LMIC

BCNET
BIOBANK AND COHORT BUILDING NETWORK

The IARC-BCNet Symposium

From Biobank Infrastructure to Research:
How BCNet Member Biobanks and Cohorts Are Contributing to Address Public Health Concerns

Organized in Collaboration
With

B3Africa Training Workshop

B3 Africa
BRIDGING BIOBANKING AND BIOMEDICAL RESEARCH
ACROSS EUROPE AND AFRICA

IARC, Lyon
27 November – 1 December 2017

Report

Table of Contents

1 Context

The Biobank and Cohort building Network (BCNet) was established by IARC in 2013 as an opportunity for low- and middle-income country (LMIC) members and international partners to jointly address existing challenges in biobanking infrastructure, including ethical, legal and social issues (ELSIs). The network's first activity was to conduct a situation analysis of biobanking in LMIC[1]. Since its inception, the network has been characterised by enormous enthusiasm, commitment and growth. Currently there are 34 institutional members from 21 countries.

The B3Africa project was launched in 2015 to provide an out-of-the box innovative solution (the eB3Kit) to bridge biobanking activities with biomedical research across Europe and Africa.[2]

The BCNet initiative and B3Africa framework are closely linked and feed into each other. On the one hand, the BCNet represents a major vehicle for dissemination of the B3Africa informatics platform (the eB3Kit) beyond the lifetime of the project. Reaching a critical mass of eB3Kit users will trigger opportunities to build broad communities of users and developers and therefore represents an important factor of sustainability for the platform.

On the other hand, BCNet members have benefited from the B3Africa project. In addition to the members already present in the project consortium,[3] additional BCNet members have been invited to collaborate on the project as "Use Cases".[4] These members receive direct support from B3Africa developers to install and configure an eB3Kit for their biobank. They further benefit, along with all other interested BCNet members, from the B3Africa Education and Training program (open to all interested biobank/research professionals), including webinars, written documentation, and other upcoming learning/training resources.

On 27-28 November, the BCNet organized a symposium "From Biobank Infrastructure to Research: How BCNet Member Biobanks are Contributing to Address Public Health Concerns" in Lyon, France. **The symposium aimed to showcase the efforts of its members and institutions in developing biobank-based collaborative research projects to address public health issues**.

Presentations for the BCNet symposium were selected following an abstract submission process. The abstract had to present a biobank-based study, including background, objective, methodology (including for sample/data management), results if available, as well as a conclusion which discussed how the eB3Kit could contribute to sustain, upscale or improve their study. Eleven abstracts (out of 18 received) were considered relevant to the symposium's thematic and format, and therefore accepted. In addition to BCNet members, "state-of-the-art" speakers were invited to present.

The symposium was held in collaboration with the second face-to-face training of the B3Africa project, which took place just after the BCNet symposium, from 28 November to 1

[1] Mendy M, Caboux E, Sylla BS, Dillner J, Chinquee JJ, Wild C; BCNet survey participants (2015). Infrastructure and facilities for human biobanking in low- and middle-income countries: a situation analysis. *Pathobiology*. 81(5–6):252–260.

[2] www.b3africa.org

[3] Makerere University, Uganda; Stellenbosch University, South Africa.

[4] The Medical Research Council, The Gambia Wroclaw Research Centre EIT+, Poland; Breast Care International, Ghana.

December 2017. All participants in the symposium were also invited to attend the B3Africa training, which offered a hands-on experience of selected tools from the eB3Kit.

In sum, the co-organisation of the BCNet Symposium and B3Africa training provided the opportunity to reach out to a wider range of LMIC institutions that would adopt and implement the eB3Kit. BCNet members benefited from a unique opportunity to learn about the B3Africa informatics platform and tools during the face-to-face training.

2 Implementation

The BCNet symposium and B3Africa training workshop took place at IARC, Lyon, France, from 27 November to 1 December 2017.

The final program consisted of:

- BCNet symposium: 27-28 November (1.5 day)
- B3Africa training – general presentations: 28 November afternoon (0.5 day);
- B3Africa training – parallel sessions (IT and users) for hands-on training: 29 November – 1 December morning (3 days).

Participants

In total, 58 participants (67% women, 33% men), attended the event, including 26 (45%) from Europe and 30 (52%) from Africa.

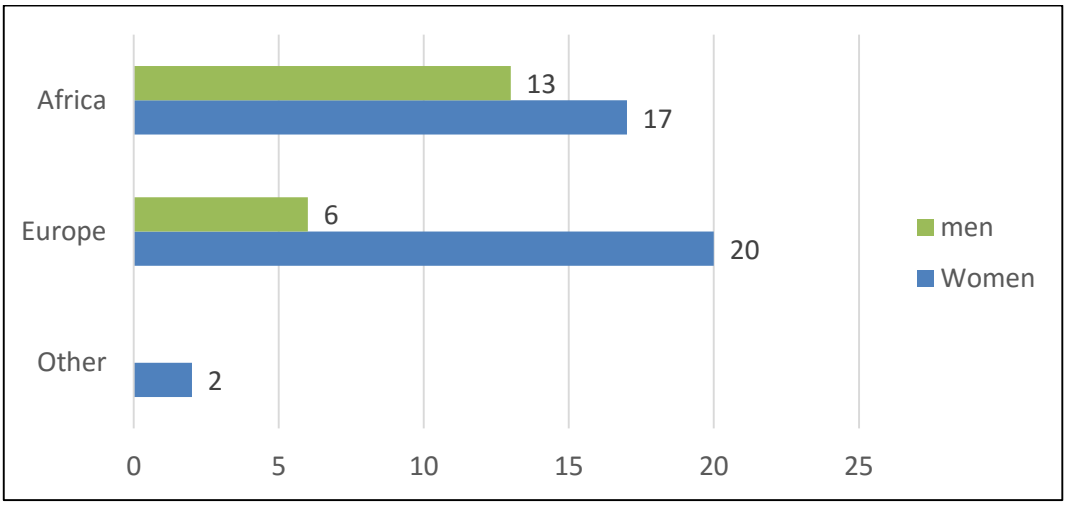
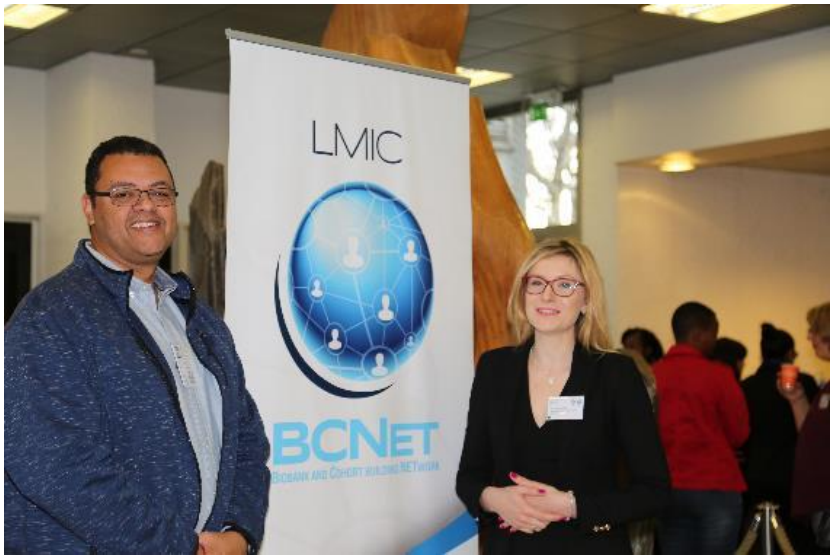


Figure 1. Participants in the symposium and training, by gender and geographical region (N=58)



30 organisations/institutions/projects were represented, including 11 (38%) from Europe and 16 (55%) from Africa.

Region	Country	Organization	# ppts
Africa	Cote d'Ivoire	Institut Pasteur de Côte d'Ivoire	1
	Egypt	National Cancer Institute, Cairo University	2
		National Liver Institute	1
	Germany/ Tanzania	Bernhard-Nocht-Institute for Tropical Medicine, East African Community's Regional Network of Public Health Reference Laboratories for Communicable Diseases (RNPHRL)	2
	Ghana	Breast Care International	2
	Kenya	International Livestock Research Institute	2
		The African Academy of Science	1
	Nigeria	College of Medicine, University of Ibadan	1
		Institute of Human Virology, Nigeria	3
	Senegal	HOGGY (Hôpital Général de Grand Yoff)	1
	Sierra Leone	Global Emerging Treatment Consortium (GET)	1
	South Africa	National Institute for Occupational Health	2
		National Health Laboratory Service (NHLS), Stellenbosch University	3
		South African National Bioinformatics Institute, University of the Western Cape	5
	The Gambia	The Medical Research Unit The Gambia	2
	Uganda	Makerere University	1
Europe	Austria	BBMRI-ERIC	1
		Medical University of Graz	2
	France	Aix-Marseille University- The European Virus Archive goes Global (EVAg) Consortium	1
		Université Catholique de Lyon, ESTBB and REECAO: Network of National and Institutional Ethical Committees in West Africa	1
		International Agency for Research on Cancer	11
	Italy	ARC-Net Centre for Applied Research on Cancer, University of Verona	1
	Malta	Laboratory of Molecular Genetics, University of Malta	2
	Poland	Wroclaw Research Centre EIT+	1
	Sweden	Karolinska Institutet	2
		Sveriges Lantbruksuniversitet	2
		Uppsala University	1
Other	Indonesia	Faculty of Medicine Universitas Gadjah Mada	1
	United States of America	National Cancer Institute	1
	19	**29**	**58**

Figure 2. Summary table of participants per region and organisation (N=58)
Institution highlighted in green are BCNet members/partners

53% of the participants were already involved in BCNet, either as members or partners. 33% were B3Africa partners or use case institutions having no previous link with the BCNet. Interestingly, the event attracted several self-funded participants (16%), including:

- 2 representatives from the East African Community's Regional Network of Public Health Reference Laboratories for Communicable Diseases (RNPHRL);
- 3 representatives from BCNet members not selected for a symposium presentation but who requested to participate;
- 2 "state-of-the-art" speakers based in France;
- 2 representatives from BCNet partners (Chairs of the symposium).

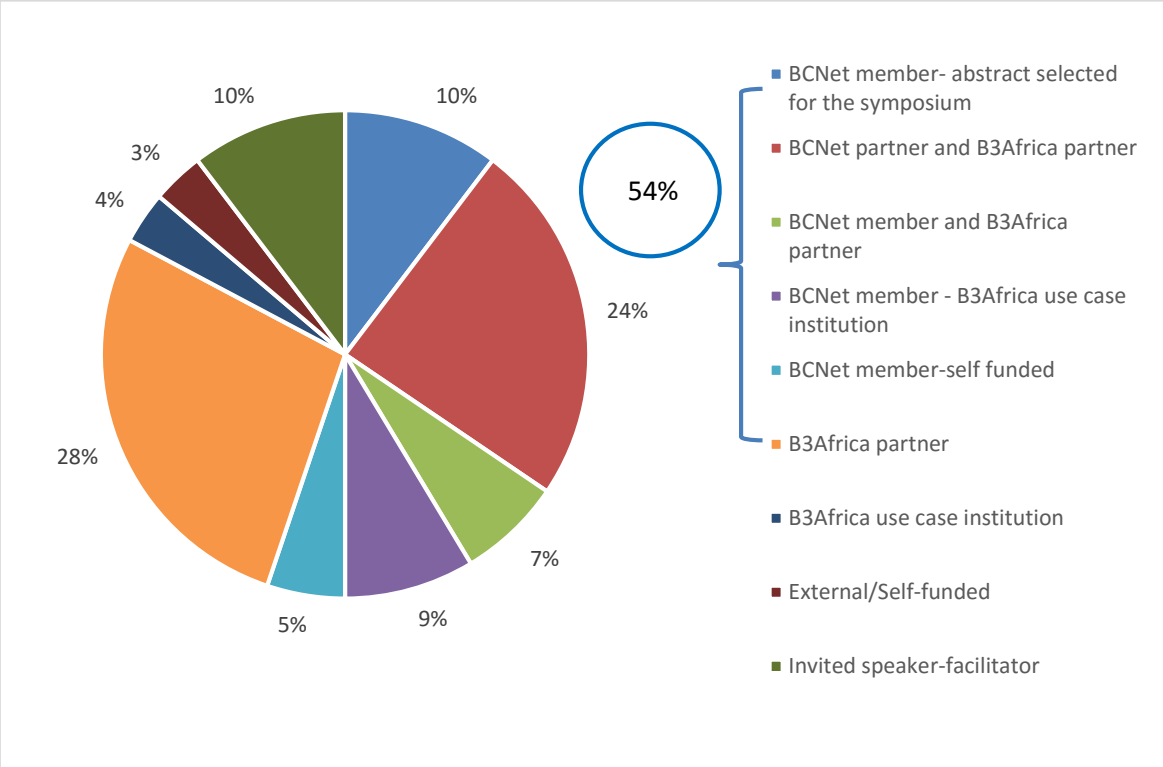


Figure 3. Participants in the symposium and training by project affiliation (B3Africa, BCNet, other) (N=58)

Most of the participants (74%) attended both the symposium and training workshop.

		Attended the training workshop	
		YES	NO
Attended the symposium	YES	43	4
	NO	11	

Figure 4. Number of participants who attended the symposium and/or training workshop (N=58)

For institutions participating in the B3Africa use case work package 7, participants from both the users and IT streams were invited.

For BCNet members and other participants discovering the eB3Kit for the first time, participants were invited to attend the users' stream only, so they could get a good overview of the eB3Kit and applications. These participants were invited to discuss what they learned in the training with their colleagues when they got back to their institution. Instructions were provided in case the institution wishes to install and implement the eB3Kit.

3 Evaluation

Evaluation of the training and symposium took place on the last day of the week (1-December). A plenary session with all participants and trainers (both IT and users) was scheduled, followed by an online evaluation questionnaire (anonymous).

30/40 participants and 1/14 trainers provided feedback through the online questionnaire. Some other participants/trainers preferred to provide feedback by email.

Among survey respondents, 68% (21) attended the 5 days of the event (symposium and training) and 8 (26%) attended 4 days. The remaining respondents attended 1-3 days.

The figures below present an overview of online evaluation respondents.

