Lessons learned from the BCNet catalogue – pilot phase

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BCNet initiative

- Biobank and Cohort building Network
- Low- and Middle-Income Countries (LMICs)

Outline

- BCNet introduction
- BCNet catalogue
- Pilot phase
- Feedback
- Conclusions
- Acknowledgement
BCNet actors: 33 LMIC members

BRAZIL: Barretos Cancer Hospital; CAMEROON: Faculty of Medicine and Biomedical Sciences, Université de Yaoundé; Université des Montagnes; CÔTE D’IVOIRE: Institut Pasteur de Côte d’Ivoire; EGYPT: Children’s Cancer Hospital Egypt — 57357, Faculty of Medicine Cairo University, Medical Research Institute Ain Shams University, Medical Research Institute Alexandria University, National Cancer Institute, National Liver Institute, South Egypt Cancer Institute Assiut University; ETHIOPIA: Jigjiga University; GHANA: Breast Care International, University of Health and Allied Sciences; INDONESIA: Faculty of Medicine Universitas Gadjah Mada; JORDAN: King Hussein Cancer Center Biobank; KENYA: Ampath Reference Laboratory; LITHUANIA: National Cancer Institute; MEXICO: Instituto Nacional de Cancerología; NIGERIA: College of Medicine University of Ibadan, Obafemi Awolowo University Teaching Hospitals Complex; POLAND: Biobank Lab Department of Molecular Biophysics University of Lodz, Wrocław Research Centre EIT+ Biobank; SOUTH AFRICA: National Health Laboratory Service (NHLS), NHLS/Stellenbosch University Biobank; SUDAN: Radio-Isotope Centre Khartoum; THAILAND: National Cancer Institute; THE GAMBIA: Medical Research Council (MRC) The Gambia Unit, MRC International Nutrition Group; UGANDA: Makerere University College of Health Sciences; UNITED REPUBLIC OF TANZANIA: Kilimanjaro Clinical Research Institute; ZAMBIA: Centre for Infectious Disease Research in Zambia; ZIMBABWE: African Institute of Biomedical Science & Technology; University of Zimbabwe College of Health Sciences.
BCNet actors: 13 international partners
BCNet catalogue: background

- Opportunity for LMICs
- Working together with coordination
- Addressing challenges in biobanking infrastructure
- Sharing resources (expertise, protocols, samples)
- Increasing visibility of members’ biobanking resources
- Facilitating participation in international projects through joint application
Purpose

- Increase visibility of biobanks
- Facilitate the sharing and discovery of biomolecular resources and samples

Development

- Joint work of IARC, BBMRI.se and Karolinska Institutet
- Compliance with MIABIS 2.0

Key entities:

- Biobank
- Sample collection
- Sample
BCNet catalogue: pilot phase specs overview

Objective
Assessment of **data operations** on the BCNet catalogue with a focus on data provisioning

Method
- Recording of targeted data through online interactive **forms** and offline static **templates**
- Collecting of feedback through online **surveys**, peer-to-peer web **meetings**, and **e-mail** follow-up

<table>
<thead>
<tr>
<th>Stage</th>
<th>Targeted data</th>
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<tbody>
<tr>
<td>1&lt;sup&gt;st&lt;/sup&gt; – early 2016</td>
<td>Biobank info Sample data</td>
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<tr>
<td>2&lt;sup&gt;nd&lt;/sup&gt; – early 2017</td>
<td>Biobank info Sample collection data Sample data</td>
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</tbody>
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BCNet catalogue: pilot phase results – figures

- 10 LMIC biobanks pre-registered
- 5 LMIC biobanks fully registered
  - BCI Ghana
  - IBRH3AU Uganda
  - MRCUTG Gambia
  - UGM Indonesia
  - WRC EIT+ Poland
- 4 sample collections recorded
- 9,000+ samples recorded
BCNet catalogue: participants feedback

- **Data quality**
  - **Biobank info** are provided with accuracy and completeness
    - Services are well described
    - Contact details are well presented
  - **Sample collection** and **sample data** are less comprehensive and complete due to two main reasons
    - **Inventory** of samples is **on-going**: sorting of «good» samples (good for studies); time- and human resource-consuming; small amount of data available at once
    - **Targeted data** set is **wider** than locally captured data; need of additional processing and mapping, including with MIABIS
    - Examples of missing sample data (not specified or not known): anatomical (98%); disease (64%)

- **Understanding and utility of MIABIS**
  - **Staff training**: initiated along the pilot phase of the catalogue
  - Integration of sample data: **continuous matching** based on MIABIS
  - Plan of managing **assisted and/or automated compliance** with MIABIS: for example on the basis of an online tool introduced during a [B3Africa](https://b3africa.org) webinar on MIABIS
BCNet catalogue: participants feedback (cont.)

Data processing automation

- New software for recording sample data
  - From home-made application to integrated system like LIMS
  - Examples of considered softwares: Item Tracker; STARLIMS; Bika LIMS

- Multiplying transitional sources
  - New sample data are recorded in this new software
  - Old sample data are migrated: tricky and time-consuming due to training needed on new software and mapping to proceed between systems

- Data preparation
  - Mapping from local database to Excel/CSV template provided
  - Coding of value according to the catalogue data dictionary

IT infrastructure

- Hardware and software
  - Data mapping with basic Excel worksheet
  - Some targeted data are still hosted on computers with old generation operating system (Windows XP) and legacy/dedicated software
  - Some slow processing units still used

- Network area and connectivity
  - No dedicated local area network (LAN): tricky to access and share data out of dedicated, not-networked devices
  - No Internet connection for some; Internet connection at low speed or low quality for others
  - It is costly to get and use an Internet access
BCNet catalogue: participants feedback (cont. 2)

- **Institutional support**
  - Collecting data on **samples** managed by 3rd tier
    - Ethical, legal, and social issues (ELSI)
    - Need of submission of several requests of approval to get clearance for sharing
    - Need of several refinement of selection of data for each submission
    - Weak efficiency on results: small data set of samples approved for sharing
  - Data management: suggestion of negotiating community version of software for BCNet members

- **Operations with the catalogue**
  - Search engine: felt as enough efficient and user friendly
  - Data import: suggestion of improving the online automation within the catalogue by the integration of a tool which offers a smoother, lighter service for recording source data
    - Eg: a MIABIS data converter/mapper
    - Cross platform tool, compatible with Windows, which is the OS mostly used by BCNet African representatives
  - Accuracy of terms: satisfying thanks to the provided data dictionary
BCNet catalogue: pilot phase conclusions

**Challenges**
- Design of a relevant data dictionary
- Adaptation of tools to participants
- Assistance in the data recording process

**Benefits**
- Identification of lack of data and IT workflow
- Increase of visibility of participants’ biobanks
- Increase of potential collaboration with other biobanking communities

**Next steps**
- Improvement of catalogue
  - Enhancement of data provisioning processes with revised data dictionary
  - Revision of user interfaces
- Linkage to other catalogues
  - Eg: BBMRI-ERIC Directory
- Extension of participation to other BCNet members
  - Registration of other BCNet members’ biobanks
  - Recording of more data with a first focus on sample collections
Acknowledgement

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  - IBRH3AU College of Health Sciences, Uganda
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- BCNet catalogue development team
  - Karolinska Institutet, Sweden
  - International Agency for Research on Cancer