**Nepal Biobanking Initiative**

**Introduction**

Nepal’s surveillance system as such the health information management system does not include non-communicable disease (NCD) indicators, neither does the periodic surveys done in the past. Learning from the efforts in the UK, China and other countries in building national databases and registries for data capturing and linkages, Nepal Biobank was founded to pool the individual patient data collected from primary studies initially, and help researchers to use these data for boosting research collaborations in the country. Further, a periodic data feeding process is proposed, where data from periodic surveys will be harmonized like other databases.

Nepal Biobank is a civil society initiative that focuses on solving critical public health and social development needs in Nepal through scientific research and innovation. The paper describes the proposed framework of Nepal biobanking initiative hereafter abbreviated as NBI. First, we present the overall framework. Second, we describe the availability of studies for pooling and establishing linkages nationally and internationally. Finally, we describe the proposed framework for data sharing and result of our feasibility study.

**Methods**

**Overall framework**

Nepal Biobank

CBS

NGOs

Hospitals records

Local & global studies

Steering committee

Staff

Security officer & IT

Central team

Expertise

Data management/IT

Data modelling

Ethics

Data feeding

Processing

Dissemination

Figure 1: Figure illustrating the framework of Nepal biobank. Abbreviations: CBS: central bureau of statistics, IT: information technology, NGO: nongovernmental organization.

Broadly the work of NBI is divided into national and international data pooling and linkages.



**National data-pooling and linkages:** We mapped the NCD indicators across available studies in Nepal which will be pooled together to provide robust estimates of disease burden and trends in Nepal. So far we identified five periodic surveys and four other studies. Most frequent indictors found across studies were BMI (9 studies), hypertension (5 studies) and diabetes (5 studies).

**<Table 1>**

**International data-pooling and linkages**

NBI is working pool NCD indicators data across low- and middle-income countries with an aim to compare the burden estimates and their trends. So far data from 30 countries has been obtained which includes a total of 977,377 participants. Most frequent NCD indictors found across these studies were body mass index (30 studies), hypertension (24 studies) and diabetes (22 studies). Most of these studies were from Demographic and Health Survey (DHS), while data acquisition from countries not captured by DHS such as China, Indonesia, Chile and Mexico are in the process.

**<Table 2>**

**Proposed framework for data-banking**

**Data feeding & management**

NBI is established by researchers at Nepal Development Society–a leading civil society organization that focuses on solving critical public health and social development needs in Nepal through scientific research and innovation. NBI aims to link shared individual patient data collected from primary studies and help facilitate researchers to use these data for boosting research collaborations in the country. Further, it has its own periodic data feeding process, where data from its own cohort of 3000 individuals will be harmonized. From 2014-2019, it has collected more than 9000 person-years of data, of whom 70% are female. Next surveys in 2019-21, has been planned to add data points including information on reproductive, environmental markers of NCDs. Further, a verbal autopsy will be conducted to assess the history of cardiovascular diseases namely heart failure, heart attack, and stroke.

The data management will be done at Nepal Development Society—which will provide a secure office space and resources to store the data.

**Data access**

Data on NBI is a public good and is provided to researchers on reasonable request. However, the users will need to comply with the policies of individual studies, and databases where the data has been sourced.

**Data dictionary**  
Data dictionary are specific to studies which will provided along with the data.

**Frequently asked questions**

*What is Nepal Biobank?*  
Learning from experiences of other biobanks in the UK and China, Nepal Biobank is an open-access platform created by Nepal Development Society (NEDS), a civil society research-based NGO (https://nedsnepal.org.np), registered in Chitwan Nepal. Please visit ‘About Nepal Biobank’ section for more information.

