REVIEW

Taking the Next Step in Biobanking Research Infrastructures: A Narrative Overview

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Abstract

BioBanking and Molecular Resource Infrastructure in Sweden (BBMRI.se) was set up in 2009 in order to harmonise the standards and processes of biobanking. The present study is a qualitative narrative overview aimed at evaluating published studies on medical and/or biobank research infrastructure. Web of Science (WOS) and PubMed databases were searched to find studies on large-scale medical research infrastructures. A total of 145 articles were found, but only merely 17 made it past the exclusion criteria. Eleven of the 17 articles listed first authors affiliated with European countries. Most of the articles discussed the need for "research infrastructures" while not addressing the subject in any detail. Consequently, this study concluded that there is a pressing need for deeper and more extensive multidisciplinary collaboration, especially on how research infrastructures are structured, managed, and branded.

Keywords: Biobanking; Research Infrastructure; PRISMA; Literature Review; Narrative Overview

Introduction

Background

Research is contingent on the study of large collections of well-documented, accurate data from large numbers of populations. These collections are stored in biobanks (or biorepositories) (1,2). A biobank can be summarised as a bank that stores, processes and distributes biological materials and data associated with the material (3). Biobanks facilitating international collaboration are essential, since researchers need to achieve statistical inference by comparing information generated by a different population/sample group (4).

The inception of modern biobanking can be traced back to the late 1990s (5). New technology made it simpler to share data in a greater capacity than had been possible in the past.

This made it easier for scientists to make useful discoveries in samples originally collected for other purposes (6). Today, biobanks are instrumental in advancing public health through the discovery of diseases (5,7,8). Currently, there is an increased investment in biobanking in the western world in general and Sweden in particular (5,9,10). However, until relatively recently, there were few advocates for the development of research infrastructure in general and even fewer for biobanking (11). However, in recent decades there has there been an increased political attention given to the formation of research infrastructures, both on a Swedish national level as well as internationally. ESFRI, an European cooperation body for infrastructure, defines a research infrastructure 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" (12).

The European Union presented an initiative seeking to harmonise biobanking standards. This initiative was known as Biobanking and Biomolecular Resources Research Infrastructure (BBMRI). BBMRI was built on existing sample collections, technologies, resources and expertise that were specifically complemented with various innovative components (13). The intent was to integrate biobanking resources into a pan-European distributed hub/infrastructure across the Europe Union countries. The chief purpose of BBMRI was to serve as a bridge between sample donors (whether patients or healthy individuals) and scientists (14). In addition, it also intended to serve as a gatekeeper in order to protect sensitive data from being disclosed wantonly.

BBMRI was launched in 2008 and has since then grown into a consortium that includes more than 50 members and involved more than 280 associated organisations (mostly biobanks) from 33 countries. This made BBMRI one of the largest research infrastructures in Europe (14). BBMRI was implemented through a new legal entity called ERIC (European Research Infrastructure Consortium). ERIC was enacted in the European Union in 2009 as a legal framework (15).

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 an international organisation established by a verdict from the Commission, which originates from an application submitted by three or more Member States (16). 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 compete effectively on an international level. Through a consortium such as ERIC, Member States can collectively fund and manage the research infrastructures in a way that would otherwise be impossible 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" (17).

The national hubs of BBMRI were established under the ERIC legal entity. They connected the national scientific community, such as universities, hospitals, research institutions etc. to BBMRI-ERIC (14). The idea was that the distributed architecture enabled positive impact on the regional development in all participating Member States. A Swedish node was set up in 2009, called BBMRI.se. It received substantial funding from the Swedish Research Council, thus constituting one of the most ambitious national endeavours to fully implement the BBMRI infrastructure (14). Nevertheless, there has been little research aimed at the management and the processes involved in setting up research infrastructures (18-20). Since research infrastructures are on the rise, there is presently a pressing need for further research in this area.

Objectives

The main premise of the present study is to shed light on the mechanisms and components involved in the formation and consolidation of a complex, large-scale research infrastructure, and if there are any inherent pitfalls tied to such an endeavour. If so, what can be done to address them? This literature review explores the available knowledge in the areas of research infrastructure and biobanking to identify knowledge gaps and areas where further research is needed.

