



Message from the Editor

The implementation of the BCNet catalogue provides the opportunity for members to showcase the biological samples stored in their respective biobanks and to inform the wider research community of the potential resources available for collaborative studies. This is the first step towards fulfilling the goal of the network, which is to conduct and promote research collaboration between members, partners, and the international community. Congratulations to BCI, Ghana; MRC, The Gambia; Makerere University, Uganda; UGM, Indonesia; and WRC, Poland for participating in the pilot phase. We are looking forward to more biobanks joining the catalogue.

The catalogue as a research platform will provide visibility to the institutions and their potential to participate in research, thus addressing the under-representation of samples and data available for genetic and molecular studies in low- and middle-income countries (LMICs).

A transparent governance structure is required for the implementation of the catalogue, to ensure a fair and transparent procedure to promote resource sharing for collaborative studies. In this regard, a governance document and draft guidelines on the roles and responsibilities of the sample/data providers and recipients and the access procedures to govern transfer are under

development. Each institution will be required to review the guidelines and adapt them to its local setting.

This edition of BCNetter is being published to coincide with the IARC@50 conference (Lyon, 7–10 June). It provides progress on the implementation of the catalogue programme and updates from network members and partners.

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Update on the BCNet Catalogue Project

In February 2014, BCNet members agreed to introduce a common catalogue to document available resources from their biobanks, to provide visibility for the valuable resources, and to make them available for research projects.

Implementation of the BCNet Catalogue

IARC, in collaboration with Karolinska Institutet, Sweden, started to design a global catalogue for BCNet in mid-2014. IARC set up the host server in mid-2015 and the platform was migrated from Sweden. The BCNet training conducted in November 2015 at IARC provided the opportunity to present a public release of the catalogue, to introduce the implementation workflow (Figure 1), and to invite BCNet members to participate in the pilot phase. Nine members registered their biobanks during the first quarter of 2016. The biobanks selected, prepared and submitted subsets of sample data. They also provided general information on their biobanks, research activities and platforms. Four additional institutions have registered information on their biobanks in the catalogue and have yet to submit data.

The process involved the checking, processing and importing of data into the catalogue, with support from IARC data management. The second semester of 2016 was devoted to the consolidation of data submitted in the pilot phase and the development of the catalogue governance structure.

What were the main challenges?

One of the motivations of the BCNet catalogue is to collect and gather sample data from BCNet members' biobanks to promote collaboration between members and with the international community. However, in establishing the catalogue, conceptual and technical challenges had to be dealt with. They include understanding the concept of combining information from different biobanks into a global searchable catalogue with the possibility of providing access and sharing of resources for research collaboration. The technical challenges arise from the necessity to combine data sets of diverse formats from multiple biobanks into a common platform in a standardized and harmonized manner.

The database was designed on the backbone of MIABIS (Minimum Information About Biobank data Sharing)¹ to ensure the highest compatibility of the catalogue with tier sample management systems. Operating a catalogue requires a robust governance structure, which is being developed to guide the process of access, sharing, and collaboration. Under this governance structure, biobanks will have autonomy over their respective data, and requests for collaboration will be sent directly to the institutions and the named principal investigators. Each institution will deal with access requests according to local regulations and conditions.

The pilot phase of implementing the BCNet catalogue has been both challenging and educational. Dealing with issues such as sample data preparation and data integration requires comprehensive management and documentation to provide data of the required quality and can be time-consuming.

What are the next steps?

Now that the pilot phase has been successfully implemented with the inclusion of nine biobanks (Figure 2), the next steps are:

1. Expanding the programme by inviting biobanks to register their information and participate in the catalogue, followed by populating the catalogue with new or additional data from sample collections
2. Promoting the catalogue by increasing awareness, and informing BCNet members of its benefit in building partnerships within and outside the network and
3. Improving the technical interfaces of the catalogue, depending on the feedback and comments provided by biobanks and users of the platform.