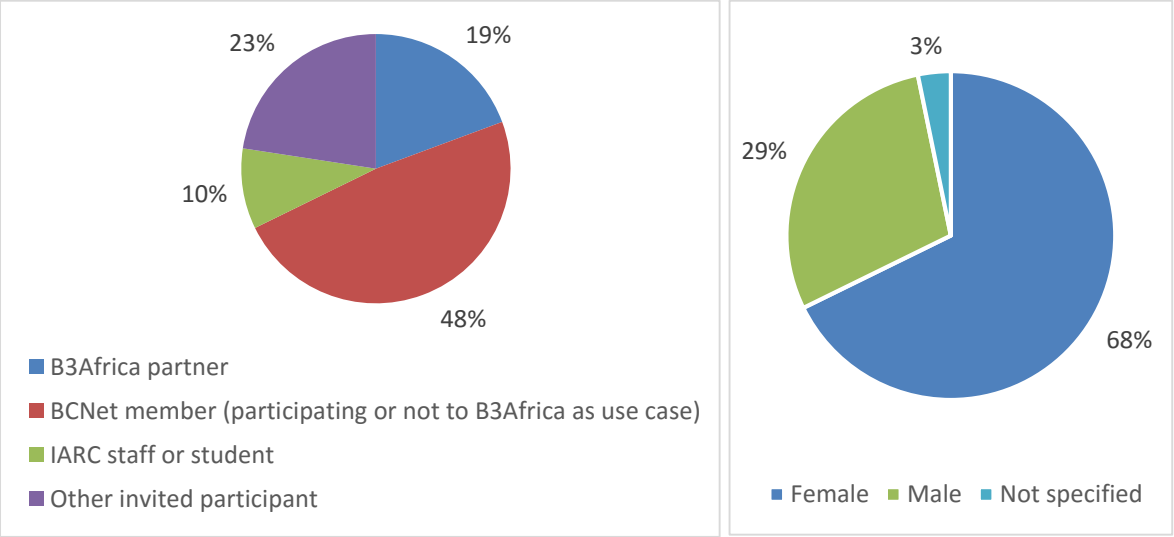


Figure 5. Respondents to the online evaluation questionnaire by project affiliation and by gender (N=31)

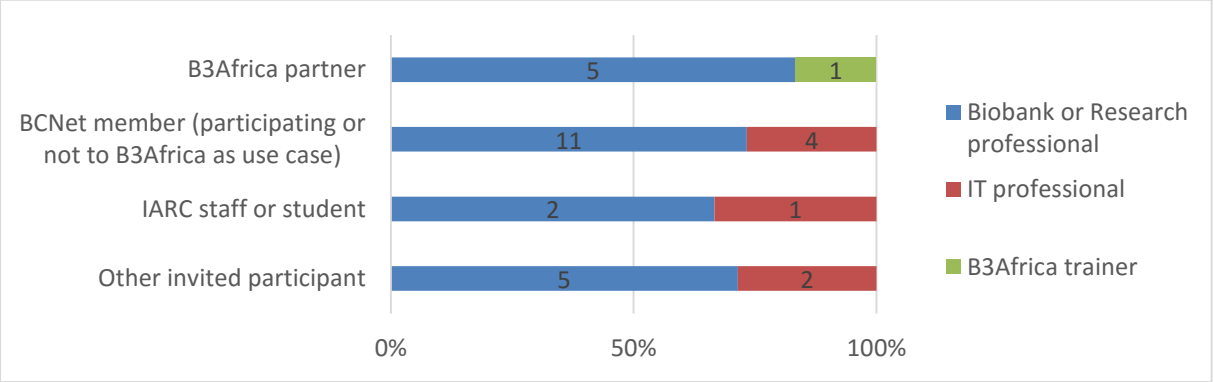
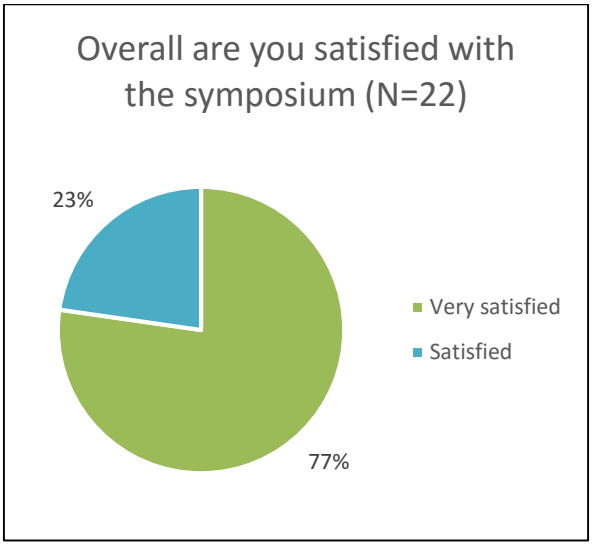


Figure 6. Respondents to the online evaluation questionnaire, by expertise (N=31)

BCNet Symposium

Overall, 77% (17/22) of the respondents declared themselves to be very satisfied with the symposium and 23% (5/22) to be satisfied.[5]



Detailed results show a generally good level of satisfaction with regard to the design and content of the symposium. Interestingly, 81% of the respondents strongly agreed that they got "new ideas or identified opportunities for future research collaborations during the symposium".

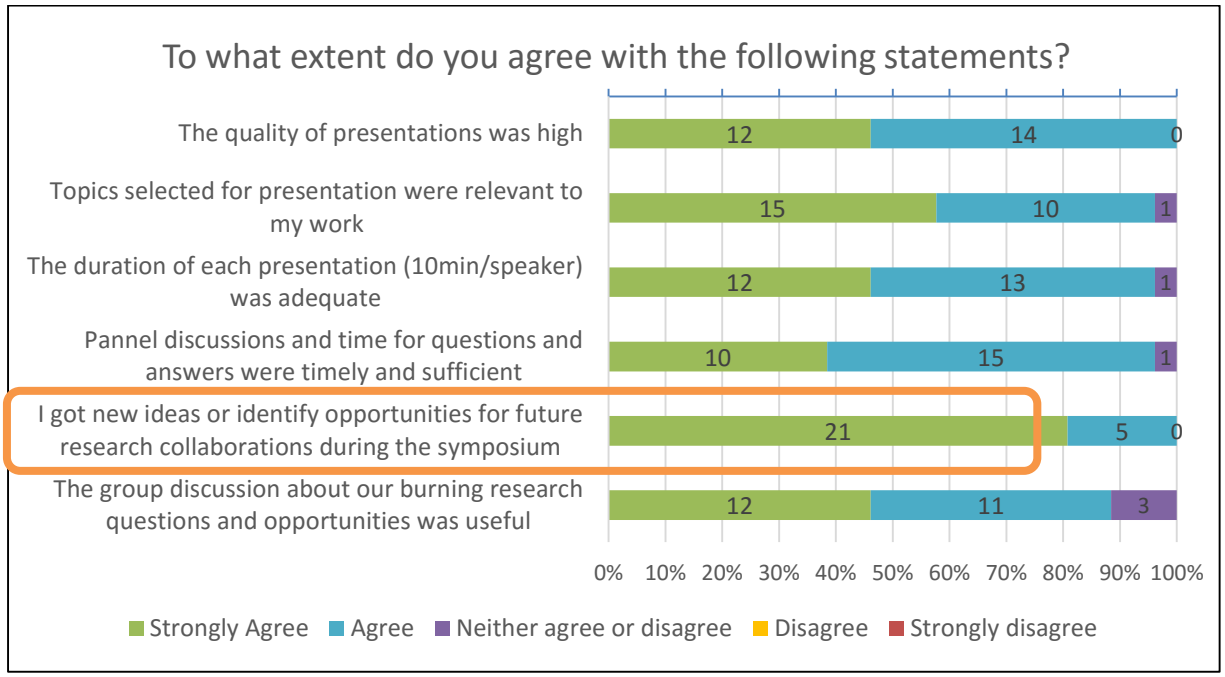


Figure 7. Level of satisfaction with regard to the symposium (N=26)

[5] 4 respondents reported to be "very dissatisfied", but then provided very positive responses to subsequent questions. This question is the only one providing answer choices from the most negative to the most positive (the others follow the opposite order). This questionnaire design error could be the cause of response inconsistencies. For this reason, we removed the 4 inconsistent answers from the analysis for this question.

In line with this perspective of new/future collaborations, 96% of the respondents were already planning to re-contact other participants of the symposium in the week following the event.

Figure 8. Number and percentage of respondents planning to re-contact other symposium participants (N=26)

Open-text answer to the question: "What have you retained from the symposium, or what struck you the most?"

- "Very pleased to have attended presentations related to effective feedback of biobanking for research, to have learnt a lot on this topic, and to have discussed with presenters and other attendees."
- "Very satisfied to get **knowledge of emerging or existing biobanks** and biobank network initiatives, and to feel **opportunities to collaborate** accordingly."
- "The structure enables the engagement among participants-trainer-organizer is high."
- "Asia is well backward in **sense of collaboration among countries**, and need to find out why we have problem."
- "Public engagement can come in different level, therefore requires different strategic approaches."
- "Equal quality, collaboration between health institutions, and **meeting together to share training and experiences are necessary** and very important."

- "Ethical, legal, research and IT. I think the **scope of both the symposium and training was quite relevant for biobankers**."
- "Experts willing to share their knowledge."
- "How much IT is spread."
- "I am new to the subject of biobanking and got a very good introduction into the area."
- **"I had some ideas and find out that another teams were already doing that, so I could get their experience from them."**
- "I have learnt a lot from the symposium."
- **"The community surrounding biobanking is impressive."**
- "I was struck by Biobank in Ivory Coast and the ASA/AESA Kenya."
- "That **biobanks in Africa are more developed than I thought**. There is a lot of opportunities in Africa."
- "Biobanks in Africa have many challenges but they are working hard to improve this filed in the continent.3
- 3The advancement of the participants since BCNet inception has been remarkable and **the collaboration potential is immense."**
- "The development of biobanks in Africa especially in Ivory Coast."
- "The **diversity of research opportunities in Africa."**
- "The capacity of the African Academy of Science"
- "The REECAO Ethical issues Network."
- "The **excellent work being done despite limitations in infrastructure**."
- "The I.T Stream (Practical Session)"
- "The ICT tools set in place to harmonize biobanks across the globe under B3Africa projects."
- "The possibility of connection with representation of different African countries, a **possibility of having new collaborations**."
- "There is also a big cultural aspect, of developing knowledge about culture and history of another countries."
- "The possibility of discussion with the group discussion permit to have another approach and **new opportunity**."
- "The **progress in most African countries**."
- "There are **a lot of opportunities for working together."**
- **"There are so many opportunities for collaborative studies with developing and developed countries."**
- "This symposium give me opportunities **to meet others researchers and I've got new ideas."**
- "What is striking is that **despite the fact that we come from all over, we all struggle with the same issues related to ethics and regulatory compliance**. "
- "Interesting is how certain biobanks went from individual banks into regional biobanks and the knowledge on how they went about it is very interesting."

B3Africa Training

Results by workshop sessions are presented below, along with relevant open-text comments and suggestions by survey respondents.

In terms of self-perceived acquisition of knowledge and skills, results are globally positive but demonstrate the need, for all applications/tools, for further training and follow-up in order to ensure that users and IT focal points feel fully confident to install/use the tools. These needs will be addressed through another webinar series and the launch of an online learning portal for biobanks over the last months of the project.

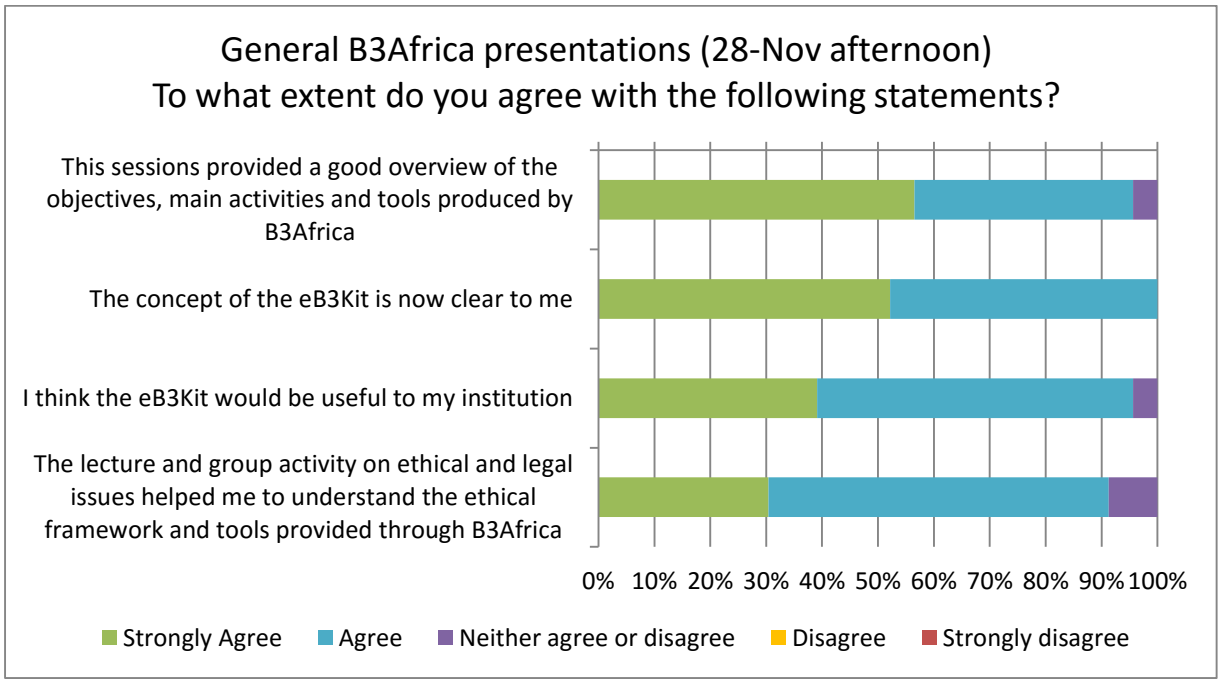


Figure 9. Level of satisfaction with regard to the B3Africa training general presentations (N=23)

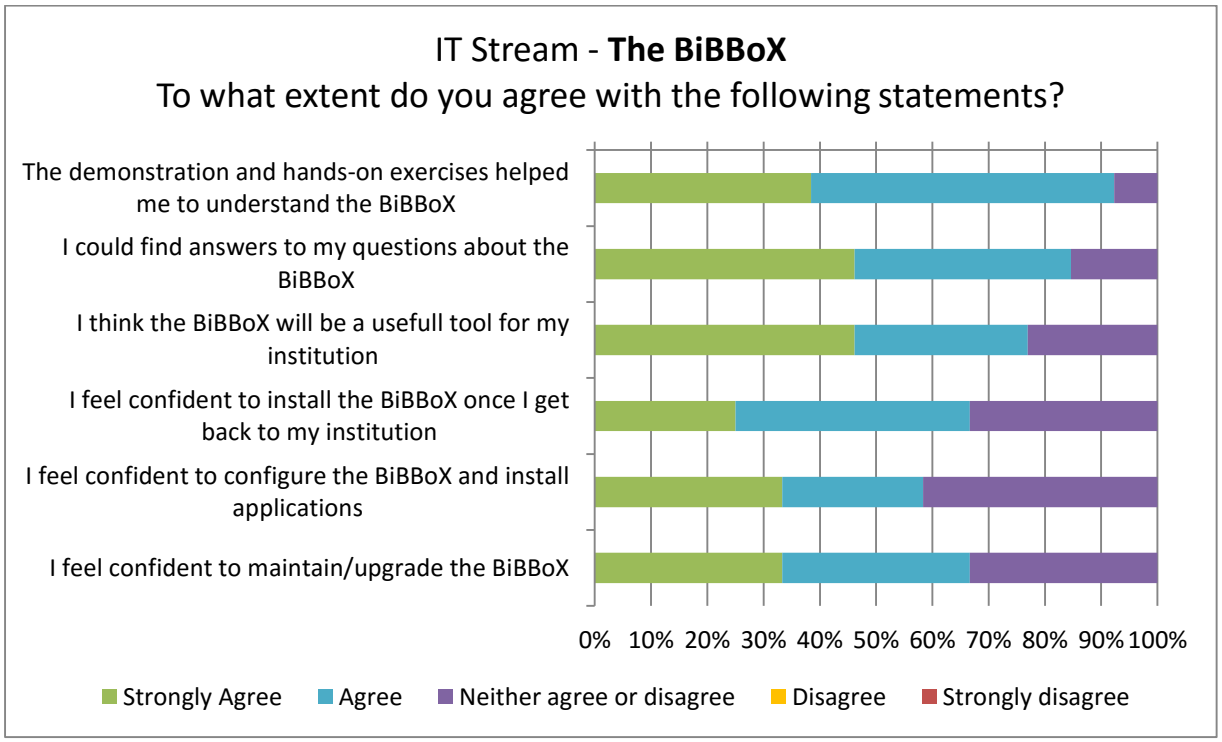


Figure 10. Level of satisfaction with regard to the B3Africa training IT stream session on the BiBBoX (N=12)

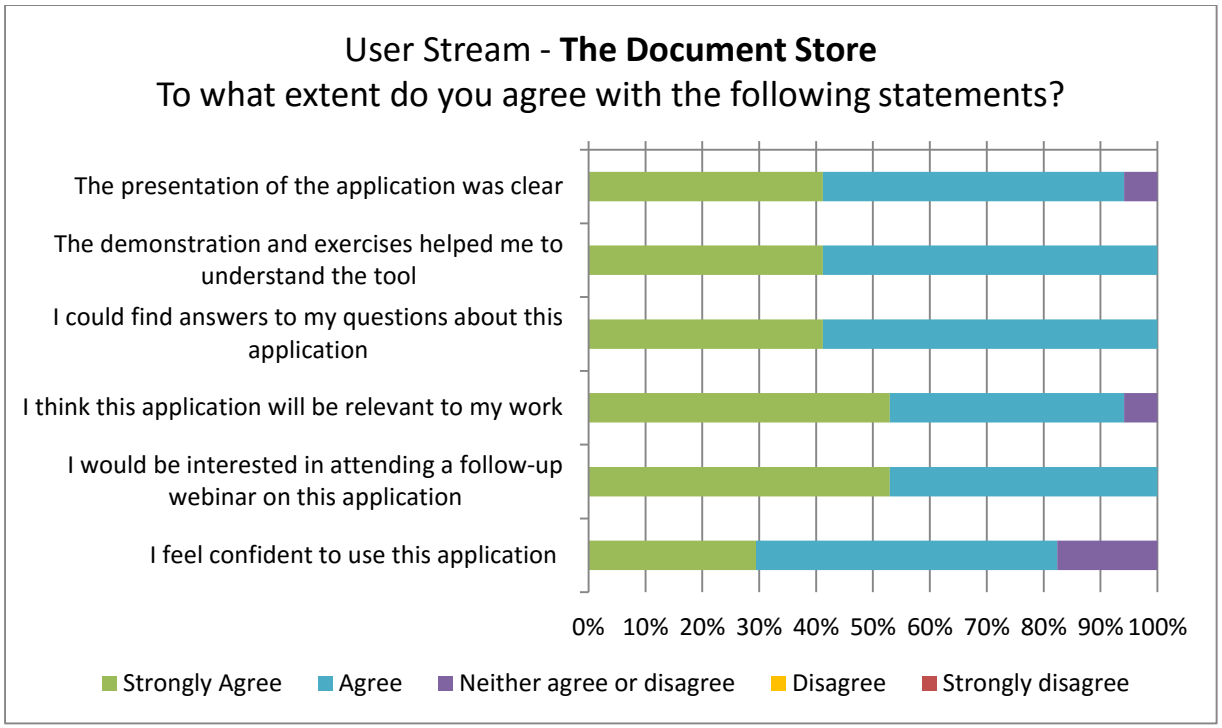


Figure 11. Level of satisfaction with regard to the B3Africa training users stream session on the Document Store (N=17)