*What is Nepal Development Society and what’s its relation with NBI?*  
NBI is established by Nepal Development Society–a leading civil society organization that focuses on solving critical public health and social development needs in Nepal through scientific research and innovation. Since 2013, NEDS has established a cohort of 3,000 rural households as a public health laboratory to conduct epidemiology studies as well as assessments of Nepalese healthcare system with a focus on the PHC level. Over the past years, NEDs contributed to collaborative research with more than 15 national and international and published over 50 scientific articles in national and international peer-reviewed journals, making it the leading organization generating and disseminating health-related evidence in Nepal.

*Where does the data come from?*  
The biobank has two approaches to data harvesting. First, we harvest data from three waves of surveys conducted by NEDS consecutively from 2014-2019 in Kaski district and two more will be carried out until 2021. Thus far, it covers nearly 3,000 individuals giving nearly 9000 person-years of data, of whom 70% are female.

*What variables the biobank has?*  
We have blood pressure (SBP, DBP, heart rate) and diabetes (fasting sugar, HbA1c) as the endpoint. Beside that have information on major modifiable risk factors for NCDs recommended by WHO. Next surveys in 2019-21, has been planned to add data points including information on reproductive, environmental markers of NCDs. Further, a verbal autopsy will be conducted to assess the history of cardiovascular diseases namely heart failure, heart attack, and stroke.

*What is the benefit of sharing data to NBI?*  
The shared data will be harmonized with the existing data in the Biobank, giving it the power to assess the markers of chronic diseases robustly. All the studies contributing the data will be credited as collaborators and included in pooled analyses.

*What about the privacy of shared data?*  
The data will be de-identified after arrival and will remain password protected. Only collaborators can access and download the data; however, cannot make changes in the data structure.

*Are there any charges for taking part?*  
There are no charges for taking part in Biobank.

*Are the data available for international collaborators?*  
The data will be available for international collaborators, on request. Please write to us at nedsnepal@gmail.com with subject “Nepal Biobank-data request”.

***Login to access data***  
A separate website for data-login will be created in future. Researchers can send their data-related queries at nedsnepal@gmail.com with subject line “Nepal Biobank-login request”.

**Data steering committee**

Nepal biobank will have a steering committee which will govern the overall management. The committee meets yearly and lays downs the priority for improving the data-users interface, management and quality of data. An advisory committee is being formed.

**Feasibility study**

With an aim to understand how in-country researches perceive about data sharing an online survey was conducted in 2017 (https://bit.ly/2CybXqK). A total of four responses were obtained from major studies from Nepal. Researchers felt that sharing the data was necessary however they expressed that they would need more support in database management. In 2019, we are planning to roll out the same survey to catch more responses from the researchers.

**Expected outputs**

The following are the expected outputs:

1. NBI will be able to pool NCD indicators across provinces and districts of Nepal to provide robust estimates on NCD indicators and trends of diseases.
2. NBI will be able to link and pool studies internationally giving an cutting edge advantage to Nepalese scholars to collaborate globally.

**Expected impact**

The following are the expected impacts:

1. In the changed federal context of the country where 77 districts and 700 municipal units have been demarcated, NBI will provide evidence to help evidence-informed decision making to policy makers and program planners at federal and district level.

2. NBI will help to catalyse research in Nepal by providing NCDI indicators data to researchers.

**Coordinating committee**

*Coordinator*

Shiva Raj Mishra, MPH (epidemiology and biostatistics) is the founding board member of Nepal Development Society. He is currently a fellow at the World Heart Federation’s Salim Yusuf Emerging Leaders Program.

*Member*

Dr. Dinesh Neupane, MscPH, PhD is the founding chairperson of Nepal Development Society. He is currently a post-doctoral research associate in the John Hopkins University.

Dr. Nipun Shrestha, MBBS, MPH, is currently a PhD fellow in Victoria University Australia.

Dr. Dan Swartz, MD is the Senior Advisor of Nepal based non-profit *Possible*.

