








# Building a Biobank Network for Health Research in Indonesia

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## Abstract

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**BACKGROUND:** Biobanks play an essential role in the development of personalized medicine since they collect large numbers of high-quality biomaterials corresponding to clinical data. Despite its extensive population diversity, research institutions in Indonesia have indicated less awareness regarding biobanking for research practices.

**AIM:** The journey to harmonize the knowledge and understanding of biobanks for health research and the development of the network in Indonesia has been summarized in this article.

**METHODS:** To build a national biobank network, in 2015 the Faculty of Medicine, Public Health and Nursing, UGM held the first national biobank network meeting in Indonesia. Follow-up meetings were then held to identify challenges and constraints faced by the network. Five annual national workshops (2015–2019) have been held.

**RESULTS:** Four working groups (WG) were formed to effectively coordinate the network, addressing the infrastructure and Laboratory Information Management System (WG 1), SOP and Best Practices (WG 2), Training and Education and Legal (WG 3), and Ethical and Social Issues (WG 4).

**CONCLUSION:** The formation of a national biobank network in Indonesia is based on the hope for multi-institutional collaboration to mainly foster the development of biobanks for health research with best available practices and provide a central hub of coordination.

## Introduction

Biobanks are a type of biorepository system that stores biological samples to be used in research. They play an important role in the development of personalized medicine since they collect large numbers of high-quality biomaterials corresponding to clinical data [1]. Indonesia is a developing country where infectious diseases are still a major problem and non-communicable diseases are also increasing dramatically. A biobank system is needed to improve the current knowledge and empower research in infections, cancer and rare diseases. The large collection of biobank samples is essential to identify the particular demographic, social and environmental characteristics in the Indonesian population. Therefore, up-to-date and well-documented data, along with the samples of human and other species biospecimens connected with the clinical and biological information, are important to track statistically significant and effectual results in retrospective, prospective, and cohort research [2].

Almost all diseases have a high diversity of molecular subgroups which makes it more complex and difficult to provide sufficient number of samples and data to conclude significant results of a study [3]. Accordingly, it is necessary to merge data from multiple biobank centers for more comprehensive analysis through a strong system of networking [4]. Those specific shared concerns justify the growing interest in developing cooperative networks of biobanks to minimize any bias arising from heterogeneity in the quality of biological samples by means of standard operating procedures (SOPs), development of common quality assurance (QA) policies, and the promotion of collaborative environments [1].

Indonesia is a vast country with a very diverse population which requires a well-developed system of networking to form standardized biobanks [5]. In any biobank, networking is important for advancing translational research. However, collecting a large-scale biospecimen collection still encounters many obstacles, partly due to the poor data sharing and weak collaboration between the biobank centers across the nation [6]. At

present, there are limited information and data regarding biobank practices in Indonesia. Biological specimen repositories in Indonesia are generated for a number of reasons and incentivized by various stakeholders which are typically academic institutions and government entities since commercial biobanks have not yet become popular in Indonesia. At present, Indonesia still has no legal rules governing the use of biobanks for health research. Under these conditions, there is an urgent need expressed by participants to build a national network or an umbrella organization for research-related biobanking activities in Indonesia. Biobank networks are a group of institutions who freely assume the commitment to collaborate in terms of public services, share the same SOPs and QA policies, and are helped by a central hub for coordination in terms of providing available services [1]. Based on these needs, this study was conducted to organize and harmonize the development of a national biobank network for research in Indonesia.

To build a biobank network in Indonesia, the Faculty of Medicine, Public Health and Nursing of Universitas Gadjah Mada (FK-KMK, UGM), has developed a standardized biobank system in Indonesia [7]. FK-KMK, UGM held its first national workshop of biobanks in 2015, including more than seven institutions as stakeholders for the initial action. A simple questionnaire to gauge the eagerness of building the biobank network among the participants was disseminated after the first national workshop. The collected questionnaire data were descriptively analyzed and discussed in detail. Follow-up workshops were then held across institutions in Indonesia, including in Universitas Indonesia-Jakarta and Universitas Andalas-Padang, West Sumatera, in order to identify the challenges and constraints faced by the network. Information regarding SOPs, QA, sample storage and bioinformatic systems for biobanking were shared within the network. Ethical-legal-social aspects of biobanking were also discussed.