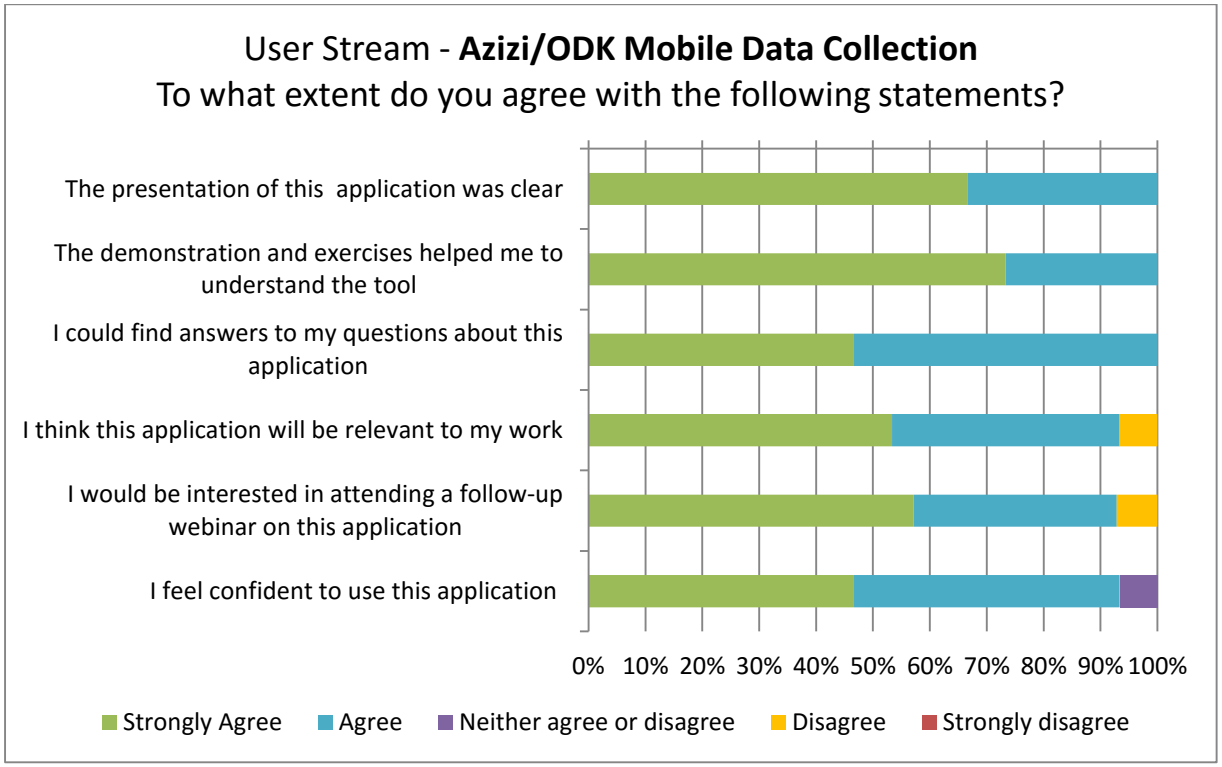


Figure 12. Level of satisfaction with regard to the B3Africa training users stream session on the Azizi/ODK mobile data collection tool (N=15)

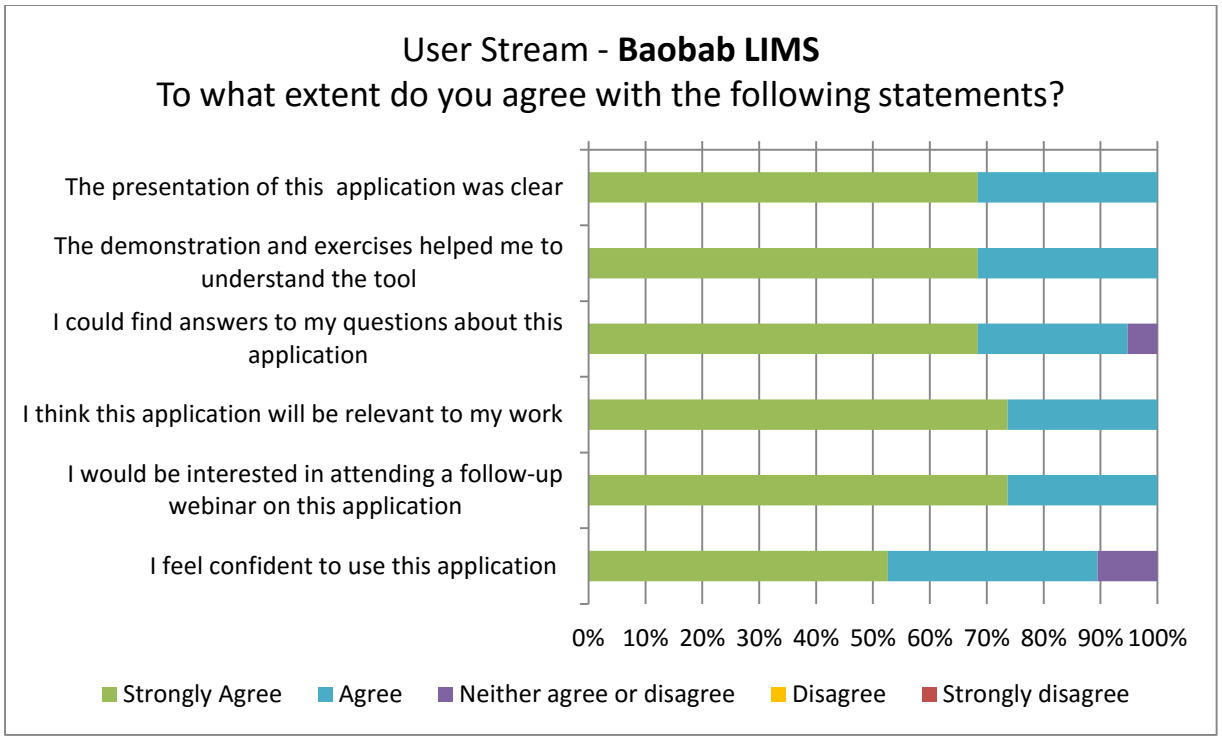


Figure 13. Level of satisfaction with regard to the B3Africa training users stream session on the Baobab LIMS (N=19)

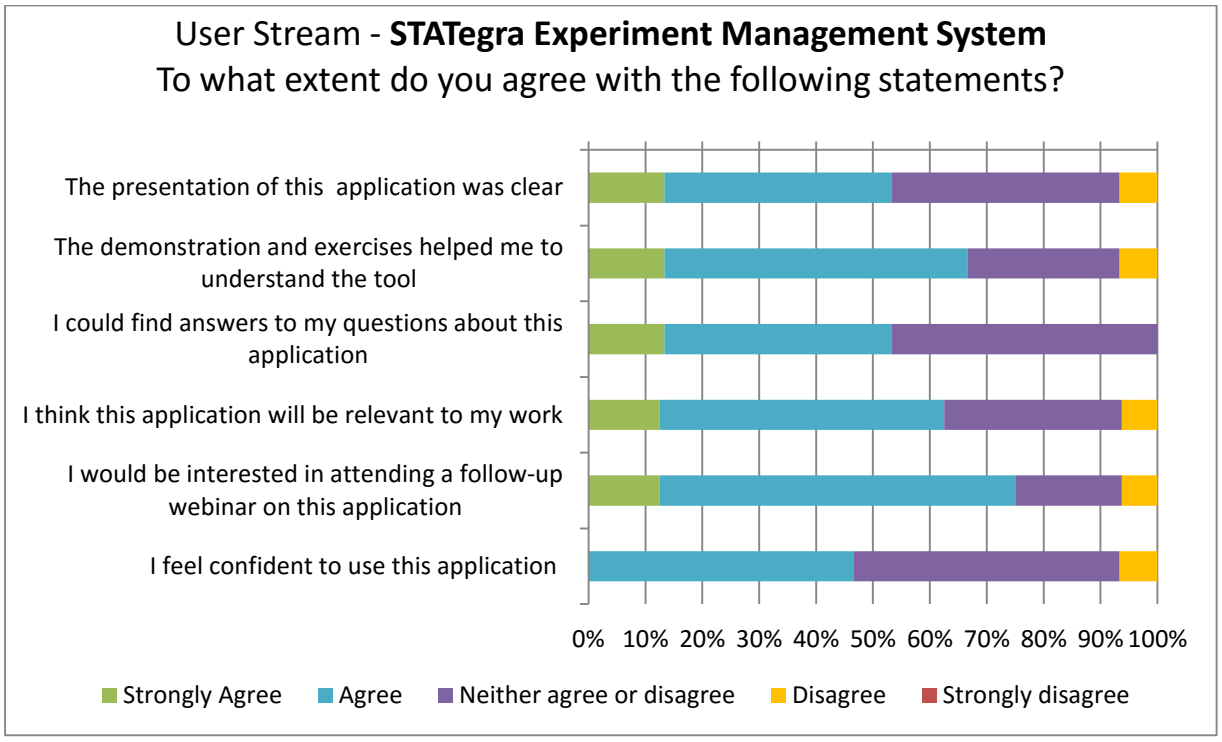


Figure 14. Level of satisfaction with regard to the B3Africa training users stream session on the STATegra Experiment Management System (N=15)

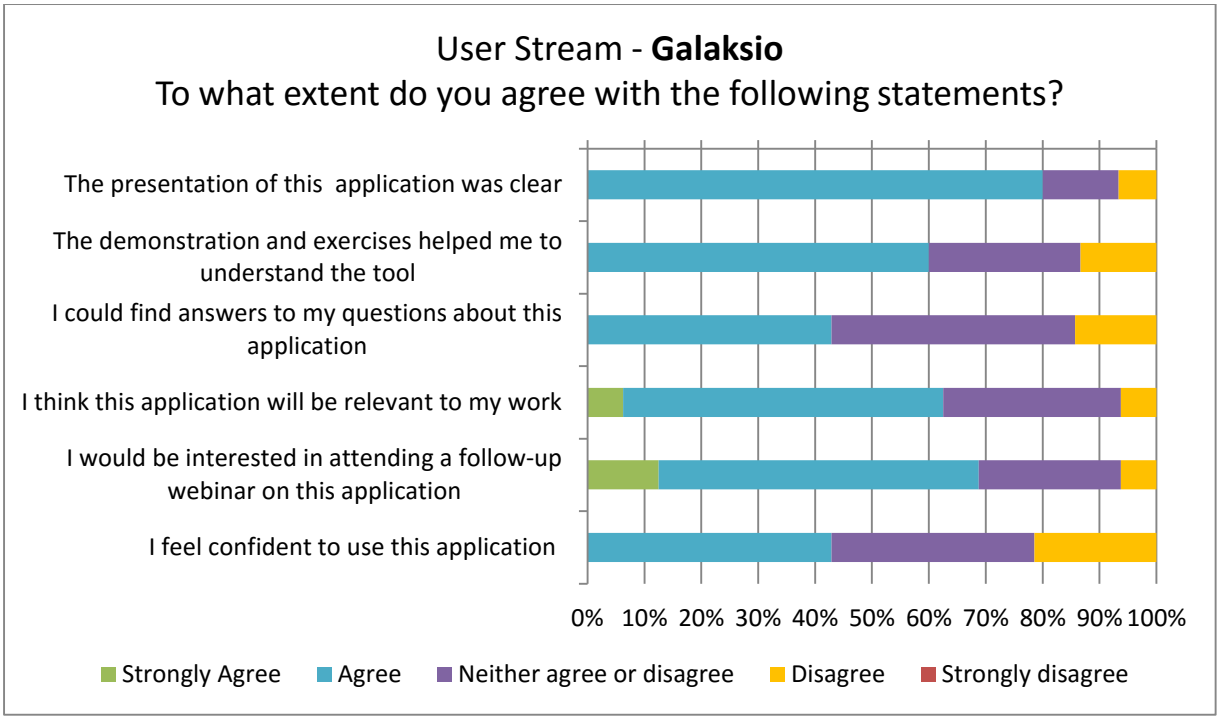


Figure 15. Level of satisfaction with regard to the B3Africa training users stream session on the Galaksio application (N=15)

Selected comments and suggestions from participants:

- Ethical and legal framework:
  "I think an outline and major points on the ethical and legal framework needed to be expanded on. What is similar and where the major difference is. And what alternative solutions one might use given the various countries involved."
- Azizi/ODK:
  "I would like to see the linking between this APP and the LIMS. Also how the integration of the LIMS output with the metadata works in Galaksio."
- Baobab LIMS:
  "Explain how this system answers MIABIS and how it harmonizes with other biobank LIMS."
- STATegra EMS:
  It would be helpful to see how you go from the LIMS to this tool for analysis. Harmonize with previous sessions and data, so that people understand the link the Baobab LIMS.
- Galaksio:
  "Follow up Webinars would be very helpful as I think it would be a useful tool."

4 Conclusion

This document reported on results from the BCNet symposium "From Biobank Infrastructure to Research", held in collaboration with the B3Africa training workshop from 27 November to 1 December 2017 in Lyon, France.

58 participants attended the event, including:

- BCNet members selected to present during the symposium;
- Guest speakers/representatives from relevant/complementary projects/institutions;
- B3Africa developers/trainers;
- Representatives from B3Africa use case institutes (IT and users);
- Training organizers.

A total of 29 research institutions/projects were represented: 62% already linked to BCNet (either partner or member) and 38% new to the initiative.

Results show a generally good level of participant satisfaction with regard to the symposium and training workshop. The combination of the symposium, during which participants could access new research collaborations, and the training workshop, in which we suggested/presented tools to facilitate such collaborations, were appreciated by the audience and generated positive feedback.

Annex: Abstracts and Biographies: Symposium Presentations

The BCNet Journey: From Biobank Training to Resources Sharing and Research Collaborations

Dr Maimuna Mendy, BCNet, France

The BCNet was established in 2013 to address the underrepresentation of samples and data available for research in low and middle-income countries. A situational analysis and needs assessment survey in the initial stages provided information for the development and training programs and thus formed the basis of the regular face to face events, webinars and online activities conducted for network members.

Network members in collaboration with partners work together to address the challenges and obstacles in biobanking in LMIC, in particular, the lack of appropriate regulations and guidelines to facilitate the sharing and secondary use of biological material and data; institutional commitment; community awareness; lack of funding and sustainability. The BCNet has initiated or contributed to several initiatives including; the IARC Common Minimum Standards and Protocols for Biobanks Dedicated to Cancer Research; the Ethics and Governance Framework for Best Practice in Genomic Research and Biobanking in Africa; the BCNet catalogue and collaboration in EU-H2020 funded projects (B3Africa and Adopt-BBMRI-ERIC).

An important focus is the network's education and training program, which targets biobankers, pathologists, researchers and technicians and covers all aspects of biobanking including quality, information technology and ethical, legal and social issues. Several members who attended the first training at IARC in 2013 took up the challenge to become local trainers and have set up research collaborations within and outside their institutions.

The theme of this symposium was selected for the opportunity to emphasise the impact of BCNet support to its members and institutions and to showcase how institutional biobanks have developed to the level where they are participating in research projects to address health issues of local concern.

Dr Maimuna Mendy completed higher degree studies in Virology (PhD) in 1994. In addition to her background in molecular virology and infectious disease and cancer, she has over 25 years' experience in assembling and managing longitudinal cohort studies in Africa, managing biological resources and coordinating the biobank activities for several scientific projects.

