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Infrastructure and Facilities for Human Biobanking in Low- and Middle-Income Countries: A Situation Analysis

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Key Words
Biobank · Low- and middle-income countries · Biobank and Cohort Building · Ethical, legal, and social issues

Abstract
Objective: To collect information on biobanking facilities in low- and middle-income countries (LMICs) as a first step towards establishing an LMIC biobank and cohort building network (BCNet) to support research, with a focus on cancer control. ***Method:*** Sixty centres were identified from sources including cancer centres, universities, hospitals, and public health facilities and invited to participate in a survey between December 2012 and March 2013. ***Results:*** Of the 27 centres (45%) that responded, most have existed for <10 years. They store between 1,000 and 1,000,000 research samples as well as samples remaining after clinical diagnosis. Sample storage is mostly in freezers, although 45% (9/20) of the centres do not have regular access to electricity. Biobank managers, sample management systems, and mechanisms for follow-up using linkages are uncommon. Many (80%; 21/26) of the centres have regulations to govern research, but regulations for the use of biobank resources (samples and data) are not well developed. ***Conclusions:*** Biobanking facilities are being developed in LMICs. Shortcomings in international visibility, sample sharing regulations, standardization, quality assurance, and sample management systems could be alleviated by international networking. Stakeholders need to work together to increase access to high-quality biological resources for scientific research.

Introduction

Biobanks contain collections of biological material and associated data obtained from a population and stored in an organized system, where the samples and associated data can be linked to the person who provided the sample [1]. They are an important resource for medical and scientific research in studying the aetiology and molecular mechanisms underlying human diseases. Biobanks are a fundamental resource for development of potential diagnostic biomarkers and supporting disease prevention in addition to the development of personalized drug treatment through translational research.

The principal participants in biobanking include the individuals who provide the samples, the communities involved, public bodies, and scientists. The key principles of biobanking, from collection to storage and final use of

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samples, should be carried out while respecting patient confidentiality and protecting the rights of the participants, with clear guidelines on informed consent procedures and ethical, legal, and social issues (ELSIs) [2, 3].

The global disease burden, its main causes, and the actions needed to combat it differ greatly between countries. Investment in biobanking infrastructures, such as biological resource centres, has enabled scientific progress on which effective disease prevention and control measures depend.

In this regard, several institutions in high-income countries (HICs) have embarked on generating large population cohorts that depend on large-scale biobanking facilities for collecting, processing, storing, and managing high-quality biological samples for medical research [4–7]. The burden of noncommunicable diseases is already higher in LMICs, and in 2012 it was estimated that 5.3 of the 8.1 million cancer-related deaths occurred in LMICs [8]. Therefore, there is a definite need in LMICs to replicate the strong international trend towards the development of infrastructure and facilities to provide high-quality samples and associated data for research on cancer and other diseases.

It has been assumed that population cohorts and biobanking facilities are either nonexistent or underdeveloped in LMICs. In many LMICs, it is also unclear what standard guidelines and protocols are available to regulate the sharing and use of biological samples for research purposes. Because of these limitations, public health workers, stakeholders, and decision-makers in LMICs lack sufficient scientific evidence to establish properly targeted and cost-effective action plans within their health-science systems.

Most of the functional biobanks in LMICs were introduced through specific programmes targeted at major health issues affecting the populations of these countries. Notably, these biobanks frequently involve large numbers of participants and were often created in HIV treatment facilities to monitor and control the spread of infection [9, 10].

Consequently, in LMICs, facilities often serve only a single research project and have funding to collect and store samples for a specific study. In such cases the sustainability of the biobank is a serious problem when the project ends. The resources and expertise required to maintain the samples are no longer available at the end of the project and the facilities rarely continue to operate or expand into systematic collection and storage centres.

The first national DNA bank in Africa was established in 2000 in the Gambia (West Africa) as one of 14 DNA collection sites established by the Medical Research Council (UK) to study the genetics of complex diseases such as malaria, HIV/AIDS, and tuberculosis [11]. Another initiative was the biobank and pharmacogenetics database that was introduced in 2008 by a consortium consisting of five African countries (Nigeria, Kenya, Tanzania, Zimbabwe, and South Africa) to establish baseline frequency distributions of single-nucleotide polymorphisms of genes important in drug metabolism among African populations [12].