Table 1. Availability of health indicators in periodic health surveys, and other observational studies in Nepal

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
|  | **Sample size** | **Non-communicable disease indicators** | | | | | | |
|  |  | **BMI** | **HTN** | **Diabetes** | **CVD** | **COPD** | **Cancer** | **Othersc** |
| **Periodic cross-sectional surveys** |  |  |  |  |  |  |  |  |
| Stepwise Approach to surveillance (STEPS) |  | + | + | + |  |  |  |  |
| Demographic and health survey |  | + | + |  |  |  |  |  |
| Nepal living standard surveya |  | + | + | + | + | + | + | + |
| Multiple indicator cluster survey |  | + |  |  |  |  |  |  |
| Nepal health facility surveyb |  |  |  | + | + | + |  |  |
| **Longitudinal studies and implementation of trials** |  |  |  |  |  |  |  |  |
| Community based management of non-communicable diseases (COBIN) |  | + | + | + |  |  |  |  |
| CVD-CKD project Dang |  | + | + | + | + |  |  |  |
| Dhulikhel heart study |  |  |  |  |  |  |  |  |
| Nepal Nutrition Intervention Project, Sarlahi (NNIPS) with Johns Hopkins University |  | + |  |  |  |  |  |  |
| Total |  | 9 | 5 | 5 | 3 | 2 | 1 | 1 |

1. Nepal living standard survey provides self-reported burden of NCDs
2. Nepal health facility survey provides service organization and availability of NCD services
3. Other includes diseases such as rheumatoid arthritis, and osteoporosis.

Table 2: Availability of blood pressure, diabetes variables across nationally representative studies in low and middle income countries

