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TOO BIG TO FAIL? – A CASE STUDY OF THE RISE AND FALL OF A LARGE-SCALE LIFE-SCIENCE RESEARCH INFRASTRUCTURE

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Too Big to Fail? – A Case Study of the Rise and Fall of a Medical Research Infrastructure

THESIS FOR DOCTORAL DEGREE (Ph.D.)

By

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For my beloved Mother.

ABSTRACT

Introduction:
Distributed Research Infrastructures are becoming increasingly more salient as science expands and universities continue to look for new means to cooperate and share expertise and expenses on large-scale projects. One area which has seen much development in recent years is biobanking, as there have been numerous attempts to harmonise the different biobanking standards over the years, none of which have been entirely successful. BBMRI.se was an EU-initiative that sought to harmonise the biobanks nationwide. BBMRI.se, was thus selected as a case for studying how a distributed Research Infrastructure was set up. At the time of its creation, the organisation constituted the largest investment ever made by the Swedish Research Council in a medical Research Infrastructure. The organisation involved all Swedish universities with a medical faculty, in addition to two other universities. However, the organisation was marred by a number of controversies and would eventually fold in 2018.

Aim:
This dissertation is to elucidate the mechanisms involved in the construction of a medical large-scale distributed Research Infrastructure, and to understand the motivations and rationale of the experts who activate themselves in constructing it. Thus, the overall aim of this doctoral thesis is to identify the benefits and constraints of forming a large-scale medical, distributed Research Infrastructure. Specifically, this dissertation looks at a real-life case while comparing it to the available literature covering the development of Research Infrastructures as well as some of the theories covering mindsharing and collective entrepreneurship. The ambition is to contribute knowledge on the determining factors in bringing a large-scale infrastructure together as well as the risks associated with it. Hence, this dissertation asks the following research question: *What are the principal lessons for researchers, entrepreneurs and funders that can be inferred from the formation of a large-scale distributed Research Infrastructure towards securing more sustainable prospects for similar, future endeavours?* More precisely, this dissertation seeks to determine what the most debated topics are within the academic discourse on Research Infrastructures (study I), after which it looks at the factors involved in constructing shaping a distributed Research Infrastructure (study II). The study then endeavours to looks at some of the pitfalls and how managerial self-governance affects organisational failure (study III). The study then seeks to investigate the mind-set of the managers/pioneers involved in setting up BBMRI.se and if they perceive the organisation in a similar fashion for the other managers (study IV) and how they have reasoned behind their motivations for joining the initiative in the first place (study V). The overall results have endeavoured to elucidate what components are at work when forming such an infrastructure at an organisational level, but also to understand the reasoning and motivation that the individuals responsible in setting up the infrastructure might have had, and how their visions and/or actions may have impacted on the organisation.

Method:
Some various designs and data collection methods were used in this dissertation. Study I was a literature study carried out as a narrative review using the PRISMA statements as a guideline. Both the Web of Science (WOS) and PubMed databases were scoured for articles. Study II-V used qualitative, semi-structured interviews with BBMRI.se managers. All of these studies took on the form of iterative, directed content analyses, with the exception of study III, which was an inductive, directed content analysis.

Results:
Study I found that the most commonly discussed topics concerned the need for developing

and expanding the use of "infrastructures". The findings indicated that the future of scientific research calls for a deeper and more widespread multidisciplinary forms of collaboration.

Study II found that it is crucial to identify the potential collaborative and deliberative organisational elements of organisational team building already at the outset of establishing a distributed Research Infrastructure. The study also found that, contrary to suggestions of extant literature, the establishment of a distributed Research Infrastructure does not necessarily counteract organisational fragmentation.

Study III identified that an organisation with high levels of task uncertainty and low levels of organisational integration will suffer from organisational fragmentation. The type of fragmentation manifested in BBMRI.se is best identified as a "fragmented adhocracy". This means that the organisation's mission statement is subject to diverse views, leading to goals that are separate, unstable and sometimes even conflicting, while also lacking in co-ordination. The study also found that the organisation lacked a "liaison device" and instead depended on a more traditional model of planning and control systems through its reliance on strategy documents and interim evaluation reports. This was in spite of the fact that this model is better suited for a more vertical organisational structure.

Study IV investigated how managers/associates of BBMRI.se perceived the organisation's brand and the role of "mindsharing". The results showed that mindsharing occurred throughout the initial two stages ("Brand Strategic Analysis" and "Brand Identity"), but would dissipate throughout the remaining two final stages ("Brand Operationalising", and "Post-Implementation Reflections"). This resulted in a fragmented brand perception, which resulted in the failure of generating a "pull-effect" for the BBMRI.se brand.

Study V looked at how collective entrepreneurial team cognition of the instigators behind BBMRI.se changes throughout the process of establishing the organisation. The study devised a new "action phase model", known as the "4 I's" of entrepreneurship, where each "I" elaborated on the entrepreneurial rationale behind the various stages of the creation process. These were "Intention", "Initiation", "Implementation" and "Introspection". The results illustrated that the respondents agreed that there was a need for BBMRI.se, while disagreeing on what the organisation should be doing and what its challenges consisted of. The homogenous mind-set would begin to dissipate once the "Initiation" stage was reached, declining further throughout the Implementation stage.

Conclusion:

The overall conclusions from study I-V have shown that distributed Research Infrastructures carries potential to form a platform to pool scientific research in the face of the ever-expanding sciences, where the demands of co-financing and scientific co-operation are becoming ever so pressing. In addition, distributed Research Infrastructures have the benefit of utilising initial synergy effects and using multidisciplinary teams. In line with the contention of Gibbons et al. (1994), this carries the potential of opening up new possibilities of scientific knowledge production. Provided there is a political incentive in place to allocate the necessary funding, the process of establishing a distributed Research Infrastructure can be done in a considerably swift timespan.

However, there are several inherent risks. Most notably, there was a lack of "infrastructuring", as defined by Star and Bowker (2002). This means that scientists as well as the policy-makers should gradually learn together through a learning process about how to creating an effective large-scale infrastructure. This may have prevented mindsharing from becoming

consolidated throughout the formation process (Aaker, 1996; Acuña, 2012; Azevedo, 2005; J. Griffin, 2009; Holt, 2016; Krishnan, Sullivan, Groza, & Aurand, 2013; Stevens, 2003). This, in turn, would also put an end to the collective entrepreneurship that had up till that point characterised BBMRI.se, in which the motivations and drivers of the initiators/managers, as well as their respective recollections of the same, were instrumental features (Cardon, Post, & Forster, 2017; Czarniawska-Joerges & Wolff, 1991; Sakhdari, 2016). Moreover, the integration of autonomous "National Champions" (leading scientists within their field) carries a risk of the "principal-agent" problem, which in turn can lead to "moral hazard" as the "National Champion(s)" may elect to undertake added risks, since someone else bears the cost of those risks (Holmstrom, 1982; Laffont & Martimort, 2002; Steets, 2010). There is also an overwhelming risk of organisational fragmentation, which, coupled with managerial neglect, may cause the eventual failure of the organisation.

LIST OF SCIENTIFIC PAPERS

I. Larsson, A. (2017). The need for Research Infrastructures: A narrative review of large-scale Research Infrastructures in biobanking. *Biopreservation and Biobanking*, 15(4): 375-383. doi: 10.1089/bio.2016.0103[1]

II. Larsson, A., Savage, C., Brommels, M. & Mattsson, P. (2018). Structuring a Research Infrastructure: A case study of building a Swedish biobank Research Infrastructure. *Social Science Information*, 57(2): 196-222. doi: 10.1177/0539018418761848[2]

III. Larsson, A., Brommels, M., Mattsson, P. & Savage, C. (2019). The Uncertain Task: A study of perceived dissonance between own goals and mission statement in a large-scale Research Infrastructure, (Submitted).

IV. Larsson, A. (2018). Celling the Concept: A study of managerial brand mindsharing of a distributed biobanking Research Infrastructure. *Journal of Nonprofit & Public Sector Marketing*, (Ahead of Print): 1-29. doi: 10.1080/10495142.2018.1526749[3]

V. Larsson, A. (2018). The 4 I's of Entrepreneurship: A study of the entrepreneurial perspectives behind a failed large-scale distributed Research Infrastructure. *Entrepreneurship Research Journal*, (Ahead of Print): 1-20. doi: 10.1515/erj-2017-0115[4]

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CONTENTS

LIST OF ABBREVIATIONS

ACTORS

Biobanking and Biomolecular Resources Research Infrastructure (BBMRI)	A collaborative network between national biobanking infrastructures in the Nordic countries. BBMRI exists as separate localised hubs in different countries, usually with a country code suffix to indicate national origin of the hub. Significant is that all hubs work to achieve common results, methods and procedures
Biobank Infrastructure Committee (BISC)	A national infrastructure set up by The Swedish Research Council (VR). It was responsible for the coordination of Swedish biobanks and infrastructure development to facilitate the efficient use of biobanks in research. It was absorbed into BISC into BBMRI.se upon the latter's formation in 2009.
Common Swedish Biobank Infrastructure (GSB = Sv. *Gemensam svensk biobankinfrastruktur*)	A joint initiative project group by the Swedish Healthcare and VR formed on February 9, 2012, that sought to establish a uniform structure and development for Swedish biobanks by strengthening co-operation between Swedish research and healthcare. Members of the GSB consisted of researchers from both BBMRI.se and the Stockholm County. GSB concluded its assignment and disbanded upon the formation of BBMRI.se
Database InfraStructure Committee (DISC)	An infrastructure set up by VR with the purpose of creating a common infrastructure for databases for scientists. Its aim was to co-ordinate existing and new, quality-assured research databases as well as conducting work related to accessibility, quality assurance and integrity. DISC disbanded in 2009 and received a new function as an expert group in VR.
Ethical, Legal and Societal Issues (ELSI)	A Research Programme established in 1990. It was founded as an integral part of the Human Genome Project (HGP) with the purpose of fostering basic and applied research on the ethical, legal and social implications of genetic and genomic research for individuals, families and communities. The ELSI Research Programme manages and funds studies in addition to supporting workshops, research consortia and policy conferences related to these topics.

European Strategy Forum on Research Infrastructures (ESFRI)	Launched in April 2002, ESFRI is a strategic instrument that seeks to develop the scientific integration of Europe, in addition to strengthening its international outreach. Its mission is to support a coherent and strategy-led approach to policy-making on Research Infrastructures in Europe while facilitating multilateral initiatives leading to the better use and development of Research Infrastructures, both at an EU and an international level.
Knut and Alice Wallenberg Foundation	The largest financier of research in Sweden.
National Biobanking Programme (NBP)	The first initiative on coordinating Swedish biobanks and building infrastructures with the aim of more efficient utilisation. It was formally discontinued in 2007.
Swedish Association of Local Authorities and Regions (SALAR = Sv. *Sveriges kommuner och landsting* (SKL))	An association representing the governmental, professional and employer-related interests of Sweden's 290 municipalities and 21 county councils.
Swedish Research Council (VR = Sv. *Vetenskapsrådet*)	Sweden's largest public research funder. It has three missions: to fund and develop basic research in Sweden, to advise the government on issues of research policy, and to inform the public of the long-term benefits of research.
Wallenberg Consortium North	A research consortium for functional genomics made up of seven Swedish universities and colleges.

CONCEPTS

Biobank	A long-term storage facility that stores biological samples (including, but not limited to: organ tissue, blood, urine, skin cells, etc.) for later biomedical analysis in epidemiological and clinical research and for individual clinical purposes. A biobank preserves the quality of the specimens until they are needed for research.

Consortium Agreement	A legal commitment defining a group of separate natural or legal persons who come together to undertake an enterprise, a transaction, or a joint activity. It is used to provide the framework for technological and organisational integration.
ESFRI Roadmap	First published in 2006 (with four subsequent publications, in 2008, 2010, 2016 and 2018). The roadmap identifies new Research Infrastructures of pan-European interest corresponding to the long term needs of the European research communities, covering all scientific areas, regardless of possible location. Potential new Research Infrastructures (or major upgrades) identified by the roadmap are expected to be realised in the next 10 to 20 years.
European Research Infrastructure Consortium (ERIC)	A legal framework outlining entities for Research Infrastructures operating under European law.
Harmonisation	The process of creating common standards across the internal market (such as throughout the European Union). Harmonisation can be defined as: “A set of procedures that promote, both now and in the future, the effective interchange of valid information and samples between a number of studies or biobanks, accepting that there may be important differences between those studies” (Burton, Fortier, Deschênes, Hansell, & Palmer, 2011, p. 166).
Research Infrastructure	A shared facility, resource, and/or related services that is used by the scientific community to conduct top-level research in their respective fields and covers major scientific equipment and/or sets of instruments.
Standardisation	The process of developing and implementing technical standards for procedures, approaches, or measures against which comparisons can be made. It is distinguished from "harmonisation" in that it tries to eradicate variations rather than reduce them.

OUTLINE

The main structure of the study is outlined in the following manner:

- Preface – Provides some words from the author on how this dissertation came to be.

- Introduction – Introduces the background and setting of this dissertation and the biobanking situation at large.

- Literature review – Dissects the literature covering some of the central and recurring theoretical themes throughout the various studies.

- Rationale of the Thesis – States the aims and the research question of the dissertation.

- Methodology – Explains the different methods used within the different studies.

- Case Description – Discusses the steps leading up to the formation of BBMRI.se, how the organisation was built up and the events leading up to ultimate disestablishment.

- Findings – Briefly outlines the central/key findings of each of the different studies.

- Discussion – Analyses recurrent themes as well as each of the separate articles in detail, along with the methodological considerations, implications for practice and research as well as the suggestions for future research. The intent of each articles is listed below:

    - Study I: Literature review. The literature review was intended to help identify the academic discussion on the area of distributed Research Infrastructures and what the most pressing needs for further research are. The outcome of this study has helped formulate the area of study for the rest of the papers.

    - Study II: The study intended to investigate the perceived key interests, importance, influences and participation of different actors in harmonising the processes and mechanisms of BBMRI.se.

    - Study III: The study intended to examine managerial self-governance when forming a large-scale distributed Research Infrastructure and the effects on the organisation's overarching mission.

    - Study IV: The study intended to investigate how managers/associates of a failed distributed large-scale Research Infrastructures perceived their brand and the role mindsharing played in light of the organisation's ultimate failure.

- Study V: The study intended to investigate the motivations of the entrepreneurs behind a large-scale Research Infrastructure and their reasons for engaging themselves throughout various stages in the process. Specifically, the study seems to understand whether or not collective entrepreneurial team cognition remains consistent throughout all processes when setting up a distributed large-scale distributed Research Infrastructure.

- Conclusion – Provides a synthesis of the results from the different studies and the overall framework of this study in addition to stating the concluding ideas and concepts of the dissertation.

- Acknowledgements - A statement of gratitude for the assistance received from various parties and people in producing this dissertation.

- Bibliography – A list of references of the works cited in this dissertation.

PREFACE

Before you lies the doctoral dissertation “Too Big to Fail? – A Case Study of the Rise and Fall of a Medical Research Infrastructure”. The thesis is written as a collection of articles (compilation thesis) and is submitted for the degree of Doctor of Philosophy in Medical Science at Karolinska Institutet.

The research described herein was conducted under the supervision of Dr Carl Savage, Dr Pauline Mattsson and Professor Mats Brommels at the Department of Learning, Informatics, Management and Ethics (LIME). This work is entirely original, except where acknowledgements and references are made to previous work. Neither this, nor any other substantially similar doctoral dissertation has been submitted for any other degree, diploma or equivalent at any other university, college or similar learning institution.

This basis for this research originally stemmed from my interest in tackling a complex case from multiple different angles and using a wide array of different insights and tools. Given my background in multidisciplinary research with my then recently concluded MBA studies and experiences from working in the government sector, I was initially contacted by two BBMRI.se managers during a summer’s day in June with an offer to conduct a Ph.D. study on the issues of large-scale biobank infrastructures and their potential to overcome existing obstacles. Given my long-standing penchant for writing and research, along with a growing interest in pursuing academic career, I decided to take on the challenge.

Upon my acceptance to enter the Ph.D. programme, the original intention was for the research project to be housed at the “Department of Medical Epidemiology and Biostatistics” (MEB) at Karolinska Institutet, with funding provided by the Swedish Research Council and the BBMRI.se Operation Grant application [ref. no. 2009-18438-71700-89], through the creation of a separate BBMRI.se work package (WP8) (BBMRI.se, 2012; Swedish Research Council, 2009). This was mainly for practical reasons as it would also secure unrestricted access to the organisation through the initial stages of the research. However, as the organisation evolved and the framework of this dissertation matured, the project was moved to the “Medical Management Centre” (MMC) at the “Department of Learning, Informatics, Management and Ethics” (LIME) at Karolinska Institutet in order to safeguard a level of distance to the research subject as well as provide the project with access to a scientific habitat closer to the research at hand. Funding was eventually also replaced and provided for by other academic actors through various research projects (with the stipulation that they would yield no influence over the content of any part of this dissertation).

As the world moves further into the age of “big science”, generating vast amounts of data and new ways of scientific cooperation, the sciences will move increasingly more towards forming Research Infrastructures. Hence, there will be a greater need to understand the mechanisms and pitfalls for future reference. This dissertation has studied one example of such a Research Infrastructure. I began laying the ground work for this thesis already back in 2011 by studying this organisation, and closely following its development up until its discontinuation in 2018.

The study had begun as a documentation of how a large-scale distributed Research Infrastructure under the European Research Infrastructure Consortium (ERIC) legal entity (as described in more detail later in this dissertation) could be built up from its inception up to the

signing of a consortium agreement in 2012. However, as fate would have it, the thesis would in due course take on a radically different turn as insurmountable difficulties began stacking up against the organisation, ultimately prompting its termination, in turn calling for a more far-reaching analysis of the events set in motion. Thus, this dissertation serves in part as a thought-provoking “cautionary tale” of what can go wrong, but also as a story of potential and hope for the future of science and large-scale Research Infrastructures.

Anthony Larsson
Stockholm, November 12, 2018

1 INTRODUCTION

This chapter describes the contextual background in which this thesis takes place. It provides a brief overview of the biobank scene at large and the events that transpired into the formation of the concept of BBMRI, including the rise and development of Research Infrastructures.

1.1 PROLOGUE

"Too big to fail" (sometimes abbreviated "T.B.T.F.") is a concept that is believed to have originated in 1914, when the Treasury stepped in to provide financial aid to New York City (Dash, 2009). The term itself has been used recurrently in the press throughout the 20th century, but is popularly attributed to US Congressman Stewart McKinney (R-Connecticut; 1981–1987), who used the term in a 1984 Congressional hearing when discussing the Federal Deposit Insurance Corporation's intervention with Continental Illinois Bank (Sorkin, 2009; Stern & Feldman, 2004). Prior to the financial crisis of 2007-2008, the Continental was considered to be one of the largest bank failures in history, which would attribute infamy to the terminological use of T.B.T.F. (Gelinas, 2009; Gorton & Tallman, 2018; Rime, 2005). Regardless, the ideology concerning T.B.T.F. has persevered and still exists in our society of today (Gorton & Tallman, 2018; Kelleher, 2018). The underlying assumption of T.B.T.F. is that there are certain organisations are so large and so interconnected that their failure would spell disaster to the greater economic system, and that they consequently must be supported by a greater institution (such as the government) should they face potential failure (Lin, 2010).

This doctoral dissertation has chronicled the rise and fall of the organisation *BioBanking and Molecular Resource Infrastructure in Sweden* (BBMRI.se). BBMRI.se was the Swedish node of the European concept of *BioBanking and Molecular Resource Infrastructure* (BBMRI), which exists/has existed at various stages in various incarnations throughout various EU-countries (Goisauf & Durnová, 2018; Norlin et al., 2012; Swedish Research Council, 2009). When BBMRI.se was founded, it was the hitherto largest state-funded investment ever made into a medical Research Infrastructure in Sweden and an organisation that was initially hailed as "too big to fail" (BBMRI.se, 2010; Eaker, Beskow, & Norlin, 2013; Larsson, Savage, Brommels, & Mattsson, 2018; Swedish Research Council, 2010).

The BBMRI's were branded as "large-scale Research Infrastructure[s]" (Van Ommen et al., 2015, p. 893). Specifically, the term "large-scale Research Infrastructure" may be appropriately defined as such if it has acquired a total financing cost of at least €1 million (≈ $1.17 million), including the non-refundable portion of VAT (FWO, 2015). In contrast, BBMRI.se received an initial funding from the Swedish Research Council at approximately €15.5 million (≈ $18.19 million) (BBMRI-ERIC, 2017; Swedish Research Council, 2009, 2016b).

Although investigating a "biobank" as opposed to a "financial bank" (where the T.B.T.F.-debate has been the most present), this study serves as a "cautionary tale" for any large-scale organisation to place too much trust in T.B.T.F. while failing to acknowledge the present and emerging problems within the organisation. As such, this study seeks investigate the mechanisms that led up to the construction of what would (at the time) be the largest medical dis-

tributed Research Infrastructure of all time in Sweden as well as the reasons that would ultimately lead to its demise (BBMRI.se, 2010; Larsson, 2018a; Larsson et al., 2018).

The modern-day development of "big science" in general, and in particular regard to biobanking, has prompted the development of Research Infrastructures in order to remedy scientific fragmentation (Yuille et al., 2008). To this end, there have been calls for Research Infrastructures to adopt a common policy approach (Viceconti & McCulloch, 2011). However, much of the previous literature on Research Infrastructures has largely all but stressed the need of forming Research Infrastructures rather than analysing the various mechanisms and preconditions involved (Larsson, 2017; Nakamura, Date, Matsuda, & Shimojo, 2004; Rugaber & Wills, 1996). Thus, the study seeks to spread some insight in a nascent area of distributed Research Infrastructures, where there is currently a dearth of available scientific literature.

1.2 THE BIOBANKING SITUATION

Throughout the first decade of the 2000s, there was a rapid progress of genomic research in humans. Biomedical and health research expanded the premise of rare monogenic diseases to also include common, multifactorial diseases (F. S. Collins, 2004). Amidst the financial crisis of 2009, Time magazine in fact proclaimed biobanking as a world-changing idea, contending that biobanking was a "safe house" for tissue samples, tumour cells, DNA and blood, was becoming a more attractive means of repository following the crisis suffered by the major US banks (Park, 2009, para. 2). The concept of biobanking as a world-changing idea was further supported by Joyce (2010), who contended that biobanking holds the key to remedying some of the worst diseases of modern age society, such as cancer, heart disease, autism, schizophrenia, diabetes etc. Large-scale population biobanks are best understood as research platforms rather than discrete research projects. The reason is that they comprise large volumes of research participants and may be designed to run for long periods of time (possible decades), in addition to encompassing great numbers of separate research projects over their lifespan (Caulfield & Weijer, 2009). A lingering problem, however, is that complex diseases seldom root in single defects. Instead, they tend to be caused by a large number of smaller effects that stem from genetic predisposition, lifestyle and environment. Successful discoveries are contingent on the study of large collections of well-documented, accurate data from large numbers of populations. These collections are stored in biobanks (also more commonly known as "biorepositories" in certain countries) (ESFRI, 2006, 2008). In this day and age, biobanks are considered instrumental in advancing public health through the discovery of diseases (Arbyn et al., 2011; Dillner & Andersson, 2011; Greely, 2007). To this end, biobank investments have been especially prevalent in the western world in general and in Sweden in particular (Greely, 2007; Hansson, 2011).

