However, a positive note from the questionnaire results was that these pharmaceutical companies have noticed the ability of biobanks to offer material for studies that aim to understand the real-world efficacy of treatments (figure 25). The novelty of biobank operations also causes some rigidities in the use of biobank services that might reduce the willingness of companies to conduct biobank researches. Therefore, the question about the challenges in conducting biobank studies in Finland aimed to find out the most remarkable stumbling blocks (figure 31). These answers (discussed shortly) will help FINBB to offer better national biobank service so that in the future, pharmaceutical companies would utilize biobanks more than today.

6.2.2 Challenges, solutions and suggestions

The questionnaire was sent before the Fingenious portal was launched, which enabled the evaluation of the problems that this portal solved or aims to solve. The most commonly experienced challenge was one of the points that Fingenious has now a solution for. That is, the lack of one-point access to submit sample and data access requests. Fingenious also unifies the requirements for access requests that formerly differed between the hospital districts. Consequently, Fingenious also alleviates and fastens the feasibility analyses by coordinating

them on a national level so that an applicant does not have to request the feasibility analyses separately from every biobank. (https://finbb.fi, 23.10.2019) Although the last one was not among the biggest challenges for many, feasibility coordination was rated as the second most important service for pharmaceutical companies (figure 29) and now Fingenious offers a tool for FINBB to do that.

Pharmaceutical companies widely wished for an access in every hospital biobank with a single contract instead of contracting separately with each of them (figures 29 & 31). This need has also been answered already, as FINBB is nowadays able to make a contract on behalf of every hospital district. Additionally, an electronical catalogue for available samples was mentioned both in the question about challenges (figure 31) and in the open question for suggestions to improve national biobank services. Luckily, FINBB is already developing such a catalogue of biobank samples available in the Finnish hospital biobanks.

Still, some challenges remain unsolved. Collaboration of all the hospital biobanks, as well as coordination form FINBB, is required when reaching towards more unified biobank services. Biobanks should, for example, agree about the common time limits for all sample release processes to reach as predictable biobank processes as possible. Predictable processes for all biobank studies, as well as faster approvals of applications, were among of the most important improvements that pharmaceutical companies wished for. A possible solution for making the biobank processes more predictable was given as one answering option for most important biobank services: an electronic portal to follow study progress (figure 29). As expected from the other results, that option was one of the three most important services pharmaceutical companies would like to use. Currently a service like this does not exist, but it would be a beneficial addition into the Fingenious portal. However, that alone is not enough to make the processes predictable, not to mention faster. Still, an active contribution from every biobank is required to enable faster approvals and predictable processes.

6.2.3 Values

Pharmaceutical companies highly appreciate the high-quality data and samples. The quality seems to be on a very good level already, as it was not seen as a big challenge. The high quality of samples and data also seems to be more of a presumption than an asset, as a higher than expected sample/data quality would be a reason to pay a service fee for only two companies (figure 27). Now that Fingenious facilitates the applying of materials simultaneously from several biobanks, the number of studies utilizing this possibility probably increases. This makes the standardization and documentation of data and sample processing even more important.

The standardization procedures described in the chapter 2.3 *Biobank standardization*, for example the ISO biobank standard, offer tools to ensure the equally high quality of data and samples between biobanks. Obeying every standardization tool in one biobank is not reasonable, but to find a common line in standardization, FINBB could offer centralized instructions for standardization procedures that every biobank should follow.

In addition to high quality of samples and data, also time and money naturally mean much to pharmaceutical companies when conducting biobank studies (figures 26 and 27). This implicates how valuable the above-described unifying actions to fasten the processes in biobanks would be for these companies. Biobanks would benefit even financially by hitting the milestones faster than expected, if a service fee suggested in the questionnaire (appendix 5, question 16, figure 27) would be taken into action. Additionally, the willingness to save money was clearly observable in the questionnaire answers. These companies would appreciate if the study results would be demonstrably used in pricing and reimbursement negotiations (figure 27). On the other hand, they would not be willing to pay a service fee to ensure the benefitting of hospitals and universities (figure 27). This is not surprising as the companies naturally want to benefit their results primarily themselves. However, the business model of FINBB enables the return of financial outcomes to hospitals and universities, which are the entities enabling the biobank studies. That is, the samples and data are mainly collected within these hospitals by hospital biobanks, which in turn are funded partly by universities (https://www.tays.fi/biopankki, 23.10.2019). Furthermore, the idea of biobanks is that the collection yields interest every time the samples are used in a research as the study results are returned to the biobank (Hainaut et al., 2017, p. 106). This kind of operational model might be in contradiction with the commercial interests of pharmaceutical companies (Mackenzie, 2014) and may reduce the interest in utilizing biobank collections in their product development.

