The BCNetter Issue No. 1/2016



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Who are we?

BCNet is the Low- and Middle-Income Country (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 infractructures for the management of high-quality biological samples and data for research, using best practice principles and guidelines.

Message from the IARC Coordinator

Best wishes for a fruitful and productive 2016 from the BCNet coordinating team. The beginning of the year is a period of reflection on the events of the past year and the development of objectives and goals for the New Year.

As a network, we have been able to achieve most of our set goals for 2015 and this would not have happened without the support and dedication of our Members and Partners.



The network is spreading across continents and it is a pleasure to welcome 9 new members into the BCNet family since 2013: Université des Montagnes (Cameroon): National Liver Institute, (Egypt); Breast Care International (Ghana); Universitas Gadjah Mada, (Indonesia); Instituto Nacional de Cancerologia, (Mexico); College of Medicine, University of

Ibadan, (Nigeria); University of Lodz, (Poland); Medical Research Council Unit (The Gambia) and the Centre for Infectious Disease Research, (Zambia). The BCNet now has 22 members from 17 countries.

In 2015, the Information Technology (IT) WG finalized the Open Source evaluation project and the Education and Training (E&T) WG, assisted by the other WGs, organised the 1st BCNet training.

BCNet's visibility has increased over the last year and the network is becoming a focal point for biobanking development in LMIC. We are able to achieve this through presentations at various international meetings, participation in international projects and supporting national workshops and training programs, such as the Indonesian biobank workshop organised by BCNet members in Indonesia in December 2015.

The highlight of the year was the BCNet training in November 2015 at IARC. The 2.5-day training workshop was attended by 27 participants from 16 countries and consisted of 12 presentations in IT, ELSI and Quality, 4 break-out sessions for group discussions, poster sessions and video interviews. Participants took the CTRNet online basic biobanking course through the ISBER website as a prerequisite for attending the face-to-face course at IARC.

Four BCNet members (Uganda, Poland, Lithuania and The Gambia) have confirmed their participation as Case Users in the EU-H2020 B3Africa project which was funded in July 2015. The respective biobanks will benefit from eB3KIT; the biobank and bio-informatic platform that will be developed for the project. They will also benefit from training programs for biobank technicians, IT personnel and ethics committee members. The platform will be extended to more members after the completion of the 1st phase.

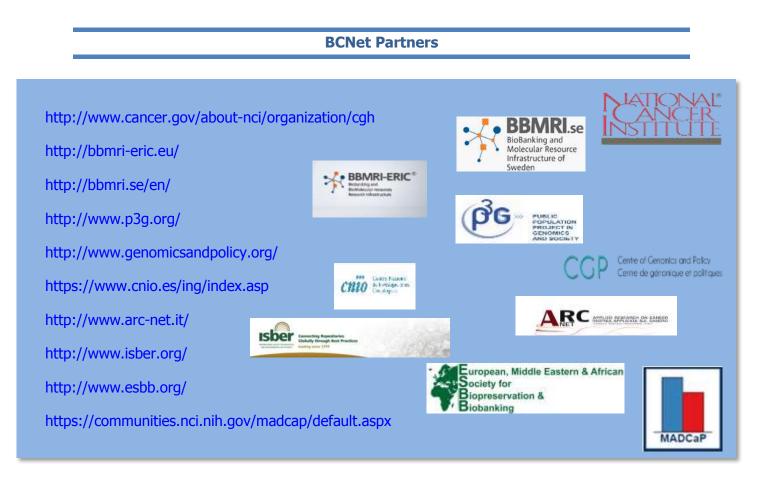


2016 has started on a high note with preparations for the piloting of the BCNet catalogue program for which 8 biobanks have confirmed participation in the pilot their phase. Understandably, this will be a learning curve for all involved and it is anticipated that the process will take 3-4 months before we will have the first set of biobank data the uploaded in catalogue. Members will be updated on the

progress of the project and we look forward to the inclusion of more biobanks in the common catalogue.

The newsletter replaces the original BCNet Updates and is designed to encourage the sharing of news and information within BCNet and with our external collaborators and colleagues. In this edition you will read about latest developments, workshops and courses from Jordan, Egypt and Indonesia. We look forward to receiving more contributions in subsequent editions.