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(1) <http://bbmri-eric.eu/documents/10181/137577/>

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Update on the BCNet Catalogue Project

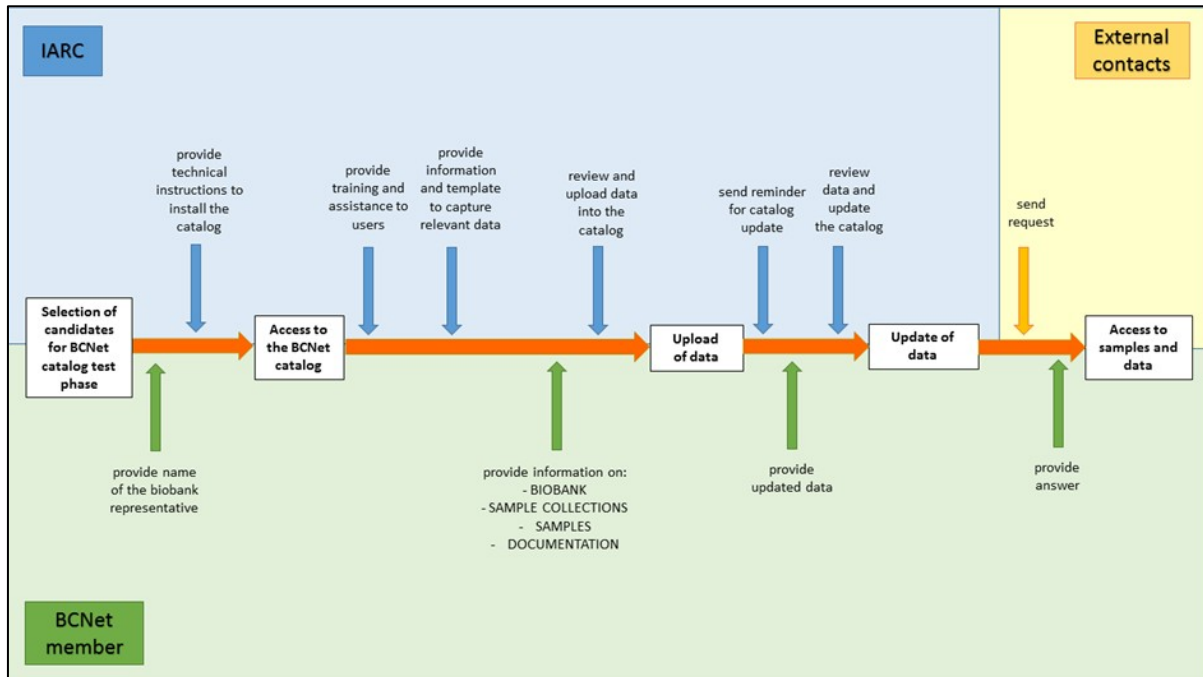


Figure 1. Workflow of the implementation of the BCNet catalogue

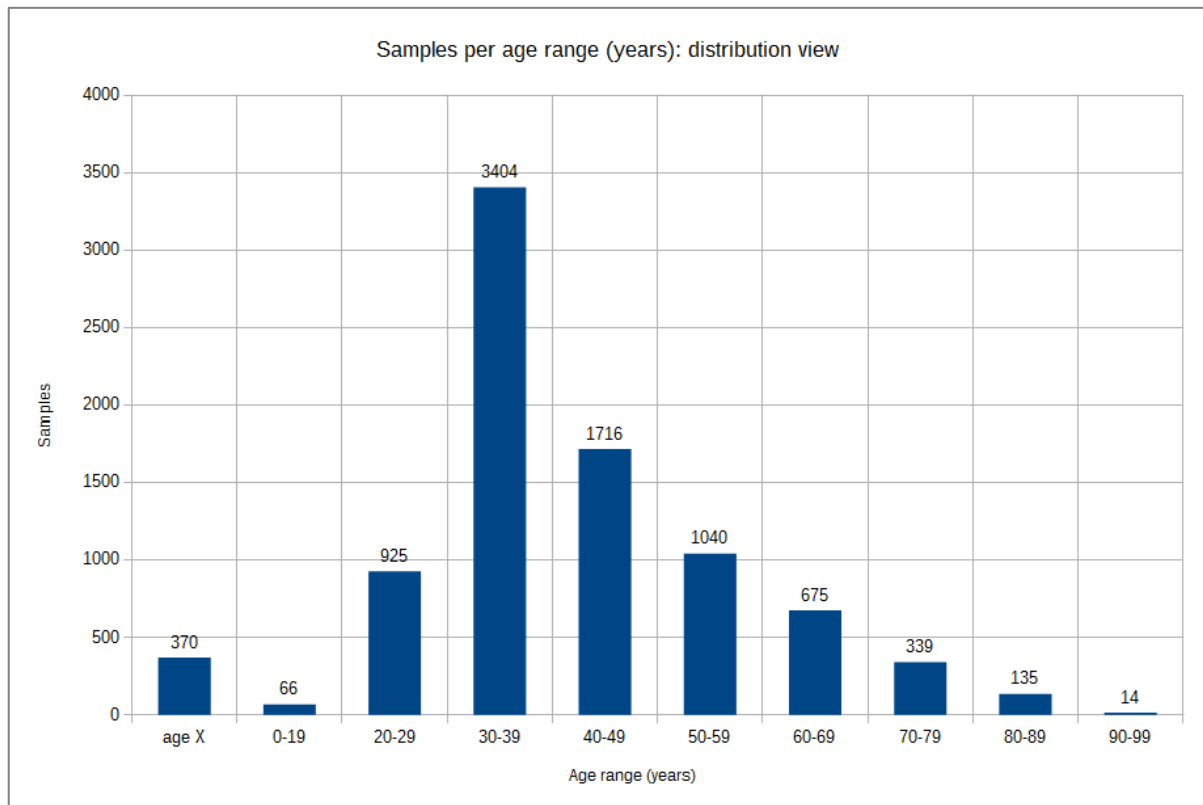


Figure 2. Subset of sample data from the BCNet catalogue

News from BCNet members and partners

The RINC/UNASUR Biobank Operative Group

Meeting in Lima to Delineate Action Plan for 2017–2018

On 5–6 May 2016, biobanking experts from Argentina, Bolivia, Brazil, Colombia, Chile, Cuba, Ecuador, Mexico, Panama, Peru, Puerto Rico, Uruguay, and Venezuela met in Lima, Peru, for the VIIth Ordinary General Meeting of the Biobank Operative Group of the Network of National Cancer Institutes and Institutions - Union of South American Nations (RINC/UNASUR), also known as the Latin American and Caribbean Biobank Network (REBLAC). The meeting took place at the National Institute of Neoplastic Diseases (INEN).

For the first time, representatives from newly incorporated biobanks participated in the meeting. They included representatives from Argentina (General Pediatric Hospital Ricardo Rodríguez), Chile (Pediatric Hospital Luis Calvo Mackenna), and Puerto Rico (University of Puerto Rico Comprehensive Cancer Center and Ponce School of Medicine and Health Sciences).



In addition, reports from the Harmonizing Processes, Minimum Technical Standards, and General Bylaws Committees were presented and extensively discussed, including important aspects for all participants' biobanks.