6.2.4 Building the best biobank network in the world – together

The launching of Fingenious was a significant leap from FINBB towards nationally coordinated and unified biobank services. The possibilities of the portal are not fully utilized yet and development of the portal should continue into the direction of making the implementation of biobank studies easier and more predictable for pharmaceutical companies and other users. As the pharmaceutical companies clearly long for a service that would create an impression of one biobank instead of six hospital biobanks, a logical next step would be to add THL Biobank, Blood Service Biobank, and Hematological Biobank under the same service as well. To enable the wished improvements in unifying the biobank services in Finland, FINBB should continue

doing what is meant for: bringing biobanks closer to each other. As their slogan in the subheading says, these improvements are possible only with close collaboration of biobanks.

Naturally, collaboration is required with the other side as well, that is, with the biobank users. A questionnaire like this was a good way to communicate with pharmaceutical companies and to find out their needs regarding to the development of national biobank services. Therefore, the questionnaire worked well in achieving the objective of this study. Although reaching a reasonable number of answerers was and will be challenging, the customer questionnaires will be usable tools for FINBB to enhance effective communication also in the future.

6.3 Academic researchers vs. pharmaceutical companies

The biggest difference between the needs of academic researchers and pharmaceutical companies was their interest in data and samples. The academic researchers' interests were widely distributed among different sample and data types, presumably depending on the researchers' area of research. Conversely, pharmaceutical companies were primarily interested in data, whereas their interest towards samples was significantly lower (figure 28). As discussed above, the therapeutic areas of interest were widely distributed among the companies and therefore, the areas of studies cannot explain this. Actually, a combining factor for both of these biobank user types was that cancer was one of their most popular research areas. This might explain the fact that tissue samples were the most popular samples for both, but it also refers to their different styles of research. As the pharmaceutical companies told, they mostly conduct biobank or biodata studies to understand the real-world efficacy of treatments. Studies like this are mainly data-based, using data from patient and prescription registers (Graham et al., 2018). Therefore, although both academic researchers and pharmaceutical companies would both do cancer research, the research of academic researchers most likely utilize both samples and data, whereas the research in pharmaceutical companies primarily focus on data. Of course, exceptions to this rule may occur to direction or another, but this study refers to such a division.

The study targeted to pharmaceutical companies was focused on national services and the one targeted to academic researchers focused on the local services. Therefore, reliable comparisons cannot be made regarding to the needs for national and local services. Still, pharmaceutical companies clearly longed for nationally coordinated services. When it comes to academic researchers, the width of a research project is often smaller than in the studies conducted by international companies (Mackenzie, 2014). This and still relatively low level of

biobank awareness among academic researchers address that local services should be prioritized when improving the collaboration with academic researchers. Academic researchers should become more familiar with the possibilities that biobanks can offer to become interested also in the national services. Therefore, FCBT and other Finnish hospital biobanks should focus on implementing active and informative advertising to academic researchers and on developing the collections to meet the needs of these local researchers. Pharmaceutical companies, in turn, showed very limited interest towards local biobank services. Their product development, in turn, more typically require data and samples depicting wider part of the population (Mackenzie, 2014). Thus, accessing as many biobanks as possible as easily as possible serves their needs the best. For this, the development of nationally coordinated biobank services is needed.

As segmentation is one of the cornerstones in marketing (Kotler & Keller, 2016), the differing needs of each stakeholder should be taken into account when planning biobank marketing in the future. The observations in this study suggest that the current main target segment for FCBT should be local academic researchers. FINBB, on the other hand, serves frequently both academic and industrial researchers. The different needs of these customer segments regarding to biobank services require specified establishment, communication, and delivery (Kotler & Keller, 2016) of the benefits that FINBB can offer to each segment. This makes the marketing more effective and distinctive even internationally.

Both academic researchers and pharmaceutical companies wished for more information about the samples and related data that are currently available at biobanks. As mentioned in the chapter 2.3.6 *IT systems and data standardization*, an electronic catalogue of available samples and data would support the efficient usage of the sample collections (Chalmers et al., 2016; Ciaburri et al., 2016; Paradiso et al., 2018). FINBB is currently developing such a catalogue and in the near future, information about the contents of the Finnish hospital biobanks can be found under the same portal.

The novelty of biobank operations in Finland reflected from the both parts of this study. In the local part of the study, the biobank awareness and the number of researchers that had used the samples or services from FCBT was still very low. Conversely, the shortages in the national services and in the harmonization of the processes among Finnish biobanks implicates the novelty of operations in the national part of the study. Luckily, Fingenious filled the gaps of several lacks in national services and is an excellent example of how the processes are being developed continuously in the Finnish biobanking field.