Recently, an innovative programme, the Human Heredity and Health in Africa (H3Africa) Consortium, was initiated by the Wellcome Trust (UK) and the US National Institutes of Health (NIH). The programme aims to improve the health of Africans through the study of genomics and environmental determinants of common diseases. It also aims to facilitate the creation of sustainable biorepositories and research infrastructure with the capacity to conduct cutting-edge scientific research in African institutions, involving a network of African scientists across the continent and international collaborators (http://h3africa.org/). The first recipients of grants from H3Africa will conduct genomic research on kidney disease, diabetes, heart disease, obesity, tuberculosis, and African sleeping sickness.

Recognizing the need to increase the level of awareness, education, and biobanking infrastructure in LMICs, and to address the underrepresentation of high-quality biospecimens for research in these countries, the International Agency for Research on Cancer (IARC), together with the US National Cancer Institute-Center for Global Health (NCI-CGH) and other international partners, took the initiative to launch the LMIC Biobank and Cohort Network (BCNet). The aim of the network is to support biobanking infrastructure in LMICs. By providing access to best-practice guidelines and tools, training personnel to collect, store and manage the biobank resources, and conducting joint cohort-building and research projects, BCNet can help to improve the infrastructure for scientific research to address public health concerns.

In the present study, we report the results of an online questionnaire that was conducted by the IARC from December 2012 to March 2013 to gather information on biobanking activities, research infrastructure, and resources as a first step in setting up the BCNet. The survey was conducted in 27 institutions from 17 LMICs in Africa, Asia, and Europe. We found that although limited information was available on biobanking activities, sample storage and biological resource management infrastructure is being developed in LMICs.

Table 1. Nature of the biobank in the participating centres

	Human biospecimens	Animal biospecimens[1]	Normal biospecimens	Diseased biospecimens
Africa	19/20 (95%)	4/20 (20%)	8/20 (40%)	15/20 (75%)
Asia	3/5 (60%)	0/4	1/4 (25%)	1/4 (25%)
Total	22/25 (88%)	4/24 (17%)	9/24 (38%)	16/24 (67%)

European centre not included in the table. [1] The sources of the animal biospecimen collections include the National Zoological Gardens of South Africa (http://www.nzg.ac.za/).

Methods

The online survey was developed using Survey Gizmo (http://www.surveygizmo.com/) and consisted of a total of 49 questions divided into two parts (see online suppl. table 1 for the questionnaire; see www.karger.com/doi/10.1159/000362093 for all online suppl. material). Initially 60 participants were sent invitation letters via e-mail; they were given a timeline of 2 weeks to submit the completed questionnaire. The deadline was extended for 1 week to accommodate late submissions.

Participants were identified from multiple sources and included participants of the European, Middle Eastern and African Society for Biopreservation and Biobanking (ESBB) 2012 conference, African Organisation for Research and Training in Cancer (AORTIC) membership, and IARC collaborators working in LMICs.

The questionnaire was designed to elicit general information on activities in relation to infrastructure, sample collection, storage, use, and governance. Respondents were also asked about their initial reaction to the idea of creating repositories for high-quality samples and their willingness to participate in a biobank network.

Of the 27 responding organizations, 21 were from Africa, 5 from Asia, and 1 from Europe. A preprocessing step, based on a previously reported study, was first applied to remove incomplete or invalid data [13]. The exclusion criteria were as follows: a questionnaire was excluded (1) if the entire section was left blank, (2) if more than half of the questions were left unanswered, or (3) if all items were answered the same. The survey data were then imported and analyzed in Excel 2010 (Microsoft, Redmond, Wash., USA) using the PivotTable function (http://support.microsoft.com/kb/213920). The responses for each question in the survey were encoded by assigning numerical values (yes = 1, no = 0), and unanswered responses were left blank. For each question, the PivotTable function was applied and pie charts, bar graphs, or tables were created using the calculated values. The authors can provide Microsoft Excel files of raw data and calculations upon request. The complete questions included in the survey are provided in online supplementary table 1.