Dr Mendy has a broad background of capacity building in LMIC settings in the area of biobanking, laboratory and field research for epidemiological based studies and since 2010 she has expanded her interest in biobanking and now has a role in coordinating the Biobank and Cohort Building Network (BCNet). Maimuna Mendy joined IARC in 2010 as Head, Laboratory Services and Biobank Group. The Group is responsible for the management of over 6 million samples including one of the largest European Cohorts (EPIC) which has a total of 4 million samples. Dr Mendy led the centralization of the IARC biobank which has brought together sample collections from individual studies on one platform and is managed centrally by a common database. Dr Mendy retired from IARC in September 2017.

Landscape of Biobanking

Ms Marianne K Henderson MS, National Cancer Institute, United States of America

Biobanking is becoming recognized across the world as a key infrastructure needed to support research and diagnosis in molecular biomarkers in human tissues and biofluids. Biospecimens that are used in discovery research must reflect the donors' health from which they originate. Managing each step in the acquisition, processing, storage and retrieval must be focused to maintain the quality of the samples. Planning to provide access to the biobanked specimens ensures the utilization of the collections and upholds the trust given by the donor with the use of the biomaterials. Following fit for purpose best practices and standards to facilitate harmonization of biobanked specimens and data allows for comparison of research results from the use of the specimens. Biobanking is an expensive opportunity that must be planned for to assure its sustainability of collections in all parts of the world. This talk will focus on the biobank continuum and current important issues facing biobankers today.

Ms Marianne K Henderson is Senior Advisor for Division Resources, Division of Cancer Epidemiology and Genetics and Senior Advisor on Biobanking, Center for Global Health of the U.S. NCI. She supports large program and contract management; and infrastructure planning for molecular epidemiology.

Ms Henderson is active in the International Society for Biological and Environmental Repositories (ISBER) (ISBER President 2011-12 and current Chair of the OAC). She is a member of the NIH AllofUS Program – Biospecimens/Phys Meas. working group; and SC member and E&T Chair of the IARC-led LMIC Biobank and Cohort Building Network (BCNet); Ms. Henderson is actively involved in large-scale biospecimen process improvements in operations, technology transfer, sustainability and repository automation.

REECAO*: an EDCTP2§ network of national and institutional ethical committees in West Africa

Gormally Emmanuelle[1,2], Traoré Karim[3], Pons Christophe[1], de Montera Béatrice[1,2], Hardy Isabelle[1,2], Bosompen Kwabena[4], Beavogui Abdoul Habib[5] & Doumbo Ogobara[3]

Increase in clinical trials in West Africa (90% in Mali), the recent epidemic of Ebola and urgent needs of clinical trials (Malaria, TB, HIV,) are new challenges in ethical management and volunteers' protection. In Sub-Saharan African countries, the high level of illiterate volunteers in clinical trials, the huge health care needs, mostly rural populations and the sociocultural specificities are important factors limiting the understanding of some complex aspects of research in these populations. To provide better protection for these populations, strengthening governance and improving operation effectiveness and sustainability of ethic committees (EC) are crucial. Multidisciplinary EC have been set up in sub-saharan Africa. Despite the commitment and sense of responsibility of these committees, they still need to better standardize procedures, increase resources, improve governance, documentation and archiving, and share experiences.

The regional ethical issues related to multicentre clinical trials and emergency research during epidemic situations lead to the need of developing regional networks in ethics. Mali, Ghana and Guinea have common challenges related to the training of members of EC, their governance and sustainability.

The goal of REECAO is to reinforce ethics of clinical trials by creation of North-South – South-South joint ethical watch; implementation of standardized procedures for protocol submission and evaluation; training of trainers in ethics and reinforcement of the governance of EC. The support of the Ministries of Health of Mali, Ghana and Guinea and the training experience in ethics of the University Catholic of Lyon will contribute to the success of this network funded by EDCTP2.

*REECAO: Renforcement de l'Ethique des Essais Cliniques en Afrique de l'Ouest
§ EDCTP2: European & Developing Countries Clinical Trials Partnership

[1]Laboratoire de Biologie Générale, Université Catholique de Lyon, 69002 Lyon, France
[2]Ecole Supérieure de Biologie-Biochimie-Biotechnologies, Université Catholique de Lyon, France
[3]Ministère de la santé et de l'hygiène publique, Bamako, Mali
[4]Noguchi Memorial Institute for Medical Research, Ghana
[5]Centre National de Formation et de Recherche en Santé Rurale, République de Guinée

Emmanuelle Gormally has been a professor of Molecular Biology at the Faculty of Sciences at the Catholic University of Lyon since September 2011. She is currently dean of the faculty and is coordinating the Master in Biobank Management. Her research interests are in hepatitis B chronic infection and liver cancer in Mali. As part of her work, she is taking part in the development of a network of ethical committees in West Africa named REECAO. This network includes Mali, Guinea and Ghana and aims at reinforcing the capacities of these ethical committees for the review of clinical research protocols. The network is funded by EDCTP.

ELSI Issues of Biobanking in Nigeria– Implications of Social Norms (a Pilot Study)

Dr Olukemi Kehinde Amodu, College of Medicine, University of Ibadan, Nigeria

Co-authors: Dr Mofeyisara Omobowale, College of Medicine, University of Ibadan, Nigeria, Dr Akindele Adebiyi, College of Medicine, University of Ibadan, Nigeria

Biobanking, which includes central location for storage and analysis of biological samples collected from different sites, will be essential for health research and community well-being. Community understanding of the importance and benefits of such a centre and social constructions of biological products, (blood, urine saliva, etc.) are however important determinants of individual and communities' willingness to participate. Using qualitative methodology, we explored social and cultural understanding of bio-repository of biological samples among the informal public in Ibadan. Social and cultural interpretations of biological products were probed. Respondents' willingness to participate and possible barriers were also examined. Respondents were purposively drawn across social spaces in Ibadan, Nigeria: six traders from two major markets; four primary-school teachers; two bank workers; five out-of-school adolescents and three students from tertiary institutions. A total number of 20 in-depth interviews were conducted in both native (Yoruba) and English languages. Interviews were recorded with the respondents' consent and were transcribed verbatim, transliterated and translated to English. Atlas-ti 7 was used for sorting and coding of data, while data were later subjected to content analysis. Interpretations were drawn thematically.

Preliminary findings revealed the social significance of human biological parts; blood is socially described as essential and sacred to human existence. Human subjects were concerned about the security of blood samples stating that it must be handled under the strictest confidentialities; must be restricted to bio-repository centre; and not be carelessly transferred to abominable religious practitioners. Concerns about the security of blood samples were somewhat associated with the indigenous belief system that recognizes evil and diabolism in human and spiritual cosmology, and the capability of the evil-doers to use human blood to cause physical and spiritual harm. However, most of the respondents were willing to participate and donate biological samples strictly for health research. A consistent dissemination to donors, of the breakthrough and findings on their biological samples was also emphasised. Adequate compensation and proper recognition of the donors found useful for health research were accentuated by all respondents. Educating the public, while paying careful attention to the underlying socio-cultural understanding and concerns, is of great importance. Thus, the use of the eB3Kit platform training and educational materials will be essential to the success of Biobanking or setting up a Biorepository in Ibadan.

Dr Olukemi K. Amodu works at the University of Ibadan, Nigeria and is currently the Director of the Institute of Child Health. She has a PhD in Molecular Biology/Genetics from the University of Ibadan, Nigeria, She obtained her Bachelor and Master degrees from the same University. She did her postdoctoral training and research fellowship (2003-2005) at the Harvard University, USA. She is highly skilled in Molecular Biology/Genetics with interest in the study of Infectious diseases (particularly host and parasite genetic variability in malaria pathogenesis) and more recently in non-communicable disease (NCDs). She is currently the Head of the Biorepository Initiative at the College of Medicine, University of Ibadan, Nigeria

Biobanking for Research: Steps Toward Success

Ms Marianne K Henderson MS, National Cancer Institute, United States of America

Scientists understand that the value of biospecimens increases as the amount of data that annotates each specimen. Biobanks for research must plan their collections to maximize the use of the specimens by planning for the governance, including appropriate consent, ability to share, visibility of the collections to all stakeholders, material transfers, and a way to collect the outcomes of the use of the specimens. A great value is the ability to collect/provide collections that have the needed population diversity of specimens for discovery research underpinning precision medicine. Diversity in collections used in biomarker discovery allows the matching of the "right drug/therapy/preventive measures" to the right patient. This talk will note key factors to consider when biobanking for research.

Ms Marianne K Henderson is Senior Advisor for Division Resources, Division of Cancer Epidemiology and Genetics and Senior Advisor on Biobanking, Center for Global Health of the U.S. NCI. She supports large program and contract management; and infrastructure planning for molecular epidemiology.

Ms Henderson is active in the International Society for Biological and Environmental Repositories (ISBER) (ISBER President 2011-12 and current Chair of the OAC). She is a member of the NIH AllofUS Program – Biospecimens/Phys Meas. working group; and SC member and E&T Chair of the IARC-led LMIC Biobank and Cohort Building Network (BCNet); Ms. Henderson is actively involved in large-scale biospecimen process improvements in operations, technology transfer, sustainability and repository automation.

The Role of Biobank in the Development of Algorithm for Nasopharyngeal Carcinoma Screening in Indonesia

Dr Jajah Fachiroh, Faculty of Medicine, Universitas Gadjah Mada, Indonesia

Co-Authors: Dr Camelia, Herdini, Department of Otolaryngology-Head and Neck Surgery, Faculty of Medicine UGM (FM UGM), Indonesia; Ms Suhada, Suhda, Molecular Biology Laboratory FM UGM, Indonesia; Ms Sumartiningsih, Molecular Biology Laboratory FM UGM, Indonesia; Ms T. Baning Rahayujati, Department of Biostatistic, Epidemiology and Population Health FM UGM, Indonesia; Dr Dewi K., Paramita, Department of Histology and Cell Biology FM UGM, Indonesia

Background: South East Asia contains "hotspot" for NPC. NPC is the highest head and neck malignancy, and 3rd highest cancer among male in Indonesia. Its hidden primary and the unspecific symptoms causes most patients come at later stage. For the last 15 years we have collected data and biosamples from healthy (N=3303) and NPC (N=2809) items for various research objectives. Currently, samples and parallel basic data were stored in our biobank. We have developed dipstick based to detect IgG anti Epstein-Barr Virus (IgG-EBV) protein, aiming for NPC screening. Positive results of IgG-EBV dipstick ("NPC dipstick") meant as those who are at risk of NPC, or transient increasing of antibody responses to EBV due to health reason. This has to be differentiated. Objective: Development of algorithm for NPC screening.

Methods: 1. Determine sensitivity and specificity of NPC dipstick; 2. Review publications on NPC screening algorithm; 3. Review publication on genetic and environmental risk of NPC to

determine population at risk; 4. Model possible algorithm (elevated antibody-EBV in environmental risk vs possible head and neck symptoms) by using collection of plasma from healthy; 4. Determine algorithm study(ies) including clinical workup needed. Collaborators: Molecular Biology Laboratory Faculty of Medicine UGM for EBV-based testing, Hepatika Mataram (West Nusa Tenggara) for production of dipstick. Sardjito General Hospital Yogyakarta, University of Andalas Padang (West Sumatera), University of General Sudirman Purwokerto (Central Java), blood bank and primary health centers in Yogyakarta for NPC and healthy subjects collection and dipstick testing.

Main results: NPC dipstick showed sensitivity and specificity of ~90%s. It is easy to use and result can be read in 5 minutes. Published data showed that cohort of population with maintained elevated IgG/IgA-EBV titer had higher risk to become NPC. High risk population were male or family of NPC (results from highest NPC incidence: China and Taiwan). Result from our study confirmed that those with symptoms in head and neck or family of NPC had higher IgA-EBV titer. Parallel test by using NPC dipstick and re-contacting subjects of the previous study is merit to perform. Further, determining laboratory and clinical workups required in order to determine status of those who screened positive by NPC dipstick.

Conclusion: Despite its advantages NPC dipstick use in clinical or population setting requires further study. B3Africa kit will useful in the use of bioinformatics to connect research and clinical/ public, application of mobile-based app for data collection and e-consenting.

Dr Jajah Fachiroh is academic staff at the Faculty of Medicine Universitas Gadja Mada, Yogyakarta, Indonesia. She is currently coordinator for the newly-formed biobank team at the faculty. Currently, in coordination with other teams, Dr Fachiroh is working toward the development of a biobank system with two affiliate academic hospitals as well as a cohort biobank. She is also a scientist in the field of cancer molecular epidemiology. With the NPC (Nasopharyngeal carcinoma) research team, they have produced methods and kits for NPC diagnosis. Currently, they are working to develop a system for NPC screening in clinical setting by using rapid test system.

Les Néphroblastomes au Sénégal *(French presentation with English subtitles)*

Ms Aïssatou Ndiaye, Hôpital Général de Grand Yoff, Sénégal
Co-Author: Dr Chérif DIAL, Hôpital Général de Grand Yoff, Sénégal

Contexte: Le néphroblastome représente 95% des tumeurs de l'enfant au Sénégal. Notre laboratoire conserve une collection de tissus tumoraux pour les cas déjà étudiés, archivés dans des blocs de paraffine. Tous les cas annuels de Néphrectomies de l'enfant au Sénégal sont traités dans notre laboratoire depuis 2010. Ces cancers sont souvent diagnostiqués tardivement.

Objectifs

- Répertorier et présenter les aspects anatomo-pathologiques et les difficultés rencontrées lors de la prise en charge des pièces de néphrectomies (solutions).
- Rechercher des partenariats pour l'étude des facteurs entrant dans la survenue et la progression de ce cancer chez l'enfant sénégalais.

Méthodologie: L'étude sera une présentation des néphroblastomes colligés sur deux années (2014/2015), chez des enfants de 0 à 16 ans. Les prélèvements sont constitués de néphrectomies, le plus souvent reçues fixées au formol, parfois reçues à l'état frais. Ces prélèvements suivent la technique histologique en vue d'une interprétation au microscope optique. Les néphrectomies sont effectuées dans le cadre des recommandations du protocole de la SIOP associant chimiothérapie préopératoire et post-opératoire, la radiothérapie n'étant pas encore disponible. Les pièces sont acheminées en cours de fixation dans du formol et le plus souvent, quelques jours après la chirurgie. Elles ne sont que rarement vues à l'état frais. Collaborateurs: Oncopédiatrie de l'Hôpital Aristide Le Dantec: chirurgie; Urologie et Médecine Interne de l'Hôpital Général de Grand Yoff: chirurgie; GFAOP (Groupe Franco-Africain d'Oncologie Pédiatrique).

Résultats: Nous avons répertorié : En 2014, 37 cas de néphrectomies chez les enfants âgés de 5 mois à 16 ans, dont 24 néphroblastomes, 3 sarcomes à cellules claires, 1 adénocarcinome, le reste était formé de lésions non tumorales. En 2015, 19 cas, de 3 mois à 14 ans, dont 16 néphroblastomes, 1 adénocarcinome, 1 dysplasie rénale. Notre étude, portant sur deux années, a montré une moyenne de 70% de néphroblastomes; des moyens d'analyses limités; un personnel insuffisant; un archivage et une collecte de données inadaptés.

Conclusion: Un réel souci d'organisation et de respect des normes de qualité nous permet de prétendre compter sur le B3Africa pour une amélioration des conditions de travail; une adaptation des ressources humaines aux normes internationales et une collaboration efficiente et régulière au domaine des biobanques à l'international, aux études et aux recherches s'il y a lieu.

Ms Aissatou Ndiaye is a senior technician in medical biology, specializing in anatomical and cytological pathologies. She began working at the Institut Pasteur in Dakar, Sénégal, in 1998, and in 2005 joined the General Hospital of Grand Yoff, in the Anatomy and Cytology laboratory, where she became the technical and administrative manager, reporting to the laboratory head, a pathologist, in 2007.

Ms Ndiaye is keen to experience new opportunities and to learn cytology and histology interpretation of optic specimens, to have opportunities to install and develop a public or private laboratory of anapath with a pathology doctor, and to train other people to be good technicians and managers, in order to improve the anatomy laboratory.

Cancer Biobank of the Egyptian National Cancer Institute: Establishment and Role in Study of Breast Cancer Stem Cells

Dr Iman Farahat, National Cancer Institute (NCI), Egypt

Dr Mervat Eldeftar; Miss Dina Ibrahim; Mr Omar Dahrog; Dr Merhan Foada; Miss Iman Taha; Dr Ahmed Abdelhafiz; Miss Nahla Elzefzafy; Professor Abdelhady Abdelwahab: NCI, Cairo University, Egypt

Background Information: Breast cancer is the commonest malignancy in women in many countries including Egypt imposing a huge social and economic burden. There is increasing evidence that breast cancer stem cells (CSCs) mediate tumor metastasis and may contribute to treatment resistance and relapse following therapy. CSCs are rare, representing

approximately one in a million cells within a tumor, and their biological properties are often very different than the major tumor cell population.