FINBB and BBMRI.fi, together with the Biobank Law and biobank standards, secure the national standardization in the biobank sample and data handling in Finland. Although the quality of the Finnish biobank collections is known to be high-level already now, FCBT and other Finnish biobanks should follow Auria Biobank's example and start the work towards accreditation of ISO biobank standard in the forthcoming years. Accreditation would strengthen the acknowledged high sample and data quality in the Finnish biobanks by offering a fact-based evidence for it. It would also improve the international standardization of the Finnish biobank operations and therefore international collaboration as well. Furthermore, applying the data sharing standards such as BRISQ, SPREC and MIABIS into the standards in use would increase the international attractiveness of the Finnish biobank materials even more. Every biobank in Finland is too small to arouse international interest on its own (Palotie et al., 2019), but by combining their forces through Fingenious and with the FinnGen project, the unique biobank collections in the Finnish biobanks can show their full potential and be appealing internationally as well.

7 Conclusion

This study consisted of two parts: 1) the local part targeted to academic researchers at Tampere University and Tays and 2) the national part targeted to pharmaceutical companies. Investigation of the needs and expectations for biobank operations both locally and nationally, and among two biobank user groups, enabled having a vision of the direction to which the Finnish biobanking should be developed. Additionally, the level of academic researchers' local biobank awareness and the best ways to increase it were explored.

Academic researchers are still widely unfamiliar with the local biobank services served by FCBT. To increase the use of biobank(s) in academic research, the researchers should become more aware of biobanks. For this, local marketing is a primary task. From the methods tested in this study, face-to-face presentation appeared to be most effective method. The other tested methods, email and leaflet, were not as effective. The receiver group was too small for email marketing to succeed. The leaflet alone was not an efficient way to share biobank information, but together with presentation, led to best results in increasing biobank awareness. Eventually, the marketing implemented as a part of this study succeeded in increasing the level of researchers' biobank awareness. Nevertheless, marketing needs to continue to reach wider awareness and better collaboration between FCBT and local academic researchers. This, in turn, may lead to their further interest in using biobanks on a national level as well.

For pharmaceutical companies, the biggest problem in national biobank services is the lack of unified services enabling seamless use of all Finnish biobanks. The Fingenious portal launched after this survey is a significant improvement towards more integrated services. FINBB as a national service provider cannot alone unify the Finnish biobank processes; rather, it should coordinate the collaboration of all Finnish biobanks to reach more unified processes. According to the survey, improvement of the predictability of biobank projects and accelerating the study set-up times should be prioritized.

Generally, the academic researchers' needs for biobank materials are more distributed among different sample and data types than the companies' needs, which are primarily focused on data. The differing needs have to be taken into account when developing services and marketing to different stakeholders, both locally and nationally. Finally, the international guidelines and standards are recommended to use as tools both for FCBT in their service development and for FINBB to offer centralized instructions for standardization procedures for biobanks. The use of common standards would unify the biobanking processes and ensure the sample quality across the Finnish biobanks.

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Appendices

1 Questionnaire for academic researchers: autumn 2018
2 Questionnaire for academic researchers: spring 2019
3 Email marketing
4 Leaflet
5 Questionnaire for pharmaceutical companies

APPENDIX 1 Questionnaire for academic researchers: autumn 2018

A questionnaire to study biobank awareness among researchers in Tampere region, round 1

This questionnaire is targeted to research groups at University of Tampere, Tampere University of Technology, and Tampere University Hospital.

The aim of the survey is to find out the level of researchers' awareness of Tampere Biobank (Finnish Clinical Biobank Tampere). This information is used to build a strategy to increase the visibility of Tampere Biobank and to make it more easily approachable to researchers. This survey also aims to find out the researchers' needs and expectations from the biobank services and sample collection. The answers are used to develop the operations of Tampere Biobank to meet those needs. The survey will be repeated later in the spring 2019 to test the effect of marketing.

This survey is a part of a master's thesis project 'Investigation of national needs on biobank services and improvement of biobank awareness among researchers and biomedical companies' by Enni Makkonen, a student from University of Tampere, Faculty of Medicine and Life Sciences.

The answers are used only for this study and will be deleted after the master's thesis project is finished in the summer 2019. If you have questions related to the survey, please send email to x.

Thank you for your participation!

Awareness

1. When did you first hear about Tampere Biobank?

In the last month
In the last 6 months
In the last 12 months
In the last 3 years
I have never heard of it

2. Where have you seen or heard about Tampere Biobank? (Please check all that apply)

University of Tampere
Tampere University of Technology
Tampere University Hospital (Tays)
Tampere Biobank's website
www.biopankki.fi
BBMRI.fi
FINBB
Medical journal
Word of mouth (colleague, friend or family)
I have never heard of it
Other (please specify below)
If other, what?