Methods

Overview

The literature study was based on a narrative overview. Put simply, a narrative review seeks to summarise different primary studies (21,22). These studies serve as a foundation from which conclusions may be drawn into an overarching interpretive overview reinforced by the reviewer's experience, models and/or existing theories (23). One of the main advantages is that it aspires to draw an understanding of the pluralities and complexities around the researched area (24). As such, narrative reviews are appropriate for

large-scale and/or comprehensive topics (25). The narrative overview is signified by making explicit search criteria and inclusion criteria (26).

Eligibility criteria

The present review aimed to identify all pertinent, modern English-language studies in the field of *large-scale medical research infrastructures*. The inclusion criteria were that the articles had to conform to the following attributes:

1. Pertaining to the areas of large-scale biobanking, medical and/or scientific research infrastructures
2. Published during the 20th and/or 21st century
3. Published in the English language

Given the dearth of available literature specifically focussing on large-scale medical research infrastructures, our review has also included some of the literature on research infrastructures in areas analogous to our subject of interest.

Information Sources

The point of departure was a search in the *Web of Science* (WOS) database. For purposes of providing full coverage of the area, an additional, identical search was done in the PubMed database.

Study selection

The articles were selected for a narrative overview using a pre-defined search string in WOS and PubMed. The process that followed was that the articles were first identified in each respective database. They were later screened, removing duplicate entries and articles written in any non-English language. The next step was to ensure full eligibility, namely that the included articles concerned large-scale biobanking, medical and/ scientific research infrastructures. Reading the abstract and keywords of each respective article ensured eligibity. The final step was to provide a list of all those articles included in the study. These articles were reviewed with their main messages summarised, along with number of citations in WOS, or PubMed (if unavailable in WOS) in the results section.

Search

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 author's research institute specialising in creating relevant academic search strings. This was done in order to exhaust the number of relevant search terms in an objective manner through an independent third-party with specialised competency in the area of database searches. No additional limits were set in regards to study design and/or time period in order to fully exhaust the possible search results. The search was performed in March 2016 and included a search period of all articles released in the 20th and 21st century.

Study selection

Although employing a narrative overview literature review, this study has opted to use the guidelines presented by the PRISMA statement for Systematic Reviews and Meta-Analyses Guidelines when reviewing articles (27). This entails 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 (28).

All retrieved publications were subsequently reviewed manually. Entries mentioning more than one of the search terms (e.g. *infrastructure* and *medical*) without linking them together in a relevant context were excluded. Articles that merely peripherally mentioned *research infrastructures* in passing in a different context were also excluded.

Data collection process

The data extraction included all retrieved articles from the selected databases by importing them into *EndNote X6* where the results were checked for potential double entries. Irrelevant studies, or those that failed to meet the inclusion criteria, were subsequently removed from the list. The final sets of articles were then tabulated into an Excel sheet with full bibliographic references for each article (date of publication, journal, issue, page number etc.).

Data items

The variables for which data were sought included:

1. Type of journal
2. Number of recurring journals
3. Country of publication
4. Type of funding (if any)

Synthesis of results

This study has applied a qualitative approach (26). It has not focussed on assessing the quality and/or bias of the individual studies as such, but rather in identifying

patterns across the articles dealing with large-scale medical research infrastructures. All included articles were analysed in two steps. First, the type of published work, journals, first author's national affiliation, date of publication and number of citations, were analysed. Second, every article was processed qualitatively in order to identify large-scale medical research infrastructures addressed by the majority of published research. This was achieved by categorising all included publications specifically dealing with medical and/or biobanking research infrastructures

Risk of bias in individual studies

A salient risk when conducting individual studies is the exclusion of population control. This has been remedied by developing a clear set of eligibility criteria at the outset of the study (29).

Risk of bias across studies

An inherent risk of publication bias is that the results depend more on the hypothesis tested rather than on the quality of research. This may lead to undesired type-1 errors, or "false positives". This stems from the risk that researcher may be more prone to publish results in support of their hypothesis as opposed to those that disprove it (30). This is particularly a problem for studies with small effect sizes. This risk is reduced by using larger studies, which provided better representation of the area (31).