During the second day of the meeting, the General Assembly unanimously approved the final draft of the General Bylaws and Action Plan. In addition, the members of the Board of Directors and the Scientific Commission for 2017–2018 were elected. The Board of Directors of the Biobank Operative Group will coordinate and develop a working agenda in conjunction with the Executive Secretariat of RINC/UNASUR.

The Latin American and Caribbean Biobank Network started its activities in 2008 and was incorporated as RINC/UNASUR in 2011. At present, 17 fully established biobanks from the region (and four others that are still in the implementation phase) participate in the Network. In 2013, REBLAC/RINC became a BCNet partner, contributing to all aspects of biobank networking, including regional experiences, harmonization issues, training and technical support, and involvement of governments.



Dr Tatiana Vidaurre (right), General Director of INEN (Peru) and Dr Gustavo Stefanoff (Brazil), General Coordinator of the RINC/UNASUR Biobank Operative Group, during the opening ceremony.

The meeting included round-table discussions of technical-scientific, ethical-legal, economic, and sociopolitical issues related to biobank activities. The role of biobanks in the support and development of oncology research in the region was also discussed.



News from BCNet members and partners



All of the biobanks have developed structured organizations in order to preserve biological samples (e.g. neoplastic and normal tissue, cells, blood) associated with clinical and epidemiological data from the donor.

All these elements are essential for the development of new technology and cancer research. Specifically, cancer research focuses on the development of biomarkers and new therapeutic banks, among other goals.