We plan to print the newsletter three times a year. Please don't hesitate to give us the email address of any stakeholders who you think would be interested in receiving it: bcnet@iarc.fr



BCNet Members



Department of Medical Sciences Université des Montagnes http://www.udesmontagnes.org/en/welcom e.html?lang=EN

Faculty of Medicine & Biomedical Sciences University of Yaounde I http://www.fmsb.uninet.cm/



Egypt

Cameroon

National Liver Institute http://www.liver-eg.com/

National Cancer Institute http://www.nci.cu.edu.eg/

Children's Cancer Hospital - 57357 https://www.57357.org/

Ghana



Breast Care International http://www.breastcareinternational.org/



Indonesia

Faculty of Medicine, Universitas Gadjah Mada http://fk.ugm.ac.id/en/



Jordan

Kenya

King Hussein Cancer Center http://www.khcc.jo/



Ampath Reference Laboratory http://www.ampathkenya.org/



National Cancer Institute http://www.nvi.lt/index.php?-1063437917



Mexico

Lithuania

Instituto Nacional de Cancerologia http://www.incan.salud.gob.mx/



University of Zimbabwe, College of Health Sciences http://www.uz.ac.zw/index.php/faculties/faculty-ofmedicine

African Institute of Biomedical Science & Technology http://www.aibst.com/index.php/en/

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Poland

EIT

LODZ

Nigeria

Wroclaw Research Centre EIT+ http://www.eitplus.pl/en/

University of Lodz http://www.biobank.uni.lodz.pl/index.php?lang=en

South Africa

National Health Laboratory Services http://www.nhls.ac.za/

Sudan

Radio-Isotope Centre Khartoum

Tanzania



Kilimanjaro Clinical Research Institute http://www.kcri.ac.tz/

The Gambia

Medical Resarch Council Unit http://www.mrc.gm/

Uganda



CIDR

College of Health Sciences, Makerere University http://chs.mak.ac.ug/



Zambia

Centre for Infectious Disease Research http://www.cidrz.org/

Zimbabwe

Website: http://bcnet.iarc.fr

Contact: bcnet@iarc.fr

News from Advisory Committee

On behalf of the BCNet family, we would like to thank Anne Carter for her valuable contribution since the establishment of the network and as Chair of the Quality WG. Anne will be retiring from her position at UKCRC in February and we wish her a successful and enjoyable retirement.

The AC is pleased to announce that Rita Lawlor will be the new Chair of the Quality WG; we wish Rita all the best in her new role.

Updates from Working Groups

Education and Training

The BCNet Education and Training (E&T) WG had a very busy year. We designed a three tiered training program to support the members of the network in advancing their knowledge of biobanking. The E&T team laid out several goals for training BCNet members:

To provide a base framework of knowledge of biobanking considerations, policies, and procedures. This goal was met by contracting with ISBER/CTRNet to allow BCNet members to access the Canadian Tissue Repository Network (CTRNet) Biobank Resource Centre education modules. The online modules are an introduction to biobanking designed to "how-to" knowledge provide for researchers and biobankers and "what is" knowledge for stakeholders (e.g. public, ethics board members). Coverage of governance; ethics, privacy and security; facility design; quality management and processes; informed consent; specimen collection and processing; storage and distribution; and data systems and records management are included in the modules. Members were provided access to the training modules, which included a preand post-test, to evaluate the knowledge gained by the training. If you are a BCNet member and have missed out on this important training opportunity, please contact bcnet@iarc.fr to seek access.

To encourage BCNet Members to explore, learn and be well-versed in their country- and organizationspecific guidelines, rules and laws that impact biobanking, specimen collection, sharing and research. This goal was met by providing a series of questions on two templates for the BCNet members to answer. They used their organizational information and researched their country's legislative record for any applicable information. Each member organization of the BCNet was invited to display their data as a poster during the training event held in November 2015 at IARC, in Lvon, France, These posters are now available for view within the member portal and are being analyzed and written up in a manuscript that will be submitted for publication in 2016.

To conduct an in-person training course present important to biobanking topics and discuss sitespecific challenges to biobanking among Members and Partners. This goal was met by creating a 2-day training program November 3-5, 2015 at IARC in France. The program included Lyon, several Partner lectures on ethical and legal (ELSI) considerations in biobanking, quality management and information technology projects for biobanks. There were also special topic presentations on sustainability and the **B3Africa** work programme. The training included time for several breakout group discussions on the challenges and possible avenues toward solutions in the BCNet biobanks. The end result of these discussions provided some overall recommendations for future next steps for the BCNet Steering Committee and its working groups, as well as those to considered IARC be by leadership.