A salient problem however, is the fact that there exists no universal definition for what a biobank is (Cambon-Thomsen, Rial-Sebbag, & Knoppers, 2007). At best there is a general agreement that it is "an organized collection of human biological material and associated information stored for one or more research purposes" (Hewitt, 2011, p. 112). Yet another contention is that a biobank can be summarised as an interdisciplinary research platform that stores, manages, processes and distributes biological materials (i.e. tissue, blood, cell cultures etc.) and data associated with the material (Eder, Dabringer, Schicho, & Stark, 2009). The type of material stored varies. Naturally there are biobanks that specialise in various different samples aimed at different purposes. As such, there are biobanks that specialise in human and

animal samples as well as those focussing on plants. Undoubtedly, human sample biobanks make up the lion share of biobanking (Y. G. De Souza & Greenspan, 2013; Groeneveld et al., 2016). The research data extracted from the samples from a human biospecimen biobank can be linked with data from various medical records, lifestyle exposure, environmental exposure and other medically applicable information (Hewitt, 2011). As such, biobanks are considered crucial instrument for researchers in medical research (Aldinger et al., 2019; Cambon-Thomsen, 2003; Kinkorová, 2016). The samples collected are then used by researchers in order to study not only molecular factors, such as genetic diseases, but also environmental factors and underlying diseases with the intention of influencing their outcome (Hewitt, 2011). Ever so often, there is a need for scientists to pool their data in order to exchange pertinent information held in other biobanks elsewhere. This is necessitated by the fact that the researchers need to achieve a statistical inference by comparing information generated by a different population/sample group. There is also a need to establish "best practices" for the management of research biobanks, as these "vary according to institution and differing international regulations and standards" (Hallmans & Vaught, 2011, p. 241). However, in order for that to happen, it is vital for biobanks to foster interoperability (Kiehntopf & Krawczak, 2011).

Biobanks as a method of collecting data has been in use since the 1950s (Catchpoole, 2017; Strong, 2000). In the early days of biobanking, the scientists harvested all the biological specimens they desired by their own devices and did not have a particular goal in mind when they did so (Greely, 2007). Furthermore, they did not routinely share their samples with other laboratories. This would be a status quo that would remain for many decades. As a matter of fact; the inception of modern biobanking as we know it can be traced back to the late 1990s, when scientists discovered that many diseases are caused by multiple genetic factors rather than one single defective gene (Astrin & Betsou, 2016; Greely, 2007). This discovery, coupled with decreased costs of genome-wide scanning, has prompted scientists to start collecting large volumes of genetic sample data. New technology also made it simpler to share data in a greater capacity than had been possible in the past. This would make it easier for scientists to make useful discoveries in samples originally collected for other purposes (Meijer, Molas-Gallart, & Mattsson, 2012). By extension, this also means that there are many different ways for biobanks to store their samples, with most common being cryogenic storage (Shabihkhani et al., 2014; Silberman, 2010). Biobanks exist in various in sizes ranging from individual refrigerators to warehouses. They are maintained by various institutions such as hospitals, universities, non-profit organisations and commercial pharmaceutical companies (Silberman, 2010).

Essentially, biobanks may be classified by their design or by their purpose (Kinkorová, 2016). In a sense, biobanking spans across research and clinical contexts and is carried out by commercial actors, charities, and public sector agencies (Tutton, 2007, 2008; Tutton & Corrigan, 2004). As such, biobanks could be understood as "sociotechnical" enterprises. That is to say that they do not only need to bring about novel arrangements for governance, but they must also gain the support of funders and the public in addition to developing scientific and technical procedures and infrastructures (Boggio, 2017; Tutton & Levitt, 2010; Vaught & Lockhart, 2012). Moreover, in biobanking, there is a fine (and blurred) line between what is "public" and what is "private" (Fortin, Pathmasiri, Grintuch, & Deschênes, 2011). This raises significant (and controversial) issues regarding the role of commercial interests in biomedical studies and the distribution of benefits emanating from the use of human tissue and personal data. With the prospect of international networking of biobanks, questions of data sharing, consent, privacy and governance remain significant concepts that need to be further debated

and resolved. Biobanks veered towards disease research are often affiliated with hospitals, where there is easy access to samples representing a variety of diseases (Bevilacqua et al., 2010). Another example are the virtual biobanks, which seek to integrate epidemiological cohorts into a common pool (Schneider, 2008; Van Draanen et al., 2017).

It is also true that biobanks have been subject to considerable political concern, where the economics of biobanking initiatives have not been well understood, often resulting in substantial costs (Ciaburri, Napolitano, & Bravo, 2017; Gee, Oliver, Corfield, Georghiou, & Yuille, 2015; Vaught & Watson, 2017). Hence, there has been an increased political incentive to expand development and operation resources to ensure long-term sustainability of biobanks, while at the same time maximising their impact (Meijer et al., 2012; Vaught, Rogers, Carolin, & Compton, 2011). That is to say, launching and running a biobank is indeed an expensive undertaking. Research has shown that it takes approximately five years of operation for a biobank to achieve a "steady state" of operation, at which point the annual costs cease to increase and sets at a stable level (Vaught et al., 2011). For this reason, ownership of samples is indeed one of the most controversial topics in biobanking (Budimir et al., 2011; Caulfield & Murdoch, 2017). Although this question is often regulated on a national level by each country's respective government, the regulation itself is not always harmonised. For instance Iceland has no less than three different laws regarding ownership of the physical samples and the data they hold. The national law of Iceland asserts that the government has custodial rights of the physical samples themselves while the donors retain ownership rights (Nwabueze, 2008; The Icelandic Data Protection Authority, 2000). Estonia, conversely, awards ownership of the biobank samples to the government while granting a strong protection of donor rights (Nwabueze, 2008; Priisalu & Ottis, 2017; Zawati, Knoppers, & Thorogood, 2014). In Sweden, personal information regarding the donors is not considered part of the biobank. Instead, this is regulated under various regulations regarding the management of personal data. The *Personal Data Act* was an example of one such law (Government Offices of Sweden, 1998). However, this law has as of May 25, 2018 been replaced by the *General Data Protection Regulation* (GDPR), along with its implementation across the entire EU (Ashton, 2018; European Parliament & Council of the European Union, 2016). Swedish law dictates that anyone who wants to run a biobank must secure permission to do so from the authorities, with and approval by a research ethics committee (Zawati et al., 2014). There is also the *Biobank Act* (Government Offices of Sweden, 2002) that aims to protect donor integrity, while also promoting research on biobank samples.

Notwithstanding, there are no internationally-accepted sets of governance guidelines which are designed to work with biobanks. Instead, biobanks tend to adapt to the broader recommendations of guidelines that are internationally accepted for human subject research (Vaught & Lockhart, 2012). Still, biobanks need ethical oversight from an independent reviewer. In Sweden, this is handled by the Swedish Research Council (VR). Its role is to enforce the standards set by Sweden's government. This is in addition to the Swedish *Ethics Review Act* (Government Offices of Sweden, 2003), which regulates the ethical aspects of sample storage. Moreover, Sweden also has a *Secrecy Act* (Government Offices of Sweden, 1980), which regulates what type of information that is to be withheld. Nevertheless, the absence of a universal storage and handling standards for the collected human-tissue sample presents a salient problem (Hewitt et al., 2017; Siwek, 2015). This may in turn lead to detrimental effects of the quality of samples that that are subjected to cross-border transports.

The amount of bureaucracy involved in transferring samples from one medical institution to another, especially between different countries, also presents a huge problem (Segel, 2017). Invariably, there are legal restrictions and ramifications that make the process cumbersome at best and impossible at worst. To exemplify, in Sweden, the state-owned biobanking samples are stored and governed regionally by each of Sweden's 21 counties, without a central administration to handle the sample inquiries (Biobank Sweden, 2018b). As of July 2007, Sweden had 651 biobanks registered with the National Board of Health and Welfare (Socialstyrelsen) (Nobel, 2008, p. 19). Although in later years this number would decrease as there were approximately 450 registered biobanks in Sweden, managing roughly 160 million samples in 2018 (BBMRI-ERIC, 2018). Chiefly, this was due to the fact that several biobanks across the country had merged in later years and that there were fewer people in charge of the different biobanks as a result (Government Offices of Sweden, 2018; Region Västra Götaland, 2018; Stockholm County Council, 2017; The National Board of Health and Welfare, 2005). More than half of the registered biobanks were (and still are) managed by the County Councils of Sweden, storing around 90% of all the available samples (Biobank Sweden, 2018a; Swedish Association of Local Authorities and Regions, 2017). Biobanks may also be located at universities and at various companies, and in rare cases, also at some government agencies (Biobank Sweden, 2018a). However, most of these biobanks lack a proper biobank structure, meaning that they chiefly consist of material collected from individual research studies (Paradiso, Daidone, Canzonieri, & Zito, 2018; Uzarski, Burke, Turner, Vroom, & Short, 2015). When it comes to the County Council's biobanks, the samples are primarily stored for the purpose of care and treatment rather than for research projects (Biobank Sweden, 2018c).

Another problem is that samples constantly vary in quality (Rush, Spring, & Byrne, 2015). This problem is accentuated by the fact that descriptions and terminology differ between countries as well as within countries, which in turn can make sample requests from different counties a logistical nightmare for researchers (Fransson, Rial-Sebbag, Brochhausen, & Litton, 2015). To make matters worse, national jurisdictional regulations for access and exchange tend to be incompatible (Eaker et al., 2013). This is a huge problem in a day and age where access to Europe-wide data and sample sets are met with increasing demands for large-scale studies. Thus, harmonisation of the biobanks had become increasingly more relevant in order to achieve reliable and comparable results (Meijer et al., 2012).

1.3 BBMRI

There have been several attempts to address the problem with differentiating biobank standards and definitions in the past, but each attempt has been with little or no success (Nobel, 2008). For this reason the European Union presented an initiative to address the problem by attempting to draft harmonised biobanking standards. This initiative was known as BBMRI (Wichmann et al., 2011). BBMRI built on existing sample collections, technologies, resources and expertise that were specifically complemented with various innovative components. The four cornerstones that comprised BBMRI were: 1) all major population-based and disease oriented biobanks; 2) biomolecular resources, including collections of antibodies and other affinity binders. This included a variety of molecular tools used to decipher protein interactions and function of bio-molecules, cells and model organisms used to study human diseases; 3) bio-computing and sample storage infrastructure; 4) scientific, technical and judicial expertise (European Commission, 2015b). These resources were integrated into a pan-European distributed hub/infrastructure for different respective countries across Europe. The chief purpose of BBMRI was to serve as a bridge between sample donors (can be either patients or healthy individuals) and scientists. In addition, it also intended to serve as a gate-

keeper in order to protect sensitive data from being disclosed wantonly (European Commission, 2015a).

BBMRI was launched as a preparatory phase (BBMRI-PP) on February 1, 2008 (Mayrhofer, 2013; Van Ommen et al., 2015). The objectives during the preparatory phase of the EU-funded BBMRI initiative were to plan for the integration of existing quality-controlled biobanks and molecular resource infrastructures into a pan-European biomedical Research Infrastructure, in addition to providing an operational concept and codes of conduct for European biobanks (Brochhausen et al., 2012; Yuille et al., 2008). BBMRI-PP lasted for three years and reached its end in January 2011 (Mayrhofer, 2014). BBMRI had at that point grown into a consortium that included more than 50 members and involved more than 225 associated organisations (mostly biobanks) from over 30 countries (Mascalzoni, 2015). This made BBMRI one of the largest Research Infrastructures in Europe (Reichel, 2015). The different perspectives concerning the concept of "Research Infrastructures" are thus discussed in more detail in section 2.2.

BBMRI was implemented through a new legal entity called *European Research Infrastructure Consortium* (ERIC), on December 3, 2013 and then became known as "BBMRI-ERIC" (Litton, 2018). However, the legal framework of ERIC was enacted in the European Union already in 2009 (European Commission, 2009). An ERIC is a consortium rather than an EU agency, which means that it is not part of the Member States as such; rather, it is a legal entity under European Union law consisting of at least one Member State of the EU and two EU member or associated states (European Commission, 2018; Lind & Reichel, 2013; Litton, 2018). The ambition with this consortium is to put the EU research policy into effect by creating a Research Infrastructure of the highest class that can render itself competitive on an international level. Through a consortium such as ERIC, Member States can collectively fund and manage the Research Infrastructures in a manner that would otherwise not be possible should each Member State be left to its own devices. The specific aim of BBMRI-ERIC is to "facilitate the access to resources as well as facilities and to support high quality biomolecular and medical research" (European Commission, 2014, para. 26).

BBMRI-ERIC installed its headquarters, referred to as the "Central Executive Management Office", in Graz, Austria (Litton, 2018; Van Ommen et al., 2015). The role of the headquarter was to provide a common access portal to the resources available in Member States in addition to facilitating access to facilities and expertise. The national hubs of BBMRI were to be established under the ERIC legal entity and connect the national scientific community, such as universities, hospital, research institutions etc. to BBMRI-ERIC (Van Ommen et al., 2015). Each Member State would then pay a membership fee to BBMRI-ERIC (Swedish Research Council, 2018). As such, BBMRI was intended to exist as separate "nodes", or "hubs", in each respective country across the European Union (European Commission, 2015b). These hubs were initiated with the same aim as the European BBMRI, but on a national scale (Brochhausen et al., 2012). The notion was that the distributed architecture enabled positive impact on the regional development in all participating Member States. However, optimal access to biological samples was contingent on BBMRI being built on solid ethics and public acceptance. For this reason, BBMRI endeavoured to analyse findings based on "ethical, legal and societal issues" (ELSI) (Mascalzoni, 2015). This resulted in the following: 1) a coordinated review board; 2) a data protection policy for cross-border data transfer issues; 3) the development of original tools aimed at facilitating harmonisation (European Commission, 2015b).

This entailed that each node was autonomous but adhered to the same values and principles set forth by BBMRI-ERIC, which primarily involved harmonisation of the biobanks across the EU (Larsson, 2017). The Swedish node was thus called BBMRI.se (Norlin et al., 2012). It became a national Research Infrastructure in 2010 after an agreement was drafted between a leading medical university in Sweden and VR. This university was the selected as the host university for BBMRI.se, although there was cooperation between all medical universities in Sweden (Dillner, 2011b; Larsson, 2017). This is discussed in more detail in the case description in section 5.

2 LITERATURE REVIEW

This chapter begins by discussing the framework from the perspective of "context, content and process" around which the literature review has been based, and the interconnectivity of sciences to form a more holistic view.

2.1 INTRODUCTION - THE FRAMEWORK

An individual researcher can rarely provide all of the expertise and resources needed in order to address complex research problems, and this cooperation is often a crucial component of scientific research. This is especially the case for complex scientific problems dominated by rapidly changing technology, dynamic growth of knowledge or wherever there is a need of highly specialised areas of expertise (Hara, Solomon, Kim, & Sonnenwald, 2003). In this way, the OECD (2016) has argued that Research Infrastructures may herald a new era of "big science" in which needs for large-scale equipment and experiments are accommodated. To this end, researchers often speak of "big science" and how the various sciences may come together and generate synergy effects (Blind & Grupp, 1999; Bunakov, Jones, & Matthews, 2015). However, the idea of unifying sciences is not new per se (Asmi, Brus, & Sorvari, 2017). In the discourse concerning the history of science, there has often been a distinction between what was known as "Mode 1" (which offers a science with clearly defined boundaries and norms, both cognitive and social) and "Mode 2" (in which scientific knowledge production gravitates more towards a more context-driven, problem-focussed, and interdisciplinary orientation that offers broader forms of collaboration) (Gibbons et al., 1994; Ziman, 2000). Still, challenging this contention, many researchers dismiss the very notion of the existence of a "Mode 1" vs. "Mode 2" type of knowledge production, arguing that there was never an era in which basic research ruled to the exclusion of applied research, nor is the present an era in which applied research rules to the exclusion of basic research (M. Collins, Kline, Kwa, & Mirowski, 2007; Pavitt, 2001; Pestre, 2000, 2003). Thus, "Mode 2", or multidisciplinary/collaborative science has always existed to a greater or lesser extent, even if it has become more emphasised in recent decades (Hessels & van Lente, 2008).

Given that scientific knowledge production exists in a multidisciplinary form, the same can also hold true for science on a broader level. To this effect, some researchers, such as Gintis (2007, 2008), have called for the unification/reconciliation of various forms of sciences (particularly that of behavioural sciences), arguing that there already are conditions for rendering coherent areas of overlap between different scientific disciplines. That is not to say that all sciences could or should be united in their entirety. Such "unifications" may take form in

many different ways, including the explanation of different scientific domain and finding commonalities between otherwise distinct scientific domains (Shapere, 2001).

In this regard, the framework for the following literature review follows the "context, content and process" as outlined by Pettigrew and Whipp (1991, p. 26). While this framework is conventionally used for understanding strategic change, it offers a conceptualisation of how the structure of literature outlined in this dissertation could be understood. Specifically, their framework communicates three different dimensions in which a development of content occurs in a continuous process through different contexts. The contention is that developments/changes cannot be understood as separate events divorced from the historical, organisational and economic circumstances from which they have sprung (Pettigrew & Whipp, 1991; Pettigrew, Whipp, & Rosenfeld, 1989). In this way, "content" may be understood as the concept in question that is to be studied. At the same time, Pettigrew and Whipp (1991, p. 165) claim that "leadership is acutely context sensitive" and that the circumstances that cause someone to become a leader/manager also means that in part that leader/manger will inherit "baggage" from former leaders, and likewise, they will also carry with them their own "baggage" from their own personal experiences, routines and preferences even into their new role. "Process", on the other hand", refers to the course of development that causes a certain change/action to become implemented (Pettigrew & Whipp, 1991).

In regards to this framework, the following literature review will first discuss some of the recurrent Research Infrastructure perspectives in the academic debate, which as such will offer *context*, or a backdrop, to the ultimate formation of Research Infrastructures. Given the dearth of available literature specifically focussing on large-scale distributed Research Infrastructures, this section has also investigated available literature on other types of Research Infrastructures discussing the phenomenon in more conceptual terms rather than drawing up on the experiences specific to other particular Research Infrastructures in order to keep the context relevant. For this reason, as the focus is placed on large-scale distributed Research Infrastructure, the specifics of any other Research Infrastructures (i.e. single-sited and digital) have not been reviewed in detail and only referred to as appropriate.

Second, the literature review has, from a *content* perspective, discussed how leaders/instigators may converge and utilise their visions and experiences and how these may be shared in what is known as "mindsharing" and how they may differ. As described above, managers will invariably carry with them a set of "baggage" from their past experiences and visions, which colours their perception and ambition of what an organisation should be. Thus, "mindsharing" constitutes an important part of the overall understanding of the formation of a distributed Research Infrastructure.

Third and finally, the practice of organisations being formed through collective entrepreneurship has provided this study with an understanding of *process*, illustrating how an action phase model may be used in order understand the entrepreneurial procedure in the formation of a large-scale organisation. As entrepreneurship often departs of the individual and their motivations, it is important to understand how their perceptions intertwine with other entrepreneurs when engaging in an entrepreneurial team, as this will heavily impact on the formation process of a distributed Research Infrastructure.

2.2 RESEARCH INFRASTRUCTURE PERSPECTIVES (CONTEXT)

2.2.1 Introduction

As there is no specific, existing, "Research Infrastructure theory" to "amend" or "refute", the ambition is to present a collection of theoretical perspectives that can tentatively explain the need, formation and life-span of a Research Infrastructure (Larsson, 2017). This thesis hopes for these insights presented here to complement one other, and taken together, will add to our general understanding of how to successfully manage Research Infrastructures.

Much of the literature on Research Infrastructures has its roots in studies on "big science" and STS, which is why, in the interest of context, it important to briefly touch upon this area in regards to its development towards Research Infrastructures (Bowker, Baker, Millerand, & Ribes, 2009; Horlings, Gurney, Somers, & Besselaar, 2012; Jiménez, 2010). Thus, it is important to mention that the research conducted on the field of "big science" and STS has changed considerably throughout the decades, moving increasingly more towards qualitative studies. For instance, during the 1960s and 1970s, there were numerous publications that combined quantitative studies with qualitative sociological case-studies. Among the more notable examples are de Solla Price (1963), Small (1973), Narin (1976) and Garfield (1979). Beyond this, there were various qualitative sociological case-studies, such as Crane (1965, 1972), Cole and Cole (1967), Zuckerman (1967) and Spiegel-Rösing (1977). During the late 1970s and 1980s, the research focus shifted from understanding Kuhn's (1996) "paradigms" and "scientific revolutions" and Popper's (1962) refutations to understanding scientific stability and rigour, with Latour and Woolgar (1979) being an important contribution in this regard. Research at this point in time focussed much on building a contention that science is not contingent on the "nearness" of the researcher, but can also act at a distance, typically by outsourcing action to autonomous non-human actors, such as networks and research organisations (Martin, Nightingale, & Yegros-Yegros, 2012). Throughout the late 1980s and 1990s, Latour's notion of agency onto non-human actors continued to cause debate in the academic community, with many researchers arguing that it was merely an agenda-setting attempt to conceal the real conflicts between human researchers (Bloor, 1999; Martin et al., 2012). Another criticism against this development is that became increasingly more difficult to take normative stance on research as there was a perceived lack of attention as to what was behind the actors' assertions (Dupré, 1993; Martin et al., 2012). Nevertheless, opposition towards this contention would remain, with for instance Knorr's (1999) account of how individual scientists still create knowledge. In this regard, STS research appears to have become much more fragmented towards the late 1990s and onwards, becoming more split between the quantitative and the qualitative-oriented disciplines, with the former more veered towards information sciences and the latter focussing more on technology and trying to understand the social influences on the content of science (Martin et al., 2012). It is on this note that Research Infrastructures slowly but surely have begun finding their own niche in the academic discourse.