The Biobank Operative Group of RINC/UNASUR has been instrumental in the professional development of biobank personnel. As a network, each participant biobank supports other participants, thus providing a strong base for mutual collaboration and growth.

Biobanks are essential elements in the development of cancer research, as they provide high-quality specimens and clinical data in an environment where data safety and ethical management of the samples are essential.

Furthermore, biobank activities also improve the clinical management of cancer patients, as they provide country-specific information critical for the development of effective strategies to prevent, diagnose and treat cancer.

The results of the group's activities will impact cancer care for future generations in the region.

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Links

RINC/UNASUR: <http://www2.rinc-unasur.org/wps/wcm/connect/RINC/site/home/>
National Cancer Institute - Ministry of Health (Brazil): <http://www2.inca.gov.br/wps/wcm/connect/inca/portal/home>
National Institute of Neoplastic Diseases (Peru): www.inen.sld.pe
University of Puerto Rico Comprehensive Cancer Center (Puerto Rico): www.cccupr.org
Ponce School of Medicine and Health Sciences (Puerto Rico): www.psm.edu
Hospital Luis Calvo Mackenna (Chile): www.calvomackenna.cl



Experts in biobanking from Argentina, Bolivia, Brazil, Colombia, Chile, Cuba, Ecuador, Mexico, Panama, Peru, Puerto Rico, Uruguay, and Venezuela at the meeting in Lima, Peru.

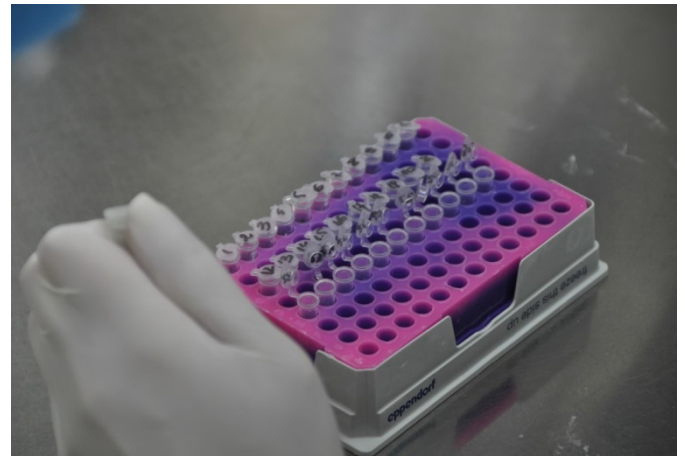
News from BCNet members and partners

The Biobank Lab of the University of Lodz, Poland

The Biobank Lab of the University of Lodz, Poland (Biobank Lodz) was established in 2014, when the biobank started to operate as a separate scientific unit of the Department of Molecular Biophysics. Biomaterials from more than 10 000 individuals throughout Poland and related clinical/questionnaire data had previously been collected from the "Role of multidrug transporters in pharmacokinetics and toxicology - in vitro tests in pharmaceutical and clinical practice" project (Supported by the Polish POIG grant 01.01.02-10-005/08 TESTOPLEK from the European Regional Development Fund). The main goal of TESTOPLEK (as part of a genetic study) was to create a genetic profile of the Polish population.

This collection was involved in the creation of a retrospective POPULOUS collection (POPULATION - LODz UNIVERsITY Biobank) and was registered in 2013 in the BBMRI catalogue of the populations collection (Biobanking and BioMolecular resources Research Infrastructure). In forming the Biobank Lab, the other collection categories, like disease-related or population-based (longitudinal/prospective models), were also included, for example breast cancer patients, pancreatic cancer patients, endometriosis patients, and populations of schoolchildren.

Currently, the main goal of Biobank Lodz is to promote research via the sharing of biospecimens and related clinical/questionnaire data to interested scientific institutions. The next step is to implement policies to share genomic data



(microarrays, whole-exome sequencing data, microbiome, targeted genotyping data) related to the different collections.

More detailed goals of Biobank Lodz include:

- 1 Centralizing the collection across the University of Lodz, and management and storage of biospecimens and associated clinical data of affected and healthy individuals;
- 2 Performing an essential service by distributing biological samples and making them available to the scientific community; and
- 3 Elucidating and studying the molecular characterization of the Biobank Lodz samples to improve scientific knowledge of genomic and genetic-related diseases.