Results

Participating Centres

Of the 60 institutions contacted, 27 (45%) completed the survey. The respondents were from Africa (n = 21), Asia and the Middle East (n = 5), and Europe (n = 1). The respondents were from academia, research facilities, hospitals, and clinics, including public health laboratories (9/24), state and governmental agencies (6/25), non-profit organizations (9/25), advocacy groups (2/24), and biomedical companies (3/23).

The respondents were involved in patient care and research, carrying out activities relating to sample collection (22/26), processing (17/25), storage (21/26), and distribution (7/25). In general, the proportion of clinical personnel involved was higher in Asian and Middle Eastern countries, whereas research staff, such as laboratory scientists, laboratory technicians, and PhD students were more common in the African institutions.

Although centres had, among their staff, laboratory personnel who also had responsibilities for sample collection and processing, 28% (5/18) of the centres had biobank managers with technical expertise in the development of biobanks. The majority of institutions had a positive initial reaction to the idea of creating repositories for high-quality samples and indicated an interest in joining the biobank network.

Biobank Infrastructure and Facilities

Human samples constituted 88% (23/26) of the biological resources stored by centres (table 1). The centres collect and process a wide range of sample types, including blood, surgical material, hair, nails, saliva, and buccal swabs.

Most of the centres discarded their biological materials after analysis, following routine clinical diagnosis; only one third of the centres reported storing leftover materials, and an equal proportion maintained a policy of discarding old leftover materials to make room for newer samples. Blood samples (including derived products), paraffin-embedded tissues, and DNA material were the most common types of samples stored, and storage at –80°C was the preferred method for blood samples, blood-derived products, frozen tissue, DNA, and RNA (table 2). Storage of other biological material, such as

Table 2. Nature of biospecimens stored in the participating centres and their storage conditions

	Stored samples by type	Stored samples in participating centres by storage condition					
		room temp.	refrigerated	–20°C	–80°C	cryofreeze	temp. not listed
Blood	63% (12/22)	2/22 (9%)	2/22 (9%)	0%	8/22 (36%)	0	2/22 (9%)
Blood-derived products	78% (17/22)	0	3/22 (14%)	3/22 (14%)	9/22 (41%)		2/22 (9%)
Bone marrow	10% (2/21)	0	0	0	0	0	2/21 (10%)
Frozen tissue	38% (8/21	0	0	0	4/21 (19%)	1/21 (5%)	3/21 (14%)
Tissue slides	59% (13/22)	8/22 (36%)	0	0	1/22 (5%)	0	4/22 (18%)
Paraffin-embedded tissue blocks	68% (17/25)	13/25 (52%)	0	0	0	0	4/25 (16%)
Formalin-fixed tissue	50% (12/24)	8/24 (33%)	0	0	0	0	4/24 (17%)
Cell lines	10% (2/21)	0	0	0	1/21 (5%)	0	1/21 (5%)
Cord blood	15% (3/20)	1/20 (5%)	0	1/20 (5%)	1/20 (5%)	0	0
DNA samples	68% (15/22)	0	0	5/22 (23%)	8/22 (36%)	0	2/22 (9%)
RNA samples	50% (11/22)	0	0	4/22 (18%)	6/22 (27%)	0	1/22 (5%)
Sperm	10% (2/20)	0	0	1/20 (5%)	0	1/20 (5%)	0
Others (urine, buffy coat, body fluids)	77% (16/21)	0	0	2/21 (10%)	9/21 (43%)	3/21 (14%)	2/21 (10%)

European centre not included in the table.

Table 3. Types of sample storage equipment available in the participating centres

	Ambient temp.	Refrigerator +4°C	Freezer				Liquid nitrogen	
			–20°C	–40°C	–80°C	–150°C	gaseous	liquid
Africa	13/19 (68%)	15/19 (79%)	17/20 (85%)	8/18 (44%)	17/20 (85%)	1/19 (5%)	4/20 (20%)	9/20 (45%)
Asia	4/5 (80%)	5/5 (100%)	5/5 (100%)	2/5 (40%)	4/5 (80%)	1/4 (25%)	2/4 (50%)	3/4 (75%)
Total	17/24 (71%)	20/24 (83%)	22/25 (88%)	10/23 (43%)	21/25 (84%)	2/23 (9%)	6/24 (25%)	12/24 (50%)

European centre not included in the table.

sperm, cell lines, and bone marrow, was reported by only 10% of the respondents. Interestingly, <30% of the centres (7/25) were involved in the distribution of samples for national and international scientific research collaboration.