On that account, it is important to consider the point of departure for Research Infrastructure literature, which is largely rooted in the need of scientific cooperation (Karasti, Baker, & Millerand, 2010; Viswanathan, Parthasarathy, & Bandi, 2017). From the outset, investigator-driven frontier research has been a key propellant of scientific progress. The scientific advances of yesteryear did indeed bring with them with them resource, knowledge and technical requirements seldom found within a single research group. To this effect, scientific development has throughout the past century transitioned from individual researchers to collaborative

efforts. This is a development that has arguably been in motion ever since the latter period of WWII and the Manhattan Project, and further gaining traction throughout the cold war era (Fuller, 2009; Jacob & Hallonsten, 2012; Remington, 1988). Etzkowitz and Leydesdorff (2000) and Taubes (1993) contend that during this time, technology progressed while the political climate underwent an ostensible change, allowing the formation of infrastructures for various forms of research collaborations to serve the broad scientific communities. This era saw a shift in scientific knowledge production towards a more context-driven, problem-focused, and interdisciplinary orientation that offered broader forms collaboration. Specifically, research in multidisciplinary teams would open for new possibilities for scientific development and knowledge production (Gibbons et al., 1994; Ziman, 1994). De Solla Price's (1963) prophecy has consequently come to fruition: while scientists continue to work on their own smaller projects, they team up with others on large-scale projects. To this end, the formation of core facilities has been central to large-scale projects (Haley, 2009; Niece et al., 1989; Orenstein, 2011).

2.2.2 Core Facilities

A "core facility" is a centralised, shared resource that provides "access to instruments, technologies, services, and expert consultation to scientific investigators" (Farber & Weiss, 2011, p. 1). In order to efficiently utilise a core facility, a potential user must have realistic expectations concerning the technical capabilities these facilities can offer (Niece et al., 1989). However, there are limitations to the extent of what a core facility can provide, and throughout modern history, many research institutions have had difficulties in funding their core facilities (Ivanetich, Niece, Rohde, Fowler, & Hayes, 1993). Sometimes, facilities have been installed in separate departments or institutions, which often restricts the usage of such facilities (be it formally or informally), to members of that particular department owning access to the core (Farber & Weiss, 2011). Other problems with core facilities include suboptimal purchases of instruments that do not meet the actual measurements of the requirements of numerous users, which can sometimes come to light only after the purchase and initial use (Farber & Weiss, 2011; Murray, 2009). Murray (2009, p. 8655) elucidates some other inherent weaknesses of the core facilities:

> Another pitfall is inadequate planning for maintenance and upkeep, often rooted in inadequate (or less than fully competent) technical staffing, which results in premature decay in instrument performance. Yet another problem is reluctance of core facility directors to recognize the educational aspects of research by refusing to train student operators.

Naturally, there has been much contention in defence of the core facilities. Still, what remains at the heart of the matter is that the technology and expertise required for several large-scale projects/endeavours are by far too costly for any single actor to shoulder alone (Biellik et al., 2009; Farber & Weiss, 2011). Moreover, the funds needed for adequate funding of such initiatives are seldom found within one organisation alone, which in turn calls for co-financing (Biellik et al., 2009).

2.2.3 The Need for Scientific Co-funding

Funding has been a long-standing thorny issue of scientific research. Research funding is often obtained through a competitive process, where multiple research projects are evaluated upon which only the most promising proposal receives funding. These processes are generally run either by government funding bodies (often referred to as "research councils"), corporate enterprises, or foundations. These actors allocate scarce funds. This means that there is often a trade-off between the anticipated success of the project, and the overall need of what the project can bring (S. Daly, 1983).

According to OECD (2015), the industry carries out more than 60% of research and development in scientific and technical fields, whereas 20% and 10% respectively is carried out by universities and governments. Still industry R&D tends to carry commercialised interest and be very specific to that particular industry's particular needs (Taylor, Phelan, Otanicar, Prasher, & Phelan, 2012). This means that in terms of scientific research, the remaining available funding is indeed in the scope of things as government funding amounts for a minor part of the budget. In comparison, as per 2015, Sweden ranked 18th place (with the United States being in pole position) of those countries spending the highest amount of funding on research and development (R&D), with an approximate spending of 3.26% of its GDP (or over $14 billion/€12 billion) (The World Bank, 2018). At the same time, Sweden's social expenditure at the same time was 26.7% of its GDP (OECD, 2018). Ironically, it is the smaller funds allocated to scientific research that is used to develop medical resources, which may ultimately aid the areas presently affected by the social expenditures (Krütli, Rosemann, Törnblom, & Smieszek, 2016). The issue of resource allocation has been a particularly pressing issue in healthcare research (Kluge, 2007).

As the balance between the likelihood of success and the overall need of the end result exists, there is a contention that research funding for the sake of knowledge itself does not render a return of investment (Crotty, 2016; Schvartzman & Schvartzman, 2008). Still, publically-funded research does have an advantage of not being restricted by the ownership of intellectual property that other funders might claim for research they have funded (Heller & Eisenberg, 1998). In spite of this, the availability of public funds for various infrastructure investments is subject to severe constraint as the conditions made stipulate that the available scarce funds must be spent in an efficient and effective manner. Evaluation methods to select and prioritise these infrastructure projects will more often than not presuppose that infrastructure projects are independent of one another (Szimba & Rothengatter, 2012). These conditions have thus prompted the development towards Research Infrastructures (Muldur et al., 2006).

2.2.4 The Rise of Research Infrastructures

It should be noted that the term "Research Infrastructure" has no single accepted definition (Farago, 2014; OECD, 2010). However, common practice has come to dictate that it refers to facilities, resources and related services that are used by the scientific community to conduct top-level research in their respective fields (Stahlecker & Kroll, 2013). The European Strategy Forum on Research Infrastructures (ESFRI) was set up in 2002 to help coordinate the development of large-scale facilities in Europe (Toom & Miller, 2018). It defines Research Infrastructures as: "facilities, resources or services of a unique nature that have been identified

by European research communities to conduct top-level activities in all fields" (ESFRI, 2011, p. 7).

To this end, it is important to emphasise that "Research Infrastructures" should not be considered "science" in and of themselves. Rather, they may be regarded as "the basic structural foundations of a research enterprise" (Sumathipala, 2014, p. 407). Nevertheless, Research Infrastructures is a fairly modern construct that has not garnered much awareness in the academic discourse prior to the mid-2000s (Larsson, 2017). Much of this stems from the (until recent years) overall lack of political attention given towards Research Infrastructures. This is, in turn, just as crucial as funding; as political endorsement tends to lead to more favourable prospects of financial investments (Beachy, 2014; Chalkidou & Anderson, 2009).

Nevertheless, this has changed much in the past decade, as Research Infrastructures have become a central focal point of various policy makes around EU. In a way, one may contend that a Research Infrastructure is inherently political in its design. That is to say, there is tension between policy and practice, as policy will generally embody the visions of the innovations, interests, control regimes, and struggles to manage the inherent heterogeneity of local day-to-day operations (Appel, Anand, & Gupta, 2015; Karasti, Millerand, Hine, & Bowker, 2016). As Research Infrastructures are both large and costly, they can in reality only be run through the cooperation of multiple well-funded partners. For this reason, the largest capital funding decisions often tend to take on political undertows rather than being based on purely scientific motives (Flanagan, 2016; Gannon, 2006). This, in turn, influences the type of scientific areas wherein Research Infrastructures emerge; as there is little chance to see one created in a narrow research area that garners little political attention and/or impact.

It should be noted that there is somewhat of a paradoxical situation in this regard, as pan-European politics for integration on the policy level may trigger the splintering of Research Infrastructures, inasmuch that national, localised iterations may appear. This illustrates the contrast between the various top-down and bottom-up efforts where steps towards Research Infrastructures occur both at an a supranational EU-level, as well as domestically towards achieving harmonisation of sciences (European Commission, 2013). Sociotechnical scholars have long suggested the adoption of the transitive verb "infrastructuring", to indicate a relational, emergent, processual, nature of infrastructure-making, wherein policy is an evolving endeavour that cuts across various established disciplines and development phases (Star & Bowker, 2002). That means that the formation of Research Infrastructures should be viewed as a reflexive learning process, in which researchers as well as policy-makers gradually learn together about how to creating an effective large-scale infrastructure.

To this end, Research Infrastructures tend to foster a "self-organising" structure, in which smaller and more independent cooperative groups are formed. This often stems from the fact that there are different forms of research funds made available to different types of research categories, which in turns leads to the formation of research communities, networks or something similar, thus consolidating the autonomous structure from the larger, existing, network structures. However, such a structure carries other kinds of ramifications than that found in other types of organisations. While it may help shape a common platform for cooperation, it may also foster an organisation that finds itself at odds with the top-management, as argued by Liinason (2013, p. 117):

> "Such self-organized collaborative groups can offer a space that might be more stable and long-term than the environment at the home university, at the same time as it can shape a common ground and be a site for the creation of collective oppositional politics".

In contrast, other studies have suggested that Research Infrastructures may actually help centralise and streamline various managerial processes, under the condition that the organisational mechanisms are adequately resourced and transparent (Howarth, Kneafsey, & Haigh, 2008).

Essentially, the structural type of Research Infrastructures can take on one of three forms: 1) *single-sited* (e.g. CERN); 2) *digital*, i.e. part of a national or an international network; 3) *distributed*, i.e. in cooperation with multiple other actors spanning across several physical locations (Pérez-Llantada, 2012; Sumathipala, 2014). The lattermost is the focus of this thesis and is the most intricate of the three as it involves different actors at different locations and requires cooperation and coordination between different academies. Previous studies have devoted much attention towards exhorting the need of Research Infrastructures in general and distributed Research Infrastructures in specific (Abayomi et al., 2013; Armstrong & Reaman, 2005; OECD, 2014; Pathak et al., 2013; Yoshizawa et al., 2014). Still, much of the present literature has chiefly concentrated on producing bodies of work on either the single-sited or digital variety of Research Infrastructures. This means that the challenges faced by distributed Research Infrastructures have been largely overlooked in the present literature (Larsson, 2017; OECD, 2014).

2.2.5 Conclusion

One of the primary aspects of a distributed Research Infrastructure is the very fact that it does involve multiple different actors from a variety of different disciplines located across several different geographical locations, which in turn adds a whole different layer of complexity as opposed to the other types of Research Infrastructures (Camarinha-Matos, Afsarmanesh, & Boucher, 2010; Vasiljevs & Skadiņa, 2012). Studies in recent years have shown that scientific cooperation is likely to increase the number of distributed Research Infrastructures in the future (Baskerville & Wood-Harper, 2016; Viceconti & McCulloch, 2011). While the inherent construction of distributed Research Infrastructures may stimulate a form of scientific multidisciplinary interaction, these interactions are not necessarily meaningful in and of themselves (Wehrens, Bekker, & Bal, 2010). This, in turn, emphasises the need to understand of how Research Infrastructures are managed and run. Thus, distributed Research Infrastructures is underrepresented in the current academic debate on Research Infrastructures (such as it is).

A more important conclusion is to seek the answer to what it means for scholars (and entrepreneurs) to adopt an "infrastructuring" lens. Researchers will continue having a political role to fill in easing the reintegration of practice and policy by establishing and sustaining relations in Research Infrastructures. Researchers can actively intervene by addressing the tensions that exist between bottom-up and top-down efforts. In doing so, they may support the collective reflection and alter mind-sets rather than letting things remain passive or opting for

confrontation. In adopting an “infrastructuring” lens, one may also understand that the conception of the organisation may differ between actors, but that a “mindshare” may nonetheless be obtained.

2.3 MINDSHARING (CONTENT)

2.3.1 Introduction

The concept of mindsharing is important because it entails that something is recognised in a manner that is familiar and identifiable in a similar manner collectively (Aaker, 1996; Engelberg & Kirby, 2001). In order to understand mindsharing, and how it may occur in the individual staff member’s perception of their organisation, it is essential to familiarise oneself with how branding functions. As expressed by Engelberg and Kirby (2001, p. 10), “an organization's identity is reflected by how different parts of the organization work together to support each other and function to deliver what branding promises.” Kotler (1997, p. 443) defines a “brand” as a “name, term, sign, symbol, or design, or a combination of them, intended to identify the goods or services of one seller or group of sellers and to differentiate them from those of competitors”. In this way, organisations build their brands for the purposes of distilling their corporate identity (Balmer, 2010; Urde & Greyser, 2015). It is possible for the success of an organisation to be dependent on the perception of its brand, and recent studies have illustrated that healthcare organisations may be especially prone to this occurrence (Indounas & Arvaniti, 2015).

Brand perception is a vital factor, since it manifests one’s innate mental image of what the brand signifies. This is entirely separate from brand identification, as that illustrates how well someone identifies with a particular brand and to what extent that brand reinforces a personal identity (Dunn, 2004). In this way, mindshare branding, serves as a concretisation of this phenomenon, as it seeks to establish a common idea within a certain concept so that it can be perceived in a similar fashion by everyone who experiences it (Holt, 2004). Hence, mindsharing may be used to determine if and how a company brand is collectively perceived amongst the staff (Engelberg & Kirby, 2001; Holt, 2004; Matiatou, 2015; Potalivo, 2014). Mindshare branding leans mainly on tacit, abstract associations in one’s personal mind that is perceived in a similar manner from person to person (Heding, Knudtzen, & Bjerre, 2016). Often, mindsharing refer to a customer’s perception of a particular brand (Engelberg & Kirby, 2001; Lundstrom, 2009). However, it is important to remember that there is a difference between mindsharing used in consumer culture and brands, as opposed to how it is used in the management of brands (Bengtsson & Ostberg, 2006). As such, mindsharing may in terms of brand management also pertain to how staff and/or stakeholders perceive a company brand (Gill, 2013; Hamidizadeh & Sanavi Fard, 2016; Peirson-Smith & Hancock, 2017). Thus, brand perception is to a large extent dependant on symbolic, non-product, characteristics (Bravo, Montaner, & Pina, 2012; O’Cass & Frost, 2002).

2.3.2 The Four Steps towards Mindsharing

Some researchers will contend that mindsharing is influenced by communicating the brand promise through sharp design and repeated, consistent verbal communication (Ross, 2010). Other researchers believe mindsharing is secured by exploring the question itself rather than being certain about one’s answer, so that one stimulates a collective thinking process (Markova & McArthur, 2015). A complicating factor, and in no doubt one of the reasons why

there exists different interpretations of mindsharing, is because it is difficult (if at all possible) to measure in any strict numbers, and may thus take on a more abstract concept (Holt, 2016; Stevens, 2003). To this effect, there is some contrasting academic support for the notion that mindsharing is actually built up incrementally through a series of different phases and that it occurs across different segments (Acuña, 2012; J. Griffin, 2009; Krishnan et al., 2013). As such, there are several steps involved in consolidating a brand forming experience. According to Aaker's (1996) and Azevedo's (2005) brand model, a successful brand has to be able to distinguish itself from other brands by reflecting the identity in a way that resonates in a comparable manner throughout the organisation.

The first step is *Brand Strategic Analysis* (Aaker & Joachimsthaler, 2000; Cravens & Piercy, 2013; Ghodeswar, 2008). This stresses the importance of analysing the underlying market drivers for the brand (e.g. the needful aspects for build a brand in that particular space).

The second step is *Brand Identity* (Aaker & Joachimsthaler, 2000; De Chernatony & Dall'Olmo Riley, 1998; J.-N. Kapferer, 2012). This refers to the character of brand and the values it personifies. As such, it considers the individual's desired positioning of the brand as opposed to its *de facto* positioning (or perception thereof).

The third step is *Brand Operationalising* (Davis & Dunn, 2002; Upshaw & Taylor, 2000; Vallaster & de Chernatony, 2005). This step considers the concrete actions taken towards forming a brand. These measures are multidisciplinary and holistic in nature. They encompass various factors such as different forms of interactions, activities and operations.

The fourth and final step is *Post-Implementation Reflection* (Aaker, 1996; Cravens & Piercy, 2013). This is a form of self-analysis in which the organisation is internally analysed by reflecting on how the outcomes matched the original aspirations. The outcomes may provide insights for assisting future strategies/approaches. Specifically, the resolution of this final step may lead to alterations on existing brand strategies, formation of new brands and/or discontinuation of existing brands.

In order to achieve a full mindshare, it must exist in and across all stages of the brand building process (Acuña, 2012; Almquist & Roberts, 2000). Failure to secure mindsharing at any stage does not entail the abortion of the brand formation process, but the brand's mindsharing attributes will be impaired, or ruined.

2.3.3 Conclusion

By securing full mindshare among one's staff, one may ensure that the organisation has a vision that is shared collectively, which in turn will markedly lessen the risk of it counteracted by staff member's self-serving motives. A full mindshare will also help strengthen the organisation's competitive edge since it may be used as a planning base to further an organisation's internal, as well as external, intellectual partnership development (Dealtry, 2005). Moreover, it is vital for mindshare to exist amongst the leadership at all levels, so that they may easily come to agreement on what it is that needs to be changed and how to continuously

improve efforts that affect strategic priorities. To this end, one cannot garner management mindshare if the individuals do not believe that continuous improvement efforts will positively influence the organisation's performance (Sarkar, 2011).

Still, the collective consciousness of mindsharing is, of course, promoted by environments that elicit cooperation (Gill, 2013). This is especially so when it comes to entrepreneurial endeavours undertaken as part of a team, as it helps reinforce the idea already from the outset, through the creation/start-up process (Acuña, 2012; Gill, 2013; Laubacher, 2012; Santos & Spann, 2011).

2.4 COLLECTIVE ENTREPRENEURSHIP (PROCESS)

2.4.1 Introduction

Traditional entrepreneurial literature has departed from the study of individual traits and personality factors of the entrepreneur, and that entrepreneurial ventures have been created *ex ante* (or before the fact) by the entrepreneur (Amit, Glosten, & Muller, 1993; Foss & Klein, 2017). That is to say, an "opportunity" becomes an entrepreneurial venture only if it can generate a specific good or service. That means that an "opportunity" does not come to pass until it has been unearthed and utilised by the entrepreneur (Casson, 2003; Hitt, Ireland, Camp, & Sexton, 2001; Kirzner, 1973; McMullen, Plummer, & Acs, 2007). However, there is conflicting literature in this regard, as there is a contrary contention that entrepreneurship and opportunity do not have to be mutually exclusive, but can co-exist as two sides of the same coin (Sarason, Dean, & Dillard, 2006). That is, opportunity is not a singular phenomenon, but should instead be viewed as idiosyncratic to the entrepreneur. Thus, an organisation built up by an entrepreneur is equally important when it comes to discussing the framework of entrepreneurial characteristics (Gartner, 1985). This point is further supported by the fact that multiple organisations are formed through collective entrepreneurial team cognition (De Mol, Khapova, & Elfring, 2015; Johnson, van de Schoot, Delmar, & Crano, 2015; Schjoedt, Monsen, Pearson, Barnett, & Chrisman, 2013). In short, entrepreneurship does not have to be about filling an existing market gap. It is equally possible for entrepreneurship to exist as an instrument for an entrepreneur to co-evolve along with the social system (Sarason et al., 2006).

2.4.2 Collective Entrepreneurial Team Cognition

The historical contention is that entrepreneurs are made up of individuals, but in later years, this notion has been challenged as it is possible for other actors to enter in entrepreneurial ventures as well, such as organisations, or multiple entrepreneurs working in teams (Baumol, Litan, & Schramm, 2007; Calisto & Sarkar, 2017; Harper, 2008). That is to say, entrepreneurship may be built on collective entrepreneurial team cognition, where collective cognition mediates between individual cognitions, firm actions and performance (De Mol et al., 2015; West, 2007). In these instances, the motivations and drivers of the managers become an essential feature (Cardon et al., 2017; Czarniawska-Joerges & Wolff, 1991). The managers' motivators and their recollection of past events in relation to the context to the formation of their innovation may in this way serve as an antecedent for future entrepreneurs (Sakhdari, 2016). However, this type of entrepreneurship is rarely discussed in present literature, which has in turn created a knowledge gap in the entrepreneurial academic debate (Hausberg & Korreck, 2018).

Essentially, collective entrepreneurship consists of three phases, in which a venture or an organisation may be formed: (1) generation, (2) selection, and (3) execution. Phase 1, or "generation" invokes the motivational aspect of idea pitching to uncover and pool for new ideas, such as that from employees or customers (Ebner, Leimeister, & Krcmar, 2009; Piller & Walcher, 2006). The advantage of this is that it can help foster a corporate culture that encourages entrepreneurship and creativity (Brentani, 2001). During this phase, the entrepreneurs are encouraged to submit business plan summaries for ideas for new products or services. These ideas are made available to the other entrepreneurs so that they may discuss and rate these ideas. This provides feedback to idea submitters and valuable knowledge to the other possible idea submitters.

For phase 2, "selection", collective intelligence techniques are used that draw upon the collective wisdom of the crowd (Santos & Spann, 2011; Surowiecki, 2004). The entrepreneurs are involved in the evaluation of new ideas and proposals, such as via rating, ranking, voting, or virtual market places etc. (Soukhoroukova, Spann, & Skiera, 2012). Thus, collective entrepreneurship assimilates collective intelligence techniques in the selection process in terms of new product or service ideas as well as for innovation proposals. On the basis of this feedback, a vast number of initial ideas/suggestions can be reduced to a manageable number of ideas with the most potential.

Phase 3, or "execution", entails the execution and launch/commercialisation of the selected proposals with potential. This phase draws on entrepreneurs to connect to various partners and investors as well as about the venture (Collinson & Gregson, 2003; Santos & Spann, 2011). By providing support, it mitigates the common obstacles for the team's entrepreneurial activities, while enabling it to implement ideas into business units.

As entrepreneurship is to a large extent about personal goal setting and goal striving, it is in a way goal directed (Frese, 2009). This is part of a venture creation process that involves self-regulatory functions that leads to the entrepreneur's sense of well-being (Gollwitzer, 1990; H. Heckhausen & Gollwitzer, 1987). Although entrepreneurship is often assumed to concern the goal of creating new ventures, several studies have illustrated that an additional goal may be a personal identity choice of identifying oneself as an individual in an entrepreneurial role (Cardon, Wincent, Singh, & Drnovsek, 2009; Farmer, Yao, & Kung-Mcintyre, 2011; Gollwitzer & Kirchhof, 1998). This is illustrated in the action phase model, which perceives entrepreneurship as a temporal goal-directed process of business creation. As such, it involves four core phases. These capture the decision-making process that precedes the actual entrepreneurial endeavour, in addition to the phases that come during and after. These indicate a distinguished set of processes, activities and behaviours that determine the entrepreneurial transformation. These processes can be referred to as the "4 I's": *Intention*, *Initiation*, *Implementation* and *Introspection* (Larsson, 2018b; Shir, 2015).