The Biobank Lodz policies and procedures were formulated according to the ISBER "Best Practices for Repositories Guidelines". The laboratory is composed of two main complexes. The Core Lab is the principal place of preparation of biological material for biobanking, and the place of storage of biological material and conducting mass genetic assays and quantitative assessments of selected parameters of deposited biological material. The Big Data Lab is the spare/emergency storage location of biological material, automated microarrays analysis laboratory, and laboratory analysis using next-generation sequencing (NGS) technology.



News from BCNet members and partners



In addition, all bioinformatics analysis is carried out using widely available commercial software.

Biobank Lodz established cooperative relationships with several important and well-known research institutions and companies in Poland: University of Warsaw, Institute of Medical Biology of the Polish Academy of Sciences in Lodz, National Institute of Public Health—National Institute of Hygiene in Warsaw, University of Gdansk, and Proteon Pharmaceuticals SA.

In 2014, Biobank Lodz became a member of the BBMRI.PL Consortium, which is a Polish biobank network in cooperation with Wroclaw Research Centre EIT+, Medical University of Gdansk, Medical University of Warsaw, Medical University of Lublin, Wroclaw Medical University, and Regional Science-Technology Centre in Podzamcze. The Consortium is an initiative of the most developed Polish biobanks to join BBMRI-ERIC as a full member. BBMRI-ERIC is one of the largest health research infrastructures in Europe today, focusing on establishing, operating, and developing a pan-European distributed research infrastructure of biobanks and biomolecular resources.

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News

PATHOLOGISTS IN CANCER MANAGEMENT

The 3rd WADIAP-USCAP School of Pathology/10th Annual Scientific Conference of the West African Division of the International Academy of Pathology in conjunction with the Friends of Africa-USCAP initiative will take place from 29 August to 1 September 2016 in Abidjan, Côte d'Ivoire.

Topics include:

- ⇒ Immunohistochemistry and Laboratory Diagnosis of Cancer
- ⇒ Leadership in Pathology Practice
- ⇒ Elements of a Quality Management Plan
- ⇒ Associated Data and LIMS for Data Management
- ⇒ International Guidelines on Ethics Issues Related to Biobanking

News from BCNet members and partners

Biobank Conference in Egypt



In an attempt to raise awareness and public engagement in Egypt of the concept of biobanking and related issues, including ethical, legal and social issues as well as best practices in sample collection for medical research, the National Liver Institute (NLI), Public Health Department, NLIS-SICRC and the National Cancer Institute (NCI), Pathology Department organized the first biobank conference in Egypt, "Biobanking on the Nile Conference: Implementation and Overcoming Challenges of Biobanking in the Middle East and Limited-Resources Countries".

The conference was held on 1–2 June 2016 in Cairo, Egypt. The conference presidents were Professor Mohamed Lotayef, Dean, NCI, Cairo University, and Professor Ahmed Elshaarawy, Dean, NLI, Menoufia University. The general secretaries of the conference were Dr Iman Gouda, NCI and Dr Sameera Ezzat, NLI.

This event brought together external and local experts: representatives of universities and governmental and nongovernmental institutions. Dr Maimuna Mendy (Head, Laboratory Services and Biobank Group, International Agency for Research on Cancer, WHO), Dr Maher Sughayer (MD FCAP, King Hussein Cancer Centre (KHCC), Jordan), Dr Nahla M. Afifi (Scientific and Education Manager, Qatar Biobank – Qatar Foundation), and Dr Ma'n H. Zawati (Executive Director, Lawyer Centre of Genomics and Policy – McGill University), who participated via video presentation) were the distinguished external speakers at the conference.

The conference covered the following topics:

1. Importance of biobanks in the advancement of research
2. The NCI and the NLI experience in establishing their biobanks.
3. Biobanking experience in the Middle East and low-income countries

4. Addressing challenges in ethical and legal issues in sample collection for research in Egypt
5. Resources essential for state-of-the-art biobanks
6. Sustainability of biobanks

The conference was well attended by people interested in the biobanking field from different medical schools and biomedical research institutes in Egypt. Active participation was noted from the participants.