The participants were asked about the location of the biobank and whether they had dedicated facilities for sample storage. The survey results showed that 11/20 (55%) of the centres kept their samples in dedicated buildings or rooms, and 17/20 (85%) kept their samples in freezers located in multipurpose facilities where diverse activities were also carried out. Fifteen percent of the participants (3/20) stored their specimens at separate storage locations outside their institutions for safe keeping. The biobank facilities were between 1 and 10 years old; only 3 of them had been in existence >10 years. The quantity of samples varied from <1,000 to 1,000,000. Fifty percent of the facilities had a sample collection range of 1,000–10,000. One facility reported having >1,000,000 samples in storage. Despite a lack of information on the quality of the samples, the impressive number of stored biospecimens in these centres indicates a certain level of experience in storage and management of a biobank. Understandably, ambient conditions, refrigerators, and freezers (–80, –40, and –20°C) are the most common form of storage facilities (table 3). Only 2 of the 23 biobanks in African and Asian centres reported the use of –150°C mechanical freezers. Surprisingly, liquid nitrogen (liquid-phase) facilities were available in 45% (9/20) and 75% (3/4) of African and Asian institutions, respectively (table 3).

Laboratory information management systems that could be adapted for cataloguing, documenting, and tracking biological samples were available in only 45% of

Table 4. Medical staff in charge of associated data collection and management

	Physicians	Nurses	Epidemiologists	Records office	Other[1]
Africa (n = 21)	11 (52%)	12 (57%)	7 (33%)	10 (48%)	4 (19%)
Asia (n = 5)	2 (40%)	1 (20%)	0	1 (20%)	2 (40%)
Total (n = 26)	13 (50%)	13 (50%)	7 (27%)	11 (42%)	6 (23%)

In some centres more than one category of staff are responsible for data collection and management. [1] PI, database, manager, students, laboratory staff.

centres (9/20), while the remaining 55% used conventional databases such as Microsoft Access and Excel to record and manage sample location information.

A regular and uninterrupted power supply, which is a key component of biobank infrastructure to operate equipment, freezers, and computers, was accessible to only 55% (11/20) of the centres; 72% (8/11) of them were also connected to backup generators. Although the majority of those without a regular supply of electricity were also connected to generators, one centre did not have any form of power except the main source. These centres with no back-up systems face a major challenge in maintaining the quality of biological samples for scientific research projects.

Temperature monitoring systems, which ensure a safe and reliable environment for the stored samples, were in place in approximately 65% (13/20) of the centres, and 46% (6/13) of them used automatic monitoring systems. Internet access was available to >85% (17/20) of the respondents.

Database variation and lack of standardization and harmonization could be a limiting factor for the interoperability between databases. In fact, in most cases, the associated data were collected by physicians, nurses or the records office, and were kept in formats different from those used to store biobank information. Researchers and principal investigators were not reported as the main data collectors, which may be a reflection of the low proportion of samples collected for research purposes (table 4).

Regular and systematic assessment of the quality of collected samples is an important factor in good biobank management. Accordingly, 80% (21/26) of the institutions have developed their own collection, processing, and storage standard operating procedures, and rarely relied on international protocols. However, these in-house standard operating procedures were not accredited and did not include procedures for quality assurance, equipment maintenance, research, and regulatory compliance. Participation in accreditation programmes was very uncommon.

Ethical, Legal, and Social Issues

ELSIs are dealt with by various mechanisms in the different ethics and scientific committees in more than 90% (24/26) of the centres. These committees are responsible for reviewing and approving research activities. However, ELSIs specific to biobanking or biobank projects are usually not included in the committees' review processes, and this is an important challenge in biobank governance in LMICs [14]. For example, most centres do not have patient-consent procedures for the systematic storage of postanalysis clinical samples for future research. Informed consent is project-specific, and broad consent, which would enable efficient use of biobanking resources, is not usually obtained from participants.

Research Collaboration

All centres reported participation in research activities, and their biobanks' foci included applied science, translational research, and population genetics. The centres stored biospecimens conducted for disease-specific research and infectious disease studies conducted in collaboration with local and international partners, including epidemiologists, health personnel, biologists, radiologists, pathologists, and surgeons.