In the first phase of this entrepreneurial process, *Intention*, the entrepreneur envisions a particular endeavour. It is at this point, the goal formation takes place. In the second phase, *Initiation*, the entrepreneur starts putting their plan into action by undertaking the necessary practical preparations. The third phase, *Implementation*, entails that the entrepreneur has begun to carry out their plan through concrete measures. At this stage, the endeavour has begun and

the operations have been set in motion. The fourth and final phase is *Introspection*. At this stage, the entrepreneur can reflect back on their actions and determine what worked well and what aspects need improving while contemplating future plans. As an action phase model, the "4 I's" has the advantage of capturing not the general process of business creation as well as its sub-processes. This includes the explorative endeavours (where the aim is to find new business ideas) as well as exploitative undertakings (where the aim is to optimize existing business ideas). Unlike previous action phase models, the "4 I's" model is able to not only synthesise results, but can also account for when (if at all) in the process there is the greatest risk of entrepreneurial fragmentation (i.e. when the respondents' motivations and perceptions begin to diverge, and when they diverge the most).

2.4.3 Conclusion

Any organisation, or venture, has been built upon the visions of the entrepreneur(s) that started it. It was formed by an opportunity that existed because the entrepreneur(s) saw one that they could form an enterprise upon. Contrary much of the traditional literature on the area, entrepreneurship can indeed be collective, with teams of entrepreneurs joining together to form an initiative, or form an organisation. Through the three phases of (1) generation, (2) selection, and (3) execution, one may understand how the collective entrepreneurial process works, and how this leads to the formation of new ventures/organisations. Still, the reasons for the venture/organisation's existence can only fully be understood if one also understands the personal motives of the entrepreneur(s) behind it, even in collective forms of entrepreneurship.

As an action phase model, the "4 I's" carries the advantage of being able to capture not merely the general process of business creation, but also its sub-processes. This covers the explorative aspects, where the ambition is to find new ventures, as well as the exploitative aspects, where the ambition is to optimise existing ventures. Unlike other action phase models, the "4 I's" has the capacity to not only synthesise results, but it can also identify if and when in the process entrepreneurial fragmentation emerges. That is to say, when the entrepreneurs' motives and visions begin to diverge, and at what stage they diverge most.

2.5 SYNTHESIS

As scientific cooperation expands, the number of Research Infrastructures is likely to increase in the future, but current research on Research Infrastructures is limited, especially in terms of distributed Research Infrastructures. To this end, there is a need for scientists to employ an "infrastructuring" lens, when building the Research Infrastructures, so that they can achieve a "mindshare" of what the organisation is supposed to do. This mindsharing capability can enable the scientists to cooperate both internally across their own institution, as well as externally with other scientists belonging to other member institutions of the Research Infrastructure. Achieving a mindshare would help ensure that the organisation works towards the same goal, while utilising synergy effects. Thus, in order to implement mindshare, it is important to understand the original motivations of those individuals who actively worked to build the Research Infrastructure through a collective form of entrepreneurship. Consequently, the literature review has highlighted a need for an in-depth study of how a Research Infrastructure is formed and what challenges it might encounter in regards to securing mindsharing and personal motivations.

As per the framework by Pettigrew and Whipp (1991) described in Figure 1, the unification of seemingly disparate sciences can through the converging of the context, content and process described above, illustrate how the formation of a distributed Research Infrastructure can be understood.

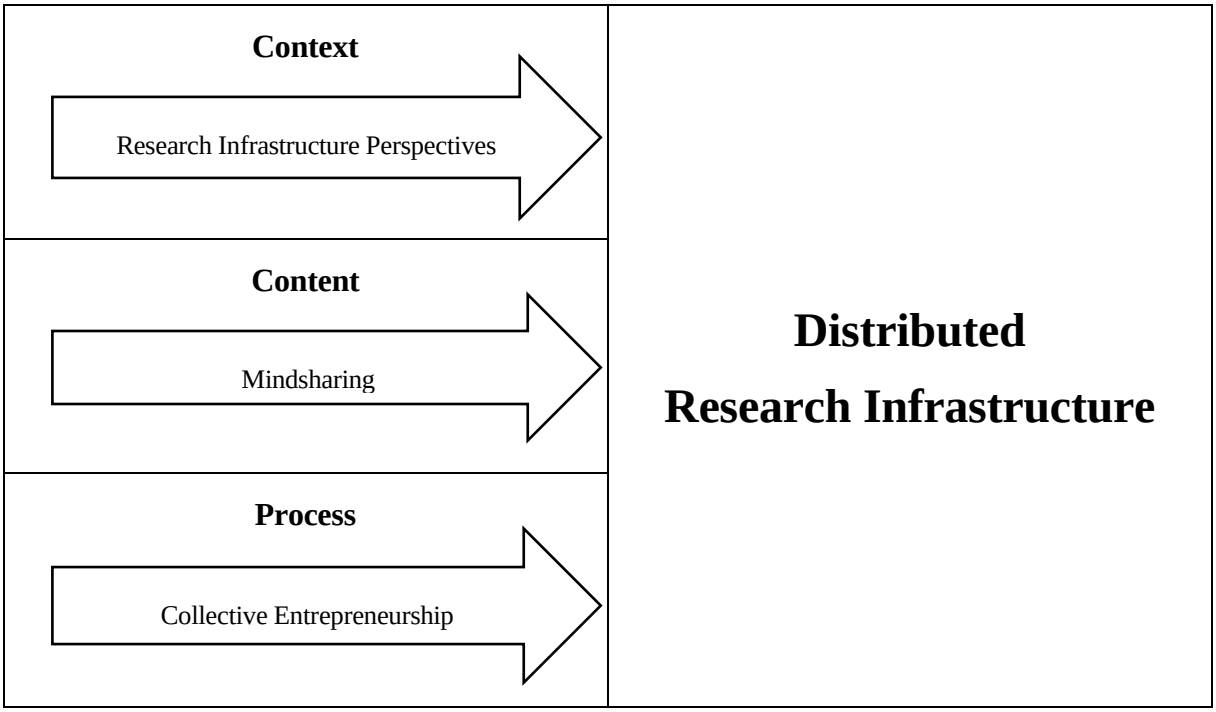

Figure 1: Depiction of how a distributed Research Infrastructure may be created by means of the unification of different sciences, as seen through the dimensions of context, content and process (Adapted from Pettigrew and Whipp, 1991)

3 RATIONALE OF THE THESIS

3.1 PREMISE

Through a series of five studies, this dissertation has sought to elucidate the mechanisms involved in the construction of a medical large-scale distributed Research Infrastructure, and understand the motivations and rationale of the experts who activated themselves in constructing it and what difficulties they encountered in doing do. In doing so, this dissertation seeks to contribute knowledge and insight to the establishment of and troubles with distributed Research Infrastructures, as there is presently a lack of available literature covering this topic.

3.2 AIM

Given the fact that Research Infrastructures are a fairly recent construct, there is currently a lack of academic literature that explores distributed Research Infrastructures and the potential risks associated in building them. Following the literature review using the framework of Pettigrew and Whipp (1991), the aim of this doctoral thesis to increase the understanding of the possibilities and pitfalls in forming a large-scale distributed Research Infrastructure by

investigating a real-life case, while building to the available (but presently lacking) literature on the subject.

Through a series of original research articles, this study intends to:

- Identify the most pressing issues/themes in the academic discourse addressing the debate on large-scale distributed medical and/or biobank Research Infrastructures (study I)
- Analyse the perceived key interests, importance, influences and participation of different actors involved in setting up a large-scale distributed Research Infrastructure (study II)
- Examine managerial self-governance when forming a large-scale distributed Research Infrastructure and the effects on the organisation's overarching mission (study III)
- Investigate how managers/associates of a large-scale distributed Research Infrastructures perceives their brand and the role of mindsharing (study IV)
- Investigate if collective entrepreneurial team cognition remains consistent throughout the processes in setting up a large-scale distributed Research Infrastructure (study V)
- Formulate the most important scientific insights from the formation of a large-scale distributed Research Infrastructure and the challenges it carries (study I-V).

3.3 RESEARCH QUESTION

The overarching question – in line with the objectives of the study is: *What are the principal lessons researchers, entrepreneurs and funders that can be inferred from the formation of a large-scale distributed Research Infrastructure towards securing more sustainable prospects for similar, future endeavours?*

4 METHODOLOGY

This section provides an overview of the research methodologies used in the five studies (illustrated in Table 1), followed by a description of the procedures for collecting data as well as the data analysis. The section concludes by describing the ethical considerations for this dissertation. For a detailed critical assessment of the methods used in the studies in regards to the validity and reliability etc., please see the methodological considerations in section 7.8.

	Study I	Study II	Study III	Study IV	Study V
Aim	To identify the most pressing issues regarding large-scale distributed medical and/or biobank Research Infrastructures	To analyse what key interests, importance, influences and participation different actors have had in structuring and harmonising the processes and mechanisms of a distributed Research Infrastructure.	To investigate what governance structures and management practices evolve over time in a distributed large-scale Research Infrastructure.	To further the understanding and development of branding policies and strategies for extant and future large-scale Research Infrastructure, while discern the respondents' degree of mindsharing in regards to the perception of the organisational brands	To investigate if collective entrepreneurial team cognition remains consistent throughout the creation and implementation of a large-scale distributed Research Infrastructure.
Study Setting	Desktop Research	BBMRI.se managerial staff and key harmonisation figures	BBMRI.se managerial staff and key harmonisation figures	BBMRI.se managerial staff and key harmonisation figures	BBMRI.se pioneers
Participant Selection	Not applicable	Purposive sampling	Purposive sampling	Purposive sampling	Purposive sampling
Study Design	Narrative Review	Qualitative study	Qualitative study	Qualitative study	Qualitative study
Data Source	Literature	Semi-structured interviews, Supportive white and grey paper documentation	Semi-structured interviews, Supportive white and grey paper documentation	Semi-structured interviews, Supportive white and grey paper documentation	Semi-structured interviews, Supportive white and grey paper documentation
Subjects	N=17 (publications)	N=9	N=9	N=9	N=7
Data Analysis	Processing criteria according to the PRISMA statement (Identification, Screening, Eligibility and Included)	Iterative, directed content analysis IIED Stakeholder Power Analysis Tool	Inductive, directed content analysis	Iterative, directed content analysis	Iterative, directed content analysis
Theoretical Framework	Not applicable	Research Infrastructures (Pérez-Llantada, 2012; Sumathipala, 2014)	Research Infrastructures (Pérez-Llantada, 2012; Sumathipala, 2014)	Branding (Aaker & Joachimsthaler, 2000) Mindsharing (Holt, 2004)	Entrepreneurship, Action Phase Model (Shir, 2015)

Table 1: Overview of the studies included in this thesis (Study I – V)

4.1 STUDY DESIGN

The study design aims to keep the methodology organised and logical (Campbell & Machin, 1999; Parab & Bhalerao, 2010). The initial study (I) was set up as a literature study as it sought assessment of the current state of research on the topic of (distributed) Research Infrastructures while also trying to identify the key issues related to this space (C. Hart, 2001). The other studies (II-V) were set up as case studies, since they investigated a contemporary event while seeking the answer to the "how's" and "why's" to the different phenomena raised throughout the various studies (Yin, 2017). The design of the studies is described in more detail below.

Study I employed a "narrative review", meaning that it aspires to summarise different primary studies (Baumeister & Leary, 1997; Cook, Mulrow, & Haynes, 1998). These summaries served as a foundation from which conclusions could be drawn into an overarching interpretive overview (Kirkevold, 1997). A major advantage of conducting a narrative review is that it seeks to draw an understanding of the pluralities and complexities around the researched area (Jones, 2004). For that reason, narrative reviews are suitable for large-scale and/or comprehensive topics (J. A. Collins & Fauser, 2005). A significant aspect of a narrative review is that it makes explicit search criteria and inclusion criteria (Green, Johnson, Claire, & Adams, 2006). Study I sought to unveil the patterns and/or significant themes discussed by the extant literature on the subject (Rose et al., 2016). The ambition was to reveal existing themes found within the contemporary academic discourse and to what degree these themes were supported by the unearthed articles, and thereby garner an understanding for what theme was the most prevalent in the ongoing academic debate on the subject (Cronin, Ryan, & Coughlan, 2008; Penrose & Katz, 2010).

Study II-V were set up as qualitative interview studies, where a specific case (BBMRI.se) was investigated as a representative of a distributed Research Infrastructure (Denscombe, 2017; N. King & Horrocks, 2010; Yin, 2017). The case study format has allowed for this study to investigate a phenomenon that is unalterable by the researcher (Benbasat, Goldstein, & Mead, 1987; Eisenhardt, 1989; Leonard-Barton, 1990; Yin, 2017). This is due to the fact that this thesis has conducted *ex-post facto* studies, meaning they study an "after-the-fact" occurrence wherein the characteristics of pertinence to the study already exist, and cannot be evoked. Thus, the interviewees were not influenced at any point in time before or during the study (Cohen, Manion, & Morrison, 2018; Silva, 2010). The employed method throughout study II-V has been in-depth semi-structured interviews with each of the individual respondents. This method allowed for open-ended questions with each respondent in which they could answer according to their own perception. This method has thus allowed for much greater spontaneity and flexibility in the respondents' individual response. Study II anonymised the respondents by replacing their names with a number. Study III eschewed any direct mention of the respondents, while study IV-V used fictitious names in order to increase the characterisation and relatability to the respondents in the study.

4.2 DATA COLLECTION

The data was chiefly collected from interviews, although in some cases supportive documents (such as "white papers" and "grey papers" etc.) were provided. Sometimes these would be publically available, other times they would be provided by the respondents themselves, and sometimes from the registrar or BBMRI.se secretaries. Participant observation of meetings

the BBMRI.se staff attended as part of their employment was occasionally carried out. The interviewees were asked to provide their views of actual events as they have experienced them before, during and after the formation of BBMRI.se. Their statements were initially used as information to build a case description. This case description was later used as a backdrop/supportive document to outline and help garner an understanding of the BBMRI.se construction consisting strictly of factual elements and devoid of analysis and/or interpretation. In no instance were the actions or decision by interviewees evaluated at this point. Rather, the analysis of the BBMRI.se construct would follow in the studies outlined below.

For study I, the Web of Science (WOS) and PubMed databases were searched in order to find extant studies of large-scale medical Research Infrastructures. The data extraction included all retrieved articles from the aforementioned databases by importing them into *EndNote X6*. The study used the guidelines as set forth by the *PRISMA Statement for Systematic Reviews and Meta-Analyses Guidelines* when processing the reviewed articles (Liberati et al., 2009). This entailed processing the selected reviewed articles via a four-phase flow diagram (Identification, Screening, Eligibility and Included). This procedure was elected in order to maximise the quality of the inclusion criteria as well as ensuring consistency and stringency in data selection (Onwuegbuzie & Frels, 2016).

The search strategy used a combination of the search terms *Biobank** OR *Biorepositor** OR "*Biological Specimen Bank**" OR *medic** AND *Infrastructure* AND *harmoni** OR *standardi** AND *scien** The search terms were selected, after minor modifications, in consultation with an academic workshop at the Karolinska Institutet university library, specialising at creating relevant academic search strings. The purpose was to exhaust the number of relevant search terms in an objective manner through an independent third-party with specialised competency in the area of data base searching. The results were subsequently checked for possible double entries. No limits were set in regards to study design and/or time period. The initial review phase included all identified articles published up until March 2016, i.e. the date when the database search was conducted (Liberati et al., 2009; Moher, Liberati, Tetzlaff, Altman, & Group, 2009).

During the identification process, the following inclusion criteria were selected:

- Qualitative studies within the areas of business management, social studies, medical studies, biology, political science, or similarly relevant scientific fields
- Subject concerned large-scale Research Infrastructures in biobanking, medical science or any other comparable are of relevance (e.g. data mining, cohort studies etc.)
- Published during the 20th and/or 21st century
- Published full-length articles (i.e. no reviews, unpublished doctoral dissertations meeting abstracts or proceeding papers etc.)

The criteria for the screening process were:

- Published in the English language
- No duplicates

The criteria for eligibility were that the articles would in some way pertain to the following topics:

- Had received at least one citation IF published prior to March 2014 (at least two years prior to this field work of study). Articles without citations but published more recent than this date were included in the study
- Published in an indexed journal containing a "DOI-number"

Entries mentioning more than one of the search terms (such as Infrastructure and medical) in a manner that did not connect the terms in a relevant context were excluded. Likewise, articles that made mere passing/peripheral mention of Research Infrastructures in irrelevant contexts were also excluded. All retrieved publications were reviewed manually. Studies failing to meet the inclusion criteria presented above, or studies that were in any other way deemed irrelevant, were subsequently removed from the list. The final remaining articles were then inserted into a Microsoft Excel spreadsheet table along with full bibliographic references to each individual article (i.e. date of publication, journal, volume, issue, page number etc.).

For study II-V the interviewees were selected through purposive sampling (Oliver, 2006; Ryan, 2010). This method of selection was chosen because it secures a higher level of reliability by effectively eliminating "coincidence", or "chance" as a variable (Denscombe, 2017; Wellington & Szczerbiński, 2007). Moreover, this selection allows the researcher to delve deeper into a particular issue that has only made available through sampling from a designated population (Ornstein, 2013). Originally, fifteen key individuals in managerial positions were selected based on their involvement in the formation and/or management of BBMRI.se, some of whom where so-called "work package leaders" (or "WP-leaders"), meaning that they were scientists in charge of their own work package within BBMRI.se. The fifteen individuals were e-mailed information regarding the purpose of the study and nine accepted. The non-responders were all internal to BBMRI.se, one of which was a WP-leader. The other non-compliance respondents had ancillary functions within BBMRI.se's operations and were mainly intended to give additional feedback. Hypothetically, the non-responders could have contributed with some valuable insight to the studies. However, in order to counterbalance, these studies employed a non-linear method. That is to say, linear models generally drop observations missing data on any attribute, but a non-linear model only drops observations that are missing data on attributes required in their classification, meaning one may use information acquired by alternate means as long as they contain relevant data (Soltysik & Yarnold, 2010). In this case, a majority of WP-leaders as well as those respondents in managerial positions involved in the installation of BBMRI.se elected to participate in the studies. Moreover, available literature, "white papers" and "grey papers" (as described in the beginning of this section) was used in certain instances in order to provide for some insight in the operations of any and all WPs that may have been lost due to lack of missing respondents.

Unlike study II-IV, study V only investigated the responses of seven (rather than nine) of the interviewees. The reason for this is that the study was solely focussed on the investigating the rationale behind those respondents directly associated with the formation of BBMRI.se. For that reason, it discounts the testimonies belonging to two of the respondents who were not involved in the planning/formation of BBMRI.se, but became affiliated at a later stage.

The empirical data for study II-V was collected through digital recordings in addition to traditional field notes. This was done in order to provide a less stressful environment for the interviewees to express their candid reflections and views concerning the subject matter. Simultaneously, this allowed for triangulation of data, as the extracted information was not dependant solely on the researcher's own recollection and interpretation (Denscombe, 2017). To the greatest extent possible, this study has availed itself to make use of the official designations and translations for names, titles and concepts etc. provided by the respondents themselves. All other pertinent translations have been made by the author.

4.3 DATA ANALYSIS

As a narrative review, study I analysed the available literature on Research Infrastructure in regards to biobanking and medical science, with the ambition of establishing different recurrent themes in order to discern the most discussed topics in the area, as well as identifying the most pressing need for new research.

Study II-V employed a directed content analysis (Guest, MacQueen, & Namey, 2012; Hsieh & Shannon, 2005). While study III took an inductive form, study II, IV and V adopted a more iterative approach (J. Daly, Kellehear, & Gliksman, 1997; Grbich, 2013; Guest et al., 2012; Miles, Huberman, & Saldaña, 2014). This means that study III had no pre-defined theory at the outset of the study, and that the theory used was generated on the basis of the empirical data that was unearthed. Inductive reasoning relies on the likelihood that a conclusion is accurate based on how strong the argument presented is. The advantage of inductive reasoning over deductive reasoning is that it may offer a route to knowledge in a situation where deductive certainty is impossible, such as information stemming from personal opinions or sentiments of respondents. While statements may be factually correct or incorrect, the feelings and opinions behind them cannot be said to be either "valid" or "invalid", but rather the arguments presented may be stronger or weaker (Hurley & Watson, 2018). The remaining studies utilised iterative approaches. The "iterative" aspect does not denote a repetitive mechanical task but a reflexive process in which patterns, themes, and categories emerge as the researcher interprets the data according to the premise and/or framework used for in the study (Srivastava & Hopwood, 2009). As expressed by Patton (1980, p. 306): "Inductive analysis means that the patterns, themes, and categories of analysis come from the data; they emerge out of the data rather than being imposed on them prior to data collection and analysis". In this context, it means that the studies had a pre-set framework in place, but developed themes and supporting structures through an inductive process (depending on the information supplied by the respondents). Although the same data set was used for some of the studies (II-V), with similar methods, the studies were able to extract different findings, given that the research aim was markedly different from study to study. This means that the studies were able to unearth original empirical findings by considering different variables and factors for each specific study.

Study II utilised an adapted version of the IIED stakeholder power analysis framework in order to identify perceptions of different actors/stakeholders and map out power configurations and potential power asymmetries within the organisation (Gilson et al., 2012; Macqueen, 2006; Mayers, 2005; Salam & Noguchi, 2006; Swiderska, Roe, Siegele, & Grieg-Gran, 2008). The study lists the following perceptions from the respondents: "Key Interests", which outlines the drivers of particular actors and their motives for choosing to get involved. "Importance" identifies the actor's role in achieving the project's purpose. "Influence" corre-

sponds to the power that the actors have exerted over the project's process and outcome. Finally, "Participation" designates the level of participation an actor has had, and to what capacity. The transcripts from each interview was analysed, and meaning units (quotations) were assigned to each of these corresponding to the four aforementioned dimensions as these were identified in the text. The findings were subsequently placed in a spreadsheet table, and summarised with a code, which can best be described as a "descriptive or conceptual label that is assigned to excerpts of raw data in a process" (Gale, Heath, Cameron, Rashid, & Redwood, 2013, p. 2). That is, the codes were grouped and categories and themes that emerged were then labelled through an iterative process (as previously described). Wherever appropriate, sub-themes were also identified. As mentioned previously, this iterative approach included both inductive and deductive elements (Grbich, 2013; Miles et al., 2014). In this case, the deductive elements consisted of that the entities chosen already pre-existed in the framework of the analysis used. On the other hand, the emerging themes (and sub-themes) were developed by inductive means, as these were dependant on the responses given by the interviewees.