The conference started the initiative of building consensus and building communication between different centres for future collaboration in biobanking-related activities. This conference raised the importance of formalizing a biobank task force in Egypt and of the task force communicating biobanking concepts and guidelines to stakeholders.



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News from BCNet members and partners

Progress Made by a South African Biobank as Part of BCNet



The National Health Laboratory Service's (NHLS) National Biobank has made so much progress since joining BCNet in 2013. After the first general assembly of the BCNet group, in 2013, which was attended by Mr Bonginkosi Duma representing the NHLS, three people attended the training and general assembly held at IARC, Lyon, in November 2015. The NHLS staff learned biobank best practices, and the benefit they received was invaluable.



*Front: Nonhlanhla Tlotleng (South Africa), Maimuna Mendy (IARC), Marianne Henderson (NIH, USA)
Back: Jerry Moseboa (South Africa), Bonginkosi Duma (South Africa)*

The training included a tour of the IARC Biobank. The information sharing during the training sessions helped us solve some of the challenges we faced in our own biobank. We have also strengthened our processes and added some equipment as part of the biobank disaster management plan, which was advised during the training session by experienced partners of the BCNet.

The two additional staff from NHLS who attended the 2015 training and general assembly have gained more knowledge and confidence in specimen handling and processes. They also felt part of the BCNet family because of the environment and the nature of the training.

As part of BCNet, we managed to gain theoretical training from CTRNet, which partnered with BCNet to give the BCNet members a course in Introduction to Biobanking free of charge. Non-BCNet members had to pay for the course, which is an eye-opener in biobanking.

We will forever cherish the efforts made by Dr Maimuna Mendy for the BCNet initiative and the support we receive from Ms Sally Moldan and the management support from Dr Christopher Wild (IARC Director).

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News

ANNOUNCEMENT OF UPCOMING H3AFRICA FUNDING OPPORTUNITIES July–November 2016

The NIH has recently released seven (7) Notices of Intent to Publish a Funding Opportunity Announcements for the second stage of H3Africa. For more information and links, visit our BCNet website updates: <http://bcnet.iarc.fr/about/updates.php>

News from BCNet members and partners



Breast Care International, Ghana

The Breast Care International (BCI) biobank is among the best biobanks in Ghana. The biobank incorporates the current international guidelines and practices in order to ensure that our stored samples are of the best quality. The BCI biobank ensures that approved quality management systems are used. Our biobank also boasts the latest equipment to ensure that our samples are stored under the right storage conditions. The BCI biobank is part of BCI, a non-profit organization dedicated entirely to creating breast cancer awareness in Ghana. The biobank is situated in the Peace and Love Hospital, a hospital specializing in breast cancer care and treatment.



During the loading of some biological samples for pick-up (Ghana Breast Health Study with NCI).

BCI was established in 2002 with its mission to bring hope, health, and empowerment to communities in Ghana through the provision and dissemination of high-quality breast cancer education, screening, counselling, advocacy, research, treatment, and support to intensify breast cancer awareness and improve the quality of life of women at risk with breast cancer. In line with its mission, over the past 14 years BCI has conducted outreach programmes in deprived communities by educating and screening the public for signs of breast cancer while increasing community awareness to help downstage the disease at diagnosis.

The organization has also been expanding the availability of clinical and diagnostic breast examination in Ghana. Therefore, through our efforts, the number of people who turn up for medical consultation with early symptoms of cancer is increasing. Patients are living longer, and the breast cancer survivor group, Peace and Love Survivors Association (PALSA), inaugurated 5 years ago, has hundreds of members and keeps growing.

As part of its awareness creation, BCI organizes the BCI Ghana Walk for the Cure annually. This year's walk will take place in Kumasi on 1 October 2016, and 50 000 people are expected to walk for the cure and also showcase survivorship.

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BCI Walk for the Cure 2014 - Sunyani in the Brong-Ahafo Region of Ghana.



Upcoming Events

- ◆ 7–10 June 2016 IARC 50th Anniversary Conference
Global Cancer: Occurrence, Causes, and Avenues to Prevention
Lyon, France
<http://www.iarc-conference2016.com>
- ◆ 19–21 June 2016 B3Africa Annual Meeting
Graz, Austria
<http://www.b3africa.org>
- ◆ 13–16 September 2016 Europe Biobank Week
Vienna, Austria
<http://europebiobankweek.eu/>
- ◆ November 2016 Sub-Saharan Biobanking Workshop
Nairobi, Kenya
- ◆ 3–8 December 2016 African Society for Laboratory Medicine
Laboratory Medicine in Africa:
Combating Global Health Threats
Cape Town, South Africa
<http://aslm2016.org>

Who Are We?