Our E&T WG was bolstered with additional members and we look forward to renewed discussions on the recommendations from the face-to-face training, future plans, and plans for evaluation of the completed E&T activities. If you have any questions or comments for the E&T WG, please email bcnet@iarc.fr



Alice Mudogo, Kenya, Alice Matimba and Georginah Nyadbadza, Zimbabwe





Ahmed Samir and Rania Labib, both from Egypt







Georginah Nyabadza, Zimbabwe, is presenteo with a prize by Marianne Henderson, NCI / ISBER



Alya Ahmed, Salman Ahmed and Amira Humeida from Sudan, with Asmaa Mosbeh, Egypt



Maimuna Mendy, IARC Coordinator, gives a presentation

News from BCNet Members

The newly-established **King Hussein Cancer Center (Jordan) biobank** is the first ISO-Compliant Biobank in the region. It incorporates current international guidelines and best-in-class practices under an approved Quality Management System. The biobank is a part of King Hussein Cancer Center, a "non-governmental", not-for-profit institution dedicated entirely to cancer care.

KHCC is one of the most comprehensive cancer centres in the Middle East and treats more than 3,500 new cancer patients each year, from Jordan and neighbouring countries. KHCC treats all cancers and performs approximately 100 bone marrow transplants a year. KHCC was awarded JCI accreditation of Health Care Organizations in 2006, 2009, 2012 and 2015, DCSC accreditation for its Oncology program in 2007, 2009, 2011 and 2013.

The Department of Pathology and Laboratory Medicine has been accredited by the College of American Pathologists (CAP) since 2009. KHCC is well recognized as a leader in cancer treatment in the Middle East. KHCC developed cooperative relationships with several world-renowned cancer centres to

Dr Maxim Al Ashhab, Biobank Pathologist benefit from the latest in-treatment protocols and exchange from the KHCC expertise and staff with these prominent institutions and allow our



expertise and staff with these prominent institutions and allow our collaborators to benefit from the samples collected in our KHCCBIO biobank. These partnerships include: M.D. Anderson Cancer Center, St-Jude's Children's Hospital, OFFIT Cancer Center, Lombardi Comprehensive Cancer Center; USA, Hospital for Sick Children Canada, Augusta Victoria Hospital, Jerusalem Palestine, American University of Beirut, Beirut Lebanon, Royal College of Surgeons in Ireland, Medical University of Bahrain, NCI-Egypt and Leeds Cancer Centre, UK.

Recently KHCC became a member in the Worldwide Innovative Networking (WIN) in personalised cancer medicine initiated by the Institut Gustave Roussy (France) and The University of Texas MD Anderson Cancer Center (USA) which is a non-profit non-governmental organisation bringing together 22 cancer centres and industry partners from five continents to address the challenge of increasing the efficacy of cancer diagnostics and therapeutics. http://youtu.be/mbAcnwReUXE

Contacts: Dr Maxim Al Ashhab. E-mail: ashhabm@mail.ru Dr Maher A. Sughayer, M.D. E-mails: msughayer@khcc.jo | msughair@hotmail.com. Full Member, Chairman, Department of Pathology and Laboratory Medicine. American Board of Pathology and American Board of Cytopathology.

Click on the links to see what's going on in Ghana

WAR AGAINST CANCER 30MINS.mp3

http://news.peacefmonline.com/pages/health/201601/267163.php

Contact: Dr Beatrice Wiafe Addai, drwiafe@gmail.com



National Cancer Institute, Egypt

Biobanking course for medical students, Cairo University

Biobanking is a new concept in Egypt and knowledge is still limited. Only two biobanks exist and the third is under construction. In order to raise awareness about biobanking among medicals students, as they represent future researchers, we conducted a two-day course for medical students at the faculty of medicine, Cairo University.

The course aimed at introducing the concept of biobanking to the target group, to provide basic knowledge about issues related to biobanking and medical research including ethics, quality, and IT and discussing applications in medical research that necessitate the presence of biobanks including pharmacogenetics and personalized medicine.

In addition to traditional lectures, we used other methods that could be interesting for the target group. We used case studies (real and hypothetical) to explain ethics, and a funny quiz to explain quality.

For marketing and advertising, we used Facebook and word of mouth only. This was useful since the target group (medical students) use social media networks extensively. However, the main drawback for this is that updates don't reach all participants.