Study Objectives: We aimed to optimize the process of isolation and propagation of CSCs in breast cancer tissue samples which may facilitate their identification and therapeutic targeting.

Methods: The Egyptian National Cancer Institute (ENCI) Cancer Biobank, funded as one of the Centers of Excellence by the Egyptian Science and Technology Development Fund (STDF), was established in 2015. ENCI biobank collected 47 tissue samples from newly diagnosed breast cancer patients for the sake of identification and characterization of breast CSCs. The isolation and self-renewal of CSCs was tested by mammosphere and colony-forming assays. Expression of breast CSCs specific markers was tested by Flow cytometry. Correlation of resulting research findings with clinical, pathological and follow up data shall be enhanced by data collected along with study samples.

Results: Among the markers tested for stem/progenitor cell properties in breast cancer are the surface protein marker CD44, CD24 and aldehyde dehydrogenase activity (ALDH). The proportion of breast CSCs and their differentiation potential showed substantial difference among different breast cancer tissue samples.

Conclusion: Establishment of a biobank at NCI (Cairo) paved the way for translational studies that require fresh tumor samples. Further study of breast CSCs and its implication in the context of breast cancer molecular classes is ongoing. We anticipate the use eB3Kit as a sample management tool will facilitate annotation and linkage of good quality consented samples to the patient data in a way that respects individuals' privacy and confidentiality.

Professor Iman Gouda Farahat MD/PhD is Professor in the Department of Pathology, National Cancer Institute, Cairo University, Egypt. Prof Farahat is the Principal Investigator at the Egyptian National Cancer Institute Biobank (Centers of Scientific Excellence Grant). She is also Consultant and Director of the Pathology Lab, Baheya Breast Cancer Centre, Egypt and, since 2015, a Consultant Pathologist at the Children's Cancer Hospital – 57357 in Cairo.

From 2007 to 2015 Prof Farahat was Consultant and Director of the Pathology Lab at the Tanta Cancer Centre, Egypt and from 2000-2005 Associate Professor of Pathology, National Cancer Institute, Cairo University. Having completed her residency at the National Cancer Institute, Cairo University in 2009, Professor Farahat was first assistant lecturer (2003 – 2009) and then lecturer of pathology until 2015.

Impacting Africa's Development Through Strengthened Research Ecosystems: The role of AESA

Dr Jenniffer Maroa, The African Academy of Sciences, Kenya

Health is a major priority for all nations but achieving equitable and quality health care for more than 1 Billion people in Africa requires robust and innovative collaborative approaches and support to strengthen the human capacity to undertake world class health R&D right here on the continent. Research capacity strengthening (RCS) is variously defined and debated in the literature, but there is consensus that strategies that target institutions, organizations, national and regional health research systems as well as developing individuals' skills are more successful. The **Alliance for Accelerating Excellence in**

Science in Africa (AESA) has been created by the African Academy of Sciences (AAS) and NEPAD (New Partnership for African Development), is supported by three global funders (Wellcome Trust, Bill and Melinda Gates Foundation and UK Government Department for International Development); and endorsed by the African Union to champion the development of research for health capacities in Africa. AESA is based at the AAS headquarters in Nairobi and represents an exciting new model for long term development of research leadership, excellence and innovation in Africa. The AESA model is predicated on strong global partnerships, including north-South and South-South collaborations, sustained investments in people, their places of work and their research programs so as to successfully shift the centre of gravity for managing R&D programs to the continent. Accordingly, **The Human Heredity and Health in Africa (H3Africa)** is one of the R&D programs that was previously managed by the Wellcome Trust but is now fully implemented by EASA. Operating as a pan-African agenda setting and research management hub, AESA and partners are providing opportunities through open calls for proposals, managing grants, and regular evaluation of these investments. The long-term vision is to produce African scientific leaders and institutions that are globally competitive, carrying out excellent science, and using research effectively to produce innovations, guide policy and practice that addresses the needs of all African countries and is globally impactful.

Jenniffer Mabuka-Maroa works at the African Academy of Sciences (AAS) Nairobi, Kenya as the Human Heredity and Health in Africa Program Manager. Prior to joining AAS, Jenn spent ~16 years doing HIV-1 basic science research. Her research broadly focused on understanding host innate and immune factors that modulate HIV-1 transmission and pathogenesis. Specifically, she investigated host immune responses in mother-to-child transmission of HIV-1 with a particular focus on breast milk transmission and explored antibody evolution in natural HIV-1 infection with the goal of informing antibody-based vaccine design. She obtained her Ph.D from the University of Washington, Seattle and completed a 3 year postdoctoral fellowship at KwaZulu Natal Research Institute for TB and HIV (K-RITH), South Africa. Before joining AAS, Jenn was a research associate with the Ragon Institute of MGH, MIT and Harvard working with Galit Alter and a visiting research collaborator at K-RITH where she was based in the Ndung'u lab.

Genetic and Epigenetic Peculiarities among Nigerian with Colorectal and Breast cancer - Cancelled

Dr Olusegun Alatise, Obafemi Awolowo University Teaching Hospitals Complex, Nigeria

Co-Authors: Dr Tomi Akinyemiju, University of Kentucky, Kentucky, United States of America; Dr Peter Kingham, Memorial Sloan Kettering Cancer Center, New York, United States of America.

Background: The colorectal and breast cancer are now major public health issue in Nigeria as in incidence appear rising significantly. African Research Group for Oncology established in 2013 disease specific tumor biobank that currently support three funded research which include: 1. Developing Colorectal Cancer Biobank and Database in Nigeria (Prospective study) (NCI Pilot grant); 2. Point of care, real-time urine metabolomics test to diagnose colorectal cancers and polyps in low- and middle-income countries (UG2/UH3); 3. Mechanisms for Established and Novel Risk Factors for Breast Cancer in Women of African Descent (K01).

Objectives:

Study 1
1. Characterize the MSI status of patients with CRC in West Africa.
2. Determine the genetic mutation patterns of CRC in West Africa compared to historical patterns in US patients

Study 2 The goal of this proposal is to adapt, implement, and validate a novel POC urine-based metabolomic diagnostic test to triage a group of high-risk patients to identify those with CRC and polyps. This test will provide affordable, real-time diagnostic capabilities so that only patients who have a very high risk of CRC and polyps will be scheduled for colonoscopy.

Study 3
1. To examine the molecular features of African breast cancer patients including metabolic and inflammatory markers, and determine if these predict tumor aggressiveness, prognosis and survival.
2. To examine the influence of traditional risk factors- obesity, parity, breastfeeding, mammography density- on breast cancer tumor aggressiveness, prognosis and survival.

Methodology: Samples banked for these studies include fresh colorectal and breast cancer tissues placed in cryovial and PAXgene kit, urine stored in cryovial, blood samples separated into plasma and buffy coat and are saved separately in the cryovial and saliva obtained in Oragene-Discover saliva kit. All samples are banked in -80 freezer located at Obafemi Awolowo University Teaching Hospitals Complex, Ile Ife, Osun State, Nigeria.

Research collaborators: Six Nigerian academic institutions. International Collaborators: Memorial Sloan Kettering Cancer Center, New York, USA; University of Alberta, Canada; University of Kentucky, Lexington, Kentucky, USA.

Results: Preliminary data from the colorectal cancer samples showed unique genetic mutations in African population when compared with African American and Caucasian.

Conclusion: The bank is growing and also challenging but the prospect is great, eB3Kit if adopted in the management of the bank is expected to assist in the management of the growing biobank.

Dr Olusegun Isaac Alatise has been an Associate Professor in the Department of Surgery, College of Health Science, Obafemi Awolowo University and a Consultant General Surgeon at the Teaching Hospital. His area of interest is in Surgical Oncology and Gastroenterology. He had his Surgical Oncology training at Memorial Sloan Kettering Cancer Center, New York, USA. He has also had other training fellowships in Endoscopy and Colorectal Surgery sponsored by the World Gastroenterology Organization, African Middle East Association of Gastroenterology and Endoscopy, and the International Council of Coloproctology. He has attended many national and international meetings as a resource person. In 2013, he participated in African Cancer Leader Institute and in 2016; he was selected as one of the '50 for 50' upcoming global cancer leaders by International Agency for Research on Cancer (IARC). In 2017, he was awarded the Prof T.A.I Grillo Excellence in Research Award by his University.

He co-founded the African Research Group for Oncology (ARGO) in 2013. The group run a clinical database and biobank for breast and colorectal cancer. He is a leader and a trainer in Oncology and Gastroenterology in Nigeria. He is a member of the Lancet Oncology Commission on Global Cancer Surgery. He is also a Co-PI on multiple prospective studies on colorectal and breast cancer in Nigeria, including a UG3/UH3 NIH grant (awarded in 2017). He has trained over 15 General Surgeons many interested in Surgical Oncology and have taken faculty positions in Nigeria. He has over 75 publications in peer-reviewed journals and 4 chapters.

Validation of Genome Wide Association Studies of Hepatocellular Carcinoma in Egyptian Population

Professor Sameera Ezzat, National Liver Institute (NLI), Egypt

Co-Authors: Dr Inas Maged NLI, Egypt; Ms Asmaa, Mosbeh NLI, Egypt; Ms Heba, Abdel Samiee, SSI, Egypt; Dr Ayat, Roshdy NLI, Egypt; Dr Asmaa, Ibrahim NLI, Egypt; Professor Imam Waked, NLI, Egypt; Professor Mohamed Abdel-Rahman, NLI, Egypt.

Background: Hepatocellular carcinoma (HCC) is a leading cause of death. HCC is associated with several risk factors such as chronic hepatitis B and C infection, consumption of aflatoxin-contaminated foods, and liver cirrhosis. Recently, a number of Genome Wide Association Studies (GWAS) have identified several loci associated with HCC. Management of HCC currently as a single disease although genetically it should be considered as multiple molecularly subtypes. Patients' stratification for various therapeutic modalities will likely improve therapeutic outcome.

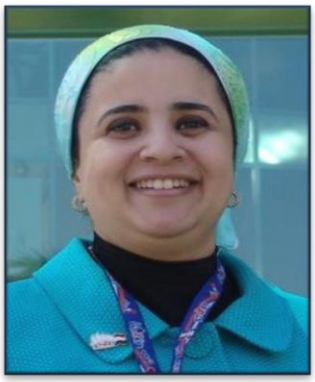
Study Objectives: The overall objective of this project is to develop better knowledge of HCC genetic profiling and to identify variants contributing to the pathogenesis of HCC and its response to treatment and prognosis. This knowledge will also aid in early detection and prevention, personalization of therapy, and development of novel HCC drugs.

Methodology: The National Liver Institute, Sustainable Science Institute Collaborative research Center (NLISSICRC) is a joint effort between the Egyptian National Liver Institute and the Sustainable Sciences Institute, a non-profit organization based in San Francisco. The aims of the NLISSICRC are: i) to develop a comprehensive Biorepository of biospecimens; ii) to establish a Center of Excellence for high quality research; and iii) to provide and facilitate training for Egyptian researchers. We are collecting the following samples: • Peripheral blood from more than 3000 subjects with hepatitis C and HCC. • Fresh frozen tissue from tumors and non-tumor tissues from more than 100 subjects with HCC. The blood tubes had a pre-printed identity label bearing a unique number for each patient. Genomic DNA was isolated from blood samples. Research studies focusing on molecular genetics, genetic susceptibility, and the utility of potential targets for therapy of HCC.

Research collaborators: Sample collection and DNA extraction is done by the NLISSICRC. Genotyping will be done at National Cancer Institute, Cairo University. Funding for this study is provided by SSI, San Francisco, USA.

Results: All published GWAS that identify susceptibility loci for hepatocellular carcinoma are reviewed. Functional assessment of SNPs and genes pathways is done. Genotyping analyses of the SNPs are in process.

Conclusion: This study will provide evidence of previously discovered SNPs and their role in hepatocarcinogenesis, since GWAS studies are lacking in Egypt. B3Africa platform can help in replicating our study in different African countries in which HCC risk factors are similar and also subjects are sharing the same genetic background.



Professor Sameera Ezzat is a Professor of Public Health, Chair of Epidemiology and Preventive Medicine Department, Director of NLI-SSI Collaborative Research Center, National Liver Institute, Menoufia University. She is PI of Genetic Epidemiology Center of Excellence at the at Children's Cancer Hospital 57357-Egypt. She graduated from Faculty of Medicine, Cairo University in 1995. Sameera got her PhD/MD degree in Public Health in 2006 from Cairo University and her thesis was in collaboration with Georgetown University, USA. She received raining at Johns Hopkins University, USA. She also served as a Director of Research at Children's Cancer Hospital 57357-Egypt, from 2008-2014.

Dr. Ezzat has conducted many research studies in the areas of Epidemiology of cancer as well as gene-environment interactions and its relationship with cancer incidence. She is a PI of many relevant grants. She worked in many grants funded by National and International agencies, such as US-NIH.

She has more than 30 international publications and she was awarded the National Motivation Award in Medical Sciences in 2011.

Data Management and LIMS strategy for the Ebola Biobank Samples to Promote Research in Sierra Leone

Professor Sahr Gevao, Global Emerging Treatment Consortium (GET), Sierra Leone

Co-Authors: ALAN CHRISTOFFELS. SANBI, UNIVERSITY OF WESTERN CAPE SOUTH AFRICA
AKIN ABAYOMI. Principal Investigator, GET, GHANA AND SIERRA LEONE

BACKGROUND: The Ebola samples generated after the last epidemic in Sierra Leone posed serious biosafety and biosecurity challenges. The samples have been catalogued and stored in three temporary repositories awaiting transfer to the main Bio Bank in Early 2018. A data management and LIMS strategy that will match the research vision for this national asset of Ebola bio specimens is under focus. Funding was secured to host a workshop on data management design strategy and LIMS usage. A team from the University of Western Cape's Bioinformatics Institute was invited to run the workshop in collaboration with the Sierra Leone Biobank and Biosecurity Team from 18th -20th July 2017.

AIM AND OBJECTIVES: The aim of the workshop was to provide training on LIMS and data management best practices. The objective was to plot a roadmap for continuous capacity development in functional data management and bioinformatics in Sierra Leone to support and sustain an escalating research agenda, when a functional biobanking facility and culture is established. Other Objectives include: to provide an introduction to Genomics; to demonstrate the use of Baobab LIMS; to provide training on installation of Baobab LIMS on LINUX; to train laboratory personnel how to capture feedback on LIMS issues via GitHub.

METHODOLOGY: The 28 participants were selected from the Ministry of Health and Sanitation, GET, and The University of Sierra Leone with varying skillsets ranging from Laboratory Technologists, Data Management personnel, Research scientists and Security Experts.

WORKSHOP: This aim was achieved through two days of lectures, practical exercises and discussions followed on the final day, by a brainstorming session to plot a roadmap for continuous capacity development. The topics include:

- An insight into the Ebola outbreak and Sierra Leone's response;
- Introduction to genomics and a laboratory information management system. This session demonstrated how B3Africa's eb3kit provides the analysis platform that incorporates a LIMS, an experimental management system and bioinformatics tools;
- African Genome Project;
- Training participants on how to configure the Baobab LIMS;
- Principles of Cloud computing and remote data processing;
- Making sense of data.

CONCLUSION: The workshop was a success as measured by the feedback from individual participants. There was excitement among participants to start working on their own research projects using analytical tools that will shortly be in their hands.

Professor Sahr Moses Gevao is Head of the Department of Hematology, College of Medicine and Allied Health Sciences (COMAHS), University of Sierra Leone. He was the Head of the Laboratory Pillar and the Chair of the Laboratory Technical Working Group during the Ebola Virus Disease outbreak in Sierra Leone and is currently leading

efforts to solve the Biosafety and biosecurity challenges resulting from the recent ebola outbreak through the creation of a biobank.

Professor Sahr is also the Country Lead of The Global Emerging Pathogen Consortium, Lead of the Viral Hemorrhagic Fever Consortium and Principal investigator of the African Center of Excellence for the Genomics of Infectious Diseases in Sierra Leone.