3. From where would you like to get more information on biobank operations? (Please check all that apply)

Biobank's own website targeted to researchers
Education and science events
My own organization's internal communication
Events organized by biobank
Personal contact
Other (please specify below)
If other, what?

4. What do you think about the following arguments?
(Strongly disagree / Disagree / Neither agree nor disagree / Agree / Strongly agree / Do not know)

I have received enough information about Tampere Biobank.
The visibility of Tampere Biobank is good enough.

Samples and services

5A. Have you used samples or services from Tampere Biobank?

Yes
No (you can skip the question 5B)

5B. Which of the following samples / services have you used from Tampere Biobank?
(Yes / No, but I knew about it's availability / No, I didn't know about it)

Tissue samples
DNA
Serum
Plasma
Laboratory services
Sampling
Sample and data release services
Preliminary report requests and other inquiries
Histological dyeing
Statistical analysis
Tissue microarray (TMA) blocks
Tissue section scanning
Serum biomarker analysis

6. Which of the following samples / services from Tampere Biobank would you be interested to use?
(Very interested / Slightly interested / Not interested)

Tissue samples
DNA
Serum
Plasma
Laboratory services
Sampling
Sample and data release services
Preliminary report requests and other inquiries
Histological dyeing
Statistical analysis
Tissue microarray (TMA) blocks
Tissue section scanning
Serum biomarker analysis

7. What kind of samples / services biobank should offer? (Please check all that apply)

Whole blood
Erythrocytes
Plasma
Serum
Tissue samples
Cells
Secretion samples (e.g. urine, saliva)
DNA
Disease-specific samples (please specify below)
Diagnoses
Health data (e.g. blood pressure, lifestyle information)
Other (please specify below)
Please specify your answer:

8. How satisfied are you with Tampere Biobank in the following areas?
(Very dissatisfied / Dissatisfied / Neutral / Satisfied / Very satisfied / Do not know)

Sample and data collection
Sample and data quality
Service selection
Service quality

9. What do you think about the following arguments?
(Strongly disagree / Disagree / Neither agree nor disagree / Agree / Strongly agree / Do not know)

It is easy to take use of Tampere Biobank's services and sample collection.
I could recommend Tampere Biobank to my colleagues.

10. How would you improve the operations of Tampere Biobank? (e.g. sample collections, sample releases, offered information)

Background information

Birth day
Birth month
Birth year
(Date of birth is used only for identifying the answerers between the two questionnaires (this one and the control questionnaire in the spring).)

Where do you primarily work? (before the merger of University of Tampere and Tampere University of Technology)

University of Tampere
Tampere University of Technology
Tampere University Hospital
Other (please specify below)
If other, what?

What best defines your current role?

Group leader
Researcher
Postdoc
Doctoral student
Assistant / trainee / student
Other (please specify below)
If other, what?

Area of research

Interested to hear more?

Would you like to hear more about Tampere Biobank? We will organize short presentations during January - February to introduce the operations of Tampere Biobank and would be pleased to get to visit your research group. May we contact you?

Yes, please. (please leave your contact information on the next page)
No thanks.

Do you want to have a chance to win movie tickets?

Of course! (please leave your contact information on the next page)
No thanks.

Contact information

Name; Email

APPENDIX 2 Questionnaire for academic researchers: spring 2019

A questionnaire to study biobank awareness among researchers in Tampere region, round 2

This questionnaire is targeted to research groups at Tampere University and Tampere University Hospital. This is the second round of the survey consisting of two almost equal questionnaires. The first one was sent in the late autumn 2018. You can answer to this questionnaire even if you did not participate in the first round.

The aim of the survey is to find out the level of researchers' awareness of Finnish Clinical Biobank Tampere (Tampereen Biopankki; in this questionnaire referred to as "Tampere Biobank"). This information is used to build a strategy to increase the visibility of Tampere Biobank and to make it more easily approachable to researchers. This survey also aims to find out the researchers' needs and expectations on the biobank services and sample collection. The answers are used to develop the operations of Tampere Biobank to meet those needs.

This survey is a part of a master's thesis project *'Investigation of national needs on biobank services and improvement of biobank awareness among researchers and biomedical companies'* by Enni Makkonen, a student from Tampere University, Faculty of Medicine and Health Technology.

All personal data given in the questionnaire will be kept confidential and will not be linked to given answers. All given data will be deleted after the master's thesis project is finished in the early autumn 2019. If you have questions related to the survey, please send email to x.

Thank you for your participation!

Awareness

1. When did you first hear about Tampere Biobank?

In the last month
In the last 6 months
In the last 12 months
In the last 3 years
I have never heard of it

2A. Where have you seen or heard about Tampere Biobank? (Please check all that apply)

Tampere University (Kauppi campus)
Tampere University (Hervanta campus)
Tampere University (City Centre Campus)
Tampere University Hospital (Tays)
Tampere Biobank's website
www.biopankki.fi
BBMRI.fi
FINBB
Medical journal
Word of mouth (colleague, friend or family)
I have never heard of it
Other (please specify below)
If other, what?