For Evaluation, we used pre- and post- tests as well as a survey for evaluation of the content. Although we had some organizational problems, participants were generally satisfied and happy with the scientific content and were willing to spread the message.

The annual conference of the Egyptian Society of progenator cell research will take place in Cairo on 27 - 28 February 2016. There will be a session on the first day entitled "Biobanking: about science and ethics".



The session will include 4 oral presentations.

An article entitled "Ethical challenges facing biobanks in the region" was published in SciDevnet MENA (Middle East and North Africa). The article is in Arabic and it aims at increasing awareness among the scientific community and the public about the status of biobanks in the Arab region and ethical issues raised by biobanks and how to deal with them.

http://m.scidev.net/mena/genomics/opinion/Challenges-health-Biobanks-MENA.html



Participants in the National Cancer Institute biobank workshop for medical students.

Contact: Dr Ahmed Samir, drahmedsamir83@gmail.com



Three-day Biobank Workshop With BCNet and IARC And Lifelines – The Netherlands 4-6 DECEMBER 2015 FACULTY OF MEDICINE UNIVERSITAS GADJAH MADA INDONESIA

The Faculty of Medicine, Universitas Gadjah Mada is working on developing its biobank unit to enhance research quality and increase publication impact. The biobank group has been actively consulting biobank facilities in Europe to assist the development process. Last year, the Faculty of Medicine, Universitas Gadjah Mada became a member of BCNet. Additionally, the participation of one group member at the "BIKE" biobank summer course at UMCG in the Netherlands has brought us in close contact with Lifelines Biobank Cohort.

A three-day workshop on biobanking was held on 4-6 December 2016. Dr Maimuna Mendy (BCNet) and Dr Baart Scheerder (Lifelines) were invited as experts in biobanking.

The program was as follows:

4 December 2015: Internal workshop for biobank. The aim of this workshop was to review and discuss the biobank plan at the Faculty of Medicine UGM, including legal, ethical and technical aspects.

5 December 2015: National Workshop on Biobank: "Building a Biobank Network in Indonesia: Opportunity and Challenge" including government, health related research/service institutes in Indonesia.

6 December 2015: Discussion and field visits to health demography surveillances (HDSS) Sleman, part of HDSS network, to seek possibilities for biobanking in a population cohort setting.

Dr Mendy and Dr Scheerder with the biobank team at FAC Medicine UGM.



Contact: Dr Jajah Fachiroh, jajahfachiroh@ugm.ac.id

Join the BCNet

If your institution is interested in joining the BCNet, follow the link to download an application form;

http://bcnet.iarc.fr/docs/BCNET_Members_Application_Form.docx

Alternatively, contact us at bcnet@iarc.fr

Update on the Catalogue

The BCNet catalogue aims at contributing to the **visibility** of the LMIC BCNet members' biobanks and sample collections and at leveraging the **collaboration** between biobanks for medical research worldwide.

The BCNet catalogue was developed by Karolinska Institutet, Sweden, in collaboration with IARC.

IARC is working closely with the nine BCNet members who have volunteered to participate.

The objectives of the pilot stage are twofold:

- 1. To assess the process of integration of sample data into the catalogue;
- 2. To validate the primary set of recorded data that are related to biobanks.

For an overview of the catalogue and a real-time follow-up of the operations, browse the BCNet catalogue website at: http://bcnetcat.iarc.fr

Upcoming Events

29 February 2016	ELSI Working Group Meeting (teleconference)	
11 – 13 April	B3Africa Use Case Meeting, Banjul, The Gambia	
7 March 2016	AORTIC Call for Projects	
5 - 8 April 2016	ISBER 2016 Annual Meeting, Berlin, Germany	
18 - 22 April 2016	Biobanking as a resource for biomedical research, Sweden	Contact:
May 2016	Middle-Eastern Biobanking Workshop, Amman, Jordan	
10 – 12 May 2016	H3Africa Consortium meeting, Sénégal	Dr Maimuna Mendy
8 – 10 June 2016	IARC@50 Conference, France	MendyM@iarc.fr +33 4 72 73 80 35
June 2016	B3Africa Annual Meeting, Austria	http://bcnet.iarc.fr
13 - 16 Sept 2016	ESBB, Europe Biobank Week http://europebiobankweek.eu	
		Ms Sally Moldan

MoldanS@iarc.fr