## The First National Workshop

The first national workshop was held on December 5, 2015, titled, "Building the Biobank Network in Indonesia: Opportunities and Challenges." The aim of this workshop was to identify the status of biorepositories in the various health research facilities in Indonesia. This meeting was attended by representatives of the research facilities from several medical faculties in Indonesia, including University of Indonesia - Jakarta, Universitas Andalas - West Sumatera, Universitas Brawijaya - East Java, Universitas Airlangga - East Java, and UGM. Representatives from the Ministry of Research, Technology and Higher Education of Republic of Indonesia were invited to share research priorities in research for health

and medicine and to discuss how biobanks can play an important role in advancing research and clinical services. National research institutes including the Indonesia National Institute of Health, Research, and Development (*Balai Pengembangan Riset Kesehatan*) and Eijkman Institute were also invited. Two experts from the Biobank Cohort Building Network International (BCNet), World Health Organization – International Agency for Research on Cancer (WHO-IARC) and the Netherlands Cohort Biobank, Lifelines attended the meeting to share their organization profiles and information on how to build a biobank and its network. Valuable information was shared regarding biobanking practices in Indonesia, including: 1) activities related to biobanks for clinical services and research in each institution; 2) types of samples already in their collections, which mostly consist of human biological specimens rather than animal or plant; and 3) the absence of a unified repository system in each institution. Storage of biological samples was commonly conducted in the research institutions or universities according to specific research needs/protocol, which was generally insufficient in terms of their management system. Furthermore, most importantly, there exists some confusion because of: 4) The inequality of understanding among different stakeholders and institutions about biobanks and their complexity, not only concerning technical aspects but also the ethical, legal, and social issues. In this first meeting, we specifically invited representatives from the Biobank and Cohort Network (BCnet) WHO-IARC and Biobank University Medical Center Groningen-The Netherlands/Lifelines cohort Biobank, who have expressed great willingness to support the establishment of a national network in Indonesia, including facilitating capacity-building as well as providing consulting expertise, but not in the form of direct funding [8], [9].

A simple questionnaire was disseminated after this national workshop to explore participants' eagerness regarding further annual national meetings and the establishment of a national biobank network for collaborative research. The questionnaire was distributed via email among the participants and 24 participants returned the form. Most participants agreed to attend another biobank meeting and in initiating a biobank network. Half of our respondents admitted to already having a biobank or similar facility in their institutions which would aid in data collection and sample sharing and all agreed to collaborate in a national network of biobanks. The questionnaire results are summarized in Table 1.

**Table 1: Questions distributed after the first national workshop**

S. No.	Question	n = 24	
		Yes	No
1.	Is there any biobank or similar facility in your institution?	14 (58.3%)	10 (41.7%)
2.	Do you agree to hold another national biobank meeting every year?	24 (100%)	0 (0%)
3.	Will you join the next biobank national meeting?	24 (100%)	0 (0%)
4.	Do you agree to initiate a biobank network?	24 (100%)	0 (0%)

## The Second National Workshop

The second national workshop was held on November 7–8, 2016, with the topic of “Building the Biobank Network in Indonesia: Management and Practice of Biobanks”. This workshop was aimed to further introduce the more intricate details of biobank’s complexity. Within this meeting, participants discussed the more detailed elements of biobanking, such as Ethical, Legal, and Societal Issues (ELSI), Laboratory Information Management System (LIMS), SOPs, QA policies, infrastructure, biosafety, and biosecurity. Seven medical institutions across Indonesia participated in this meeting, including Dharmais Cancer Hospital - Jakarta, University of Indonesia - Jakarta, Universitas Andalas - Padang (West Sumatra), Eijkman Institute - Jakarta, Universitas Jenderal Soedirman - Central Java, Universitas Diponegoro - Central Java, and UGM - Yogyakarta. BCNet WHO-IARC and Lifelines continued to greatly contribute their personnel and resources of expertise and experience in building biobank units and national networks. The location of each institution currently participating in the biobank network is depicted in the provided map of Indonesia (Figure 1).

In the second national workshop, the formation of the national biobank network was formalized. The presence of the national network was expected to accelerate the building of biobanks in different institutions. Accordingly, it was decided to form four working groups (WGs) adapted from BCnet [8]. The WGs were: WG 1 (Infrastructure and LIMS), WG 2 (SOPs and Best Practices), WG 3 (Training and Education), and WG 4 (Legal, Ethical, and Social Issues).