BCNet is the Low- and Middle-Income Countries (LMIC) Biobank and Cohort Building Network, which was established in 2013 to provide a platform for collaboration between its members, partners, IARC, and the international community. BCNet aims to support biobanking and cohort-building activities and to develop sustainable infrastructures for the management of high-quality biological samples and data for research, using best practice principles and guidelines.



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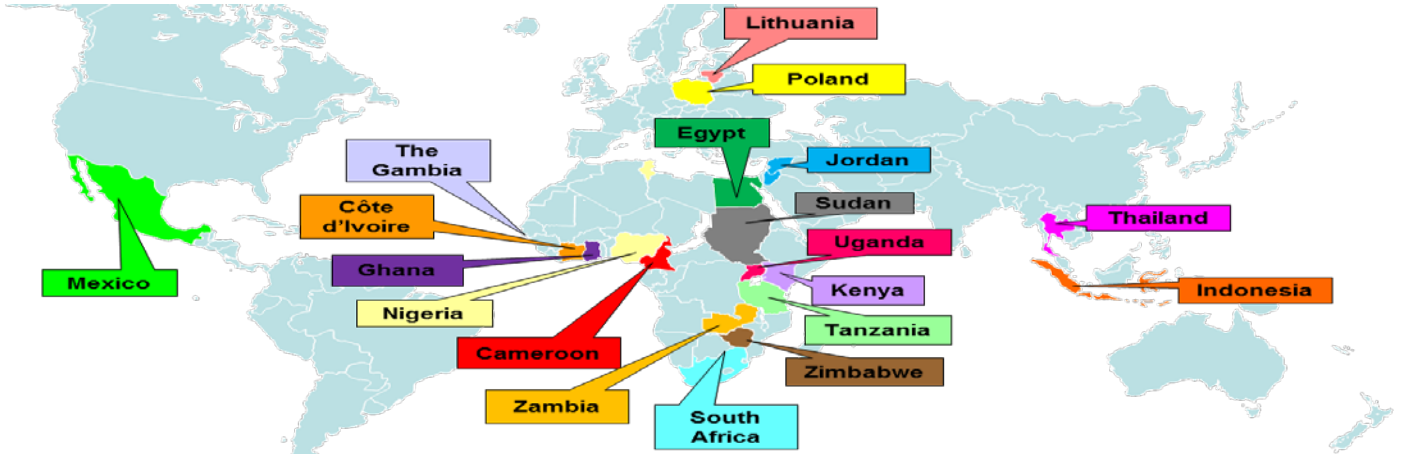
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BCNet Partners



BCNet Members



 Department of Medical Sciences Université des Montagnes Cameroon	 Faculty of Medicine & Biomedical Sciences University of Yaounde I Cameroon	 Institut Pasteur Côte d'Ivoire	 National Liver Institute Egypt	 National Cancer Institute Egypt
 Children's Cancer Hospital – 57357 Egypt	 Breast Care International Ghana	 Faculty of Medicine Universitas Gadjah mada Indonesia	 King Hussein Cancer Center Jordan	 Ampath Reference Laboratory Kenya
 National Cancer Institute Lithuania	 Instituto Nacional de Cancerologia Mexico	 College of Medicine, University of Ibadan Nigeria	 Obafemi Awolowo University Teaching Hospital Nigeria	 Wroclaw Research Centre EIT+ Poland
 Biobank Lodz University of Lodz Poland	 National Health Laboratory Services South Africa	 RICK Radio-Isotope Centre Khartoum Sudan	 Kilimanjaro Clinical Research Institute Tanzania	 National Cancer Institute Thailand
 Medical Research Council Unit The Gambia	 College of Health Sciences Makerere University Uganda	 Centre for Infectious Disease Research Zambia	 University of Zimbabwe, College of Health Sciences Zimbabwe	 African Institute of Biomedical Science & Technology Zimbabwe