As study III took on an inductive approach, it relied more on the directed content analysis in constructing an overarching image of how the different WPs interacted within the BBMRI.se organisation.

Study IV-V operated in a similar way to study I in its use of extracting meaning units from the interviews and identifying categories, themes and sub-themes. However, in analysing patterns across data sets, study IV would take its point of departure from the notions of brand building and mindshare formation as presented by Aakers (1996), Azevedo (2005) and Holt (2004). In synthesising their understanding, there are four stages, or themes, of perceived brand formation. These are based on how the respondents have viewed the formation of BBMRI.se and what it signifies to them. Thus, each stage contains different sub-themes that seek to tether out recurrent topics and how the respondents relate to them. Firstly, there is "Brand Strategic Analysis", which seeks to answer the question "why do I/we need/want this?" It seeks to establish the underlying drivers, or rationale among the respondents for wanting to commit to the BBMRI.se initiative. Secondly, there is "Brand Identity", which aims to answer "what is this brand all about?" It looks to probe the respondents' conception of the brand identity and what values they believe it embodies in reality. Thirdly, there is "Brand Operationalising", which seeks to answer "how do we go about building this brand?" It endeavours to detect the perceived actions/ambitions in realising the brand, or what factors that that has impeded it. Fourthly, and finally, there is "Post-Implementation Reflections", which seeks to answer "how did I/we do?" Thus, it aims to understand how the respondents feel about the brand building with the benefit of hindsight. In other words, what worked well and what could have been done differently.

Study V took its departure in investigating entrepreneurial aspects as envisioned through a four-phase action phase model (Hidi & Renninger, 2006; Shir, 2015; Van Gelderen, Kautonen, & Fink, 2015; Vann, Rosa, & McCrea, 2018). As this was an iterative study, this means that four original main themes were set up based on four different themes ("Intention", "Initiation", "Implementation" and "Introspection"). Subsequently, various quotations, or "critical events", were extracted from the interviews as "meaning units", through an inductive process. These covered each respondent's motivations and rationale for engaging themselves in the events leading up to the formation of BBMRI.se, in terms of their understanding of various goals and to what extent these had been achieved.

4.4 ETHICAL CONSIDERATIONS

This study was vetted by the Regional Ethical Review Board in Stockholm (2012). The review board concluded that no ethical approval was needed for this study (ref no. 2012/1863-31/5), and issued an advisory statement that there were no impediments from an ethical perspective in conducting the type of research undertaken in this dissertation.

Prior to the start of the interviews, the respondents were briefed regarding the purpose and stipulations of the interview. Informed consent was secured from all interviewees and all respondents had the opportunity discontinue the interview or withdraw their participation at any given time (Hesse-Biber, 2016; Watts, 2008). The interviews were subsequently transcribed by either the author, or in some cases, by a professional transcribing service that guaranteed full confidentiality.

Kvale and Brinkmann (2009) contend that a researcher's report should not be seen as a representation of data that has been "seasoned" with the researcher's own comments and reflections. Rather, the account given by the researcher should be viewed as a social construction in which the researcher's narrative provides a specific view on the reality in which the respondents live. Kvale and Brinkmann (2009) and Fink (2000) argue that from a researcher's point of view, it is important that the exact research data is used as it has been acquired. Should any tampering be allowed, such as *a posteriori* revisions by respondents wishing to portray themselves more favourably etc., the subsequent analysis of data risks becoming faulty, misleading or unreliable. Nevertheless, this study has taken meticulous care to ensure that the responses made by the interviewees have been as accurate as possible. This is further reinforced by the fact that the case description that outlined strictly factual issues such as the strategic and operating bodies of BBMRI.se, was submitted to and vetted by the BBMRI.se management for factual veracity through December 14 to December 18, 2015, with additional subsequent factual confirmation by the BBMRI.se directors on January 27 and June 17 2016, as well as on March 21 and April 3, 2018.

The names of the respondents were withheld in order to increase confidentiality in accordance with the AoIR guidelines (Ess & AoIR Ethics Working Committee, 2002). This means that although the identities of the respondents could potentially be disclosed by someone willing to invest the necessary time and energy, the anonymization will prevent the respondent's authentic names from being directly linked to this dissertation by means of conducting a search on a search engine (Madge, 2012). Notwithstanding, this study has not anonymized the use of BBMRI.se as an organisational name. The primary reason for this is the fact that this study was vetted and approved by the aforementioned ethical review board with the understanding that this study concerns BBMRI.se. Consent to this effect was also given by the then incumbent director of BBMRI.se. A secondary reason for meriting the disclosure of the BBMRI.se organisation name is that it carries great significance to the subject matter at hand regarding large-scale Research Infrastructures. Moreover, this case in particular may also be of interest to the other extant national BBMRI-nodes, as well as other similar present or nascent Research Infrastructure initiatives that may draw insights from the mechanisms involved in BBMRI.se's ultimate failure. Some other government actors, such as VR, are also mentioned by name, as these are public institutions. However, since they have merely played an

indirect or a peripheral role in the course of events described, the results of this dissertation should have no impact on these actors one way or another.

5 CASE DESCRIPTION

The following section briefly describes the early initiatives take towards harmonising biobanking standards, the creation of BBMRI.se, its implementation, structure and formally the difficulties that would eventually end the organisation.

5.1 THE INITIAL STEPS TOWARDS BIOBANK HARMONISATION

In Sweden the first initiative to coordinate the biobanks and building an infrastructure to this end, was taken by the *National Biobanking Programme* (NBP). This time-limited initiative was in turn funded by the Knut and Alice Wallenberg foundation via the *Wallenberg Consortium North* (WCN) and the Swegenes programme (Nobel, 2008). NBP was chiefly aimed to improve the overview of Swedish biobanks, and create a mode of standardisation of the routines exercised by the biobanks. On this note, the main difference between "harmonisation" and "standardisation" lies in the level of its strictness. Fuertes (2008, p. 327) defines the differences as follows: "Harmonization involves a reduction in accounting variations, while standardization entails moving towards the eradication of any variation".

NBP was a joint national programme of the medical universities in Sweden that carried a total budget of €6 million (≈ $6.9 million). Its aim was to promote accessibility and quality, which meant that all participating biobanks had to commit to using a common set of quality standards and to provide access to samples after prioritisation solely on scientific grounds (Hansson, Dillner, Bartram, Carlson, & Helgesson, 2006; Helgesson, Dillner, Carlson, Bartram, & Hansson, 2007; Nobel, 2008). In 2005, NBP was evaluated by an international review panel. The panel concluded that NBP was conceptually beneficial but lacked the ability to achieve coherence and coordination among the Swedish biobanks. The outcome inspired several other actors to form in order to achieve that which NBP could not do (Ahrén, 2008; Nobel, 2008). One intended actor was *Biobank Sweden*[5], which sought to be a continuation of NBP by focussing on the same type of research (Nobel, 2008). However, it never left the planning stage as it was little more than a planning grant from VR. Continued planning was made redundant once BBMRI.se came into effect.

A practical problem to the biobank situation was that there were large quantities of biobank collections that were underutilised in spite of the harmonisation initiatives. The reason for this was chiefly economic (Nobel, 2008). Funding utilisation of biobanks is indeed costly (Caulfield et al., 2014). Biochemical analysis and withdrawal of large quantities of samples carry tremendous costs respectively, not to mention conducting modern genomic analyses on biobank samples. In fact, these costs are so steep they are generally not even covered by individual grants in Sweden (Nobel, 2008). The only realistic way to manage this obstacle would be for biobanks to work together as a more cohesive unit, but thus far this had been met with

[5] This actor is distinct from the namesake organisation that was formed in 2018 as well as the namesake BBMRI.se publication.

limited success at best (Clément et al., 2014). This was in no small part due to the lack of proper Research Infrastructures to handle such research. This was also preceded by a political discussion in Sweden that resulted in no less than three different government research bills. These research bills in part aimed to reduce the political influence over the Research Infrastructures and instead make them more autonomous from governmental control (Government Offices of Sweden, 2004). Furthermore, the research bills also sought to increase the government spending on science and research, which would make additional funds available to proceed with the development of Research Infrastructures (Government Offices of Sweden, 2008, 2012).

The need of a Research Infrastructure had been acknowledged by VR since the early 2000s (Sandberg, 2012). This led VR to start looking deeper into various areas for Research Infrastructures. One of these infrastructures was the *Database Infrastructure Committee* (DISC), which was founded in 2006 (Carlhed & Alfredsson, 2010). One of the chief purposes of DISC was to promote the development of an effective infrastructure for sharing data resources in Sweden that would provide scientists with swift access to high quality data (E. T. Meyer & Schroeder, 2015; Sandberg, 2012). DISC mainly focussed on coordinating databases within the scientific fields of social science, human studies and epidemiology.

In 2007, VR also set up a temporary committee that would handle biobank issues: *Biobank InfraStructure Committee* (BISC) (Von Der Lehr, 2012). Its chief aim was to have national responsibility for coordinating Swedish biobanks and developing infrastructure to enable efficient use in research. It was designed to have strong coordination with DISC, with the ultimate goal of integrating the two. A problem with just integrating these two units was the fact that the databases were not constructed in the same manner and there were complications surrounding the safeguarding of personal integrity. This called for the harmonisation of biobank databases in themselves rather than just collecting all the results under one and the same umbrella and cross-checking these under one large database (Nobel, 2008). However, the situation was not altogether unique for Sweden as many other countries in Europe were facing similar problems regarding biobank dissonance at around the same time. ESFRI (2006, p. 26), declared in 2006 that: "Bioinformatics is now a prerequisite for all experimental and applied biology, including drug discovery, human genetics and epidemiology". This was the prelude to an initiative that sought to establish a sustainable life-science Research Infrastructure in Europe. One of the 35 projects that ESFRI presented in accordance with this vision was BBMRI, which was finally established in 2008 (Wichmann et al., 2011). The idea was that BBMRI would facilitate a large-scale European Research Infrastructure aimed at high-quality biomedically relevant sample collection. An innovative essential with this collection would be the possibility to link related clinical and epidemiological information. In addition, BBMRI would provide an inventory of existing biobanks while establishing a common framework for sample harmonisation and classification (Swedish Research Council, 2009).

This initiative appeared to have had particularly favourable preconditions in Sweden, as the country had several structural advantages lacking in most other countries, in addition to already having undertaking extensive preparatory work. For instance, Sweden inherently carries an extensive registry of its population (Council of Europe, 2001). It also issues a unique civics registration number to all of its inhabitants (irrespective if they are citizens or foreign national residents), which makes each individual easier to identify. The open healthcare services also foster a research-friendly environment. This in turn provided auspicious preconditions for utilising the existing Swedish biobanks in a larger scale and integrated the existing

data into a more cohesive unit. The ultimate aim of BBMRI was to integrate the biobanks both on a national level and, eventually, on a European level, thus giving access to research material in a manner that had thus far not been possible. BBMRI thus sought not only to integrate the standards of biobanking, but also to provide a new framework of definitions and concepts to which all biobanks could adhere (Kaye, 2016). Indeed, Sweden was not the first country to set up a national BBMRI infrastructure, as both Austria and the Netherlands had already acquired national funding (European Commission, 2015b; Nobel, 2008). Nevertheless, the fact that Sweden already had a history of various biobank programmes helped foster the idea that BBMRI had a solid premise in Sweden.

5.2 THE GENESIS OF BBMRI.SE

In 2009, some leading Swedish professors in the field of biobanking would commence the initiative towards forming a Swedish BBMRI node, "BBMRI.se", after having been approached by VR (Larsson, 2018b; Skoglund, Drawfarc, & Fransson, 2016; Van Ommen et al., 2015). Shortly thereafter, an "Operation Grant" application was submitted to VR, which outlined the activities and the proposed initial staff members (Swedish Research Council, 2009). The application was ultimately approved (Nobel, 2008; Norlin et al., 2012). The intention was for BBMRI.se to replace BISC (Nobel, 2008). Subsequently additional measures would be taken in order to secure the implementation of the BBMRI.se

Gemensam Svensk Biobanksstruktur (GSB) was the name of the overarching mission tasked with bringing about the harmonisation of Swedish biobanks (Swedish National Biobank Council & BBMRI.se, 2013; Swedish Research Council, 2015b). The mission was commissioned by *The Swedish Research Council* (VR) and the *Swedish Association of Local Authorities and Regions* (SALAR [Swe: SKL]) (Swedish Research Council, 2012b). It consisted of a project group, headed by a chairperson and comprised an additional eight members; four representatives from BBMRI.se and another four from the *Swedish National Biobank Council* (NBR) (Swedish National Biobank Council & BBMRI.se, 2013). The aim of the GSB-mission was to present viable suggestions as to how available biobank resources may be utilised in order to provide a superior and secure healthcare This at the same time while maintaining a highly advanced level of research that respects all pertinent laws and regulations as well as the integrity of the subjects.

An agreement between VR and the to-be host institution was ratified in 2010 (Divers, 2011; Swedish Research Council, 2013, 2016b). The host institution for BBMRI.se was to collaborate with other medical faculty universities in Sweden (Dillner, 2011b; Skoglund et al., 2016). This application would thus mark the formation of BBMRI.se as a biobank Research Infrastructure in Sweden. Ultimately, BBMRI.se was formed and its operations begun. In December 2012, BBMRI.se entered a consortium agreement, which outlined the general purpose of BBMRI.se and the actors involved in it. The signing of this consortium agreement would establish BBMRI as an ERIC Research Infrastructure (Litton, 2018; Mayrhofer, 2013). The reason it took over two years from that BBMRI.se was founded to that the agreement was set in place, was that new regulatory frameworks had to be developed and the fact that these were new, meant that the host university had to engage in prolonged negotiations with VR (Swedish Research Council, 2013). The initial overall impression by observing academic and government bodies was that they were impressed by the fact that BBMRI.se had formed in

such a short period of time (BBMRI.se, 2012). There were initially some reservations presented by one of the BBMRI.se founders regarding the feasibility of the consortium agreement (Skoglund et al., 2016; Swedish Research Council, 2013). In a 2012 interim evaluation, VR also contended that while the leaders of BBMRI.se understood that the mandate for coordinating the necessary functions had to be earned by interacting with the users and collaborators, the organisation had an unclear way of reporting the number of users, making evaluation of usage difficult (Swedish Research Council, 2012a). The report also asserted that BBMRI.se had an unclear relationship between its different governing bodies and that the "Executive Director's" role came across as "too dominant relative to the to the [Governing] Board and the [member university] nodes" (Swedish Research Council, 2012a, p. 26). VR concluded that BBMRI.se played a fundamental role for the European BBMRI, which it asserted would be "unthinkable without the Swedish input" (Swedish Research Council, 2012a, p. 27).

The ERIC was officially launched in January 2013 and involved all seven Swedish universities with medical faculties. Subsequently, two additional Swedish universities would join BBMRI.se at different stages. However, as mentioned previously, the signing of the consortium agreement was controversial. Representatives from one of the participant universities sent a formal letter to VR on February 15, 2013, raising concerns about possible conflicts of interest between VR and BBMRI.se (Skoglund et al., 2016; Swedish Research Council, 2015a). The complainants criticised that too much dominance over BBMRI.se was vested into the hands of the host institution, which would manifest through the negligence of sharing vital information with the other member universities. Another issue stemmed from the contention that the host university had taken furtive action to alter the terms of the consortium agreement in a way that benefited the host university at the expense of the other member universities (Swedish Research Council, 2013). A key point in their criticism was that there was a perceived conflict of interest between the host university and VR, as staff members serving in both organisations simultaneously had handled various processes pertaining to BBMRI.se. The letter also contended that these grievances had been, and was continuing to be, ignored by both the host university and VR.

As a concept, BBMRI.se had a distributed "hub and spoke" infrastructure, wherein the hubs coordinated activities such as collection, exchange and analysis of samples and data for the major domains. Each biobank, or molecular resource and technology centre, was linked to a specific hub (Litton, 2018). Public or private partners (e.g. universities, hospitals, companies) providing biological samples, data, technologies or services could be connected to a BBMRI hub. This structure sought to provide flexibility, as new members could be connected at any given time. As such, the ambition was for the structure to easily be adapted to emerging needs in biomedical research (Swedish Research Council, 2009).

The BBMRI.se (2015a, p. 4) strategy document defined the main goal of the organisation in the following manner:

> *"…to create a harmonised, efficient and internationally leading nationwide biobanking infrastructure that will provide a long-term, strategic support for Swedish medical research, healthcare and biomedical industry. The BBMRI.se infrastructure will provide a comprehensive state-of-the-art service to researchers, both regarding sample collection for biobanking pro-*

jects, as well as regarding assistance with exploitation of biobanks for research. BBMRI.se will develop and provide the tools and the expertise required for creating new valuable sample collections as well as for improving accessibility and usefulness of already existing sample collections".

Throughout its lifespan, BBMRI.se would have a total of three different directors (Larsson et al., 2018; Skoglund et al., 2016). Moreover, BBMRI.se consisted of eight work packages (WPs), led by different work package leaders, or "WP-leaders" (BBMRI.se, 2010; Litton, 2011; Swedish Research Council, 2009). For some WPs, these would be from the host university and in the other cases they would be from other member universities. The individual areas of responsibilities were as follows:

WP1 - Management and Administration

WP1's purview was the coordination, information and administrative activities of BBMRI.se. It was responsible for the international relations and benchmarking activities. Its directors were responsible for formulating the goals and visions of BBMRI.se. In addition, its directors were responsible for monitoring progress and reporting to the BBMRI.se board as well as the Swedish Research Council.

WP2 - Swedish Federation of Population-Based Biobanks

The aim of WP2 was to integrate the major population-based research biobank cohorts in Sweden. Several existing Swedish biobank cohorts have a long biobanking history and a large number of incident cases of major diseases. A joint national biobank platform could thereby be obtained and immediately exploited for medical research, using the combined scientific experience also for optimising strategies when establishing new cohorts. The federated cohort had accumulated enough major disease events (presently >12.000 deaths, >6.000 incidents of myocardial infarcts, >4.000 incident of stroke and > 20.000 incidents of cancers) for immediate gene-gene and gene-environmental interaction analyses with a high statistical power. Using BBMRI.se to link to new cohorts and new technologies, the existing cohorts were expected to greatly benefit from participation in the federation. Improved interaction with regional and national disease registries was crucial for the development of BBMRI.se. Participating biobanks were required to commit themselves to use common quality standards and to provide open access to samples, prioritised only on scientific grounds.

WP3 - Clinical Biobanks

WP3's role was to facilitate consolidation of the Swedish clinical biobanks into nationwide, standardised and quality-assured biobanking networks. These networks involved those representing the entire population with the ambition of providing resources for clinical diagnosis as well as for basic and clinical research. This meant that WP3's task was to develop a long-term strategic plan for the role of large-scale biobanking at the interface between clinical practice and research. Furthermore, it was tasked to facilitate national consolidation and networking of clinical biobanks. Additionally, WP3 was to support a common framework for quality improvement and harmonisation of standards. One of the cornerstones of WP3's activity was to seek out collaboration with relevant medical specialty societies that were active in building and developing clinical biobanks.

WP4 - Biomolecular resources

The objective of WP4 was to ensure ready access to advanced expertise, technologies, and reagents for Swedish scientists for optimal use of sample collections. These resources were intended to provide state-of-the-art molecular analyses and investigations by exploiting emerging technologies, while access to actual biobank samples propels the development of new technologies. These tasks were run parallel with the EU-level BBMRI program, which sought to secure Sweden's leading role in biobanking research. WP4 also sought to spread knowledge about molecular analysis of biobank samples through direct counselling, development of databases, training courses, conferences and workshops. The web catalogue *Biobanking Analysis Resource Catalogue* (BARC) was developed to help scientists gain an overview of how to best utilise valuable biobank samples, from pre-analytical sample preparation methods to the analytical technologies and molecular resources. Furthermore, WP4 developed documentation standards and standardisation of laboratory protocols relevant to biobank research by using the database *MolMeth*. This database detailed laboratory protocols for molecular analyses by promoting meta-studies that could combine results from multiple independent studies, thereby enabling them to be analysed from a multitude of different perspectives. WP4 also evaluated pre-analytical sample handling methods as well as identifies the need for new technologies and supports the development of new advanced methods for large-scale analysis of biobanked samples.

WP5 - Biobank Informatics

WP5 was tasked with developing the IT-infrastructure for BBMRI.se, which sought to link information about phenotypes and genotypes by connecting large databases. WP5 sought to address the lack of biobank informatics, as this was a problem that congested the processing of large complex data streams in modern clinical and epidemiological research. WP5 collaborated closely with other national and international biobank and healthcare infrastructures. WP5 also offered researchers an overview of existing biobank samples. This was done by the development of a register of research sample collections. The goal was to assemble all national studies and medical sample collections intended for research in this register and compile a national inventory of research sample collections. Additionally, WP5 sought to promote a common terminology for biobanks with the intent of improving communication between scientists while defining concepts associated with the information structure.

WP6 - Sample management

WP6 area of responsibility concerned the physical facilities for biobanking within BBMRI.se. Specifically, it was tasked with finding the appropriate storage solutions (liquid nitrogen etc.), sample retrieval, vicinity and means of operating these in a practical sense. WP6 sought national collaboration/integration with local biobanking facilities and was also responsible for the quality assuring BBMRI.se's procedures and sample processing.

WP7 - Ethical and legal aspects of biobanking

The overarching goal of WP7 was to develop and promote a coherent and concise concept of ethical practices in biobanking research. WP7 conducted scientific studies on how different rules could be interpreted so in a manner that considered the integrity of the human donors as well as the research interests for new medical treatments. The reported results were subse-

quently published in international scientific journals. WP7 staff consisted mainly of non-clinical personnel, such as senior ethicists, lawyers, students, communications officers etc.

WP8 - Fundraising and Financing

WP8's planned objective was to ensure continuous and long-term financial support to BBMRI.se (Swedish Research Council, 2009). However, its goal would subsequently evolve into identifying patterns and mechanisms in the building of a large-scale medical Research Infrastructure, using BBMRI.se as a case.

Nevertheless, the WPs as a construct would be officially disestablished from the formal BBMRI.se structures in 2015, as per its updated official strategy plan. Instead, the plan was for BBMRI.se to erect “Service Centres” that would “offer a defined set of services” in the coming years (BBMRI.se, 2015a, p. 7). However, as explained in the next section, this vision would never be fully realised.

5.3 THE END OF BBMRI.SE

For reasons dissected in more detail throughout this dissertation, a series of irreconcilable financial and organisational disagreements between the participating member universities began escalating. Issues stemming back to the previously mentioned complaints against the consortium agreement began intensifying, along with complaints regarding the abolition of the WPs. Several formal complaints were lodged by member university representatives of the BBMRI.se organisation at various stages and the internal conflict was becoming increasingly more palpable (Skoglund et al., 2016; Swedish Research Council, 2015a, 2017).