Discussion

Creating good research infrastructure effectively contributes to scientific discovery, and biobanking is an important component for these developments. Biobanking facilities are well established in HICs, where large amounts of funding and resources have been invested in developing biobanks and biorepositories as part of the research infrastructure [15–17]. In comparison, these facilities tend not to be developed in LMICs, and this has had a negative impact on the availability of high-quality samples for scientific research.

The current survey was conducted to review the situation of biobanking facilities in LMICs and to provide tangible evidence and information on biobanking activities in these regions. The inclusion response of only 27 centres (out of 60 contacted) representing 17 countries is clearly not fully representational given participants were selective, identified through the ESBB, AORTIC, and IARC. As a result, the centres that contributed to this study are likely to have a relatively higher level of development than centres that did not complete the survey. Additionally, some centres with potential resources were not contacted due to a lack of contact information. In addition, African countries were more highly represented in the study than LMICs from other regions; only five participants were from Asia and the Middle East, and one from Europe. Taken together, this means the information gathered should be considered as providing a preliminary indication only of the situation. Nevertheless, the study gives an overview of the state of individual biobank facilities and activities in LMICs and identifies areas for improvement.

Disparities between centres were noted with respect to infrastructure. Facilities are more developed in some centres than in others. For example, the South African National Health Laboratory Service (NHLS) biobank has established a national biobank network that is coordinated from Johannesburg and already stores over one million samples. Makerere University (Uganda) has its own liquid-nitrogen plant to supply the biobank with liquid nitrogen for biospecimen storage. Some of the advances may be due to better support from decision-makers and more organized and developed complementary structures. Greater access to local and international funding for research and a higher level of awareness of the benefit of biobanking for scientific research have also contributed to the reported development in some centres (e.g. Institute of Oncology, Vilnius University, Lithuania; Institut Pasteur, Tunisia, and KHCC, Jordan). The Ugandan centre has recently been awarded funding from H3Africa for a pilot project to develop an integrated biorepository to annotate and store biospecimens, making them available for genomic discovery projects by the H3Africa Consortium and African and international researchers.

Despite the differences between the centres and the regions (tables 1, 3, 4), it is clear that biobank activity is increasing in LMICs. However, for logistical and regulatory reasons, these developments are taking place at a slower pace compared with HICs, thus resulting in a shortfall of high-quality samples available for molecular and genetic studies in countries where disease burden is high.

The results of the survey suggest that several potentially remediable factors may contribute to the underdevelopment of biobanking in LMICs. These include a lack of funding for infrastructure and equipment, insufficient numbers of trained staff to develop and use appropriate tools, non-utilization of biobank IT, and the absence of quality assurance programmes. Other factors include a lack of public awareness and uncertainties about ELSIs. It should be noted that some of these challenges are not unique to LMICs; biobanks in HICs face similar issues at different levels. However, because of competition for limited resources, the situation is particularly challenging in LMICs [18].

Biobank Infrastructure and Facilities

Because biobanks are not always considered as development priorities in LMICs, limited funds are at their disposal. This, coupled with the heavy reliance on government subvention, which in most cases covers only staff and reagent costs, limits progress in biobanking. Without international standardization, good maintenance programmes, equipment such as freezers and liquid nitrogen tanks, reliable electricity supply, and alternative sources of power supply, as reported by the majority of the institutions, biobanks will struggle to maintain best recommended practices, which are prerequisites for providing high-quality samples for research. This, in turn, restricts their potential to attract additional funding from external sources.

In LMICs, allocating staff to biobanks is a challenge when there are not enough trained staff available to run health care services, and the need for skilled biobank staff with the right training and experience is often underestimated. In general, the centres do not employ dedicated trained personnel. Where present, these personnel play a key role in the development of biobanks. They know and understand the local health priorities and scientific possibilities, and can advise those who want to use samples for research. They can also assist with the necessary formalities, such as the best approach to use for internal review boards and medical ethical committees. They are responsible for implementing ethical recommendations and ensuring transparency towards donors who have provided their samples; in this way, trust can be built through public awareness. A lack of dedicated personnel can be remedied by increasing financial support to the biobank and training.

