Reducing the International Burden of Stroke Using Mobile Technology (RIBURST)

The Stroke Riskometer research project

Welcome to the first issue of the RIBURST newsletter. These newsletters will be issued quarterly, in March, June, September and December each year.

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What is the RIBURST study?

RIBURST is a worldwide study conducting cross-sectional, cohort and interventional (primary prevention) research on stroke and other major non-communicable diseases (NCD) such as heart attack, dementia and type 2 diabetes mellitus.

What is the Stroke Riskometer?

By bridging the gap between high absolute risk and population-wide primary prevention strategies, motivating and empowering people to know and control their risk of having a stroke, the Stroke Riskometer basically offers a new (third) primary prevention strategy called "motivational population-wide strategy" and opens a new era in primary disease prevention across the globe.

The Stroke Riskometer app already involves over 300 renowned stroke experts from 102 countries making it the largest international collaborative mobile health project.

Steering Committee

In August, the Steering Committee of the RIBURST study was created. The members are as follows:

Chairperson: Professor Valery Feigin, National Institute for Stroke and Applied Neurosciences, AUT University, Auckland, New Zealand

Steering Committee members (members of the Statistical Advisory Committee are denoted by *)**:**

Dr. Rita Krishnamurthi	National Institute for Stroke & Applied Neurosciences, AUT University, Auckland	New Zealand
Rohit Bhattacharjee	National Institute for Stroke & Applied Neurosciences, AUT University, Auckland	New Zealand

Dr. Priya Parmar (Biostatistical support)	National Institute for Stroke & Applied Neurosciences, AUT University, Auckland	New Zealand *
Tasleem Hussein (Information technology support)	Software architect, ICT development unit, AUT University, Auckland	New Zealand
Assoc. Prof. Alain Vandal	Head of Department of Biostatistics and Epidemiology, AUT University, Auckland	New Zealand *
Assoc. Prof. Dominique Cadilhac	Head of Translational Public Health Research Division in Stroke and Ageing Research, School of Clinical Sciences, Monash University. Also Head of Public Health: Stroke Division, Florey Institute of Neuroscience and Mental Health	Australia
Prof. Graeme Hankey	Professor of Neurology, School of Medicine and Pharmacology, The University of Western Australia. Also Consultant Neurologist, Sir Charles Gairdner Hospital, Perth, Western Australia	Australia
Prof. Tissa Wijeratne (responsible for overseeing the project in South Asia)	Professor of Neurology (Visiting) and Clinical Associate Professor in Medicine, Melbourne Medical School, University of Melbourne. Also Senior Neurologist & Director Stroke Unit & Neuroscience Research Unit, Western Health Sunshine Hospital	Australia
Dr. Wenzhi Wang	Beijing Neurosurgical Institute	China
Dr. Miguel Barboza	Stroke Neurologist, Hospital Dr. Rafael A. Calderon Guardia, San Jose	Costa Rica
Dr. Daniel Mantilla	Fundación Oftalmológica de Santander-FOSCAL - FOSCAL Internacional	Colombia
Dr. Hrvoje Budinčević	Neurologist, Department of Neurology, Sveti Duh University hospital, Zagreb. Also Head of Stroke and Intensive Care Unit at Department of Neurology, Sveti Duh University Hospital in Zagreb	Croatia
Dr. Thomas Truelsen	Senior Physician, Dept. of Neurology, Rigshospitalet, Copenhagen	Denmark
Prof. Yannick Béjot	Department of Neurology, University Hospital of Dijon Burgundy, Medical School of Dijon, University of Burgundy	France
Prof. Man Mohan Mehndiratta	Janakpuri Super Specialty Hospital, New Delhi	India
Dr. Mehdi Farhoudi	Professor of Neurology, Director, Neurosciences Research Center (NSRC), Neurology Department, Tabriz University of Medical Sciences	Iran
Dr. Paola Santalucia	Stroke Neurologist and Cardiologist, Foundation Maggiore Hospital Policlinico, Milan	Italy
Assoc. Prof. Kamarul Imran Musa	Senior Medical Lecturer (Epidemiology and Biostatistics). Also Public Health Physician, Dept. of Community Medicine, School of Medical Sciences, Universiti Sains Malaysia, Penang	Malaysia
Dr. Fernando Góngora-Rivera	Vice-President of the Mexican Stroke Society. Also Neurologist, Autonomous University of Nuevo León, San Nicolás de los Garza	Mexico