To this extent, three member universities in particular accused the host university of undertaking improper actions (Skoglund et al., 2016; Swedish Research Council, 2013, 2015a). At this point in time, BBMRI.se also began experiencing some staffing issues, with some staff members either stepping down from their functions, resigning, or requesting employee relocation (BBMRI.se, 2014a, 2014b, 2015b; Skoglund et al., 2016; Swedish Research Council, 2015a).

The dissatisfaction reached its peak on December 7, 2015, when BBMRI.se representatives from the three aforementioned member universities authored a joint statement to VR, officially accusing the host institution of managerial maladministration (BBMRI.se, 2015d, 2015c; Skoglund et al., 2016; Swedish Research Council, 2015a). This would lead to the launch of an independent, external investigation by an auditing firm in the spring of 2016. Concurrently, an internal review by the host institution was also launched. Both of these reports would indicate that there, among other items, had been questionable and/or erroneous distributions of funds. The host university’s top management did attempt to respond to the complaints, and the BBMRI.se management even expressed intentions to draft a new action plan; however, these actions would do little to curb the events that had now been set in motion (BBMRI.se, 2015b; Skoglund et al., 2016; Swedish Research Council, 2016a).

As a result of these reviews VR announced in March 2016 that it would withdraw additional funding to BBMRI.se, with the exception of the two-year decommissioning grant the research council customarily awards decommissioning infrastructures (Swedish Research Council, 2016a, 2017). The decommissioning grant was set to SEK 8 million (≈ €776,000 or $883,000) of which the organisation was set to pay SEK 1.1 million (≈ €107,000 or $122,000) for its 2016 membership fee to BBMRI-ERIC (Swedish Research Council, 2017). This effectively spelled the end for BBMRI.se and the organisation would ultimately officially fold once its final mandate expired on April 1, 2018 (Larsson et al., 2018; Swedish Research Council, 2018). In late 2017, the formation of "Biobank Sweden" was announced (Swedish Research Council, 2018). This was a new Research Infrastructure for biobanking that placed a former BBMRI.se member university as the host university. This Research Infrastructure would integrate the remnant of BBMRI.se under a new umbrella, along with national biobank NGOs, industry representatives, regional counties and interest groups (Government Offices of Sweden, 2018; Larsson et al., 2018). Biobank Sweden also replaced BBMRI.se as a member of BBMRI-ERIC, where is its work would focus on issues pertaining to ethics, law and social issues within the international BBMRI organisation (Swedish Research Council, 2018).

As a large-scale distributed Research Infrastructure, BBMRI.se developed in a relatively short time span, owing much to the fact that there were similar concurrent sentiments in Sweden as well as on a European Union level (D'Agnolo & Bravo, 2013; Fransson et al., 2015; Jain, 2017; Swedish Research Council, 2009; Van Ommen et al., 2015).

6 FINDINGS

This section provides a brief summary of the key findings for each of the five studies.

6.1 STUDY I

A total of 145 studies using the bibliographic databases WOS and PubMed were identified. 17 articles were included. The results showed that approximately two-thirds of the publications listed a first author affiliated to a European country. The most commonly discussed topics concerned the need for developing and expanding the use of "infrastructures". Two of the articles mentioned BBMRI by name. Nine of the articles were cited five times or more since publication. Even though there was a relative scarcity of total number of articles, the analysis illustrated that the available articles' first authors were fairly well-distributed amongst different countries. To that effect, all continents were represented among retrieved articles. However, the first author was affiliated with a European country in eight out of 12 cases. Most of the studies were funded through grants, although approximately 1/3 of the studies did not specify the origin of funding. In one sole case the authors claimed that they had received no funding for their research.

The study identified four recurring themes, or needs, that were discussed throughout the different papers: 1) Cultural/Procedural Harmonisation, 2) Data Harmonisation, 3) Infrastructure and 4) Regulatory Harmonisation. The results indicated that most (11) studies discussed "3) Infrastructure", as in the "need of infrastructure" in order to achieve a higher purpose, e.g. facilitating further investments and securing greater degrees of interdisciplinary collaboration.

Six studies discussed “1) Cultural/Procedural Harmonisation”. This targets the “softer” values within an organisation. Five articles discussed “4) Regulatory Harmonisation”, which called out to regulatory/political actors to facilitate the developments of Research Infrastructures. Finally, four studies cited “2) Data Harmonisation”. This targeted the technical fragmentation that presents obstacles for cooperation in large-scale Research Infrastructures. The findings ultimately indicated that the future of scientific research calls for deeper and more widespread multidisciplinary forms of collaboration. A more detailed overview of the identified themes is illustrated below:

1. Cultural/Procedural Harmonisation – Emphasises the need of securing harmonisation of “softer components” i.e. employees and/or managers at the various institutions. It suggests the impediment is mainly attitudinal and/or relates to exclusionary design in that institutions regulations and/or values, norms, cultures and traditions.

2. Data Harmonisation – Emphasises the need of updating the technical procedures and/or hardware to a uniform system that is used by all participating members.

3. Infrastructure – Emphasises the need of an actual infrastructure, usually in the form of a physical infrastructure, but sometimes in more a conceptual sense. While this is doubtlessly the most wide and abstract of the four types of needs, the articles would emphasise the general and practical need of establishing a Research Infrastructure for a given (larger) purpose rather than a particular aspect of said Research Infrastructure.

4. Regulatory Harmonisation – Emphasises the need of securing harmonisation on higher, political level, usually via policy-making. These articles would often highlight the need of coordinating various political efforts as to ensure legal frameworks that serves as common practice for all members and will enable them to successfully implement an effective Research Infrastructure.

6.2 STUDY II

BBMRI.se came to fruition due to two fortuitous processes that ran independently, but in parallel, to one another (one domestic and the other of European/foreign origin). Leading scientists within their field, known as “National Champions” were recruited to BBMRI.se, where they gained much influence and autonomy as “WP-leaders”. The study unearthed two concepts that played an important role in discerning these themes, namely “deliberation” *vis-à-vis* “collaboration” (Benhabib, 1996; Gutmann & Thompson, 2004; Kingdon, 2002). The former is rooted in Habermas’ (1995, 1996) theory and seeks to establish a “public sphere” in which actors of different backgrounds may converge to exchange ideas and experiences. Dominant actors are “policy entrepreneurs” who look for various “windows of opportunity” to move items onto the agenda in order to “claim credit” for successful endeavours and to be on the “winning side” on issues that are viewed favourably in the public eye (Kingdon, 2002; Mayhew, 2004). In a deliberative setting, actors act opportunistically with the ambition of creating a collective conversation (Kingdon, 2002). That is to say, there is an understanding that there are “barriers”, e.g. conflicting interests, standards and/or values, and that the concept of “deliberation” exists as a procedural solution as a mean of dealing with these prob-

lems (Benhabib, 1996). The latter, "collaboration", seeks to create "authentic dialogue" and "consensus building" to problem-solving by increasing the distribution of knowledge between the actors involved (Healey, 2006; Innes & Booher, 2003). Previous literature has suggested that the two are diametrically opposed concepts (Coleman, 2012; Norton, 2015).

Via an adapted version of the IIED stakeholder power analysis framework, this study identified the perceptions of the respondents by looking at four different dimensions (Gilson et al., 2012; Macqueen, 2006; Mayers, 2005; Salam & Noguchi, 2006; Swiderska et al., 2008). These were "Key Interests", i.e. the drivers of particular actors. It sought to understand why the respondents chose to get involved. "Importance" explains the actor's role in achieving the project's purpose. "Influence" corresponds to the power that the actors have wielded over the project's process and outcome. "Participation" looks at the level of participation an actor has had, and to what capacity they have done so. By analysing the data derived from the respondents, twenty-five overarching sub-themes were uncovered along with twenty-three categories.

In terms of "Key interests", the respondents agreed that there was an overarching need to simplify Swedish biobanking research, while making it more effective and cost-efficient and globally competitive. Still, the task to establish BBMRI.se was considered unclear and different respondents interpreted the purpose differently. Although the respondents agreed that various ethical and legal frameworks regulated their work, the overall assessment indicated fragmentation among the respondents' key interests.

As for "Importance", the respondents contended that BBMRI.se had been established following coordinated actions of different actors, such as ESFRI and VR, while building upon prior national initiatives. The participation of all Swedish medical universities was also lifted. The respondents were split in regards to whether or not other coordinating-oriented biobank organisations carried any significant impact on BBMRI.se. Some of the respondents rather spoke of the importance of conveying a credible image. Regardless, BBMRI.se was marred by conflicts that would bear consequences in several different ways.

"Influence" was, according to the respondents, something that emanated indirectly from events occurring at the EU-level as well as a result from previous harmonisation initiatives. However, VR was considered to exercise direct influence on BBMRI.se. An additional factor was the financial and legal constraints, which influenced what BBMRI.se was able to do. The respondents expressed that the desire to seek various forms of academic collaborations also influenced the organisation. To this end, there was some contention that the existence of parallel national biobanking organisations, such as NBR, had a disruptive and divisive influence on BBMRI.se's harmonisation initiative. Additionally, some of the respondents highlighted the inter-academic conflicts. They emphasised that some of the managers were not team players and to this extent, they had put their own prestige above the organisation's well-being.

In regards to "participation", the respondents agreed that having scientific experts participating in the same forerunning organisations carried significance. The involvement of all medical universities was seen as essential. However, the respondents largely regretted that the county clinics, industry and NGOs had not been involved. On the other hand, the individual leading scientists were seen as having been highly active, and that these were able to act with

large degrees of autonomy. Thus, the autonomous scientists had felt obliged to engage themselves because of their personal stakes in the BBMRI.se initiative. To this end, the autonomous structure of BBMRI.se gave rise to additional disagreements and confusion in regards to organisation's direction. This also propelled interpersonal differences among the different "National Champions", which would ultimately worsen the already existing fragmentation.

The results showed that the respondents had engaged themselves in BBMRI.se thinking it would be a collaborative effort but they found themselves disappointed to learn that the organisation was more dominated by deliberative elements. In conclusion, the resulting autonomous structure caused discord while also fuelling interpersonal disagreements. These would eventually take on such proportions that BBMRI.se would ultimately lose its funding and be forced to close down its operations. The lessons learnt from this study is that it is crucial to identify the possible collaborative and deliberative elements already at the outset of establishing a distributed Research Infrastructure, while at the same time also ensuring that there is a functioning form of communication between the involved parties. A concluding finding indicates that contrary to the suggestion of extant literature, the establishment of a Research Infrastructure does not necessarily counteract organisational fragmentation, or at least not in the case of a distributed Research Infrastructure.

6.3 STUDY III

BBMRI.se aspired to create a harmonised, efficient and internationally leading biobanking infrastructure across the nation, which would in turn provide strategic long-term support for Swedish medical research, healthcare and biomedical industry. To this end, BBMRI.se sought cooperation from several different members and scientific disciplines in working towards the same organisational goal. Nevertheless, the WP's goals would carry their own agenda. Each WP carried different functions. While some WPs performed investigative tasks, other WPs focussed on providing service functions. Still, this distinction seemingly had no direct impact on the WP's ability to adhere to the larger organisational goal of harmonisation. The WPs were able to work in different and multidisciplinary environments. Yet, a major challenge was the inherent risk of various "National Champions" and their WPs pursuing own goals that detracted from the designated overarching mission of BBMRI.se.

Specifically, the "principal-agent" problem appears to have existed within BBMRI.se. In simple terms, the "principal-agent" problem means that the organisation, or the "principal", hires managers, or "agents". The intention is to delegate the operating decisions to the "agents" (Auranen & Nieminen, 2010; Eisenhardt, 1989). Both "principals" and "agents" work towards their own interest since they seek to maximise their respective gain (Baker & Anderson, 2010; Van der Meulen, 1998). Notwithstanding, the "agents'" pursuit of self-interest promulgates a conflict of interest. This is known as an "agency problem", since the agents are not particularly interested in the outcome of the principal's activities per se (O. Hart, 1995; Smith & Street, 2012). This problem partially stems from the asymmetrical information flow, where the "agents" possess information they share neither with other agents nor with the principal (Prakash & Gugerty, 2010). This is not necessarily a serious problem had all the agents worked towards the same goal with the principal. Nevertheless, the problem becomes apparent when the perceived objectives do not align with that of the principal. Even in the instances where the agents do share some of the goals with the principal, they are not necessarily prioritised above the "agent's" own goals (Smith & Street, 2012).

In the case of BBMRI.se, this led to goal divergence, with different actors aiming for different goals. This, in turn led to "task uncertainty", which was fuelled by the organisation's autonomous sub-units. Because the greater the autonomy, the greater the task uncertainty, i.e. the perceived obfuscation of the organisation's mission (Engwall, 1995; Knudsen, 2003; Whitley, 1984a, 1984b). An organisation with a high level of task uncertainty and a low level of organisational integration will suffer from organisational fragmentation, and the type manifested in BBMRI.se can best be identified as a "fragmented adhocracy". This means that the mission statement is subject to diverse views, leading to goals that are separate, unstable and sometimes even conflicting, while also lacking in co-ordination (Engwall, 1995; Foss, 1996; Whitley, 1984a, 1984b). This development would ultimately spell the end for BBMRI.se. Moreover, BBMRI.se appears to have employed the traditional model of planning and control systems through its reliance on strategy documents, interim evaluation reports and vertical organisational structure, rather than employing a "liaison device" (BBMRI.se, 2015a; Dillner, 2014; Skoglund et al., 2016). The latter entails that BBMRI.se would have sought to appoint an "ambassador" to go between the organisational units/WPs in order to ensure what is known as "lateral linkage", i.e. congruence to the organisation's purpose (Mintzberg, 1979; Rainey, 2014). The study concludes that this may have had adverse effects on the communication across the different WPs and that a possible remedy could have been to set up a Project Management Office (PMO), a dynamic entity aimed at defining and maintaining standards or by implementing mechanisms ensuring clear and unequivocal communication of the organisation's overarching goals to all of the autonomous subunits (Chin, 2004; Darling & Whitty, 2016; Lavoie-Tremblay et al., 2012).

6.4 STUDY IV

The framework drew upon an adapted brand identity model originally devised by Aaker (1996) and Azevedo (2005). The model identified four stages of a brand building process, in which a brand is successfully built in a way that it carries a universal meaning and sentiment to all concerned parties. These were: "Brand Strategic Analysis", "Brand Identity", "Brand Operationalising", and "Post-Implementation Reflections" (Aaker, 1996; Aaker & Joachimsthaler, 2000; Cravens & Piercy, 2013; Davis & Dunn, 2002; De Chernatony & Dall'Olmo Riley, 1998; Ghodeswar, 2008; J.-N. Kapferer, 2012; Upshaw & Taylor, 2000; Vallaster & de Chernatony, 2005). Through thematic grouping, this study was able to identify a total of 23 sub-themes. These sub-themes would then help build up an understanding over the transpired events.

The first stage, "Brand Strategic Analysis" showed that the respondents chiefly took an initial interest to the BBMRI.se brand because it seen as remedy to the existing problems of biobanking research. The respondents saw a need to strengthen research competitiveness and to standardise research. Some respondents also thought that BBMRI.se had some unclear motives and that it was not entirely clear what the organisation actually was about. The respondents also contended that there were largely self-serving motives that propelled the creation of BBMRI.se and that the host university had used financial pressure to have the other universities join BBMRI.se.

The second stage, "Brand Identity", indicated that one of the initial ambitions of BBMRI.se was foster a sense of "inclusiveness" to ensure that all approached partners/members would

able to join in. However, the respondents said that this was in stark contrast to the exclusionary manner in which BBMRI.se would behave in practice. Specifically, the fact that neither the county nor the hospital biobanks were involved in BBMRI.se was seen as an indication of this. There was also some criticism from some of the respondents against the host university and its BBMRI.se management for having forcing the other member universities' hand by using funding as leverage. The respondents also expressed that there had been some interpersonal disagreements between some of the WP-leaders. However, the respondents agreed that BBMRI.se was supposed to help guarantee quality assurance and streamline processes. They added that BBMRI.se in this capacity had much greater potential to succeed than had any of the prior biobank harmonisation initiatives, and that there was strength in the fact that BBMRI.se was based on an existing European design and that it served as a structural prototype listed in ESFRI's Roadmap.

The third stage "Brand Operationalising", illustrated that there was some diverging views on how BBMRI.se should go about to engage its stakeholders. One respondent believed that there should have an internal "Scientific Council" implemented within BBMRI.se that would have consisted of representatives from all member universities in order to ensure full consensus of the organisational processes. Another respondent favoured the recruitment of "key opinion leaders," i.e. renowned scientists in their field, who were supposed to exert their influence around different venues and spread information about the uses of harmonised biobanking. Another respondent stressed the need of working towards obtaining interoperability between the academy and healthcare, while yet another respondent regretted that the healthcare biobanks had not been involved in BBMRI.se. The "National Champions" were integral to the original BBMRI.se application to VR, as they were leading experts who were proficient in all aspects concerning building and operating a biobank. Still, the structure of BBMRI.se was viewed as "unclear" and "ambiguous", since each of the WPs had high degrees of autonomy, while at the same time there were several blurred lines in many different areas between the different WP and it was not always clear what each individual WP should be doing, which would sometimes result in overlaps. The respondents seemed to agree that there were salient conflicts that marred the organisation. To this extent, several respondents were very critical of the BBMRI.se management

The fourth and final stage, "Post-Implementation Reflections", conveyed an image largely coated with bitterness and resentment. The respondents contended that there had been "vicious rumours" circulation around the BBMRI.se situation, and that self-serving factors had gotten in the way of success. Several respondents also expressed that there was distrust and personal conflicts between the different WPs and between the WPs and the BBMRI.se management. Some respondents attested that they had been subjected to bullying while others expressed that they had felt betrayed when they felt that the original agreements had not been fulfilled. The respondents also added that BBMRI.se had operated in a suboptimal manner towards its customers as well, as the organisation had failed to position its brand name, leading to several customers confusing BBMRI.se with the biobanks of the various member universities. However, the respondents did agree that the formation of BBMRI.se as such had been a major accomplishment and had proved that such a feat could be done, in spite of all the obstacles.

In understanding how these stages interacted, it is important to consider the role of "mind-sharing" between the different stages and how each respondent perceived the organisational brand. According to Murphy (1997), branding is about establishing the *Gestalt*, or the form as

a whole, of a product or service. Thus, study IV makes an important distinction between "branding" and "marketing", with the former being a "push" factor inasmuch as it promotes a message in order to achieve sale results. The latter, on the other hand, constitutes a "pull" factor, since it passively encourages consumers to buy a product or service without directly asking them to do so (Mooney & Rollins, 2008; Zhang, Fang, Yang, & Zhang, 2018). The results showed that mindsharing occurred throughout the initial two stages ("Brand Strategic Analysis" and "Brand Identity"). However, it would dissipate throughout the remaining two final stages ("Brand Operationalising", and "Post-Implementation Reflections"). This gave rise to a fragmented brand perception, which resulted in the failure of generating a "pull-effect" for the BBMRI.se brand.

6.5 STUDY V

A new "action phase model" was devised, known as the "4 I's" of entrepreneurship (Larsson, 2018b; Shir, 2015). Each "I" elaborated on the entrepreneurial rationale behind the various stages of the creation process. These were "Intention", "Initiation", "Implementation" and "Introspection" (which was elaborated in further detail back in section 2.3).

The results illustrated that for "Intention" there was an overall consensus, inasmuch that the respondents had all been motivated by the same driving force, i.e. the need to strengthen the Swedish biobank infrastructure.

When it came to "Initiation", most respondents had previous experience in working with biobank harmonisation initiatives, albeit in smaller scale. The respondents who had not, had advanced experience of working professionally with biobanking in either the county or the industry. The external respondents had acted upon a government assignment.

In terms of "Implementation", the researchers agreed BBMRI.se had effectively begun once the consortium agreement was signed. Some respondents had tried to connect and implement their past experiences from other biobank settings into their BBMRI.se operations. Another respondent had (albeit mistakenly) hoped that her new-found leading position in BBMRI.se would grant her a mandate to introduce a (in her view) more favourable alternative to the consortium agreement. However, there was a financial incentive to sign the consortium agreement and begin operations, as VR had stipulated that additional funding would secured only upon the launch of BBMRI.se and initialisation of its operations. Moreover, there was a perceived lack of communication. This was in turn tied to the innate structure of BBMRI.se. That is to say, it had mainly been constructed to centre around one Executive Director. This Director had, moreover, been granted far-reaching authority. This, in combination with the fact that VR had established a communication channel solely with the host university and none of the other member universities, resulted in a perceived lack of communication between the respondents themselves as well as between their respective WPs. Unlike many other organisations, BBMRI.se lacked a traditional business plan. One respondent claimed that BBMRI.se's structure instead relied on the "National Champions'" individual experiences and expectations.

In regards to Introspection, there was agreement among the respondents that BBMRI.se's greatest feat was the fact that it ever came to be in the first place. Although one respondent contended that BBMRI.se had helped promote cooperation and means to bridge interpersonal differences, several other respondents were critical to how the course of events had panned out. Specifically, the respondents criticised the aspect of BBMRI.se being surrounded by ambiguity, with the Director highlighting the fact that researchers would often still identify with their own universities rather than BBMRI.se, irrespective of them conducting BBMRI.se affairs. The Director meant that this impacted negatively on the BBMRI.se brand name. The organisational structure was also seen as ambiguous by some respondents, citing unclear and/or unconvincing financial structures. Some respondents also felt that the BBMRI.se executive management at the host university had acted in a deceitful manner by overruling an existent consortium agreement, in favour of a different one, since that one had been neither processed nor approved of by the other respondents, or those who they considered to be the "concerned parties". Additionally, some respondents believed there was a "conspiracy of silence" between certain researchers. That is to say, these researchers would not dare speak out against various types of failures and some would even go so far as to betray their own goals in the interest of securing more funding. In the end, BBMRI.se was perceived to have been marred by various degrees of distrust, and these had in turn been caused by various managerial issues. Specifically, some respondents singled out the former BBMRI.se Director. According to some of the respondents, he was perceived as an uncharitable, uncooperative individual who placed more interest in sating his own ego than in building a sustainable, working environment.

At the end of the day, the respondents agreed that there was a need for BBMRI.se, while disagreeing on what the organisation should be doing and what its challenges consisted of. The homogenous mind-set would begin to dissipate once the "Initiation" stage was reached, declining further throughout the "Implementation" stage. In summary, the results show that managerial structure, personal ambitions and lack of transparency and communication were the major contributing reasons to the ultimate failure of BBMRI.se.