Discussion

Study selection

The initial search in WOS returned 52 cited articles whereas the search in PubMed revealed 93 articles (i.e. 145 articles in total). There were no duplicate articles in each respective database, but 20 articles overlapped with WOS and PubMed. Although no limit was set on the time period, all articles found were published between the years 1996-2016. 42 articles were excluded from WOS due to lack of relevance (save for one that was excluded for being in a language other than English). All of the 10 retained articles were original research. 66 articles were excluded from PubMed due to lack of relevance (save for two that were excluded for being in a language other than English) in addition to the 20 that overlapped with WOS. 6 out of 7 retained articles were original research, while the last one was a commentary. This means that 17 articles in all were ultimately included in the study. The procedure for selecting the articles is depicted in Figure 1:

Study characteristics

The 17 articles included in the review were published during the period 2003-2015. Most of the studies were of a theoretical nature, with two articles investigating empirical data. They were relatively evenly spread through different journals, although the journals of *Biopreservation and biobanking* and *Pathobiology* saw a slightly greater representation with two publications each, as demonstrated in Table 1.

The most cited article was (33), discussing the need of larger infrastructures to enable studies of multifactorial diseases, with 31 citations (with an approximate of 3.1 citations per year). Two of the articles mentioned *BBMRI*, nine of the articles were cited 5 times or more since publication. Although a relative scarcity of articles, the analysis showed that the available articles' first authors were relatively well distributed amongst different countries, with all continents represented. However, in 8 out of 12 cases, the first author was affiliated with a European country, indicating research infrastructures to be a more European-centred topic, as shown in Table 2.

Most of the articles were funded through grants, while a considerable amount (approximately one-third) did not specify the origin of their funding. Only in one isolated case did the authors disavow any occurrence of funding, as illustrated in Table 3.

Synthesis of results

The main points discussed in each of the reviewed articles may be summarised as follows:

Abayomi et al. (34) discuss the need of well-developed governance, ethics, infrastructure, and bioinformatics as prerequisites for the establishment and evolution of successful human biobanking. According to WOS, it has a total of 5 citations. Armstrong and Reaman (35) promotes the need of multidisciplinary, cooperative groups offering opportunities for psychological research and lift shared research infrastructures as a scientific benefit. According to WOS, it has a total of 13 citations. Doiron et al. (36) believe that a shared infrastructure helps create a collaborative environment. According to PubMed, it has a total of 8 citations. Dove (37) calls biobanks "a key emerging research infrastructure, and those established as prospective research resources comprising biospecimens and data from many participants are viewed as particularly promising drivers of biomedical progress". The article has no citations, according to WOS. Filocamo et al. (38)

stipulate that a coordinated IT infrastructure has enabled the standardisation of procedures and activities, making it easier for biobanks to gain a critical mass, while helping to raise awareness among the general public. According to WOS, it has a total of 4 citations. Litton, Muilu, Björklund, Leinonen, and Pedersen (39) contend that "database infrastructure has become a critical component for competitive life sciences research and discovery" and argues that there is a need to standardise research data. According to WOS, it has a total of 7 citations. Mendy et al. (40) raises the issue that investment in biobanking infrastructure has enabled scientific progress, while upholding innovative programmes facilitating the creation of sustainable biorepositories and research infrastructures with the capability to conduct cutting-edge scientific research. According to WOS, it has a total of 1 citation. Norlin et al. (41) analyse BBMRI when discussing the aim to facilitate data discovery through harmonisation of data elements describing a biobank at the aggregate level. According to WOS, it has a total of 11 citations. Park et al. 42) uphold the biobank as an important infrastructure for biomedicinal research in order to actualise personalised medicine. According to PubMed, it has a total of 2 citations. Pathak et al. (43) discuss the need to develop scalable informatics infrastructures and conclude that there is a need for large-scale standardisation. According to WOS, it has a total of 11 citations.