## The Third National Workshop

The third workshop was held on November 6–7, 2017, and was hosted by the University of Indonesia in Jakarta. The topic of this 2-day workshop was “Strengthening the Research Biobank Network through Capacity Building.” A seminar regarding capacity building in biobanking was held before the workshop. The workshop itself discussed about the follow-up of the previous years’ issues regarding the national network. Each WG had the opportunity to revisit the suggested program made in the previous meetings or finalize some programs into their yearly program. Besides communication through WhatsApp® groups, each WG agreed to continue regular meetings through Skype® to strengthen the connection of the national network. WG 1 had a program to design and distribute a questionnaire regarding biobank infrastructures and facilities in each institution to provide a clear picture of biobank activities in Indonesia. WG 2 created a program to share best practices and/or SOPs developed in each institution and initiate a SOP template to be used within the network. WG 3 focused on constructing good education and training materials for Indonesian biobankers through finalization of biobank modules which are expected to be used nationally. Meanwhile, WG 4 agreed to initiate recommendations in the form of a formal draft document of biobank recognition to be submitted to the national government to advocate for legal regulations for biobank research. Each WG consists of representatives from each institution within the network without specific qualification.

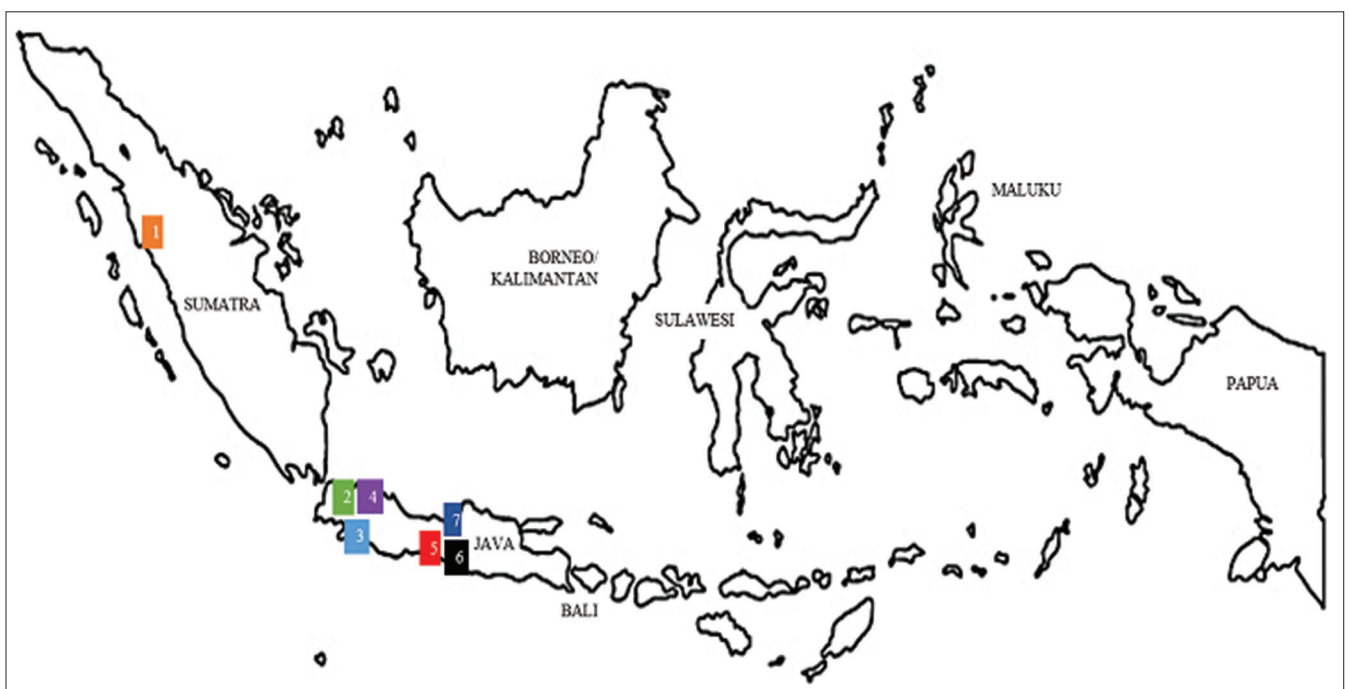


Figure 1: Distribution of the present biobank network in Indonesia indexed by numbered box; 1. Universitas Andalas, 2. University of Indonesia, 3. Dharmais Cancer Hospital, 4. Eijkman Institute, 5. UGM, 6. Universitas Diponegoro, and 7. Universitas Jenderal Soedirman

## The Fourth National Workshop

The fourth network workshop was conducted on November 12–13, 2018, hosted by Universitas Andalas, Padang (West Sumatera) with the topic, “Defining Business Model of Institutional Biobank.” During this workshop, there were several key decisions made based on the network reflections of the previous year program. Considering the unresponsiveness from the Ministry of Research, Technology and Higher Education regarding the formal biobank recognition document prepared by WG 4, the network strongly felt a need for a direct communication with the Indonesia National Institute of Health, Research, and Development in order to push for clarification of the complex legal matters involved in biobank practice in Indonesia. Each WG expressed a concern for the sustainability of its program which was mainly caused by the challenges in communication and time management.