He was previously the Deputy Vice Chancellor and Head of the College of Medicine and Health Sciences (2005-2009) and Pro Vice Chancellor, University of Sierra Leone (2007 – 2009). He was Chair Faculty of Laboratory Medicine, West African College of Physicians (2010- 2015). Prof Gevao an IFBA certified specialist in Biosecurity and is a 1982 graduate of the College of Medicine, University of Lagos, Nigeria and obtained the Fellowship of the West African College of Physicians in Laboratory Medicine in 1988. He was a Commonwealth Medical Fellow at the Royal Postgraduate Medical School London, UK from 1991-1992.

Selecting a Laboratory Information Management System for Biorepositories in Low- and Middle-Income Countries: The H3Africa Experience and Lessons Learned - Cancelled

Dr Samuel Kyobe, Makerere University College of Health Sciences, Uganda

Biorepositories in Africa need significant infrastructural support to meet International Society for Biological and Environmental Repositories (ISBER) Best Practices to support population-based genomics research. ISBER recommends a biorepository information management system which can manage workflows from biospecimen receipt to distribution. The H3Africa Initiative set out to develop regional African biorepositories where Uganda, Nigeria, and South Africa were successfully awarded grants to develop the state-of-the-art biorepositories. The biorepositories carried out an elaborate process to evaluate and choose a laboratory information management system (LIMS) with the aim of integrating the three geographically distinct sites. In this article, we review the processes, African experience, lessons learned, and make recommendations for choosing a biorepository LIMS in the African context.

Mr Samuel Kyobe is a Lecturer of Medical Microbiology in the College of Health Sciences, Makerere University. He qualified as MD from Makerere University in 2009 and worked as a Medical Officer at Rubaga Hospital Kampala for one year, then joined the Department of Microbiology as a Research Assistant in the Molecular Biology Laboratory. In 2014, he completed a Masters of Medicine degree in Medical Microbiology from Makerere University. His thesis examined the development of a novel tool for real time PCR genotyping of Mycobacterium tuberculosis complex by MIRU/VNTR utilizing HRM. He is currently pursuing a PhD in Human Genetics at Makerere University in collaboration with BCM and UC Berkley, examining the role of HLA in pediatric HIV disease progression. He has a special interest in the field of biobanking and coordinates various biobanking research projects in Uganda including the NIH funded H3Africa biorepository and the EU-H2020 funded B3Africa program.

Bridging the Research Gap with Effective Data Collection Toolkit: Addressing Breast Care International Biobank Challenges in Breast Cancer Control in Ghana

Mr Isaac Ewuah Mensah, Breast Care International, Ghana

Co-Authors: Dr (Mrs) Beatrice Wiafe Addai, Breast Care International, Ghana; Emma Brew Abaidoo, Breast Care International, Ghana

Background Over 80% of deaths from chronic diseases occur in LMICs. Although approximately 17,000 new cases of all types of cancer occur accounting for 13,000 deaths annually, Ghana has historically had very limited treatment options for cancer patients. As the leading cause of cancer deaths among Ghanaian women, breast cancer has been identified as one of the neglected non-communicable diseases. In 2012, Globocan reported that approximately 2,260 people were diagnosed with breast cancer in Ghana with a high age standardized mortality rate of 11.7 per 100,000. Although, it is acknowledged that early detection reduces mortality, 80% of newly diagnosed breast cancer patients delay presentation. Research plays a major role in cancer control. In low-and-middle-income countries like Ghana, a lack of harmonization amongst regulations, procedures and databases currently limits opportunities for research collaborations. Breast Care International (BCI), BCNet a member and B3Africa Education and Training Program interested in all components of the Eb3Kit (LIMS, Bioinformatics, Experiment Management, Mobile Data Collection, Ethical and Legal Framework). BCI Biobank uses Excel, Word Document, Hospital Administration and Management Software (HAMS) for data collection.

Objective: To have access to a specific well designed data collection toolkit like the eB3Kit, with user friendly interface, sustainability features and components to collect data effectively for the biobank; to enhance its research.

Methodology: BCI Biobank since its inception has 2000 samples including Formalin Fixed Paraffin Embed Tissue (FFPE) from Tru Cut biopsies samples. The samples are archived based on accession numbers at room temperature. Immunohistochemistries are carried out on these blocks to patients' treatment and to generate data on our cancer types, age, distribution and other demographics which are relevant for research. The accession numbers are traceable to demographics of the subject on the biobank database which we will integrate into eB3Kit.

Collaborators: BCI collaborates with African Organisation for Research and Training in Cancer (AORTIC), International Agency for Research on Cancer (IARC) and National Cancer Institute (NCI).

Conclusion: eB3Kit will enhance data collection and database management of our samples, boost BCI biobank research collaborations within and across continents. The implementation of the eB3Kit will produce reliable, analytical database to engage biobanks' stakeholders such as institutions, governments and policy makers.

Mr Isaac Ewuah Mensah is the IT Officer of Peace and Love Hospitals, Breast Care International (BCI) and BCI Biobank. He is also the Assistant Screening Coordinator of BCI and a member of the B3Africa Ghana Team. Mr Mensah has a BSc in Information Technology. He has served on several Research Projects such as Ghana Breast Health Study by National Cancer Institute, USA, African Organisation Research And Training Into Cancers (AORTIC) Research on Knowledge, Attitude And Practices on Breast Cancer

among Ghanaian Women, International Breast Cancer And Nutrition Project conducted by BCI. I have also served on event committees as a local organising committee member for the following; BCI Ghana Walk for the Cure (Nationwide Breast Cancer Awareness Program) from 2011 to Date, Globeathon (Global Marathon to End Women Cancers), Peer Navigation Program for Breast Cancer Survivors, National Basic Oncology Training for Community Based Nurses. I was part of the first Susan G. Komen Race for the Cure in Ghana.

The BCNet Catalogue: from data collection to research

Mr Ny Haingo Andrianarisoa, IARC, France

The Low- and Middle-Income Countries Biobank and Cohort Building Network (BCNet) catalogue has been developed to contribute to the visibility of LMIC biobanks and promote collaboration between BCNet members and scientists worldwide.

It has been designed in compliance with biobank standard MIABIS 2.0. This presentation will focus on how biobankers and researchers can use the catalogue to do research. Thus it will answer the five following questions: What is the catalogue about? What are the collected data about? Who can use it? What can be done with it? What is planned afterwards?

Ny Haingo Andrianarisoa joined the International Agency for Research on Cancer (IARC), a specialized agency of the World Health Organization (WHO), at early 2015 as research assistant in data management. He deals with IT and data within the activities and projects of the IARC Laboratory Services and Biobank (LSB) group. He is in charge of IT implementation and support of the catalogue of the Low- and Middle-Income Countries' Biobank and Cohort building Network (BCNet). He also participates in BBMRI-ERIC working groups as IT representative of IARC biobank.

During his research fellowship at LIRIS, a French National Center for Research in Science (CNRS) IT-focused lab, and at the National Institute for Applied Sciences (INSA) of Lyon, France, he worked on data access and integration for combining and leveraging of both database federation principles and grid computing technology. He served for five years as IT manager of Remera, the French major Regional Registry of Birth Defects. He led for over six years the digital transformation of the Health Regional Observatory of Auvergne-Rhone-Alps, France. In addition, he held for more a decade a position of assistant professor in computer science at the University of Lyon, France.

Polish National Biobanking Node – Fresh Ideas for Biobanking in Wroclaw Research Centre EIT+

Dr Irena Dus-Ilnicka, National Biobanking Node, Wroclaw Research Centre EIT+, Poland

Co-Authors: MSc Martyna Kurczyńska, Wroclaw Research Centre EIT+, Poland; Małgorzata Jabłońska, Wroclaw Research Centre EIT+, Poland; MSc Daria Stankiewicz, Wroclaw Research Centre EIT+, Poland; PhD Łukasz Kozera, Wroclaw Research Centre EIT+, Poland

National Biobanking Node (NBN) with the headquarter in Wroclaw, Lower Silesia, Poland, is a population based and specialized biobank started in 2012. The aim of NBN was to collect the biological material and clinical data from the population of Lower Silesia including:

- healthy volunteers,
- patients with cardiovascular diseases
- patients with autoimmune diseases.

Speaking of third group of patients, during these years of action, Wroclaw NBN collected biological material taken from patients with disorders like:

- Systemic sclerosis,
- Granulomatous encephalitis,
- Psoriatic arthritis,
- Primary Sjogren Disease,
- Rheumatoid Arthritis,
- Systemic lupus erythematosus.

Wroclaw NBN biobank collected also variety of patients' data based on general health and life style information. NBN also offered their patients a screening program including measurement of body composition, blood pressure, lipid profile, glucose and insulin level.

NBN received funding granted by Ministry of Science and Higher Education, January 2017 – due to joining BBMRI-ERIC as a full member – for the creation of Polish Biobanking Network. With other 6 units from Poland, NBN will be creating several solutions enabling Polish biobanks to join EU infrastructure.

NBN will carry 5 years follow up research on the population studied in the previous survey within the project. Researchers hope, that results presented with the use of this screening program are going to show an answer for what are the metabolic problems of Lower Silesia population. Other tasks of NBN are: 1. Expert teams activities in the European biobanking network BBMRI-ERIC. 2. Educational and advisory activities in the academic community who aspire to create biobanking facilities. 3. Supervision of the implementation of Polish Biobanking Network project and the inclusion of polish biobanks in cooperation within scientific and commercial projects with European entities.

Dr Irena Dus-Ilnicka has a PhD in Molecular Biology, with knowledge of GCP and ICH guidelines. She is a teacher of clinical pharmacology and is Head of the Biobank Laboratory at the national Node of Biobanking in Wroclaw, Poland.

Centre de Ressources Biologique (CeReB) de l'Institut Pasteur de Côte d'Ivoire : Stratégies d'organisation *(French presentation with English subtitles)*

Dr Simini Doumbia, Institut Pasteur de Côte d'Ivoire

Co-Authors : Dr Agbo-Soumahoro Coumba, Institut Pasteur, Côte d'Ivoire ; Dr Diané Maxime, Institut Pasteur, Côte d'Ivoire ; Mr Agahan Aymard, Institut Pasteur, Côte d'Ivoire ; Dr CISSE Souleymane, Institut Pasteur, Côte d'Ivoire ; Pr Dosso Mireille, Institut Pasteur, Côte d'Ivoire

Justificatif: L'Institut Pasteur de Côte d'Ivoire (IPCI) dispose de nombreux échantillons du fait de ses missions d'appui à la santé publique. Afin de répondre aux critères internationaux de mise en collection de ressources biologiques, un Centre de Ressources Biologiques /Biobanque a été créé officiellement à l'IPCI avec le soutien du gouvernement ivoirien.

Objectifs: Mettre en place les indicateurs d'activités, de performance et de qualités biologiques au CeReB et le cadre réglementaire régissant un centre de ressources biologique.

Méthodologie : Pour assurer la réorganisation du CeReB, des indicateurs ont été définis afin d'orienter les domaines d'activités assignés au centre. Pour évaluer le cadre juridique du fonctionnement d'un tel centre, une recherche documentaire a été effectuée. Les services du Journal Officiel de la République de Côte d'Ivoire, les archives de l'Institut Pasteur de Côte d'Ivoire ont été consulté. De plus une recherche en ligne via Google Scholar a été réalisée afin de rechercher les textes réglementaires et éthiques existant sur la question de la gestion des ressources biologique en Côte d'Ivoire.

Résultats : Les indicateurs ont permis de définir des activités de stockage sécurisé des échantillons biologiques issus soit des soins, soit des activités de surveillance, soit de la recherche et un pool technologique consistant en l'identification Malditoff et en l'encapsulation d'acides nucléiques. L'analyse documentaire a permis de mettre en évidence la législation, les recommandations nationales existantes. Un total de 12 textes ont été retrouvés parmi lesquels 6 concernaient les aspects réglementaires liés à l'activité et à l'encadrement des biobanques. Quatre documents faisaient référence à des lois portant sur la protection de données à caractère personnel et individuel, tandis que deux documents étaient relatifs à l'éthique et à la protection de la vie privée. Toutefois, aucun document faisant allusion à la bioéthique n'a été retrouvé.

Conclusion : Cette étude met en évidence la nécessité de légiférer sur les conditions de fonctionnement d'un centre de ressources biologiques, de constitution et de déclaration des collections dans le cadre de la recherche et sur la bioéthique.

Dr Simini Doumbia is Head of Department of biological resources / BioBank, Researcher Public Health-Epidemiology at the Institut Pasteur de Cote d'Ivoire. She is currently enrolled in a PhD in Human and Tropical Biology, theme: "Research in public health: development of a biological resource Centre in a country with limited resources: case of Côte d'Ivoire, Abidjan DEA in Public Health and Developing Countries, Paris VI University Diploma in Biobanking and human Biological Resources, Amiens Free listener :Degree in Biological and Medical Engineering: Development of Applied Research and Biomedical Innovation, Paris VI Development of knowledge on «Land transport of dangerous goods» , Paris Creation and management of databases in Microsoft Access and Epidata, Paris Legal and regulatory obligations of a Biological Resource Center, 3C -R Training Paris MS of Biological and Medical Sciences, Toulouse

Latest Zika virus outbreak: Lessons learnt from the perspective of the "European Virus Archive goes Global (EVAg)" EU funded consortium

Dr Christine Prat, Aix-Marseille University, France

Zika virus (ZIKV) has emerged in the Americas in February 2014 on Easter Island, Chile, and has since been causing an unprecedented outbreak in several countries in the Americas. In May 2015, PAHO issued an alert for the first confirmed case of Zika virus infection in Brasil, and on the 1st of February 2016, WHO declared a Public Health Emergency of International

Concern (PHEIC). In this context, the "European Virus Archive goes Global", EVAg, a non for profit EU consortium grouping virology biobanks worldwide, distributed more than 300 ZIKV related products.

The main mission of EVAg is the development and maintenance of a large biological resource of authenticated viruses and related products in order to facilitate their access to both academics and industries. Together with this mission, one of the EVAg goals is also to support Public Health response during viral outbreaks. The Zika outbreak EVAg coordinated response was to propose a set of products available via its online catalogue, among which WHO recommended its Zika standards for use in molecular detection.

A unique web based entrance for the request of viruses and derived products developed by several EVAg members allows a retrospective analysis of the demand. During the ZIKV outbreak, more than 300 products were distributed worldwide, the majority in the first trimester of 2016, with a peak in February, immediately following the WHO PHEIC declaration. We will present a thorough analysis of the EVAg products end-users, their geographical localization, the type of organization they belong to, their domain of activity, as well as their intended use. This analysis might reflect the concerted worldwide actions or individual initiatives, as well as highlight that preparedness is key to face a viral emergence.

After a PhD studying the impact of a replicating virus on synaptic plasticity in Toulouse, France, **Dr Christine Prat** worked for 2 years in diagnostic biotechnology companies in Oxford, UK, specialising in Knowledge Transfer between academia and industry. She then took the position of Deputy Director of the french National Reference Center on Arboviruses, in Marseille, France, at the Armed Forces Biomedical Research Institute. In 2015, she joined the H2020 funded European Consortium "the European Virus Archive goes Global, EVAg", as a Business Developer.

@EVAg_EU
https://www.european-virus-archive.com/

Annex: Biographies: Participants

Professor Akin Abayomi is the Chief Pathologist and Head of the Division of Haematology at the University of Stellenbosch, South Africa (www.sun.ac.za/haema). He studied at the Royal Medical College of St Bartholomew's Hospital at the University of London where he attained his first graduate degree in Medicine. He went on to specialize in Internal Medicine and Haematology, obtaining fellowships from the Royal College of Medicine and the Royal College of Pathologists of the United Kingdom as well as the College of Medicine of South Professor Abayomi has worked in several countries around the world in both Internal Medicine and Haematology. His focus has mainly been on the complications of HIV and the development of laboratory and clinical capacity to rise to the challenge of the HIV epidemic in the developing world and Africa. He is the PI to the Tygerberg Lymphomas Study Group and the Global Emerging Pathogens Treatment Consortium (www.getafrica.org) and a member of the H3Africa and B3Africa consortia. Akin Abayomi is the Director of the NHLS Stellenbosch Cape Town Biobank. He is also interested in the impact of climate change on health and the footprint of humanity on Africa, ecological integrity and human-wildlife interaction.

Professor Alash'le Abimiku, is a co-founder and the Executive Director of the International Research Centre of Excellence (IRCE) at the Institute of Human Virology Nigeria (IHVN), and a Professor at the Institute of Human Virology, University of Maryland School of Medicine, Baltimore; She has over 2 decades of establishing laboratory infrastructure and science in Nigeria with long-term collaborations with the USA. Prof. Abimiku's research focuses on the role of HIV subtypes in disease pathogenesis using mother to child model; and effects of co-infections such as TB on HIV pathogenesis as a successful independent researcher. Prof. Abimiku has trained a cadre of Nigerian scientists and is internationally recognized for her leadership in HIV research, and in promoting laboratory diagnostics and medicine in Africa. She currently serves as a member of the international scientific advisory group for University of Cape Town, and as Board chair of the African Society of Laboratory Medicine.