Peterson (44) considers how a roadmap may present a strategic shift in how research networks may move from direct funding of a harmonised national infrastructure of cooperating research networks to a model of local engagement. According to WOS, it has a total of 3 citations. Riegman et al. (33) stress the need to harmonise and streamline

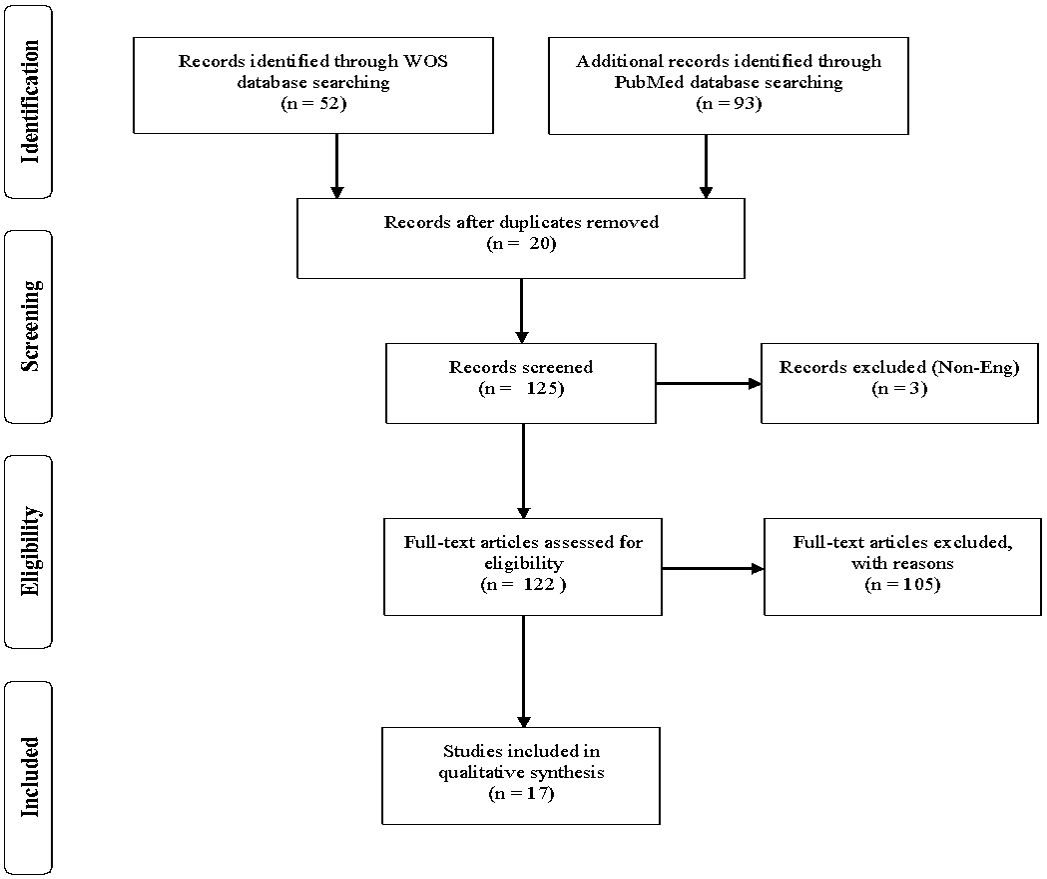

Figure 1. Flowchart of the different phases of article processing throughout the systematic review (adapted from Moher, Liberati, Tetzlaff, Altman, & the PRISMA Group (32)

Table 1. Journals involved in publishing articles on biobank/medical Research Infrastructures

Rank	Journal	No of Articles
1	Biopreservation and biobanking	2
2	Pathobiology	2
3	Biomarkers in Medicine	1
4	Emerging Themes in Epidemiology	1
5	European Journal of Human Genetics	1
6	Genome Medicine	1
7	Journal of the American Board of Family Medicine	1
8	Journal of the American Medical Informatics Association	1
9	Journal of Pediatric Psychology	1
10	Journal of Law Medicine & Ethics	1
11	Orphanet Journal of Rare Diseases	1
12	Osong Public Health and Research Perspectives	1
13	Public Health Genomics	1
14	Social Science & Medicine	1
15	Twin Research	1