## The Fifth National Workshop

The latest national network meeting was organized by UGM on November 11–12, 2019 with “Biobanking for Health Research in Indonesia” as the topic. The most important decision discussed during this meeting was on the network’s legal sustainability. As one of the limitations of our biobank network, since no formal organization is yet to be formed, the participants kept changing from one workshop to another. It was discussed and considered important that a more formal form of organization will help the programs to achieve their overall target. While this discussion is still pending a final decision, it was agreed that an *ad hoc* committee would be formed to develop a strategic planning document to navigate the collective efforts and programs for the national biobank organization. The plan to form a formal organization is currently pending due to the COVID-19 pandemic as many of the biobanks, including at UGM, need to adjust with the current working situation. Meanwhile, this situation requires the network to be activated to

strengthen their collaboration. In the past 4 national workshops, our WGs were more focused on ELSIs and therefore, in the 5<sup>th</sup> national workshop, we changed our strategy to apply a more technical approach related to biobank practices. A short summary of all meetings from each year is outlined in Table 2 in which there are no technical SOPs in each workshop or networking activities. Despite each workshop having different themes or topics, terms of reference were compiled to provide the local committee and speakers in hosting the workshop.

## Discussion

Networking is seen as an essential tool to harmonize and accelerate the development of biobanks in Indonesia by creating niches for collaboration among biobank developers in different institutions. Through four formed WGs 1–4, it is expected that recommendations or guidelines for biobanks in Indonesia could be produced and used within the network. WG 1 works to identify the infrastructure, LIMS, and expertise existing in each institution related to biomaterial collection, processing, and long-term storage. WG 2 works on reviewing the best practices from different resources, comparing them with the local, regional, and national situation, and where and when possible, drafting an SOP template for various activities in the biobank network, such as sample collection, transportation, analyte processing, and storage. Sharing SOPs is recommended to broaden the knowledge and references in drafting a comprehensive SOP so that it can be adjusted and translated into each institution’s needs [10]. WG 3 is anticipated to identify what biobankers need to gain expertise so that they can meet the requirements, find reliable resources for education and training activities, and identify the way to efficiently educate and train the biobankers and stakeholders (researchers, clinicians, technicians, faculty, and government representatives).

Meanwhile, WG 4 aims to identify the most effective way to approach the government and the current ethical committee network in Indonesia that

**Table 2: The summary of the outcomes from biobank network workshop for health research 2015–2019**

S. No.	National Workshop	Host	Theme	Outcome (s)
1.	December 5, 2015	Universitas Gadjah Mada, Yogyakarta	“Building Biobank Network in Indonesia: Opportunity and Challenge”	Initiation of national biobank meeting; overview of the current biobank projects across the country
2.	November 7–8, 2016	Universitas Gadjah Mada, Yogyakarta	“Building Biobank Network in Indonesia: Management and Practice of Biobank”	Agreement to a joint annual meeting hosted in different institutions; formation of a national biobank network; establishment of working groups
3.	November 6–7, 2017	University of Indonesia, Jakarta	“Strengthening the Research Biobank Network through Capacity Building”	Formal draft document on biobank for health research handed to the Ministry of research, technology and higher education
4.	November 12–13, 2018	Universitas Andalas, Padang	“Defining Business Model of Institutional Biobank”	Consideration for a formal legal entity and a strategic planning
5.	November 11–12, 2019	Universitas Gadjah Mada, Yogyakarta	“Biobank for Health Research in Indonesia”	Agreement to form ad-hoc committee to establish network organization so that network sustainability can be preserved

biobank activities can be legally protected. While the other three WGs have mostly technical tasks, WG 4 is needed to tackle some of the important societal issues. For example, the legal/ethical concept of informed consent is one of the most complicated issues discussed by participants, since it poses several challenges in its implementation. In Japan, collecting biological samples is uncommon because of its complex ethical issues and strict legal aspects [11]. Specific informed consent for specific research is usually used by the researchers. However, informed consent for long-term sample collection, with various research purposes and undetermined future research, is uncommon. WG 4 is also expected to make a workflow recommendation to address the issue of informed consent and when possible draft a broad consent agreement form suitable for the Indonesian population. Each WG has its specific WhatsApp® group that is being used for communication and discussion. However, in practice, these strategies have been less successful in increasing the research collaboration within the national biobank network.