Dr. Yogini Ratnasabapathy	Consultant Geriatrician and stroke rehabilitation lead physician, Older Adults and Home Health Department, North Shore and Waitakere Hospitals, Auckland	New Zealand
Assoc. Prof. Suzanne Barker-Collo	Dept. of Psychology, Faculty of Science, University of Auckland	New Zealand
Rufus Olusola Akinyemi	Senior Research Fellow, Neuroscience and Ageing Research Unit, Institute for Advanced Medical Research and Training, College of Medicine, University of Ibadan, Ibadan, Nigeria. Institute of Neuroscience, Newcastle University, Campus for Ageing and Vitality, Newcastle upon Tyne	Nigeria
Prof. Julio Torales	Professor of Psychiatry and Medical Psychology, Faculty of Medical Sciences, Universidad Nacional de Asunción	Paraguay
Dr. Shireen Sindi, PhD.	Karolinska Institutet, Department of Neurobiology, Caring Sciences and Society Aging Research Center (ARC)	Sweden
Prof. Nijasri Charnnarong Suwanwela	Professor of Neurology, Division of Neurology, Department of Medicine, Faculty of Medicine Chulalongkorn University, Bangkok	Thailand
Dr. Derrick Bennett	Senior statistician, Clinical Trial Service Unit and Epidemiological Studies Unit (CTSU), Oxford University	UK *
Prof. Carol Brayne	Professor of Public Health Medicine, Department of Public Health and Primary Care, University of Cambridge. Also Director of the Cambridge Institute of Public Health	UK
Dr. Mohammad Forouzanfar	Assistant Professor of Global Health, Institute for Health Metrics and Evaluation, University of Washington	USA *
Dr. Kevin Sheth	Chief of the Division of Neurocritical Care and Emergency Neurology and Chief of Clinical Research in Neurology, Yale University	USA

Introducing NISAN – the Institute (For more information, refer to our website: nisan.aut.ac.nz)

The National Institute for Stroke and Applied Neurosciences (NISAN) at AUT University, Auckland, New Zealand, is the headquarters for the RIBURST study. NISAN conducts epidemiological studies and clinical trials to improve health and outcomes in people with major neurological disorders. Current research programmes focus on Stroke, traumatic brain injury and neuromuscular disorders.

Research with this aim is unique in New Zealand and NISAN is a hub for information sharing and developing a cohesive network between existing research and clinical groups with interests in neuroepidemiology, public health, neurorehabilitation, neuropsychology and biostatistics.

The goals of NISAN and the themes of its research are:
- Advancing knowledge in the field of health and rehabilitation, through high quality innovative research into living with a neurological condition;

- Trials of management and rehabilitation interventions, to test affordable and widely applicable treatment strategies to inform recovery;
- Population health research (e.g., epidemiological studies) and systematic reviews, to inform future clinical trials;
- Fostering collaborative public health and rehabilitation research into prevention, restoration and adaptation associated with neurological illness and injury;
- Exploring the impact of neurological disease and impairment on people and their family/whanau, in relation to their

- ability to participate in activities and roles that are important to them;
- Encouraging students to undertake research in population/community health and rehabilitation;
- Promoting and disseminating findings of population health and neurorehabilitation research at a national and international level;
- Developing and promoting professional and public brain injury/neuroscience education, including development and implementation of Public Health curricula.

Research project Manager profiles

Dr Rita Krishnamurthi, NISAN Senior Research fellow

Rita undertook her undergraduate and postgraduate studies in Sydney, Australia specialising in Biomedical Science. She then started as a research assistant at the Royal North Shore Hospital, Sydney, working on cardiovascular research.

Rita moved to New Zealand in 1991 and joined the University of Auckland as a Senior Research Technician working on various projects. In 2000, she began her PhD studies in the field of Parkinson's disease, and after completing her doctorate, Rita worked as a Research Fellow at the Liggins Institute and the Department of Molecular Medicine and Pathology, University of Auckland. She joined AUT University in late 2009 as a Senior Research Fellow and Cerebrovascular Research Programme Lead.