|  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Country/Year** | **Type** | **Implementing Organization** | **Female** | | | **Male** | | | **Households Sample** | **BMI** |  | **Blood pressure** | | **Diabetes** | |
| **Resp.** | **Age** | **Sample** | **Resp.** | **Age** | **Sample** |  |  | **Measurement** | **questions** | **testing** | **questions** |
| [Albania 2017-18](https://www.dhsprogram.com/what-we-do/survey/survey-display-525.cfm) | Standard DHS | The National Statistical Institute (INSAT) | All Women | 15 - 49 | 10,861 | All Men | 15 - 59 | 6,142 | 15,823 | Yes |  | Yes | Yes |  | Yes |
| [Angola 2006-07](https://www.dhsprogram.com/what-we-do/survey/survey-display-282.cfm) | MIS | COSEP, CONSAÚDE | All Women | 15 - 49 | 2,973 | NA | NA | NA | 2,599 | Yes |  |  | Yes |  | Yes |
| [Armenia 2010](https://www.dhsprogram.com/what-we-do/survey/survey-display-354.cfm) | Standard DHS | The National Statistical Service of The Republic of Armenia and the Ministry of Health | All Women | 15 - 49 | 5,922 | All Men | 15 - 49 | 1,584 | 6,700 | Yes |  |  | Yes |  | Yes |
| [Azerbaijan 2006](https://www.dhsprogram.com/what-we-do/survey/survey-display-279.cfm) | Standard DHS | State Statistical Committee of Azerbaijan | All Women | 15 - 49 | 8,444 | All Men | 15 - 59 | 2,558 | 7,180 | Yes |  | Yes |  |  | Yes |
| [Bangladesh 2011](https://www.dhsprogram.com/what-we-do/survey/survey-display-349.cfm) | Standard DHS | National Institute of Population Research and Training (NIPORT) and Mitra and Associates of Dhaka | Ever Married Women | 15-49 | 17,842 | Ever Married Men | 15 - 54 | 3,997 | 17,141 | Yes |  | Yes | Yes | Yes | Yes |
| Benin 2011-12 (1 | Standard DHS | The Institut National de l’Analyse Économique (INSAE), of the Ministry of Plan | All Women | 15 - 49 | 16,599 | All Men | 15 - 64 | 5,180 | 17,422 | Yes |  | Yes |  |  | Yes |
| [Bolivia 2003](https://www.dhsprogram.com/what-we-do/survey/survey-display-238.cfm) | Standard DHS | Instituto Nacional de Estadistica, INE | All Women | 15 - 49 | 17,654 | All Men | 15 - 64 | 6,230 | 19,207 | Yes |  |  | Yes |  |  |
| [Burundi 2016-17](https://www.dhsprogram.com/what-we-do/survey/survey-display-463.cfm) | Standard DHS | Institut de Statistiques et d’Etudes Economiques du Burundi (ISTEEBU) | All Women | 15 - 49 | 17,269 | All Men | 15 - 59 | 7,552 | 15,977 | Yes |  |  | Yes |  |  |
| [Dominican Republic 2013](https://www.dhsprogram.com/what-we-do/survey/survey-display-439.cfm) | Standard DHS | Centro de Estudios Sociales y Demográficos (CESDEM) | All Women | 15 - 49 | 9,372 | All Men | 15 - 59 | 10,306 | 11,464 | Yes |  |  | Yes |  | Yes |
| Egypt 2015 (2) | Special | Ministry of Health and Population, National Population Council, El-Zanaty and Associates | All Women | 15 - 59 | 9,209 | All Men | 15 - 59 | 7,462 | 7,516 | Yes |  | Yes | Yes |  | Yes |
| Egypt 2008 (3) | Standard DHS | Ministry of Health and Population/El-Zanaty and Associates | Ever Married Women | 15 - 49 | 16,527 | NA | NA | NA | 18,968 | Yes |  | Yes |  |  | Yes |
| [Gabon 2018](https://www.dhsprogram.com/what-we-do/survey/survey-display-546.cfm) | Standard DHS | Direction Générale de la Statistique | All Women | 15 - 64 | 12,300 | All Men | 15 - 64 | 9,000 | 11,600 | Yes |  | Yes |  |  |  |
| [Ghana 2014](https://www.dhsprogram.com/what-we-do/survey/survey-display-437.cfm) | Standard DHS | Ghana Statistical Service (GSS) | All Women | 15 - 49 | 9,396 | All Men | 15 - 59 | 4,388 | 11,835 | Yes |  | Yes | Yes |  |  |
| [Haiti 2016-17](https://www.dhsprogram.com/what-we-do/survey/survey-display-503.cfm) | Standard DHS | Institut Haitien de l’Enfance (IHE) | All Women | 15 - 49 | 14,371 | All Men | 15 - 64 | 9,795 | 13,405 | Yes |  | Yes |  | Yes |  |
| [India 2015-16](https://www.dhsprogram.com/what-we-do/survey/survey-display-355.cfm) | Standard DHS | International Institute for Population Sciences (IIPS) | All Women | 15 - 49 | 699,686 | All Men | 15 - 54 | 112,122 | 601,509 | Yes |  | Yes | Yes | Yes | Yes |