In our case, there are no minimum resources needed to start a national biobank network in which all parties, including individual PIs, who have biospecimen collections and eagerness to learn and connect with other biobank centers can join the network. However, the geographic situation has been one of the challenges in developing biobanks in Indonesia. Indonesia consists of approximately 17,000 islands and Java is the main inhabited island with almost 60% of the Indonesian population [12]. Disconnected land masses and vast maritime stretches have presented some difficulties and limitations to centralize political control of the nation, including in building a national network of biobanks. Soo *et al.* stated that location is an important factor in establishing a biobank since researchers are more likely to use the services if they are easy to find and nearby, reducing the use of expensive couriers [13]. Colledge *et al.* proposed several issues related to problems in building a network to form a large-scale biobank in a high-income country [9]. One of the main reasons for the insufficient data sharing is the “feeling of territoriality” that makes sharing samples still low in an institution’s agenda, even in “common” areas of research, such as cancer and infectious disease [5]. In other cases, some biobank centers already have a desire to share, but they are not aware of any networks nor completely understand the procedures of sharing data or samples. Due to this lack of awareness, they are currently only working with researchers who have the same specific interest in their biospecimen samples [5]. Some biobanks are also still skeptical that the current networking will succeed in bringing them together to form a large-scale national biobank network. Other obstacles in networking establishment include a lack of a standardized protocol to follow which would guarantee the standard quality of the samples, as well as a lack of understanding concerning the complicated legal issues related to sample sharing, and

proprietary issues related to intellectual property rights and patents [14]. Those issues seem to be particularly relevant within low- and middle-income countries, including Indonesia [8], [15]. Various geographical sites and different interests among institutions give further challenges to form a large-scale biobank in low- and middle-income countries, especially in Indonesia that has a diverse population [8].

At the same time, we still must face major obstacles related to legal regulations. Specific regulations have not yet been established addressing the concept of biobank as a bio-preservation unit to collect human or other biospecimen samples for research purposes. Up to now, the existing regulations regarding biobanks are limited for clinical services and do not accommodate the research purposes, including the Decree from Ministry of Health No. 62/2013 regarding tissue collection and stem cells for clinical services and No. 48/2012 regarding biobanks for stem cells and cord-blood. Institutions in Indonesia need a legal umbrella to protect their biospecimen preservation activities and raise awareness about the value of a unified system for biological preservation and data protection. The initiative of a national biobank network serves to advocate the government for the legal regulation of biobanks for research, to organize and harmonize expertise and facilities, and to conduct collaborative research using appropriate standards and best practices.

Moreover, while geographical and time barriers are also two major constraints for the national biobank network to achieve its shared goals, present-day communication technology presents affordable solutions with real-time applications. These networking channels can aid in the formation of a legal organization and provide the solution-net for our present and future networking situation. Engagement with representatives of the government and other related stakeholders also needs a sustainable effort from the network groups as the only non-governmental platform working on this issue. The main government representatives and stakeholders that should be engaged in our national biobank network are from the Ministry of Health, Ministry of Research and Technology, and Ministry of Education. At present, various expertise represented in this network, along with their direct links to the various respectable academic hospitals, are the main strengths of the network [16]. At present, the network consists of only the representatives from the western part of Indonesia. While this reality reflects some of the disparity in Indonesia, it also serves as an opportunity to act as a catalyst for the strengthening of research efforts in the eastern parts of Indonesia which have different biological and sociocultural characteristics compared to the western parts of Indonesia. Each institutional biobank is unique, and some of the organizations are in different stages of development. In addition, each of the biobanks who join the workshops have their own

business plan, management, and way to how to handle specimens. What we are trying to do is actually to bring together all current knowledge on biobanks with examples, so that each of the organizations knows how to work towards their own specific biobank business plan. After 4 years, we could finally include representatives from the government/regulators into the meetings to realize the need for regulation for biobanks in health research. To foster speeding up regulations related to biobanks, the presence of a formal organization of network is essential. The future of the national biobank network will depend on how its programs can include as many universities, hospitals and research institutes as possible into the biobank knowledge-sharing platform, which will eventually stimulate the overall growth of sustainable biomedical research practice in Indonesia.

## Conclusions

A biobank network is considered strategically important to support biobank growth in Indonesia. It allows sharing of valuable information about best practices for biobanks and provides a central hub of coordination in Indonesia. By forming WGs within the network, it is hoped that each WG can actively produce recommendations or guidelines which can be used within the network and will be submitted to the government to advocate for appropriate rule-making concerning the development of biobanks for research in Indonesia in order that its activities have legal protection.

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