Dr Muna Affara Morrill has have spent the past 8 years working in the MRC Unit the Gambia (MRCG), as the manager of the malaria laboratory and the Deputy Head of Laboratory Management. This involves the coordination and management of the lab work across multiple studies. With 8 years of experience working on varied malaria projects within the sub region, I have a good grounding in both the field and molecular work surrounding the investigation of asymptomatic malaria infections, as well as working on a number of clinical trials investigating novel drug and vaccine candidates. In the laboratory we run a shared platform service for all projects and we are now aiming to establish a laboratory information management system (LIMS) to link our field, lab and biobank. I will soon be moving to work on a new project, coordinating the deployment of nine mobile labs across the East African Community Countries, to establish an early outbreak response network to epidemic diseases in East Africa. Mobile data capture from remote areas and a functional LIMS to link the mobile laboratories, will form an integral part of this project.

Dr Dominique Anderson is currently a Post-doctoral fellow at SANBI and is involved in the B3Africa project, working on Baobab LIMS and community engagement with respect to biobanking. She has a PhD in Biochemistry and has previously worked in R&D in the Biotechnology industry. I have a keen interest in project management and training individuals.

Mr Suyesh Amatya has a background in computer and software engineering. He mainly works in the areas of biobanking and research management, LIMS, bio-resource cataloguing, integration of heterogeneous databases and unstructured date, experienced in developing informatics systems for health sciences, etc. He works as a System Developer at Karolinska Institutet.

Ms Deborah Boateng has a BSc Biochemistry. She is a laboratory Scientist at the Peace and Love Hospital, based in Kumasi, Ghana and a member of Breast Care International. Ms Boateng is also a member of the Ghana Medical Laboratory Scientists, the BCNet and IBCN.

Ms Anja Bedeker has a background in the Social Sciences. I have degrees in Psychology and Psychometric assessment and I am a registered Psychometrist with the Health Professions Counsel of South Africa. I am currently employed as a research associate at the South African National Bioinformatics Institute (SANBI). I am responsible for creating, assisting and implementing SANBI's biobank community engagement projects. I am also responsible for designing and implementing research designs and assessment measures to assess the effectiveness of our community engagement projects and using those results to improve the community engagement tools.

Ms Anouk Berger has a master's in Learning and Teaching Technologies as well as in Biology and Medical Biology. She is Head of the Education and Training Group at IARC since 2012, where she promotes, coordinates and manages an integrated portfolio of fellowships and courses, in support to the Agency's educational mission and research program. Ms Berger associates a mixed background in biology and educational technologies with 20 years of experience in research laboratories, in the academic field as well as at the WHO and IARC. She combines expertise in the different disciplines that are required for the design and implementation of strategies for training and development of human resources in public health and biomedical sciences. Ms Berger has a wide experience in the conception, development and implementation of training materials, courses and programs in the fields of microbiology, medicine, epidemiology and public health. She has a particular interest in e-learning.

Mr Oskar Danielsson has a Bachelor's degree in Cognitive Science from Linköping University, Sweden. Since 2014 he is working at Hariett AB, a company working with eLearning and IT pedagogy, where he design and develop eLearning courses, apps and manage Learning Management Systems. In 2017 he joined the B3Africa team at Sveriges Lantbruksuniversitet (SLU) in Uppsala as a developer.

Dr Elodie Caboux completed higher degree studies in Biology (PhD) at Ecole Pratique des Hautes Etudes, Paris in 2012. In addition to her background in molecular biology, Dr Caboux has 15 years' experience in biobanking. Dr Caboux joined IARC in 2001 and is the IARC biobank processes management assistant since 2014. She has expertise in biospecimen identification, collection, processing, management and storage as well as related and associated data collection and management. She is accredited for international air transport of biological samples since 2005 (International Air Transport Association, IATA). She is providing support to IARC scientists and collaborators and is participating to technical and practical training to members of the Biobank and Cohort Building Network (BCNet) established and coordinated by IARC since 2010. Dr Caboux has expanded her interest in high quality sample procurement. She is interested in preanalytical issues related to biobanking and is involved in Standards Operating Procedures development. Ethical and Legal Issues is of important in her daily missions to ensure the proper use and transfer of samples. Dr Caboux is part of the development team of the IARC informatic system for management of sample that is regularly upgraded according user's needs and requirements. Dr Caboux is the IARC representative for BBMRI-ERIC in the CEN/TS and QMS expert committee.

Mr Faghiri February is a Senior Technical Officer in the Department of Haematology, Faculty of Medicine and Health Sciences, Stellenbosch University. He completed an MSC in Biotechnology at the University of Western Cape in 2003. Over the past 10 years he has worked on various research projects with a focus on human and cancer genetics. In addition to research, he has taught various undergraduate programs in Biotechnology, Genetics and Bioinformatics, mostly but not limited to the Human Genetics Focus Area (2007-2014). He has also taught modules at post-graduate level at both the University of Stellenbosch (2010-

2014) and University of the Western Cape (2007-2009). These include Introductory Bioinformatics and Gene expression in Human Disease. In 2014, he taught specific components on Biotechnology and Transcriptomics in Cancer to Non-Biology MSc students in Nanotechnology in the NanoSchool at the University of Western Cape. He has co-authored 6 peer-reviewed articles and has presented various courses and seminars on Gene Expression in cancer, Introductory Bioinformatics and Transcriptomics. As a Senior Researcher at GENEdiagnostics in 2015-2016 he was involved in the training of DST interns, and presented courses to Undergraduate students on Basic Molecular Biology Techniques and Bioinformatics during university holidays. He was also involved in the planning and development of new genetic test for diseases. In his current position in the division is responsible for Data Security and QC. As part of the B3Africa consortium he has been involved with our software developer partners at the South African National Bioinformatics Institute (SANBI) with the testing of our new Baobab LIMS system (WP3 – LIMS in a box as a part of the B3Africa Consortium). In addition, he acts as research advisor to post-graduate students and frequently gives lectures and seminars to resident MMED students and registrars in the Haematology Department.

Dr Florian Gehre holds a microbiology degree from the Humboldt University of Berlin, Germany, and did his PhD work at The Rockefeller University, New York, USA. Following his PhD, he pursued a Master in Public Health (MPH) at Imperial College, London. From 2011-2017 he was a Postdoctoral Researcher at the Medical Research Council Unit the Gambia (MRCG) and the Institute for Tropical Medicine (ITM) in Antwerp, Belgium. His research in Gambia focused on tuberculosis and the transmission dynamics of *Mycobacterium tuberculosis* and *M. africanum* in West Africa. This includes household-based as well as population-based transmission to measure the transmission blocking effects of public health interventions (such as Enhanced-Case-Finding) on community TB transmission. Moreover, he is an active member of several West African capacity building networks that monitor drug-resistance in the region. Since September 2017 he is employed by the Bernhard-Nocht-Institute for Tropical Medicine (BNITM), Hamburg, Germany. In his current position he supports the East African Community (EAC) to establish a mobile laboratory based early outbreak detection network to identify epidemic-prone (viral) diseases in Kenya, Tanzania, Rwanda, Uganda, Burundi and South Sudan.

Mr Mwangi Kamau is a Biorepository Technical Assistant at ILRI Kenya. His duties entails storing and retrieving samples, generating barcodes for sample I.D's, Liquid nitrogen dispatch to Research associates and Scientists, Assisting in field work activities and data collection, Maintenance of Various vaccines in small Dewar tanks and updating the Azizi Lab collector portal after conducting samples audit.

Mr Kekuta Kandeh is an IT professional with qualifications in Microsoft, VMware and Cisco systems. He has more than 15 years of computer support experience. His role as an IT Client Support Specialist for MRCG Unit the Gambia is to support and manage computer hardware and network systems for the MRCG unit. Kekuta is the IT lead for the MRCG collaboration with BCNET/B3Africa in the implementation of the Eb3kit/Baobab LIMS system for the Biobank.

Dr Tomas Klingstom received his postgraduate education at the SLU Global Bioinformatics centre at the Swedish University of Agricultural Sciences. In 2011 he obtained his MSc degree in Molecular Biotechnology engineering at Uppsala University which he combined with studies in law and economics. His current work is focused on developing the bioinformatics component of the eB3Kit to provide a comprehensive platform for data management and analysis, thereby enabling researchers to better manage quality and privacy concerns in high throughput omics research. Tomas won the Anders Wall scholarship for the young researcher of the year in 2010 as well as national awards for engineering student of the year and the economics student of the year in 2011.

Dr Rita Lawlor is a graduate of Trinity College Dublin with a doctorate in Oncological Pathology from the University of Verona where she was the co-founder and coordinator of the ARC-NET (www.arc-net.it) cancer research centre at the University of Verona, Italy. She is director of the ARC-Net biobank and coordinates the biobank activities for national and international projects. Dr Lawlor manages the Italian effort within the International Cancer Genome Consortium (www.icgc.org) for pancreas cancer and is co-PI for the European funded project on "Integrative Analysis of Gene Functions in Cellular and Animal Models of Pancreatic Cancer" (http://www.cam-pac.eu/) and "Biomarkers of tumour recurrence in pancreatic cancer" (Bio-Pac). She is part of the working group to define the standards for Research Biobanks of the Veneto Regional Government of Italy and the joint AIOM-SIAPEC, scientific Italian societies of Oncology and Pathology, commission to define biobanking for cancer research. She is a member of the board of directors of ISBER, International Society for Biological and Environmental Repositories (www.isber.org) and is past president of ESBB, the European, Middle Eastern and African Society for Biopreservation and Biobanking (www.esbb.org) where she started the African Biobanking working group. Her current research interests are in molecular diagnostic markers and therapeutic targets and the role of cancer heterogeneity and molecular characterization of samples in the application of individualised medicine.

Ms Wibke Loag has a Diploma in Health Information Management from the Hochschule Hannover - University of Applied Science and Arts, Germany. She commenced her Masters in Medical Informatics (MSc) at the Beuth University of Applied Science Berlin, Germany in October 2016. In 2002 she started her profession as a data manager in cancer research at the University Hospital Hamburg-Eppendorf (UKE) in Mammary Carcinoma Risk Factor Investigation (MARIE). She joined the Department of Infectious Disease Epidemiology at the Bernhard-Nocht-Institute for Tropical Medicine (BNITM) in Hamburg in 2005. At the BNITM she takes care of several epidemiological studies on febrile illnesses in African children, where she develops, programs and manages study databases. She collaborates closely with colleagues from the African cooperation partner Kumasi Center for Collaborative Research in Tropical Medicine (KCCR) as well as from different hospitals in the Ashanti Region, Ghana. Since the BNITM implemented the software Mysamples 2.0 as a Laboratory Information Management System (LIMS) in 2013 she is experienced in establishing, administering and maintaining the software. In an upcoming project the BNITM supports the East African Community to establish a mobile laboratory-based early outbreak detection network to identify epidemic-prone (e.g., viral) diseases in Kenya, Tanzania, Rwanda, Uganda, Burundi and South Sudan. In this project she is responsible to establish and maintain a decentralized LIMS.

Ms Mantombi Maseme is a South African medical scientist who holds two B. Med. Sc. Honours degrees from the University of the Free State. Her career started at the National Health Laboratory Service (NHLS) Universitas academic hospital in Bloemfontein where she later completed her medical science internship in microbiology. Mantombi has been working in various positions as a medical scientist, with experience in routine laboratory diagnostics in line with Quality Management Systems (QMS) of medical laboratories as well as research positions. These include positions at the NHLS mycobacteriology referral laboratory in Braamfontein mainly stationed in the molecular tuberculosis (TB) testing section, a position at the National Institute for Communicable Diseases' (NICD) Special Bacterial Pathogens Reference Laboratory and the current position where she is based at the National Institute for Occupational Health's (NIOH) Biobank department. Mantombi also spent 3 years in laboratory technical support and medical sales where she worked at Hain Lifescience South Africa and Aberrant Medical supplies, respectively. Her career interests are biobanking, infectious disease and drug research as well as bioethics and health systems regulations.

Mr Ziphozakhe Mashologu has been at the forefront of development, enhancement, integration, and delivery of web based solutions that fit various unique business requirements, and has accomplished that through valuable knowledge and experience gained from over a decade in the ICT industry. He prides himself with the ability to effectively master the interactions between applications, data, processes and people. Specialities: Deliver professional Web 2.0 designs; Advanced application development (Python/PHP/JAVA etc.); Opensource consultation and solutions; Business intelligence

Dr Michaela Th. Mayrhofer is a political scientist and historian educated in Vienna, Louvain-la-Neuve, Essex and Paris. Prior to her involvement in BBMRI-ERIC, she was investigator in several national and international research projects focusing on the politics of biotechnology and the life sciences. Her academic career led her to various positions and stays at the Centre de Recherche Médecine, Sciences, Santé et Société, the University of Vienna, the Institute of Technology and Society Studies at the Alpen-Adria-Universität Klagenfurt/Vienna/Graz, the Technical University of Vienna, the Fondation Brocher and the Medical University of Graz. Currently, she serves as BBMRI-ERIC's Chief Coordination & Policy Officer.

Mrs Roxana Merino Martinez has a background in computing engineering and informatics with expertise in bioinformatics, LIMS, IT infrastructures and teaching. She is currently working as Project Manager at the Karolinska Institute and participates in several EU projects related to biomedical research infrastructures. Mrs Merino Martinez leads Work Package 7 "Use Cases" which implements a proof of concept for the B3Africa project in African and European biomedical research institutions. This project will potentiate biomedical research collaboration in principle, between EU and Africa but it can also open the door to more effective international research collaboration in the areas of biobanking, bioinformatics and ELSI. The same concept could be implemented, for instance, in Asia and South America, making a great contribution to a global and efficient use of valuable bio-resources and knowledge on human diseases.

Ms Dominique Meunier is a Canadian Project Manager holding a master's degree in International Studies and relying on 15 years in the health sector, including 9 years at the international level (humanitarian assistance, development and research). Capacity building has been a core element of her professional journey. She provided coaching and on-the-job training to health professionals in different countries, in the frame of humanitarian projects. She also designed and facilitated training courses and programs for humanitarian workers on project management as well as on transversal issues, such as gender and disability/ vulnerability. Ms Meunier joined the WHO-International Agency for Research on Cancer in 2015, where she currently contributes to the management of training and dissemination activities for the B3Africa and the BCNet projects.

Ms Dina Mofed Ibrahim has a Master's from Cairo University and is currently a medical laboratory scientist at the Al-motamyez Lab in the microbiology, immunology, clinical chemistry and haematology units. She is also one of the members of the Egyptian biobank at the National Cancer Institute and is collaborating in preparation of the joint SIOP (International Society for Pediatric Oncology) with the institute in the management protocol of Wilms Tumor. Dina is also a teaching assistant at the Arab Academy of Advanced Science and Technology.

Dr Heimo Muller studied mathematics in Graz and Vienna, concluding with a thesis on data space semantics. He then worked on data visualisation at Joanneum Research, and lectured in MultiMediaArt at the University of Applied Sciences in Salzburg. As Marie Curie fellow, I worked at the Faculty of Arts of the Vrije Universiteit Amsterdam in an interdisciplinary program on word and image studies. From 1999-2004, I was head of the Information-Design program of the University of Applied Sciences FH Joanneum. At the Medical University of Graz I developed an interactive data exploration system and investigated large inhomogeneous clinical data collections. I am currently principal researcher in the areas of data modelling and information visualization in several national and EC funded projects (RD-Connect, BBMRI-ERIC CS-IT and B3Africa).

Mrs Petronilla Ozumba is a Program Manager with the Institute of Human Virology Nigeria. A medical laboratory scientist with over 15 years of experience, she coordinates and provides managerial oversight and supervision of IHVN 3 biorepositories, providing mentoring and capacity building of staff on molecular techniques and sample management and tracking. She participates in IHVN's CDC-funded pre and in-service laboratory training program as a master trainer. She manages specimen and associated data using Freezerworks 2015 software and supports specimen processing and archival for research and projects. She currently manages the IHVN Human Heredity and Health in Africa (H3Africa) biorepository (I-HAB). In this capacity her role has expanded to include coordination and managerial oversight of IHVN and I-HAB biorepository activities.