Table 2. Journal country of origin for the articles cited

Rank	Country	Number of Articles (%)
1	USA	3 (17.6%)
2	Netherlands	2 (11.7%)
3	Sweden	2 (11.7%)
4	UK	2 (11.7%)
5	Austria	1 (5.9%)
6	Canada	1 (5.9%)
7	France	1 (5.9%)
8	Italy	1 (5.9%)
9	Japan	1 (5.9%)
10	South Africa	1 (5.9%)
11	South Korea	1 (5.9%)
12	Spain	1 (5.9%)

Table 3. Most common type of funding

Rank		Funding	No of Articles
1		Grant	8.5
2		None Stated	5
3		Project	1.5
3		European Commission	1
4		No financial involvement	1

biobanking through infrastructures. According to WOS, it has a total of 31 citations. Rosemann (45) postulates that the coexistence of divergent socio-epistemic practices has enabled also the generation of multiple forms of economic value. Thus, integration of local institutions into the global bioeconomy does not necessarily result in the shutting down of localized forms of value creation. According to WOS, it has a total of 1 citation. Van Ommen (46) believes that the efforts of the pan-European BBMRI-ERIC will improve accessibility and interoperability between the academic and industrial sectors which will ultimately benefit personalised medicine. According to WOS, it has a total of 5 citations. Yoshizawa et al. (47) argue that there is a need for common infrastructures and platforms in large-scale human genomic research and policy development, while also pressing for a greater understanding of issues and practices that relate to the ethical, legal and social implications (ELSI). According to WOS, it has a total of 1 citation. Zatloukal and Hainaut (48) contend that biobanking infrastructures have a critical

impact on the discovery, development and implementation of new drugs for cancer treatment, hence it is deemed essential to harmonise biobanking procedures. According to WOS, it has a total of 17 citations. Zika et al. (49) stipulate that practices in biobanking may pose a barrier to cross-border research and collaboration by limiting access to samples and data. Hence, the authors call for EU-funded biobanking projects aimed to improve interoperability and sustainability. According to WOS, it has a total of 16 citations.

Conclusion

Summary of evidence

This study sought to make an objective and impartial assessment of the present research and/or discussions on research infrastructures in medical sciences in general and in biobanking in particular. This review has described how publications in the field are presented to the public and in which publications they surface. Based on our findings, one may deduce that the topic is more prevalent in biomedical publications, although the issue is also raised in publications specialising in ethical, psychological and social scientific issues. The results of the articles show that there is an overall consensus for the need of large-scale research infrastructures, but at the same time there is also a lack of literature specifically focused on the topic of research infrastructures.

Analysed separately, the United States had the largest representation of first author associations, with three publications. The Netherlands, Sweden and the United Kingdom followed with two publications each with first author affiliation. Although there were isolated representation from countries located in other continents, such as Asia and Africa, the vast majority of first author affiliation could be found in European countries, suggesting the topic is of greatest relevance in Western Europe, and to some extent in the United States.

Apart from a few that did not declare funding source, all articles, save but one, received funding from a project, grant or government agency.

Limitations

The aim of this analysis was to identify publications that addressed the mechanisms and components involved in the formation and consolidation large-scale medical and/or biobanking research infrastructures. As such, the intent was to assess every pertinent article that did so in a qualitative manner. For this reason, the articles evaluated have not been ranked beyond mentioning the number of publication in any given journal, and this merely for purposes of determining whether there has been a discernible pattern of publication. Hence, the PRISMA flowchart presented earlier in review omits the final, optional phase of meta-analysis synthesis (32).

Analytical summary

Implications of the harmonisation of the medical sciences and biobanks are relevant not just for the biobanks per se, but also for the very foundation of future research collaboration in large-sale research infrastructures. The future of scientific research will undoubtedly call for deeper and more widespread multidisciplinary collaboration, hence the need to adequately provide the best prospects for research optimisation.

The narrative overview literature analysis of the articles published in the field showed that focus was placed on stressing the need for better infrastructures in order to cater to multidisciplinary sciences. With further development of this field and the intricate design of research infrastructures, this issue will likely surface frequently during the course of the academic discourse of “big sciences” and collaborative science. To this end, instigators will need to know how to build, manage, brand and promote research infrastructures, not only to serve investors, but primarily to serve the scientific community at large.

Conflict of Interest

None declared.

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