Rita is currently involved in a number of research projects, including Stroke Epidemiology. She is a co-director of the ARCOS studies as well as a member of the Global Burden of Disease Project Stroke expert panel. She is Principal Investigator on the studies: Subarachnoid Haemorrhage Outcomes in the Community, and Primary Prevention of Stroke in the Community (a pilot study). Rita also coordinates and lectures in the postgraduate Stroke Management paper at AUT University.

Rohit Bhattacharjee, NISAN Research Officer

Rohit joined NISAN after completing his Master of Public Health at the University of Auckland in 2010. He has previously worked with the University of Auckland's Centre for Health Services Research and Policy.

Rohit is particularly interested in health related quality of life, and aims to continue gaining research experience in assessing the impact of neurological conditions and their treatments on patient quality of life.

Rohit is currently the Study Manager for the Brain Injury and Neuroaid Supplementation (BRAINS) study and works on the SMART DVD Self-Rehabilitation and BIONIC4YOU studies. He has previously been involved with ARCOS IV and the Beat Fatigue study.

Rohit is also Project Manager of the Stroke Riskometer project and will be involved in developing smartphone interface and IT logistics of the study and integrating study data with NISAN Data Management systems.

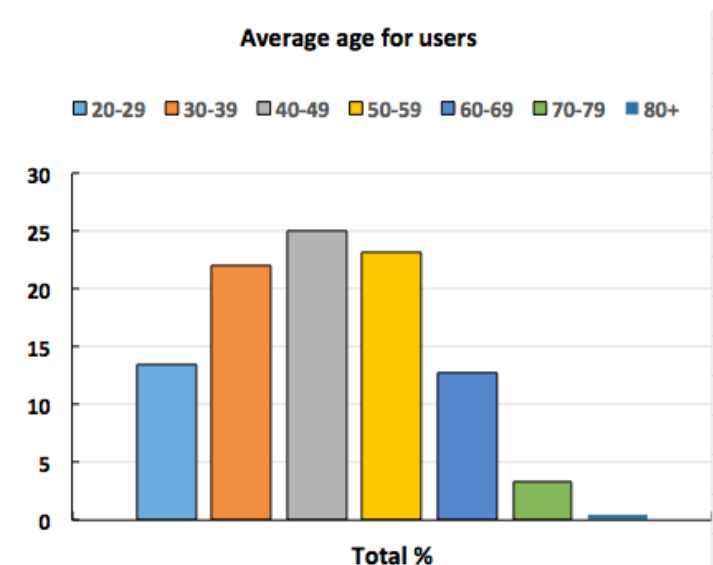## Current progress of the RIBURST study

The study is progressing very well, and now has about 6,600 study participants. As of 3 months ago we had over 70,000 downloads, and we are likely to have far more now.

At present we have participants from 108 countries.

Distribution by sex is fairly even
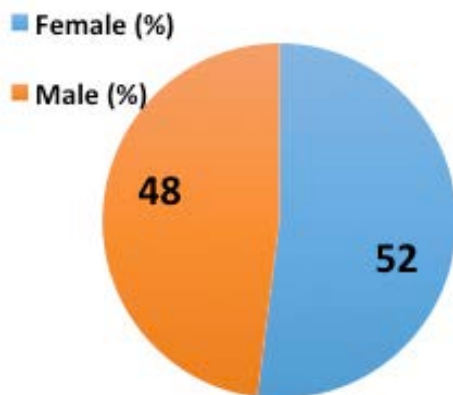
The average age for users is 45.5 years.

So far, the majority of study participants are from Russia.