Mr Campbell Rae is currently employed as a software developer at the South African National Bioinformatics Institute, but his portfolio extends to more creative endeavours as well. An experienced artist and 3D animator since 1993, Campbell's many creative pursuits have come from his early days as a cartoonist and art training at school. Following school he realized the early stages of computing the potential that digital tools had for creativity and that has led him to a 20+ year career in the film industry. He is an experienced photographer and scriptwriter and coming from an animation background easily transitioned to directing and filming or short films and commercials. He currently handles most of the creative work that needs design, photography, animation and video whether for online use or printed. In his spare time he tries to play chess and electric guitar and composes old 8bit classic video game style music.

Jane Reichel is a professor in Administrative Law at the Faculty of Law at Uppsala University and is since 2011 tied part-time to CRB. She is currently vice dean and chairman of the research committee at the Faculty of Law. Jane's research focuses on the ongoing processes of globalization and Europeanization and its effect on administrative law, the legal discipline dealing with public authorities and their role in the society as well as their relations with individuals. Administrative matters can no longer be addressed solely within one nation state at the time. In her research Jane addresses how this development affects the role of authorities and how administrative rules are to be applied in an international context. How can administrative ideals of efficiency, transparency and legal certainty in decision-making be achieved? How can command and control over administration function in a network of agencies acting beyond the state? An area of specific interest is cross-border data protection, especially medical research and biobanks. The ability of new technology to

collect, store and share large amounts of information gives rise to opportunities and challenges, which necessitates administrative solutions that apply across borders.

Dr Robert Reihs works in the field of bioinformatics with the focus in the field of biobanks and patient registries. His focus is to help structure the data in this field and make the area interoperable. He is part of Work Package 2 "Integration" of the B3Africa project, building the BiBBOX environment. His vision in this project is to provide an integrated system for biobanks, helping especially small and new biobanks to select the best tools for their needs and structuring the data so that they are easy to use in later research.

Dr Lidia Ryabova, has a clinical Master's degree in Opthalmology. She currently works at the Malta Biobank with a special interest in Information technology.

The Malta BioBank

The Malta Biobank was developed in the context of Thalassemia project and neonatal screening program jointly between University of Malta and Malta Department of Health.

It is the national node (BBMRI.mt) in Bio-Banking and Bio-Molecular resources research Infrastructure, European research infrastructure Consortium BBMRI-ERIC (www.bbmri-eric.mt) of the European Union (EU). The biobank now forms part of the new inter-faculty Centre of Molecular Medicine and Biobanking at the University of Malta. It is founding partner in EuroBioBank (www.eurobiobank.org) and RD-Connect (www.rd-connect.eu) and associated partner in EURenOmiccs (FP7) (www.eurenomics.eu).

It strategically positioned to engage neighbouring Mediterranean countries in bio-banking thought BBMRI-ERIC's Euro-Mediterranean Engagement Working Group (WG3), and new Co-operation for Science and Technology (COST) Action in Euro-Mediterranean countries.

Dr Carmen Swanepoel is a trained molecular biologist and currently a Principal Medical Scientist within the Division of Haematopathology and jointly appointed by the National Health Laboratory Services (NHLS) and Stellenbosch University (SU) at Tygerberg Hospital, Western Cape, South Africa. I've been concerned with research, the development of diagnostic laboratory tests, the teaching and training of staff and students in laboratory skills, managing research funds, projects as well as quality management. I've also been involved in the development and am currently overseeing the research and training flow cytometry laboratory, cell culture facility and the NHLS/Stellenbosch University Biobank (NSB) within the faculty's Pathology department. The bulk of my time I fulfil the role of scientific and operational manager of NSB. I oversee the day to day biobanking operations in association with other research and technical staff. Over the years I've also gained expertise in other biobank and genomic related operations ranging from governance, ethics, LIMS, sample and data protection, sample QC, risk management and Quality Assurance through to sustainability. Promoting the science of biobanking and genetics within South Africa and the rest of Africa is a key mission of NSB and we as a group are involved in various projects associated with biobanking, cancer and genetic research especially room temperature storage technologies. Other research interest includes molecular applications in leukemia and lymphoma diagnosis as well the role of epigenetics particularly miRNA's in haematological pathologies.

Ms Santa Slockenberga received her LLD in medical law in November 2016. Her research focuses on the coexistence of the EU and Council of Europe in regulating health-related direct-to-consumer genetic testing. Currently, she is a legal expert in B3Africa project and works towards bridging biobank research in Europe and Africa. In addition, she has been teaching in the fields of EU law and medical law and since 2011, she is lecturing in several medical law related subjects at Riga Stradins University (Latvia) for both undergraduate and graduate students, including supervision and teaching at Uppsala University. Since 2014, Santa Slokenberga teaches the summer school course "Comparative human rights in healthcare" at Yale University. Prior to starting her doctoral studies, Santa Slokenberga worked as a legal advisor for Deloitte Latvia.

Ms Mandile Samantha Thobela is a Medical Biological Scientist in Microbiology, registered with the Health Professions Council of South Africa (HPCSA). She worked as a Medical Scientist at the Centre for Enteric Diseases at the National Institute for Communicable Disease (NICD), a division of the National Health Laboratory Service (NHLS). She holds a Master of Science in Medicine (MSc. Med) which she obtained from the University of the

Witwatersrand, with a Dissertation entitled "Characterization of *Campylobacter* isolates from a South African population". She recently became appointed as a Medical Scientist at the National Biobank at the National Institute for Occupational Health (NIOH), NHLS. Her professional interests lie in Medical Research, where the advent of technology can be exploited to fill the current existing research gaps, which can alleviate the high burden of morbidity and mortality in the country.

Ms Tooba Ulhaq is currently enrolled at the University of Malta as a student of Bachelor of Science in Networking and Computing. Her target goal being proficient at primary technology is that she must also be knowledgeable in the latest technologies about my areas of studies as Java programs, understanding of database design and database stored procedures, general knowledge of software development, software testing, and the other major professional disciplines which are needed to make different projects a success.

Annex: Program

IARC-BCNet Symposium

From Biobank Infrastructure to Research: How BCNet Member Biobanks and Cohorts Are Contributing to Address Public Health Concerns

AGENDA

IARC, 27-28 November 2017

Monday 27 November 2017

Chair: Dr Maimuna Mendy

08:15-08:45 Registration

09:00-09:50 Introductions

Welcome to IARC (10′)	Dr Christopher Wild International Agency for Research on Cancer (IARC), France
The BCNet Journey: From Biobank Training to Resources Sharing and Research Collaborations (15′)	Dr Maimuna Mendy BCNet, France
Landscape of Biobanking (15′)	Ms Marianne K Henderson National Cancer Institute (NCI) United States of America
Overview of the Symposium (10′)	Ms Anouk BERGER IARC, France

09:50-10:30 Ethical, Legal and Social Issues in Biobanking

REECAO: an EDCTP2 Network of National and Institutional Ethical Committees in West Africa (10′)	Pr Emmanuelle Gormally Ecole Supérieure de Biologie-Biochimie-Biotechnologies Université Catholique de Lyon, France
ELSI Issues of Biobanking in Nigeria– Implications of Social Norms (a Pilot Study) (10′)	Dr Olukemi K Amodu Institute of Child Health, College of Medicine, University of Ibadan, Nigeria
Questions and Answer (20′)	

10:30-11:00 Coffee (30′)

11:00-12:30 Biobank for Research

Biobanking for Research: Steps Toward Success (20′)	Ms Marianne K Henderson National Cancer Institute (NCI) United States of America
The Role of Biobank in the Development of Algorithm for Nasopharyngeal Carcinoma Screening in Indonesia (10′)	Dr Jajah Fachiroh Faculty of Medicine, Universitas Gadjah Mada, Indonesia
Les Néphroblastomes au Sénégal (French presentation) (10′)	Ms Aïssatou Ndiaye Hôpital Général de Grand Yoff, Sénégal
Cancer Biobank of the Egyptian National Cancer Institute: Establishment and Role in Study of Breast Cancer Stem Cells (10′)	Dr Iman Farahat National Cancer Institute, Cairo University, Egypt
Questions and Answers (40′)	

Annex: Program

12:30-12:45	Announcement: The African Biobank Survey	Professor Alan Christoffels South African National Bioinformatics Institute, University of the Western Cape, South Africa
13:00-14:00	Lunch – Cafeteria	
	Chair: Dr Rita LAWLOR	
14:00-14:40	Back from lunch exercise	Ms Anouk Berger and Ms Dominique Meunier, IARC, France
	Preparation for the group discussions What are the opportunities for moving from biobanking activities to research?	Ms Marianne K Henderson National Cancer Institute (NCI) United States of America
14:40-15:30	Biobanking and Genetics	
	Impacting Africa's Development Through Strengthened Research Ecosystems: The Role of the Alliance for Accelerating Excellence in Science in Africa (AESA) (10')	Dr Jenniffer Mabuka-Maroa The African Academy of Sciences, Kenya
	Validation of Genome Wide Association Studies of Hepatocellular Carcinoma in Egyptian Population (10')	Professor Sameera Ezzat National Liver Institute, Egypt
	Questions and Answers (30')	
15:30-16:00	Tea (30')	
16:00-17:10	IT for Biobanking and Research	
	Data Management and LIMS strategy for the Ebola Biobank Samples to Promote Research in Sierra Leone (10')	Professor Sahr Gevao Global Emerging Treatment Consortium (GET), Sierra Leone
	Bridging the Research Gap with Effective Data Collection Toolkit: Addressing Breast Care International Biobank Challenges in Breast Cancer Control in Ghana (10')	Mr Isaac Ewuah Mensah Breast Care International Peace & Love Hospital, Ghana
	The BCNet Catalogue: From Data Collection to Research (10')	Mr Ny Haingo Andrianarisoa IARC, France
	Questions and Answers (30')	
17:10-17:30	Closure of the day	

Annex: Program

Tuesday 28 November, 2017

Chair: Ms Marianne HENDERSON

09:00-10:20 Biobank Organisational Challenges and Quality

Polish National Biobanking Node – Fresh Ideas for Biobanking in Wroclaw Research Centre EIT+ (10')	Dr Irena Dus-Ilnicka National Biobanking Node, Wroclaw Research Centre EIT+, Poland
Centre de Ressources Biologique (CeReB) de l'Institut Pasteur de Côte d'Ivoire : Stratégies d'organisation (French presentation with English support) (10')	Dr Simini Doumbia Institut Pasteur de Côte d'Ivoire
Latest Zika virus outbreak: Lessons learnt from the perspective of the "European Virus Archive goes Global (EVAg)" EU funded consortium (10')	Dr Christine Prat Institut de Recherche pour le Développement, Ecole des Hautes Etudes en Santé Publique, Aix-Marseille University, France
Questions and Answers (40')	
Introduction to the Group Discussions (10')	Ms Marianne K Henderson National Cancer Institute (NCI) United States of America

10:20-10:30 Group Picture

10:30-11:00 Coffee

11:00-12:30 Opportunities for Moving from Biobanking Activities to Research

Group Discussions:

What are the opportunities for moving from biobanking activities to research?

Group work 40'

- What are the burning research questions you would like to investigate?
- How would you approach them?
- What are the challenges, but most importantly, the opportunities related to these questions?

Report from each group 50'

Ms Marianne K Henderson
National Cancer Institute (NCI) United States of America

Dr Elodie Caboux
IARC, France

Dr Rita Lawlor
ARC-Net Centre for Applied Research on Cancer, University of Verona, Italy

12:30-13:00 Symposium Conclusions: wrap up and next step — Dr Maimuna Mendy, BCNet, France

13:00-14:00 Lunch – Cafeteria

Annex: Program

B3Africa Training Workshop

AGENDA

IARC, 28 November- 1 December 2017

Chair: Ms Anouk BERGER

Tuesday 28 November, 2017

14:00-14:15	Overview of the Workshop	Ms Anouk Berger IARC, France
	Welcome to the B3Africa Training (virtual presentation)	Professor Erik Bongcam Rudloff Swedish University of Agricultural Sciences, B3Africa Coordinator
14:15-14:50	The B3Africa Project and the eB3Kit (15')	Ms Roxana Merino Martinez Karolinska Institutet, Sweden
	B3Africa and Beyond (20')	Professor Akin Abayomi National Health Laboratory Service/ Stellenbosch University, South Africa
14:50-15:00	Questions and Answers	
15:00-15:30	Legal Perspectives to Data Security and B3Africa Solutions (30')	Professor Jane Reichel & Dr Santa Slokenberga Uppsala University, Sweden
15:30-16:00	Tea	
16:00-17:00	Practical Session: Towards Building an ELSI Checklist for Biobank Research (60')	Professor Jane Reichel & Dr Santa Slokenberga Uppsala University, Sweden
17:00-17:20	Ensuring that Quality is Front and Center for Biorepositories in Africa	Professor Alash'le Abimiku Institute of Human Virology, Nigeria
	Questions and Answers	
17:20-17:50	The eB3Kit – IT infrastructure and APPs (10') The eB3Kit – Roles and Permissions (10') Questions and Answers	Mr Wangoru Kihara International Livestock Research Institute, Kenya Dr Heimo Müller Medical University of Graz, Austria
17:50-18:00	Closure of the day	
18:00-19:30	Welcome Reception	IARC Cafeteria - ALL

Annex: Program

Wednesday 29 November: Parallel Sessions

	Users Room Sasakawa A&B	IT Room R08
09:00-10:30	**The Document Store Application & Ethics** • Presentation of the eB3Kit's document store application; • Example of a structure and of documents to be included; • Demonstration of how to upload document and create folders/subfolders; • Practical exercise: log-in to your document store, create folders and upload a documents; • Report on issues and share ideas	Installing and configuring the BiBBoX
10:30-11:00	Coffee	

11:00-13:00	**Azizi Mobile Data Collection Tool**
	• Presentation: AZIZI mobile data collection tool (30')
	• Demonstration (30')
	• Practical Exercise (Auditorium) (60')
	  ○ Upload ODK on your mobile device
	  ○ Access new forms
	  ○ Fill in questionnaires
	  ○ Submit collected data
		Installing and configuring the BiBBoX

13:00-14:00	Lunch – Cafeteria	
14:00-15:30	**Azizi Mobile Data Collection Tool** • Practical Exercise ○ Extract data (export to Excel) • Report on issues and share new ideas • Questions and Answers	Installing and configuring the BiBBoX
15:30-16:00	Tea	
16:00-17:30	**Baobab LIMS** Demonstration and Exercises: set-up (manually) Baobab LIMS • Set up mail settings • Set up the laboratory parameters (including creating users, roles and permissions) • Set up suppliers' parameters • Set up instruments' parameters (including QC results, calibration certificates, etc.) • Set up the storage parameters • Set up the analysis category • Set up the sample type parameters • Set up other parameters • Create kits • Report on issues and share new ideas	Installing and configuring the BiBBoX

Annex: Program

Thursday 30 November, 2017: Parallel Sessions

	Users Room Sasakawa A&B	IT Room R08
09:00-10:30	**Baobab LIMS** Demonstration and Exercises: Use Baobab LIMS • Add a client (PI or research group) • Add a project/study • Link to the study ethical approval and consent forms in the document store. • Add new kits • Set up shipment • Register biospecimens • Create a storage request • Create an analysis request • Perform analysis • Capture result- Generate reports • Demonstration: data import from an Excel sheet • Report on issues and share new ideas	Installing and configuring the BiBBoX
10:30-11:00	Coffee	
11:00-13:00	**Baobab LIMS (continued)**	Installing and configuring the BiBBoX
13:00-14:00	Lunch	
14:00-15:30	**STATegra Experiment Management System (EMS)** Demonstration and Exercises: • Create/annotate a study • Import data from Baobab LIMS • If no LIMS in place, annotate samples • Set up the analysis parameters • Search for a study/samples • Report on issues and share new ideas	Installing and configuring the BiBBoX
15:30-16:00	Tea	
16:00-17:30	**Galaksio** Demonstration and Exercises: • Send data from STATegra to Galaxy • Analyse data on the Galaxy server using Galaksio • Search for a bioinformatics workflow using the Galaksio interface • Create a dataset collection • Input data to the workflow • Adapt the parameters • Run the workflow	Installing and configuring the BiBBoX
19:00	Dinner	All

Annex: Program

Friday 1 December, 2017

	Users Room Sasakawa A&B	IT Room R08
09:00-10:30	**Galaksio (continued)** • Download the data that has been produced • Discuss/analyse the output files from the workflow • Report on issues and share new ideas	Installing and configuring the BiBBoX
10:30-11:00	Coffee	
	Users & IT Room Sasakawa A&B	
11:00-13:00	Training Evaluation Debriefing of both streams Conclusions and Certificates	
13:00-14:00	Lunch	
14:00	End of the training	