2B. What kind of marketing/share of information from Tampere Biobank have you encountered during the last 6 months?

Biobank presentation at our group meeting
Information package sent by email
Leaflet(s)
I attended to the Biobank Seminar on April 12
Other (please specify below)

Nothing, except for this/these questionnaire(s)
If other, please specify:

2C. Please give us some feedback about the marketing/share of information from Tampere Biobank you have encountered. (E.g. How informative was it? How did it work as a marketing method for the biobank?)

3. From where would you like to get more information on biobank operations? (Please check all that apply)

Biobank's own website targeted to researchers
Education and science events
My own organization's internal communication
Events organized by biobank
Personal contact
Other (please specify below)
If other, what?

4. What do you think about the following arguments?
(Strongly disagree / Disagree / Neither agree nor disagree / Agree / Strongly agree / Do not know)

I have received enough information about Tampere Biobank.
The visibility of Tampere Biobank is good enough.

Samples and services

5A. Have you used samples or services from Tampere Biobank?

Yes
No (you can skip the question 5B)

5B. Which of the following samples / services have you used from Tampere Biobank?
(Yes / No, but I knew about it's availability / No, I didn't know about it)

Tissue samples
DNA
Serum
Plasma
Laboratory services
Sampling
Sample and data release services
Preliminary report requests and other inquiries
Histological dyeing
Statistical analysis
Tissue microarray (TMA) blocks
Tissue section scanning
Serum biomarker analysis

6. Which of the following samples / services from Tampere Biobank would you be interested to use?
(Very interested / Slightly interested / Not interested)

Tissue samples
DNA
Serum
Plasma
Laboratory services
Sampling
Sample and data release services
Preliminary report requests and other inquiries
Histological dyeing
Statistical analysis
Tissue microarray (TMA) blocks

Tissue section scanning
Serum biomarker analysis

7. What kind of samples / services biobank should offer? (Please check all that apply)

Whole blood
Erythrocytes
Plasma
Serum
Tissue samples
Cells
Secretion samples (e.g. urine, saliva)
DNA
Disease-specific samples (please specify below)
Diagnoses
Health data (e.g. blood pressure, lifestyle information)
Other (please specify below)
Please specify your answer:

8. How satisfied are you with Tampere Biobank in the following areas?

(Very dissatisfied / Dissatisfied / Neutral / Satisfied / Very satisfied / Do not know)

Sample and data collection
Sample and data quality
Service selection
Service quality

9. What do you think about the following arguments?

(Strongly disagree / Disagree / Neither agree nor disagree / Agree / Strongly agree / Do not know)

It is easy to take use of Tampere Biobank's services and sample collection.
I could recommend Tampere Biobank to my colleagues.

10. How would you improve the operations of Tampere Biobank? (e.g. sample collections, sample releases, offered information)

Background information

Where do you primarily work?

Tampere University, Kauppi Campus
Tampere University, Hervanta Campus
Tampere University (City Centre Campus)
Tampere University Hospital
Other (please specify below)
If other, please specify:

What best defines your current role?

Group leader
Researcher
Postdoc
Doctoral student
Assistant / trainee / student
Other (please specify below)
If other, please specify:

Area of research

For those who answered to the first questionnaire as well (others, please click Next and then Finish to save the data)

Birth day
Birth month
Birth year

(Date of birth is used only for identifying the answerers between the two questionnaires (this one and the first questionnaire in the autumn).)

Do you want to have a chance to win movie tickets?

(Two sets of two movie tickets are raffled between all those who answered to the first questionnaire last autumn and to this second questionnaire.)

Of course! (please leave your contact information on the next page)
No thanks.

Contact information

Name
Email

APPENDIX 3 Email marketing

(in English below)

Hei tutkija,

Tarvitsetko ihmisperäisiä näytteitä tutkimuksessasi, mutta näytekeräys vie liikaa aikaa ja vaivaa? Tampereen Biopankki toimii ensisijaisesti tamperelaisten tutkijoiden hyväksi, ja tarjoaa monipuolisen ja jatkuvasti kasvavan näytekokoelman tutkijoiden käyttöön.

Tampereen Biopankki kerää näytteitä suostumuksen antaneilta potilailta tulevia tutkimustarpeita varten, tavoitteenaan kehittää lääketieteellistä tutkimusta. Biopankki helpottaa tukijan työtä, sillä tutkijan ei tarvitse kerätä ja säilöä omia näytteitään. Biopankin kautta tutkija pääsee käsiksi kattavaan ja erilaisilla rekisteritiedoilla rikastettuun näytekokoelmaan hyvin kohtuullisella hinnalla. Näytekokoelmaa kehitetään jatkuvasti tutkijoiden toiveiden mukaan.