7 DISCUSSION

The section begins by discussing some of the overarching themes that have been unearthed through the research across the different studies and that carry a significant impact on the turn of events. As study II-V recurrently brought up the role of the "National Champions" as well as the events leading up to BBMRI.se's ultimate failure, this section has engaged an in-depth discussion on how "champions" may affect an organisation, and how an "organisational failure" should be understood/assessed. This section then proceeds by outlining the general approach and the results discovered throughout the various studies of this dissertation (more detailed discussion of each study is found in the individual studies respectively). The section concludes by discussing the "tragic flaw" and how the inherent structure of BBMRI.se initially helped and ultimately hurt the organisation.

7.1 INTRODUCTION

Following the aim and the research question, this dissertation has endeavoured to uncover the principal lessons in forming a large-scale distributed Research Infrastructure. As such, he areas studied within the boundaries of this dissertation were largely identified through an

initial literature search (study I) which sought to identify the relevant topics within the academic discourse, as well as exposing some pertinent literature gaps in regards to distributed Research Infrastructures. As per the findings in section 6, study I illustrated that there is an overall need for a wider discussion on Research Infrastructures and that the future of scientific research calls for a deeper and more widespread multidisciplinary forms of collaboration.

Using BBMRI.se as a case, the thesis began by looking at the practical policies surrounding the formation of a distributed Research Infrastructure in order to provide some valuable context and insight into the circumstances to which a similar endeavour might be set up (study II). Throughout study II we were introduced to the BBMRI.se organisation and learnt that it surfaced as a result of two parallel processes, one occurring in Sweden and one in Europe, and that these two processes converged at a fortuitous moment at enabled the speedy establishment of the BBMRI.se structure. We also saw that the "deliberative" and "collaborative" themes were at work. Looking at the dimension of "Key interests" among the respondents, there appeared to be much agreement inasmuch that they all believed in the need to simplify biobanking research. As for the dimension of "Importance", the respondents agreed that actors such as ESFRI and VR had been instrumental in building the organisation, as had the participation of all Swedish medical universities. However, the first sign of disagreement was discerned in this particular dimension, as some believed that other biobank coordinating-orienting organisations, such as NBR, carried significance to BBMRI.se, whereas other contended that they did not. At this stage, it became apparent that BBMRI.se had begun to manifest ideological struggles. At the next dimension, "Influence", several respondents showed conflicting attitudes, with some arguing that NBR had in fact actually had a NBR, had a disruptive and divisive influence on BBMRI.se's harmonisation initiative, while others highlighted inter-academic conflicts and argued that the BBMRI.se managers had not been cooperative, and had put their own personal prestige above the well-being of the organisation. In the dimension of "Participation", the respondents emphasised that BBMRI.se had an autonomous structure and that individual leading scientists had been highly active. These scientists were in most cases "National Champions" and several respondents attested that the interpersonal differences these "National Champions" would worsen an already existing fragmentation, as many of these had entered the organisation thinking that it would consist of chiefly collaborative organisation building, but were disappointed to learn that deliberative aspects dominated the organisation.

The thesis then progressed into discussing some of the possibilities, but also the dangers and/or risks of distributed Research Infrastructures, and of placing too much autonomous control in the hands of "champions", i.e. leading scientific experts within a particular field (study III). As such, study III showed that the structure of BBMRI.se fostered a "principal-agent" problem, in which the "National Champions" and their WPs would in practice pursue their own goals to a greater extent than that of the designated overarching mission of BBMRI.se. This would then lead to goal divergence, and later "task uncertainty", which would cause the organisation to manifest organisational fragmentation in a "fragmented adhocracy". This fragmentation would precipitate the course of events that would eventually lead to the organisation's downfall, as there were too many actors, or "National Champions", working in different directions without an integrated organisational linking mechanism that could keep everyone on the same page.

As such, study II and study III (and to some extent even study I) elaborated on the "context" aspect, as outlined by Pettigrew and Whipp (1991) in the framework of the literature review

in section 2. The most important lessons inferred from these perspectives is that there is a growing interest in the harmonisation of sciences and that in response to taking on various complex and large-scale scientific challenges, there have been attempts of bringing together a wide array of different scientific backgrounds and/or perspectives by forming Research Infrastructures. While it in this context may be possible to unify/integrate various forms of scientific disciplines, the trouble with large-scale distributed Research Infrastructures appears to lie more in the existence of various self-serving ambitions, whether conscious or sub-conscious.

The next aspect discussed was how the organisational brand of a failed distributed Research Infrastructure may be perceived in similar or different ways by the people behind it. This was done to discern at what stage the respondents would stop perceiving the organisation and its goals in a similar way and at what point the "mindsharing" stopped, if it had indeed ever existed (study IV). This study delved more into the "content" aspect, as outlined by the Pettigrew and Whipp (1991) framework in the literature review, and how the "baggage" the respondents had carried with them had affected their perceptions of what the organisation should be like, and to what extent this aligned with the other respondents perceptions. The added insights drawn from the framework highlights the significance of personal experiences and the ramifications they may carry if they are not aligned with the other team members. For that reason, study IV began looking more at the individual level of the individual respondents in regards perceived the BBMRI.se organisational brand. This study showed that although most respondents shared similar sentiments at the earlier stages of the process in regards to what BBMRI.se was about, the respondents began displaying very differentiating perceptions halfway through the process. Thus, a critical organisational weakness was that the respondents failed to achieve a "mindshare" in regards to the BBMRI.se profile, which would only serve to promulgate the fragmentation of the brand perception even further.

The concluding section looked at the drivers and motivations of the organisation's initiators for engaging themselves from an entrepreneurial perspective (study V). This study focussed on the "process" aspect of the framework in the literature review (Pettigrew & Whipp, 1991). The added insights drawn from this study in that regard concerns an understanding of how the process works when entrepreneurial scientific pioneers join forces to ensure the formation of a distributed Research Infrastructure and how their personal motivations may impact on the ensuing results. Similar to study IV, study V was also focussed on the individual level. However, unlike study IV, this investigation looked more at the respondents' reflexive perceptions of their own selves and their individual roles in transpired events. As such, it took on a more pragmatic stance of what was actually done as opposed to the more idealistic conception of what the organisation ought to be like. One of the most important insights drawn from study V was the localisation of where in the entrepreneurial process things had gone awry. Similarly to the brand perception, the entrepreneurial fragmentation had begun approximately halfway through the process. The "National Champions" had agreed on the premise of the venture, but once it came to implementing the BBMRI.se infrastructure, there were conflicting ideas, along with some vocal criticism against how the organisation had turned out.

The findings have thus highlighted some important recurring aspects. First of all, there was a contention that the "National Champions" played an integral and pivotal role in the construction and operation of BBMRI.se. Thus, a further discussion on the role of "champions" in an organisation is merited. Secondly, the respondents highlighted many of the problems with the organisation, and given the ultimate fate of BBMRI.se, it is relevant first to discuss what it is that actually constitutes an organisational failure, as well as how the findings of the different

studies tie in to the course of events as they transpired. Hence, these issues will be explained in further detail throughout this section.

7.2 CHAMPIONS

"Champions" exist in many different ways and take on various forms and functions wherever they emerge. "Champions" have been a long-standing tradition in the corporate enterprise sphere, but they also fill an important role in the academic sphere as well, where they often serve as influential forces (Wolfe, 2006). As such, a "champion" is defined by their struggle to overcome natural resistance to change and someone who provides "the time and energy to make things happen" (Daft, Murphy, & Willmott, 2010, p. 459). Another way of phrasing it is that "champions are people who serve their organizations as advocates, wholeheartedly associating themselves with a cause or principle" (Rosania, 2001, p. 54). This means that the "champion" needs to convince other members of an organisation that a certain new idea carries merit. However, one should bear in mind that it is not necessary for the "champion" to be inherent to the actual organisation itself. Rather, the "champion" could also be an external actor who acts as an influencer, or an advocate, on behalf of the organisation. One should also take note of the fact that "champions" often carry significantly different preferences to that of "non-champions", and that the behaviours that "champions" adopt as a result of this is consistent across different cultures (Almeida & Teixeria, 2017; Howell & Sheab, 2001; Shane, 1994).

As knowledge production has become ostensibly more multidisciplinary in recent decades, there has also been a shift of technological policy in the academic discourse to move from the wider philosophical considerations to placing a more instrumental focus on national prestige and economic objectives (Lundvall & Borrás, 2005). As the new technology policies are implemented, policy-makers have often made use of such policies to promote "National Champions" in specific areas/sectors (Lundvall & Borrás, 2005; Ulnicane, 2015). These "champions" have often played an instrumental role in forming the knowledge production. Under the auspices of the universities, they may in many cases take on entrepreneurial roles in addition to important economic functions (Ulnicane, 2015). However, it is important to distinguish a "champion" from a "scientific entrepreneur". Although they may share certain characteristics, a "scientific entrepreneur" will generally take on a wider array of tasks and is more attuned to the concept of "risk-taking" (Miner, 1996). That is to say, a "scientific entrepreneur" is different inasmuch that they are interested in introducing new concepts and visions to an organisation, while at the same time they tend to be more impressionable to new ideas as they proceed (Miner, 1996; Shapin, 2008). A "champion" on the other hand, may be defined according to the following traits (Shane, 1994, p. 397):

> They provide autonomy from the rules, procedures, and systems of the organization so that innovators can establish creative solutions to existing problems. They gather organizational support for the innovation by building coalitions between managers in different functional areas of the organization. They create loose monitoring mechanisms that allow innovators to make creative use of organizational resources. They establish mechanisms for making consensus decisions on innovations. They use informal methods to persuade other members of the organization to provide support for the innovation, and they protect the innovation team from interference by the organizational hierarchy.

In addition, “champions” are more frequently used for what is known as the “third mission” of the academies. In simple terms, this concept defines a vision, or an ambition, for academics to expand their role beyond merely teaching (first mission) and research (second mission). Instead, the aspiration is for academics to also make socio-economic contributions (third mission) (Göransson, Maharajh, & Schmoch, 2009). While there is an overall support in the academic discourse for the notion that “champions” promote innovations, there is also a contention that the “champion’s” individual traits reflect on their level of success (Snyder, 2007). In addition “champions” are susceptible to being affected by the “principal-agent” problem. In this context, this means that they have a propensity of pursuing their own goals/interests under the pretext that they are acting in the interest of the organisation (Coakes & Smith, 2007; Hendy & Barlow, 2012; Jenssen & Jørgensen, 2004; Shaw et al., 2012). This, in turn, may lead to “moral hazard”, meaning that the “champion” may undertake more risks, because someone other than themselves bears the cost of those risks (e.g. the organisation for which they work) (Holmstrom, 1982; Laffont & Martimort, 2002; Steets, 2010).

7.3 ORGANISATIONAL FAILURE

According to “Schumpeter’s gale”, organisational failure (or destruction) is part of an evolutionary process that paves way for new learning experiences and more successful business endeavours in the future (Schumpeter, 1942). As stated by Wilkinson and Mellahi (2005, p. 233): “Failure is a fact of life from which most organizations cannot escape, and the importance of understanding and learning from failure need hardly be stated”. Nevertheless, one major recurrent problem is that organisations that learn from failure tend to be extraordinarily rare. This is not due to the lack of the managers’ commitment to learning, but rather of managers thinking of failure in the wrong way (Edmondson, 2011). Thus, a good starting point would be to define what it is in this context that actually constitutes a “failure”. A general definition of an “organisational failure” is that the organisation has failed to achieve sustainability and/or has failed to deliver on its promised goal (Amankwah-Amoah, 2015; Cannon & Edmondson, 2005; M. W. Meyer & Zucker, 1989). A more decisive definition is provided by Marks and Vansteenkiste (2008, p. 810): “The actual demise of the organization when an entire company goes out of business or a plant, office, or other unit is closed [...] the organization completely ceases to exist”.

Organisational failure may entail actions as well as inactions by managers and stems from a downward spiral of extended and/or unrestrained organisational decline (Nutt, 2002). This decline ultimately leads to the loss of legitimacy in addition to an inability for the organisation to meet its obligations (Amankwah-Amoah, 2015; Hambrick & D’Aveni, 1992). Cameron, Kim and Whetten (1987, p. 224) define organisational decline as “a condition in which a substantial, absolute decrease in an organization’s resource base occurs over a specified period of time”.

Needless to say, organisational failure does not occur instantaneously. Rather, it is preceded by a processes consisting of two phases. This is stage 1, the “incubation” phase, and stage 2, the “trigger/dissolution” phase (Amankwah-Amoah, 2015; Turner, 1976).

Stage 1 is often characterised by issues such as “miscommunication; poor operating procedures; barriers to information flow; out-of-date assumptions, routines and processes; inattention to minor errors; failure to carry out necessary checks; ill-defined goals; intolerance of errors; and a tendency to hide errors to provide the conditions for organisational problems and consequent failure to occur” (Amankwah-Amoah, 2015, p. 1343). At this stage, it is not unusual for staff members to start deviating from their regular routines. Errors, oversights and system malfunctions begin occurring on a more regular interval across the organisation (Turner, 1976). These issues tend to brew and fester over time in the absence of managerial actions to remedy the situation (Reason, 1990). Stage 1, i.e. the “incubation” period, will accumulate errors, omissions, misperceptions and so forth and pave way for stage 2, which is the “trigger” (or “dissolution”) period. This phase is typically ignited by a (sometimes seemingly minor) event that will ultimately be the proverbial “straw that breaks the camel’s back”, thus leading to the organisation’s demise (at least in its contemporary form) (Amankwah-Amoah, 2015; Turner, 1976). Rudolph and Repenning (2002, p. 24) argue that the organisation will generally have experienced “tipping points, thresholds of accumulated interruptions beyond which performance rapidly collapses" before stage 2 is reached. In many cases, failure is the result of unobserved/ignored issues and events over a lengthy period of time (Turner, 1976). This is in particular regards by the senior management of the organisation, or as expressed by Ropega (2011, p. 476), “management does not notice the critical situation in time, which due to delayed or incompetently carried out repair actions”. These issues often involve ill-concealed conflicts between different members of the organisation in addition to staff and/or associates “jumping ship” (Wiesenfeld, Wurthmann, & Hambrick, 2008).

Still, the “incubation” period of stage 1 is generally characterised by specific types of failures. To this end, Spacey (2016) contends that there are in fact 14 types of organisational failures, which are outlined in Table 2:

	Type of Failure	Description
1	*Change Failure*	Denotes a failure of strategies, programmes, projects and initiatives. By and large, a change is considered "failed" if it is considered as such by its key stakeholders (Newton, 2007; Sarker, Sarker, & Sidorova, 2006).
2	*Conflict of Interest*	Occurs when an actor has an interest or incentive that conflict with their duties, i.e. a situation wherein an actor may be rewarded for poor performance, or let self-interest stand in the way of optimising operations (Davids, 2008).
3	*Cronyism*	An extension of an unfair economic advantage to friends and allies. This may include job offers, promotion etc. that are designed to benefit certain members of a group or circle of people (Viner, Powell, & Green, 2004).
4	*Culture of Fear*	An occurrence wherein fear is used or manipulated in order to achieve objectives (Furedi, 2006; Kish-Gephart, Detert, Treviño, & Edmondson, 2009).
5	*Malicious Compliance*	Occurs when an employee uses an organisation's own rules against it by taking them too seriously or literally (DeHart-Davis, 2017).
6	*Misuse of Statistics*	A pattern of unsound statistical analysis misused to lend weight to misrepresentation of facts (Gardenier & Resnik, 2002).
7	*Negative Selection*	When a leader selects and promotes incompetence as a mean of preventing their position from being challenged by potential usurpers (Biloslavo & Dolinšek, 2010; Rees-Mogg, 1959).
8	*Perverse Incentives*	A negative, albeit unintended, consequence of a performance goal, evaluation criteria, incentive program, regulation or system, where negative outcomes are in fact rewarded (Grindle, 1997; Steets, 2010).
9	*Resistance to Change*	The lack of employee support for a strategy, which can manifest itself as anything from exuding low engagement to actively trying to derail the initiative (Bovey & Hede, 2001; Elving, 2005).
10	*Self-dealing*	A breach of fiduciary duty (the legal obligation to act solely in another party's interests) involving (directly or indirectly) making self-serving deals (Enriques, 2000; Rahaim, 2005).
11	*Setting up to Fail*	A malicious strategy aimed at giving an actor a task that is deliberately designed to fail. The doomed assignment is generally an order of magnitude too much work relative to the resources or capabilities available (Kitt, 2009).
12	*Success Trap*	When early successes lead an organisation to develop facilities, structures, processes, infrastructure, etc. that eventually becomes a liability as the situation, or the organisational direction, changes down the road (Cyert & Williams, 1993; Wang, Senaratne, & Rafiq, 2015).
13	*Tone at the Top*	Denotes the ethical climate of an organisation's senior managers, board of directors and/or audit committee in which they espouse prevailing, or nonchalant, attitudes towards such matters as fiduciary duty, financial diligence, risk, legal compliance, employees, society etc. (Bandsuch, Pate, & Thies, 2008; Patelli & Pedrini, 2015; Treviño, Weaver, & Brown, 2008).
14	*Trained Incapacity*	A condition wherein certain types of training or experiences may lead an individual to be unable to think beyond of a set of constraints and/or assumptions that they have previously formed (i.e. the inability to "think outside the box") (D. King & Lawley, 2016).

Table 2: 14 Types of Organisational Failures (adapted from Spacey, (2016)

7.4 THE PRECONDITIONS FOR RESEARCH INFRASTRUCTURES (STUDY I-II)

The results uncovered by study I indicates that the most commonly discussed theme in the academic discourse is the actual need of Research Infrastructures (Larsson, 2017). Based on the article's country of origin, the topic of Research Infrastructures appears to remain European-centred topic. Thus, ESFRI's (2006, 2008, 2017) investments in Research Infrastructures should, for all intents and purposes, have come at an opportune moment. Still, study I and II also concluded that while emerging Research Infrastructures will likely continue to evolve in the near future, managers looking to launch a Research Infrastructure will need to make sure they are doing it for the right reasons. Specifically, there will be an increased need for these managers to not only to understand the mechanisms and components of the Research Infrastructure in question, but to also possess the know-how of how to build, manage, and brand them in a manner that is congruent to its intended purpose.

Study II concluded that the interaction of "top-down" and "bottom-up" factors facilitated the construction of BBMRI.se. This contradicts the notion of extant literature, which suggests that Research Infrastructures is a "bottom-up" endeavour (Larsson, 2017). To this end, setting up a Research Infrastructure can indeed be a rapid endeavour, provided that the circumstances are right and that there is sufficient political will in order to see the endeavour come to fruition. In the case of BBMRI.se, the process was expedited even more so given the fact that there were two separate, but parallel, political initiatives converging to create a fortuitous window of opportunity. First, there was the aforementioned ESFRI Roadmap, that outlined support for various Research Infrastructures across the EU, of which biobanking was one in particular (ESFRI, 2006, 2008, 2011). Second, there were political developments working on a national level in Sweden. Specifically, the Swedish drafted a series of three government bills that enabled the funding of BBMRI.se (Government Offices of Sweden, 2004, 2008, 2012). Leading Swedish scientific biobanking experts were recruited to help set up the organisation, which would be divided up into eight different WPs, based on the experts' area of specialisation. These leading experts would become known as "National Champions" and these people would eventually both enable and doom the BBMRI.se organisation.

7.5 STAGE 1 – "INCUBATION" PHASE (STUDY III-V)

What is worth mentioning is that while BBMRI.se was founded by expert pioneers, it lacked a traditional business plan (Swedish Research Council, 2009). There is some scientific debate as to whether or not the lack of a business plan plants a "bad seed" in an organisation. For instance, Delmar and Shane (2004) argue that a business plan is must in acquiring legitimacy in the initial stages of a start-up phase. However, this position is challenged by Beuker (2008), who argues that a business can indeed be initiated without a plan, provided that it is done by actors who are exceptionally knowledgeable and experienced in their field. Should we, for the sake of argument, go along with the latter's contention, and agree that the lack of a business plan did not factor in to the organisation's ultimate failure, there is still the matter of staff members harbouring distrust towards one another and being left with a sense of betrayal and disappointment. Another detail worth mentioning in this context is that upon its original formation, BBMRI.se, seemingly in keeping with its belief in its T.B.T.F.-status, actually lacked a bailout plan (Swedish Research Council, 2009).

Should one try to identify as to where the "incubation" phase, or stage 1, begins, it is easy to direct one's attention to the letter of complaint dated February 15, 2013 (Skoglund et al.,

2016; Swedish Research Council, 2015a). While this was a very specific point of origin that would indeed bear much significance to the later events set in motion that would cause the downfall of BBMRI.se, it was still a response to a chain of events that had already been set afoot. At the root of it all, the original problems can to a great extent be ascribed to the "wide eyed" and "larger-than-life" roles attributed to each of the "National Champions", in whom large degrees of managerial trust was placed on the foundation that they possessed a track record of conducting extraordinary research.

BBMRI.se was fruit of an evolutionary process of collective entrepreneurship and the sciences that engaged it was diverse. This ought to have stressed the importance for the "National Champions" to be fully transparent about their operations and intentions. As the studies of this dissertation have indicated, it is clear that the "National Champions" did, at least initially, share a vision of accomplishing the stated objective of the organisation. Nevertheless, it is evident that the respondents also held very different views as to what should be done to achieve the goals in question. To this end, stage 1 began with the lack of procedural transparency and professional candidness. To a certain extent, elements of this might have subsisted in the organisation already from its outset, but as uncovered in study IV, the onsets of stage 1 could already be witnessed in the second phase of branding, i.e. the "Brand Identity" phase. Some respondents envisioned a more expansive role for BBMRI.se, while others were more sceptical. In study V, similar tendencies were seen, specifically in regards to the transition from the first stage, "Intention", to the second stage of "Initiation", and even more so when it transitioned on to the third stage, "Implementation". What was noticeable here is that the respondents all had different backgrounds and reasons for joining BBMRI.se, and that they all tried to shape the organisation according to their vision, and according to their own respective experiences.

As study III illustrated, the organisation has an inherent risk of the "principal-agent" problem, meaning that the "National Champions" tried to pursue their own agenda, which would ultimately blur the original mission of BBMRI.se. This consequently led to further organisational decline, involving factors such as "goal divergence", "task uncertainty" and eventually a "fragmented adhocracy". The matter was not helped by the fact that the organisation lacked "lateral linkage" between the various WPs, which only served to deepen and consolidate the rift between the different "National Champions" and their WPs. In this regard, Sizer (1984, p. 209) probably best expressed the root cause of the stage 1-problem in saying that "the villain is the specialist system". That is to say, the system that BBMRI.se had built around the "National Champions" and their expertise also had a built-in mechanism for hurting the organisation.