Newly translated versions of the app are getting released almost every week. Remember: it is important to time the release of each new translated version of the app with the media campaign in the world (such as World Stroke Day on the 27th of October) or the country (or countries) concerned. To attract media attention we have developed a standard media release which we would be happy to share with you for further adaptation on the per-need basis – just let us know if you need it

Study participants by country (%)

or you would like to develop your own media release. We encourage you to profile the app together with the information about significance of the primary prevention of stroke in your country to increase stroke awareness. This could be best done in cooperation with your local Stroke Organisations. We have found that TV interviews are the best approach to profile the app and raise stroke awareness (e.g., just one minute national TV interview with Prof. Michael Piradov in Russia resulted in 30,000 downloads within a few days after the interview).
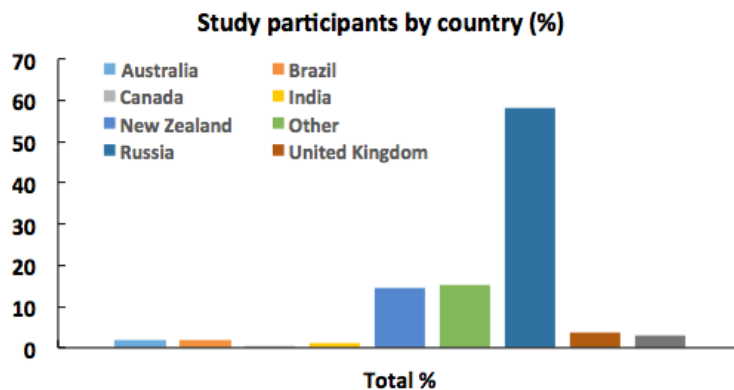
We have prepared a document containing 'myths and facts about stroke', which could form part of possible media releases for those collaborators who want to pursue this option. It is set out at the end of this newsletter, and the Word format file is available from the NISAN secretariat.

Updates from participating sites

Russia

The Research Center of Neurology (Prof. Michael Piradov, Prof. Yury Varakin, Dr. Michael Kravchenko) in Moscow coordinates the RIBURST study across all Russia. They recently initiated a survey to analyse the usage and acceptability of the Riskometer by Russian people. The Stroke Riskometer leaflet was presented at the All-Russian Congress of Rehabilitology in Moscow in June. The leaflet design, printing and distribution (80,000

copies) was supported by Takeda, with contributions from Dr Alexandr Merkin, Prof. Alexander Komarov and Dr Alaxender Borodulin.

Italy

Dr. Paola Santalucia and her team presented the Stroke Riskometer at the European Heart Network (EHN) annual workshop that was held in Edinburgh in May, and it was a success. They pointed out the importance of the tool in terms of individual prevention at a mass level, education and research and Dr. Santalucia reported that people were really very interested! They are

also working with the Italian Ministry of Health to make the app feely available for all Italian citizens.

China

Dr Wenzhi Wang intends to introduce the Riskometer app to the people through media releases in China. He also plans to report to the Chinese Ministry of Health, to persuade them to promote this significant activity.

Malaysia

Prof Datin Dr Norlinah Mohamed Ibrahim has arranged for a media release in Malaysia and intends to present a business case to the Malaysian Ministry of Health. The Stroke Riskometer app will be launched in Malaysia at the World Stroke Day Celebration on 27 October.

Brazil

Dr Sheila Martins and Prof. Norberto Luiz Cabral are organising a media release in Brazil on World Stroke Day on the 27th of October. They are also working with the Brazilian Ministry of Health to make the app feely available for all Brazilians.

India

Prof. Jeyaraj Durai Pandian, Prof. Man Mohan Mehndiratta and Prof. Dipes Mandal are preparing a media release for Hindi and Bengali versions of the app. They are also working with the Indian Ministry of Health to make the app feely available for all citizens of India.

Releases and app updates

In addition to the English version of the app, the Russian, Chinese and Brazilian versions of the app are also live and available to download. The Italian, Malay and French apps are also very close to release, and the remaining languages are in prototype phase.

Updates on ongoing Randomised Control Trials based on the Stroke Riskometer app

MARS – The MARS trial (Changing behaviour to reduce stroke risk using the Stroke Riskometer mobile app: A pilot RCT) is underway in Auckland and Dunedin, NZ. Recruitment is progressing well and expected to be concluded by the end of the year. Preliminary results should be available by mid-2017.