A key component of a biobank is its IT system, which is used for cataloguing, managing, and monitoring samples and associated data. Thus, limitations in IT support, underutilization of biobank software and computerized

systems, and a heavy reliance on conventional databases (Microsoft Access or Excel) limit the potential use and utility of the biological resources available in the centres.

Without computerized platforms and software to drive quality assurance programmes and workflow, standardization and harmonization of the operations and data, in the interests of interoperability between databases, becomes difficult and challenging. Although the responding centres indicated that their biobank data can be linked to other clinical and related databases, the lack of harmonization and interoperability between databases makes this a difficult task.

Interoperability is central to any network, and in order to facilitate collaboration between the BCNet partners, the network will consider introducing common data collection programmes and quality management tools, such as Biological Reporting for Improved Study Quality (BRISQ) [19] and Standard Preanalytical Code (SPREC) [20] and MIABIS (Minimum Information About Biobank Sharing) for comparability between individual collections for the purpose of sharing and for joint studies. Importantly, standardized systems for managing samples will allow straightforward participation in international biobank catalogues (e.g. those at BBMRI-eu or p3g), which will increase the visibility and recognition of the facilities internationally.

Ethical, Legal, and Social Issues

Most countries responding to the survey reported the establishment of ethics committees. These structures were put in place to regulate research activities, clinical trials, and therapy, but not specifically for the questions related to biobanks [21]. Thus, ELSIs regarding future sample use are often unclear. In addition, there are hardly any communication systems to inform the public, donors, and stakeholders about the role of biobanking and how society benefits from the use of biological samples for scientific research. Such an approach is required, not only to encourage and stimulate participation in providing samples, but also to contribute to establishing trust between the public and scientists, which is necessary for the sustainability of biobanks.

A study about public knowledge of and attitudes towards biobanking that was conducted in Nigeria showed that, in general, the public accepted the role of biobanking in research and were willing to participate if the studies were explained to them. However, the public had varying levels of knowledge on the different types of consent and consent procedures [22]. Other issues that need to be taken into account are the cultural differences between certain ethnic groups in LMICs, the countries' regulations and laws, and language issues. These could be barriers to the harmonization of regulations and sharing of samples, particularly when sending samples abroad for international collaboration.

In the majority of the institutions, specific consent was favoured over broad or tiered consent when patients are being recruited for participation in research studies. This has implications for future inclusion in research projects of samples collected for clinical diagnosis. If there is no broad consent permitting extended use, the utility of these valuable resources is limited. It would be of great benefit to scientific research in LMICs if the samples collected under standardized guidelines and protocols could be put to the best possible use, taking into account the best interest of the participants and the public benefit.

Research Collaboration and Networking

In order to encourage national and international partnerships and research collaboration through networking, IARC, together with other experienced biobank institutions, is prepared to coordinate the biobank activities in LMICs within the framework of a network. Although detailed information on research activities in LMIC biobank centres is beyond the scope of the current survey, the responding centres have shown a wide range of foci and interests. This is illustrated by their scientific research activities and published work, including research on hepatitis infection and liver cancer (Egypt), human papillomavirus, and cervical and head and neck cancer, breast cancer, and lymphoma (India, South Africa, Jordan) [23–28]. Also of interest is the research on public health and nutrition carried out by the Medical Research Council (UK), the Gambia [29–31].

The investment by H3Africa in biorepositories will certainly contribute to the building of research infrastructure and these repositories would be natural partners for BCNet members. In particular, one BCNet partner (Makarere University, Uganda) is a participant in the H3Africa project. The links between institutions and biobanks as part of these networks will enhance the improvement of facilities, provide increased numbers of high-quality samples, and provide access to necessary resources for national and international collaboration.

In conclusion, it is clear that biobanking activities are taking place in LMICs, but these efforts need to be backed by the appropriate level of funding, resources, and institutional and public support to provide the right environment and facilities for the collection, storage, and management of high-quality samples for scientific research.

BCNet is being set up to support the development of LMIC biobanking through networking and collaboration between LMIC members and international biobanking societies and organizations. The network aims to provide access to standardized protocols, best-practice principles, and appropriate guidelines and tools for developing high-quality LMIC research infrastructure. The first common project is to develop a catalogue of its members biological resources which will be made available for sharing between its members and with the international community.

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