7.6 STAGE 2 – "TRIGGER/DISSOLUTION" PHASE (STUDY I-V)

Stage 2 signifies the "trigger" (or "dissolution") phase. The single most important "trigger" was the December 7, 2015 joint statement letter sent to VR by BBMRI.se staff members from three member universities (BBMRI.se, 2015d, 2015c; Skoglund et al., 2016; Swedish Research Council, 2015a). It was this letter that would initiate the scrutiny into the organisation, which would in turn ultimately prompt the dissolution of BBMRI.se. In Rudolph and Repenning's term (2002, p. 24), BBMRI.se had indeed experienced multiple "tipping points" throughout the years, with several letters and complaints issued to the host university and the BBMRI.se Director(s). Although the strategic plans were updated throughout the years, they did little to address the matters lying at the heart of these complaints.

As seen, chiefly through study II-V, the BBMRI.se organisation harboured several different types of systemic errors. Drawing upon Spacey's (2016) previously mentioned depiction of organisational failures, it is clear that BBMRI.se fulfils several different categories of failure. Most ostensibly is the "change failure", since there is no denying that BBMRI.se lost its support from its key stakeholders and financier, VR. There was also an apparent lack of "infrastructuring", in the sense that the actors did not gradually learn together about how to creating an effective large-scale infrastructure (Star & Bowker, 2002). As evidenced through study IV and V, any semblance towards an "infrastructuring" process ended approximately halfway through the process.

There was also a case of "conflict of interest", as the WP's goals tended to reflect the "National Champion's" own agenda. This is reinforced by the initial 2013 accusations forwarded by staff members regarding the revisions made to the originally agreed-upon consortium agreement (Skoglund et al., 2016; Swedish Research Council, 2015a). Although the host university was able to utilise the shared funds in the way described by the external investigation, it further deepened the rift between the host university and the other member universities and (eventually) VR (BBMRI.se, 2015d, 2015c; Skoglund et al., 2016; Swedish Research Council, 2013, 2015a, 2017).

The fact that the BBMRI.se management was reported to VR by member universities indicates "resistance to change", as these staff members and WPs disapproved of the direction BBMRI.se was heading. Still, BBMRI.se was to a certain extent also a victim of the "success trap". That is to say, the BBMRI.se endeavour had indeed been fortunate in successfully acquiring large amounts of government funding. It had also signed on several reputable "champions" who had been highly successful in their respective fields and possessed a vast amount of social capital. Regardless (as time would tell) that luck would soon run out and many of the "National Champions" would find themselves embroiled in various forms of conflicts with one another throughout the latter periods of BBMRI.se's existence.

Nothing in any of the individual studies through study I-V suggests "trained incapacity". However, there are clear indicators of "tone at the top" in that the management disregarded or, at the very least, neglected to act on any of the chief complaints issued to the organisation throughout the years.

A full overview of the types of organisational failures found in BBMRI.se is illustrated in Table 3.

	Type of Organisational Error	BBMRI.se
1	***Change Failure***	✓
2	***Conflict of Interest***	✓
3	***Cronyism***	×
4	***Culture of Fear***	×
5	***Malicious Compliance***	×
6	***Misuse of Statistics***	×
7	***Negative Selection***	×
8	***Perverse Incentives***	×
9	***Resistance to Change***	✓
10	***Self-dealing***	×
11	***Setting up to Fail***	×
12	***Success Trap***	∂
13	***Tone at the Top***	✓
14	***Trained Incapacity***	×

Table 3: Types of organisational failure present in BBMRI.se. Adapted from Spacey (2016). ✓ = Indicators of this failure type have been manifested. × = Indicators of this failure type have not been manifested, or are not discernible. ∂ = Partial indicators of this failure type has been manifested

Thus, as the results show, BBMRI.se displayed signs of four types of organisational failures along with onsets of one additional type of organisational failure. While just one of these organisational failures may be enough to cause the downfall of an organisation, the results indicate that the situation of BBMRI.se was most dire indeed and serves as a case in point to stress the need of remedying organisational problems already in the early stages of stage 1. As discussed by Turner (1976), failure is preceded by issues and/or events that have been either neglected or ignored over an extended period of time, but once stage 2 is reached, the collapse is irreversible. As Wiesenfeld, Wurthmann and Hambrick (2008) point out, stage 2 is generally characterised by open conflicts, which was most certainly the case of BBMRI.se. Moreover, this stage is also characterised by key actors "jumping ship", and in the case of BBMRI.se, this was most decidedly done by its main funding body, VR, as well as several staff members choosing to either stepping down from their functions, requesting relocation, or leaving the organisation altogether (BBMRI.se, 2015b; Dillner, 2011a; Skoglund et al., 2016).

7.7 THE TRAGIC FLAW

Despite its ultimate failure, it is important to point out that the way in which BBMRI.se came to be does not mean that it was devoid of positive aspects, or that it neglected to contribute towards the development of biobank harmonisation. In ancient Greek tragedy, it is popular to speak of a “tragic flaw”, or *hamartia*, which is derived from a term that means "to miss the mark" or "falling short" (Grenz, 2000, p. 184).

In this manner, hamartia refers to a protagonist’s error, or “tragic flaw”, which leads to a series of plot actions ultimately culminating in a reversal of their good fortune to bad. This “error”, or “flaw”, may stem from factors such as ignorance, poor judgement, character weakness or wrongdoing, but importantly, the error must be great enough for the consequences to be as ineluctable and irreversible as they are severe (Nyusztay, 2002; Østerud, 1976). The flaw is “tragic” in that it brings about an irredeemable situation from which the protagonist cannot recover, no matter how much they try.

Thus, one may compare the fate of BBMRI.se to that of one following closely to the protagonists of hamartia. The intentions behind the construction of BBMRI.se in no doubt carried noble intents, and the respondents were all attuned to the scientific need to securing biobank harmonisation. To this end, BBMRI.se was the intended lodestar that would accomplish what no other actor had accomplished in Swedish history, another fact to which the respondents would agree. The introduction of “National Champions” also awarded the organisation with the competence and motivation towards accomplishing the harmonisation, as these “National Champions” held much clout across the country. This had been a problem with many of the previous harmonisation initiatives, since they had in many cases been very regionally focussed. Collection nation-wide “National Champions” allowed for the organisation to exercise their social capital and helped the organisation gain credibility among its customers, investors and other stakeholders. The structure of BBMRI.se was in one sense decentralised across all the participating member universities and their autonomous WPs. On the other hand, it was considerably centralised in authority granted to the host university and the fact that they were the only ones to engage with VR, which was responsible to the most substantial part of the organisation’s funding.

In this way, BBMRI.se did indeed carry a “tragic flaw”, because the factors that led to its speedy success were also the inherent factors that would eventually lead to its demise. To this end, BBMRI.se effectively served as a real-life “tragic hero” of the modern-day scientific community.

7.8 METHODOLOGICAL CONSIDERATIONS

In regards to study I, one may contend that a risk of bias in individual studies is carried the exclusion of population control. This bias was mitigated through the employment of a clear set of eligibility criteria at the outset of the study (Bilandzic, Fitzpatrick, Rosella, & Henry, 2016). Another issue concerns the inherent risk of publication bias. This entails that the results are more dependent on the tested hypothesis and less so on the quality of conducted research. This may in turn lead to undesired type-1 errors (or “false positives”) since it is possible that the researcher feels more inclined to publish results that are in support of a stated hypothesis rather than the results that contradict it (Scargle, 2000). This is a more salient

problem for studies with small effect sizes. For study I, this risk has been reduced through the use of larger-scale studies that have provided for a better representation of the area of Research Infrastructure studies (Ioannidis, 2005).

As for study II-V, some additional elaboration on the methodological considerations is required. While one may raise the argument that the fairly limited selection of respondents could act as a constraint towards this study, it should be noted that only managerial initiators were necessitated. This was because this thesis endeavoured to acquire in-depth information about these specific respondents' motives and perceptions. Hence, the trade-off for acquiring a larger selection of respondents might have resulted in a poorer understanding of each of the individual respondents while also deflecting the initial focus of this thesis (Kvale & Brinkmann, 2009).

Admittedly, it is possible that some of the prospective interviewees who declined or neglected to participate may have possessed information and/or views of interest. For that reason, additional information was sought from alternate sources, such as electronic correspondence, written documents, memorandums, meeting minutes, personal correspondence, and/or other interviewees. Although no systematic observational notes were recorded, supporting insights about the BBMRI.se process and mechanisms were obtained through participation in meetings, conferences and events associated to BBMRI.se.

Although it may seem paradoxical for an *ex-post facto* study to collect respondents' *ex-ante* recollections, it is not uncommon for similar "after-the-fact" studies to be used as a substitute in lieu of conventional experiment research that seeks to test the cause-and-effect relationships between different variables (Lunenburg & Irby, 2008). Furthermore, this type of research is a suitable option for situations where it is not practical, and/or ethically acceptable, to conduct conventional experimental study design (Silva, 2010). In fact, the employment of *ex-post facto* works to the advantage for study II-V, as it certifies that the respondents have not been influenced by the researcher or any member of the research team at any point throughout the course of the studies (Cohen et al., 2018; Silva, 2010).

This dissertation has utilised a multiple paper dataset in regards to study II-V. This pertains in specific to the conducted interviews, which have been analysed according to different premises and theories and thus unearthed information that is new and original for each study. According to Kirkman and Chen (2011), this is an acceptable practice as the determinant is the unique contribution each of the studies is able to provide. On this note, Lee and Mitchell (2011) argue that there has, historically, been a consensus of justifying the reuse of data as long as the research questions and theoretical grounding are differentiated. To address the question as to how one may know if each article is able to make a unique theoretical and empirical added value contribution, it is important to ensure that there is a unique and clearly defined research question in each of the papers in question. Although most of the theories were used uniquely in this dissertation, some overlap in some theoretical touchpoints may occur when using the same datasets even if the theories used are distinct in and by themselves. As per Kirkman and Chen (2011), this is acceptable as long as the research question is unique as these constitute a different theoretical explanation for each specific phenomena. This is a notion that is supported by Fine and Kurdek (1994), who argues in factor of multiple submissions of single datasets provided that the different articles have distinct purposes.

Interviews inherently include a risk of “recall bias”. This is particularly true for those involving retrospective studies (Kopec & Esdaile, 1990; Riegelman, 2005). Specifically, the level of bias tends to be more prominent in two instances (Godlonton, Hernandez, & Murphy, 2016). The first case occurs as a response to negative changes for objective indicators. The second case occurs as a response to positive changes for subjective indicators, that is to say, to something that has impacted the respondent on a personal level. Consequently, great care was taken to postulate a clear formulation of the aims in each individual study. The respondents were also made to verify their responses through follow-up questions in the event of them providing vague and/or ambiguous responses (Szklo & Nieto, 2014). Moreover, an interview guide was used in order to ensure a more standardised mode of data collection. In addition, the respondents were provided with the time they needed before answering any of the questions in order to ensure that they had the possibility to reflect through the sequence of events in the way they recalled them (Hassan, 2006).

Another problem inherent to interviews is the risk of “social desirability bias”. This effectively means that the interviewee could be over-reporting behaviour they deem “good" and/or under-reporting behaviour they deem “bad” (Rovai, Baker, & Ponton, 2014). For the purposes of study II-V, this risk was mitigated by certifying that the wording presented during the interviews were relayed in as neutral and value-free tone as possible and by ensuring the respondents that there were no “right” or “wrong” answers. In addition, the authentic names of each respondent were all withheld, as to provide for further neutrality, detachment and reassurance, thus reducing the need of having to portray oneself a certain way (White & McBurney, 2013). The same technique was used to mitigate any occurrence of the “interviewer effect” (David & Sutton, 2011).

For any research, it is important to consider the factor of “trustworthiness”. It is important to acknowledge that the research conducted is *credible* (i.e. conveys accuracy), *transferable* (i.e. can be applied to other contexts), *confirmable* (i.e. based on participants’ responses rather than the opinions of the researcher) and *dependable* (i.e. can be replicated by a different researcher and achieving similar results) (Hold, 2015). For this reason, it is essential to be clear about the terms and definitions used throughout the dissertation (Williams & Morrow, 2009). In addition, it is also important to consider the factors of “validity” and “reliability”, as outlined in more detail below.

7.8.1 Validity

In order to secure a high level of validity, it is important to ensure that the study actually investigates what it sets out to investigate (Ryan, 2010). For study I, this was achieved by having clearly defined exclusion/inclusion criteria. As qualitative studies, study II-V have availed themselves to uphold validity by presenting each respondent’s experiences and interpretations in a manner as accurate and truthful as possible. This was accomplished through the construction of an interview guide prior to the interviews. This ensured that each presented question was correctly understood by each respective respondent. This also enabled the possibility to ask the respondents follow-up questions for added clarifications whenever necessary. The validity of a study may also be strengthened by the researcher being able to review, re-evaluate and revise the findings on a continuous basis throughout the research. Since multiple respondents were interviewed for study II-V, this study has been able to achieve triangulation

(Ryan, 2010). This means that the study is not based on information gathered solely from one single source, but rather on several different sources independent from one another in regards to the researched phenomenon (Bryman & Bell, 2015).

7.8.2 Reliability

Reliability aims to show how dependable a study is by testing its consistency. In simple terms, this means that other researchers should be able to obtain similar results should they study a similar subject in a similar field using the same set of methods. It should be emphasised that a high reliability does not seek to enable the replication of identical results. Rather, reliability seeks to enable the reader to follow the researcher's tracks in order to see what the researcher has done, alternatively neglected to do (Ryan, 2010). For study I, this achieved through a clearly defined search string and the use of a robust guideline, the PRISMA statement, when identifying articles. In terms of study II-V, a higher level of reliability has been ensured through the use of *purposive sampling*, which excludes the serendipitous factors that would make it impossible for another researcher to conduct a similar study. Admittedly, while the research conducted captures the interviewees at a specific point in time, the interviews were conducted via a pre-set interview guide, which served as a framework for each of the interviews. Hence, barring any "error" or "bias" factors as those described above in section 7.8, the respondents would have been able to convey similar responses to a different researcher, thus, achieving dependability. Beyond this, these studies have taken all the necessary steps to follow the established methodological frameworks concerning proper interview techniques and etiquette (Denscombe, 2017).

7.9 IMPLICATIONS FOR PRACTICE AND RESEARCH

The results of the studies carry several different implications for potential future distributed Research Infrastructures. These can be divided into "practical" and "research" implications.

7.9.1 Practical Implications

- The future of scientific research will call for a deeper, more widespread and more sustainable multidisciplinary cooperation, thus emphasising the need to optimise the preconditions of bringing such cooperation to pass. A distributed Research Infrastructure may provide this, but this requires a deeper understanding and respect for the components and mechanisms involved (study I and II).

- A distributed Research Infrastructure may consist of "collaborative" as well as "deliberative" elements. Future initiators of distributed Research Infrastructures will need to decide what type of organisation they want to build and ensure that there is no ambiguity in regards to what type of organisation they wish to pitch to new prospective members/associates (study II).

- Large-scale Research Infrastructures can be set fairly rapidly given that there is enough political support (study II).

- A "liaison devise" (or alternative mechanisms ensuring clear and unequivocal communication) could prevent much of the perceived overlap in operations and reduce the risk of "task uncertainty" and organisational fragmentation (study III).

- It is important to ensure that Research Infrastructures are constructed in such a way that they serve the customers/clients/users above and beyond anyone else, rather than personal prestige of certain managers (study III).

- The implementation of "National Champions" with far-reaching autonomy in a Research Infrastructures may lead to a "principal-agent" problem (study III).

- Goal divergence results in fragmentation (study III and IV).

- In order to achieve managerial "mindshare" in a Research Infrastructure, it is important to account more for social and individual incentives and less for instrumental motivations, such as mission statements (study IV).

- BBMRI.se ultimately failed due to deficiencies in the organisation's transparency, communication, trust and organisational culture (study V).

- Large-scale distributed Research Infrastructures initiated without a business plan may exhibit similar problems to that of BBMRI.se due to the reliance on the entrepreneurs' individual experiences and expectations (study V).

7.9.2 Research Implications

- Extant research on large-scale distributed Research Infrastructures is fairly meagre and mostly focusses on the need of establishing distributed Research Infrastructures. Thus, more research is needed in order to spread a wider understanding of how distributed Research Infrastructures operate as well as research covering the human condition of those who choose to engage themselves in initiating distributed Research Infrastructures (study I, IV and V).

- "Collaboration" and "deliberation" are not necessarily diametrically opposed to one another, but can co-exist in the same organisational structure (study II)

- Research Infrastructures do not necessarily counteract organisational fragmentation (study II and III).

- Fragmentation may be innate to the Research Infrastructure as a concept, or it may vary depending on the type of Research Infrastructure (study III).

- Managerial issues (social aspects) and inherent task uncertainty (cognitive aspects) may interplay and compound the organisational fragmentation (study III).

- Organisational fragmentation can impede the ability to produce a "pull-factor" when establishing a brand name (study IV).

- Mindshare research is more suited for retrospective analysis and/or evaluation, than for attempting to predict outcomes in advance (study IV).

- Too much autonomy for "National Champions" or collective entrepreneurs may contribute to organisational fragmentation (study V).

- Collective entrepreneurial team cognition may in some cases exist only partially when forming a large-scale distributed Research Infrastructure (study V).

7.10 FUTURE RESEARCH

Although the findings of this dissertation endeavours to add new insight to the research on distributed Research Infrastructures and how such constructs may take the necessary precautions to safeguard themselves against organisational failure, many questions remain that fall beyond the scope of this thesis.

For instance, study I concluded that there is more research needed in response to the issues raised concerning the need of more developed and widespread infrastructures in order to accommodate for the continued development of multidisciplinary sciences. Specifically, this means that there is a continued need for additional research into Research Infrastructure as a concept by and large, but in particular regard to how they are built and managed.

Study II indicated that there is a continued need for wider forms of communication between the participating actors within a Research Infrastructure. There is also a need to uncover how to best identify potential collaborative and deliberative elements and how to make them complement one another.

Study III raised the question of whether or not single-sited and/or virtual Research Infrastructures carry the same problems with fragmentations manifested in the same way as they are in distributed Research Infrastructures. In other words, a topic for future research is to see if organisational fragmentation is innate to Research Infrastructures as such, or if it is contingent on the type of Research Infrastructure.

Study IV posed the question if the “pull-factors” involved in branding are different to “single-sited” and/or “virtual” Research Infrastructures as opposed to “distributed” Research Infrastructures. Another topic for future research is if there are other types of branding beyond mindsharing that is affected by organisational fragmentation, such as e.g. cultural branding, emotional branding, and viral branding etc.

Study V elicited the question of further research in how to raise awareness of various managers’ agendas and how to use this knowledge in establishing a common ground from the outset that is bereft of personal prestige and hidden agendas. Another point for future research is how to ensure that “National Champions” share the same interest in the initiative surrounding any future distributed Research Infrastructure that may come to pass.

8 CONCLUSION

This dissertation sought to answer the research question: *What are the principal lessons researchers, entrepreneurs and funders that can be inferred from the formation of a large-scale distributed Research Infrastructure towards securing more sustainable prospects for similar, future endeavours?*

In seeking the answer to this question, the results from this dissertation have illustrated that the scientists behind BBMRI.se did not employ an "infrastructuring" lens, nor were the scientists behind the organisation permeated in a mindshare mind-set. In this sense, the actions of BBMRI.se did not sit well in relation to that proscribed by the literature in this regard, as it made eager attempts at utilising the "window of opportunity" that was at work, which implemented the organisation in a swift manner. However, it is important not to confuse "eagerness" with "readiness". While the scientists had ostensibly aligned mind-sets at the initial stages, it would become apparent that their motivations were vastly different halfway through the process. This lack of congruity appears to have been innate to the scientists, but was concealed at the outset of the venture. Nevertheless, since the formation process was expedited (perhaps even rushed), there was little time for "infrastructuring" to occur. It is possible that had one allowed for an "infrastructuring" process to take place, there might have been possible to ensure mindsharing throughout the entire development, and that the team entrepreneurship could have continued to have worked as one. As the events ran their course, the organisational fragmentation became progressively more consolidated, and eventually the end of the organisation became an inevitable fate.

It is true that there has been a long-standing debate as to what extent an organisational failure is prompted by firm-specific factors such as the lack of managerial expertise or by external factors, such as the rate of technological change, the level of competition, globalisation, general industry decline and/or outsourcing etc. (Mellahi & Wilkinson, 2004). To this end, external factors do provide relevant context of the complex and bureaucratic quagmire that surrounded the organisation as a distributed Research Infrastructure, which are important to observe. Nevertheless, it is important to remember (particularly in regards to the organisation this thesis investigates), that the managers of an organisation will more often than not possess the experience, resources and know-how to respond to challenges arising from the external environment (Amankwah-Amoah, 2015; Amankwah-Amoah & Debrah, 2014). As described in Table 3, there were a total of four and a half reasons as to why BBMRI.se ultimately failed. While the studies covered by this thesis looked at this organisation in particular, it is important to remember that at the time, BBMRI.se represented one of the most expensive distributed Research Infrastructures the world had seen thus far. For that reason, it sends a precedent for future distributed Research Infrastructures that may fall into the same, or similar, pitfalls. One of the lessons learnt from the aforementioned "Schumpeter's Gale", is that there can be creation in destruction, i.e. newer organisations/initiatives may in the future learn from their predecessor's shortcomings and come better equipped to tackle the challenge(s) (Schumpeter, 1942). At the end of the day, distributed Research Infrastructures will come to play an increasingly more important role in science in the years to come. For that reason more attention and consideration must be given towards preventing the "principal-agent" problem by developing mechanisms and routines in order to ensure that any joining "National Champion's" priorities are in line with the organisation's interest as this may otherwise lead to "moral hazard", i.e. when an actor increases their exposure to risk when they believe they are insured, or safeguarded, against potential mishaps (Laffont & Martimort, 2002). This is of particular note since this is a problem that is in and of itself often associated with T.B.T.F., a

mentality that was traditionally exuded within several major financial banks before the 2008 financial crisis, but was also an attitude that was present in the biobank infrastructure of BBMRI.se prior to its ultimate demise (BBMRI.se, 2015a; Dillner, 2014; Holmstrom, 1982; Kvalnes, 2011; Skoglund et al., 2016; Swedish Research Council, 2009). Needless to say, there must also be effective means of communication, but beyond that, there needs to be enough checks and balances in place across the system to address and remedy any and all potential grievances from staff members against possible misgivings about organisational and/or managerial conduct.

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