Dr. Michael Kravchenko, Research Centre of Neurology, Russia, has created a Wiki page for the Stroke Riskometer (SR) community. You can find it here: http://strokeriskometer.mybb.us/ and you will see that it has 2 sections, one for everyone and one for SR collaborators only. It is hoped that this will be a good place to share your experiences, suggestions, plans etc. Sub-forums for different language communities are planned. Please feel free to join and share any feedback or ideas you may have.

New Stroke Riskometer app endorsements

International endorsements

The Lite version of the Stroke Riskometer app has been endorsed by:

New publications

1. Feigin VL, Norrving B, George MG, Foltz JL, Roth GA, Mensah GA (2016). Prevention of a stroke: A strategic global imperative. *Nature Reviews Neurology, 12*, 501-512. doi: 10.1038/nrneurol.2016.107
2. Feigin VL, Wang W, Fu H, Liu L, Krishnamurthi R, Bhattacharjee R, Parmar P, Hussein T, Barker-Collo S (2015). Primary stroke prevention in China - a new approach. *Neurological Research 37*(5).

3. Feigin, V., Varakin, Y. Y., Kravchenko, M. A., Piradov, M. A., Tanashayan, M. M., Gnedovskaya, E. V., Bhattacharjee, R. . . . Barker-Collo, S. (2015). A new approach for stroke prevention in Russia. *Annaly-Nevrologii, 9*(4), 11-15.
4. Feigin, V. (2016). Primary stroke prevention needs overhaul. *International Journal of Stroke.* doi:10.1177/1747493016669850

General news

World Stroke Organization (WSO) and ESO and several national stroke organisations have placed info about the app on their websites:

WSO: http://www.world-stroke.org/education/stroke-riskometer

ESO: http://www.eso-stroke.org/eso-stroke/strokeinformation/stroke-riskometer.html.

The preliminary data we analysed from RIBURST study participants suggest that the data are real (no unexpected findings). Cross-validation of the data is planned for NZ and the study should be underway soon.

Please contact the secretariat (brigitte.vangils@aut.ac.nz), if:

- You change affiliations or contact details
- You require promotional materials for your country
- Your Ministry of Health or other major health service provider/company would like to consider provision of the app for your country
- You initiated an app-based study or use the app for your project

- You published a journal article or presented a talk/poster related to the app
- You want to suggest a new collaborator, especially from a country not currently involved in the RIBURST study
- You plan to submit a grant application utilising the app in the study design
- You received a research grant for a study utilising the app in the study design
- If your Stroke NGO would like to endorse or have endorsed the app

MYTHS AND FACTS ABOUT SROKE (can be used for media release)

Myth: Stroke is a rare disease
Facts: Stroke is one of the most common diseases and 1 in 6 of us will have a stroke in our lifetime. There are 10.5 million new strokes happening in the world annually, meaning that every 3 seconds someone in the world is struck by stroke and every minute someone dies from stroke.

Myth: Stroke can't be prevented, there's nothing you can do about it
Fact: Stroke is largely preventable. Early detection and effective control of stroke risk factors can greatly reduce the possibility of stroke. The number of people suffering stroke would be more than halved if all recommended risk reduction strategies were taken in the community.

Myth: Stroke hits without warning
Fact: Transient Ischaemic Attacks or TIAs ("mini-strokes") can happen prior to a stroke. These signs of stroke disappear within minutes or hours, but should be seen as a clear warning that a more severe stroke might follow. Early medical attention and treatment can prevent this. There is nothing trivial about a so-called "mini-stroke" - seek medical help immediately.

Myth: Stroke only affects older people

Fact: Stroke affects all ages. Around a quarter of all strokes will occur in people under the age of 65. About 200,000 children have a stroke every year worldwide.

Myth: Stroke is a bad luck and it strikes at random

Fact: The majority of strokes happen in people who have some risk factors for stroke. Knowing your risk of having a stroke and knowing your individual risk factors and controlling them appropriately will help you to reduce your chances of having a stroke. The first step to reduce your risk of having a stroke is to know your risk and risk factors you may have, and this is where Stroke Riskometer can help.

Myth: Stroke risk is largely determined by genetic makeup

Fact: Over 80% of strokes are determined by lifestyle and other modifiable factors.

Myth: There is no effective treatment for stroke

Fact: Early hospitalisation and adequate treatment can substantially improve stroke outcome.