Tällä hetkellä Tampereen Biopankin näytekokoelma sisältää mm.

- diagnostisia patologian kudosnäytteitä (FFPE-blokkeja), mm. syöpäkasvaimista
  - ~3,4 miljoonaa näytettä
- kliinisen genetiikan näytteitä (veri-, solu- ja kudosnäytteitä)
  - ~30 000 näytettä
- prospektiivisia eli uusia kerättäviä veri- ja kudosnäytteitä (jokaisesta verinäytteestä tehdään seerumi-, plasma- ja DNA-näytteet)
  - näytteitä tällä hetkellä ~7 000 henkilöltä

Mitä tutkijan täytyy tehdä saadakseen näytteitä tutkimukseensa?

1. Ota yhteys biopankkiin, niin selvitämme tarvitsemiesi näytteiden saatavuuden.
   - Lähetä täytetty esiselvityspyyntölomake sähköpostilla osoitteeseen biopankki@tays.fi (lomake tämän viestin liitteenä).
2. Kun olet saanut biopankilta myönteisen vastauksen näytteiden saatavuudesta, täytä ja lähetä varsinainen näyte- ja tietoluovutushakemus.
   - Hakemus tarkastetaan ja annetaan tieteellisen ohjausryhmän arvioitavaksi.
   - Biopankin johtaja tekee päätöksen aineiston luovutuksesta ohjausryhmän lausunnon perusteella.
   - Laaditaan luovutussopimus ja sovitaan aloituskokous käytännön asioiden sopimista varten.
3. Käytä biopankkinäytteitä tutkimuksessasi ja raportoi tutkimuksen etenemisestä Biopankille 6 kuukauden välein.
4. Tutkimuksen jälkeen palauta raakadata ja näytteistä analysoidut tulokset Tampereen Biopankkiin. Näin näytekokoelman tutkimuksellinen arvo kasvaa.

Lisätietoja ja tarvittavat lomakkeet löydät osoitteesta www.tays.fi/biopankki. Voit ottaa yhteyttä Tampereen Biopankkiin joko sähköpostilla biopankki@tays.fi tai puhelimitse 03 311 65205 (toimisto) tai x (laatukoordinaattori Johanna Mäkelä).

Kysy lisää biopankkitutkimuksen mahdollisuuksista ja luodaan yhdessä uusia terveysinnovaatioita!

Yhteydenottoasi odottaen,

Tampereen Biopankki

Dear researcher,

Do you need human biological samples in your research, but sample collection takes too much time and effort? The primary purpose of Finnish Clinical Biobank Tampere is to operate for researchers' benefit in Tampere region by offering an extensive and continuously growing sample and data collection for research use.

Finnish Clinical Biobank Tampere collects and stores biological samples and data from the consent given patients for future medical research. Biobank makes researcher's work easier, as you do not need to collect and store samples on your own. Through Biobank, the extensive collection of samples enriched with data from various health registers is available for researchers with very reasonable price. The sample collection is developed continuously to meet researchers' needs and wishes.

Currently, our sample collection consists of

- diagnostic pathology tissue samples (FFPE blocks), e.g. cancer tumors
    - ~ 3,4 million samples
- clinical genetics samples (blood, cell and tissue samples)
    - ~ 30 000 samples
- prospective blood and tissue samples (every blood sample is divided into aliquots for serum, plasma and DNA extraction)
    - currently, samples from ~7 000 persons

What researcher needs to do to get biobank samples for research use?

1. Contact biobank. We will find out if the material of your interest is available.
    - Fill out the preliminary request form (you can find it attached to this email) and send it to biopankki@tays.fi.
2. When you get a positive response of the material availability, fill out the actual sample and data release application.
    - The application is checked, and the scientific steering group evaluates it.
    - Director makes a decision for sample release based on the statement from the steering group.
    - After a positive decision, starting meeting is arranged and Material Transfer Agreement (MTA) prepared.
3. Use biobank materials in your research and report the progression of the project in every 6 months to the Biobank.
4. After the research, return the raw data and other results analyzed from the samples to the Biobank. This increases the scientific value of the sample collection.

More information and all the needed forms can be found in www.tays.fi/biopankki. You can also contact Finnish Clinical Biobank Tampere by emailing to biopankki@tays.fi or calling 03 311 65205 (office) or x (quality coordinator Johanna Mäkelä).

Ask for more information about the possibilities of biobank research and let's create new health innovations together!