| [Kenya 2014](https://www.dhsprogram.com/what-we-do/survey/survey-display-451.cfm) | Standard DHS | Kenya National Bureau of Statistics (KNBS) of the Ministry of Planning and National Development | All Women | 15 - 49 | 31,079 | All Men | 15 - 54 | 12,819 | 36,430 | Yes |  |  | Yes |  | Yes |
| [Kyrgyz Republic 2012](https://www.dhsprogram.com/what-we-do/survey/survey-display-383.cfm) | Standard DHS | National Statistical Committee (NSC) and the Ministry of Health (MOH) | All Women | 15 - 49 | 8,208 | All Men | 15 - 59 | 2,413 | 8,040 | Yes |  | Yes | Yes |  |  |
| [Lesotho 2014](https://www.dhsprogram.com/what-we-do/survey/survey-display-462.cfm) | Standard DHS | Ministry of Health (MOH) | All Women | 15 - 49 | 6,621 | All Men | 15 - 59 | 2,931 | 9,402 | Yes |  | Yes | Yes |  | Yes |
| Maldives 2009 (4) | Standard DHS | Ministry of Health | Ever Married Women | 15 - 49 | 7,131 | Ever Married Men | 15 - 64 | 1,727 | 6,443 | Yes |  |  | Yes |  | Yes |
| Namibia 2013 (5) | Standard DHS | Ministry of Health and Social Services (MOHSS) | All Women | 15 - 49 | 9,176 | All Men | 15 - 64 | 4,481 | 9,849 | Yes |  | Yes | Yes | Yes | Yes |
| [Nepal 2016](https://www.dhsprogram.com/what-we-do/survey/survey-display-472.cfm) | Standard DHS | New ERA | All Women | 15 - 49 | 12,862 | All Men | 15 - 49 | 4,063 | 11,040 | Yes |  | Yes | Yes |  |  |
| [Peru 2012](https://www.dhsprogram.com/what-we-do/survey/survey-display-434.cfm) | Continuous DHS | Instituto Nacional de Estadística e Informática (INEI) | All Women | 15 - 49 | 23,888 | NA | NA | NA | 27,218 | Yes |  | Yes | Yes |  |  |
| [Philippines 2013](https://www.dhsprogram.com/what-we-do/survey/survey-display-436.cfm) | Standard DHS | National Statistical Office (NSO) | All Women | 15 - 49 | 16,155 | NA | NA | NA | 14,804 | Yes |  |  | Yes |  | Yes |
| [Senegal 2010-11](https://www.dhsprogram.com/what-we-do/survey/survey-display-365.cfm) | Standard DHS | Agence Nationale de la Statistique et de la Démographie (ANSD) | All Women | 15 - 49 | 15,688 | All Men | 15 - 59 | 4,929 | 7,902 | Yes |  |  | Yes |  | Yes |
| South Africa 2016 (7) | Standard DHS | Statistics South Africa (STATS SA) | All Women | 15 - 49 | 8,514 | All Men | 15 - 59 | 3,618 | 11,083 | Yes |  | Yes | Yes | Yes | Yes |
| [Tajikistan 2017](https://www.dhsprogram.com/what-we-do/survey/survey-display-521.cfm) | Standard DHS | Agency on Statistics under President of the Republic of Tajikistan | All Women | 15 - 49 | 10,718 | NA | NA | NA | 7,843 | Yes |  | Yes | Yes |  | Yes |
| [Timor-Leste 2016](https://www.dhsprogram.com/what-we-do/survey/survey-display-514.cfm) | Standard DHS | The General Directorate of Statistics (GDS) | All Women | 15 - 49 | 12,607 | All Men | 15 - 59 | 4,622 | 11,502 | Yes |  |  | Yes |  | Yes |
| [Turkmenistan 2000](https://www.dhsprogram.com/what-we-do/survey/survey-display-179.cfm) | Standard DHS | Maternal and Child Health Center/Ministry of Health/Medical Industry of Turkmenistan (MCH/MOH and MIT) | All Women | 15 - 49 | 7,919 | NA | NA | NA | 6,303 | Yes |  | Yes | Yes |  |  |
| [Ukraine 2007](https://www.dhsprogram.com/what-we-do/survey/survey-display-280.cfm) | Standard DHS | Ukranian Center for Social Reforms (UCSR) in close collaboration with the Ukranian State Statistics Committee (USSC) | All Women | 15 - 49 | 6,841 | All Men | 15 - 49 | 3,178 | 13,379 | Yes |  | Yes |  |  |  |
| Uzbekistan 2002 (8) | Special | Analytical and Information Center of the Ministry of Health of Uzbekistan and National Department of Statistics of Uzbekistan | All Women | 15 - 49 | 5,463 | All Men | 15 - 59 | 2,333 | 4,168 | Yes |  | Yes |  | Yes | Yes |
| [Zambia 2018](https://www.dhsprogram.com/what-we-do/survey/survey-display-542.cfm) | Standard DHS | Central Statistical Office (CSO) | All Women | 15 - 49 | 12,219 | All Men | 15 - 59 | 11,043 | 13,625 | Yes |  |  | Yes |  | Yes |