Looking forward to your contact,

Finnish Clinical Biobank Tampere

APPENDIX 4 **Leaflet**

Finnish Clinical
Biobank Tampere

Biobank Research Can Help the Entire Medical Field

Finnish Clinical Biobank Tampere collects and stores biological samples and data related to donor's health for future research needs.

Biobanks aim to improve medical research and product development, enhance diagnostics and eventually public health. Sample collection is done together with diagnostic samples, always with the donor's consent.

Finnish Clinical Biobank Tampere holds sample collections of diagnostic tissue samples, clinical genetics samples, including blood, cell and tissue samples, and prospective blood and tissue samples. The collection is growing continuously, and researchers' needs are taken into account when planning new collections.

Samples are released for research as pseudonymized to ensure the donor's privacy. After the research has been completed, the sample and related research data are returned to the biobank. Therefore, the value of the sample 'yields interest' as the sample and data related to it can be used in future research projects.

Our sample your research

Biobank Can Make Your Work Easier

- No need to collect or store samples
- Extensive and continuously growing sample collection
- Samples enriched with data from various registers
- Tailored sample collection for your research needs

Steps in Biopank Research

1. Research question arises
2. Contact biobank
3. Feasibility analysis
4. Request for data and samples
5. Transfer of the data and samples
6. Research using biobank materials
7. Return of the data to biobank

We Help You to Improve Your Research and Achieve Higher Goals

Biobank collects the research material, brings the samples and their valuable data to researchers, and ensures high quality of the research.

For more information please contact:

**Finnish Clinical
Biobank Tampere
Tampere University Hospital
FM5, 1st floor.
Biokatu 12, 33520 Tampere
Tel. +358 3 311 65205
biopankki@tays.fi**

Finnish Clinical
Biobank Tampere

APPENDIX 5 Questionnaire for pharmaceutical companies

BUILDING THE BEST BIOBANK NETWORK IN THE WORLD – TOGETHER

This questionnaire is targeted to the Finnish pharmaceutical companies participating in the FinnGen project. The aim of the survey is to find out the needs and expectations on biobank services in Finland among these companies. The results of the survey are used to develop the biobank services to meet the identified needs on both national and local level. The ultimate goal is to build the best biobank network in the world – together.

The survey is a part of a master's thesis project 'Investigation of national needs on biobank services and improvement of biobank awareness among researchers and biomedical companies' by Enni Makkonen, a student from Tampere University, Faculty of Medicine and Health Technology. The survey is implemented as a collaboration between the Finnish Biobank Cooperative (FINBB) and Finnish Clinical Biobank Tampere.

The aggregate level results of this survey will be shared with the participating companies by the end of June 2019 and published in the master's thesis. All personal data will be kept confidential by Tampere University, Finnish Clinical Biobank Tampere and FINBB. If you have questions related to the survey, please send email to x.

It will take approximately 10 minutes to complete the survey. Thank you for your participation!

Background information

1. Personal details (optional)
Name
Affiliation

2. What is your role in or relationship with the FinnGen project?

3. Are you a decision-maker in the initiation of biobank studies in your organization?
Yes
No
Do not know

4. How well do you know Finnish biobanks?
Familiar and we have used their services
Familiar, but we have not used their services
Not familiar at all

Research

5. How do your organization's research projects fall into the following categories? Please fill in the approximate numbers of projects within the last year.
Biobank studies:
Register studies:
Clinical studies:
Other studies (please specify below):
If other, please specify:

6. Which therapeutic area(s) are of interest to you or your organization? Please choose all relevant options.
Rare diseases
Ultra-rare diseases
Cancer (hereditary)
Cancer (non-hereditary)
Obesity

Diabetes
Gastroenterology
Cardiovascular diseases
Psychiatry
Memory disorders
Other neurological disorders (please specify below)
Arthritis
Osteoporosis
Ophthalmology
Rheumatology
Pulmonology
Dermatology
Immunology
Imaging
Medical devices (please specify below)
Other (please specify below)
Please specify, if asked:

7. What biodata/biobank study types are relevant for you or your organization? Please choose 1 to 3 most important options.

Biobank study including sample processing and data (not FinnGen-related)
Biobank study only including data (not FinnGen-related)
Biobank study including sample processing and data (FinnGen add-on/spin-off)
Biobank study only including data (FinnGen add-on/spin-off)
Register study not concerning biobanks
Patient recall for clinical studies through biobanks
Other (please specify below)
If other, please specify:

8. For what purposes do you or your organization primarily conduct biodata/biobank studies? Please choose three most important options.

Understanding disease mechanisms
Developing better diagnostic practices
Identification of novel drug target(s)
Identification of high responders/non-responders
Quicker recruitment of study subjects for clinical studies
Understanding real world efficacy of treatments
Understanding treatment adverse events
Uncovering off-label use
Understanding burden of disease
Other (please specify below)
If other, please specify:

9. Please assess how important the following biobank/biodata services are for you. Please scale from 1 to 5 (1 = Not important, 5 = Very important).

Feasibility coordination
Scientific support in protocol writing
Available electronic biobank samples and related data catalogue
Data and sample access request submission (approval applications) via electronic self-service portal
Data and sample request submission (approval applications) by a service team member
One contract to access all Finnish hospital biobanks
Finding collaborator clinicians for biobank studies
Project management services
Electronic portal to follow the study progress
Data delivery platform for researcher-driven data analytics
Data analytics services
Laboratory services
Sampling
Histological dyeing

Tissue microarray (TMA) blocks
Tissue section scanning
Serum biomarker analysis
Other (please specify below)
If other, please specify:

10. Which of the following (biobank) sample or data types are relevant for your research? Please check all that apply.

Whole blood
Erythrocytes
Plasma
Serum
Tissue samples
Cells
Secretion samples (e.g. urine, feces, saliva)
DNA
Disease-specific samples (please specify below)
Diagnoses
Medical records (e.g. medications, procedures, laboratory values)
Health data (e.g. lifestyle information)
Other (please specify below)
Please specify, if asked:

National services

11. On a scale 1 to 5, how valuable would nationally coordinated biobank services be to your organization? (1 = Not valuable at all, 5 = Extremely valuable)

12. How would you define a successful biodata/biobank study? Please choose three most important options.

Milestones are met in targeted time or faster
Study is conducted within or less than the agreed budget
Study results are as expected or exceed the expectations
Data and samples are of high quality
Results are published in top-tier journal(s)
Other, please specify
If other, please specify:

13. In your opinion, what are the key challenges in conducting a biodata or biobank study in Finland? Please choose 1 to 5 most important challenges.

Lack of national feasibility coordination
Feasibility assessments take too long
Lack of electronic catalogue of biobank sample and related data catalogue
Lack of clinician network for data collection
Study set-up time, including applying for approvals, is too long
Lack of one point of access to submit data and sample access requests
Different submission requirements for data and sample access requests, varying per hospital district
Contracting separately with hospital districts
Lack of consolidated data platform from different data sources
Getting the data/samples takes too long
Data is of poor quality
Samples are of poor quality
Lack of data analytics services
Other (please specify below)
If other, please specify:

14. The FinnGen project's genomic data will be returned to Finnish biobanks and will be available for biobank studies via FINBB. Which are the most important aspects of biodata studies in your opinion? Please choose five most important options.

Access to longitudinal phenotype data combined with genotype data
Innovative ways to connect investigators and companies to conduct biodata studies
Innovative ways to fund the investigator-initiated studies by returning the benefits to the next round of studies
The results of the biodata studies are shared with investigators, hospital decision makers, clinical staff, and study subjects
The biodata studies help pharma companies to give up non-functional drug molecules earlier, thus saving time and resources
The biodata studies shorten the clinical development time of new drugs
The biodata studies help hospitals to renew their clinical decision making and treatment (e.g. which drug or medical device is safe, effective, and efficient)
The biodata studies enable medical devices' pilot testing and validation for life science companies
The biodata studies fulfill all ethical and legal aspects
The returned genomic data is reliable and secure
The returned genomic data with combined sample data will inspire top-level investigators and companies to collaborate with FINBB and the Finnish research ecosystem
The returned genomic data helps physicians to personalize diagnostics, treatment decisions, and medication follow-up on tolerability and efficacy
The returned genomic data helps healthcare professionals and genetic counselors to inform and motivate patients to carry on lifestyle changes that prevent outcomes of serious conditions such as obesity, diabetes, strokes, memory diseases, and some cancer
Other (please specify below)
If other, please specify:

15. Please define how much your company would be willing to invest in national-level biodata or biobank studies in the next three years in Finland?

< 100 000 EUR
100 000 – 1 000 000 EUR
1 000 000 – 5 000 000 EUR
5 000 000 - 10 000 000 EUR
More than 10 000 000 EUR
Do not know

16. What would be the most probable condition(s) of the biodata/biobank studies which you or your organization would be willing to pay a service fee for? Please choose 1 to 3 most likely options.

Milestones are hit earlier than targeted
Data quality is higher than expected
Study meets its protocol-defined objectives
Study results are demonstrably used in the development pipeline of the drug/therapeutic area in question
Study results are demonstrably used in pricing and reimbursement negotiations
Exclusivity of biodata for a certain period of time
The data and financial outcome return to Finnish hospitals and universities
Other (please specify below)
If other, please specify:

17. How would you improve the Finnish biobank operations? (e.g. access to sample collections, sample/data selection and quality, national or local services, etc.)