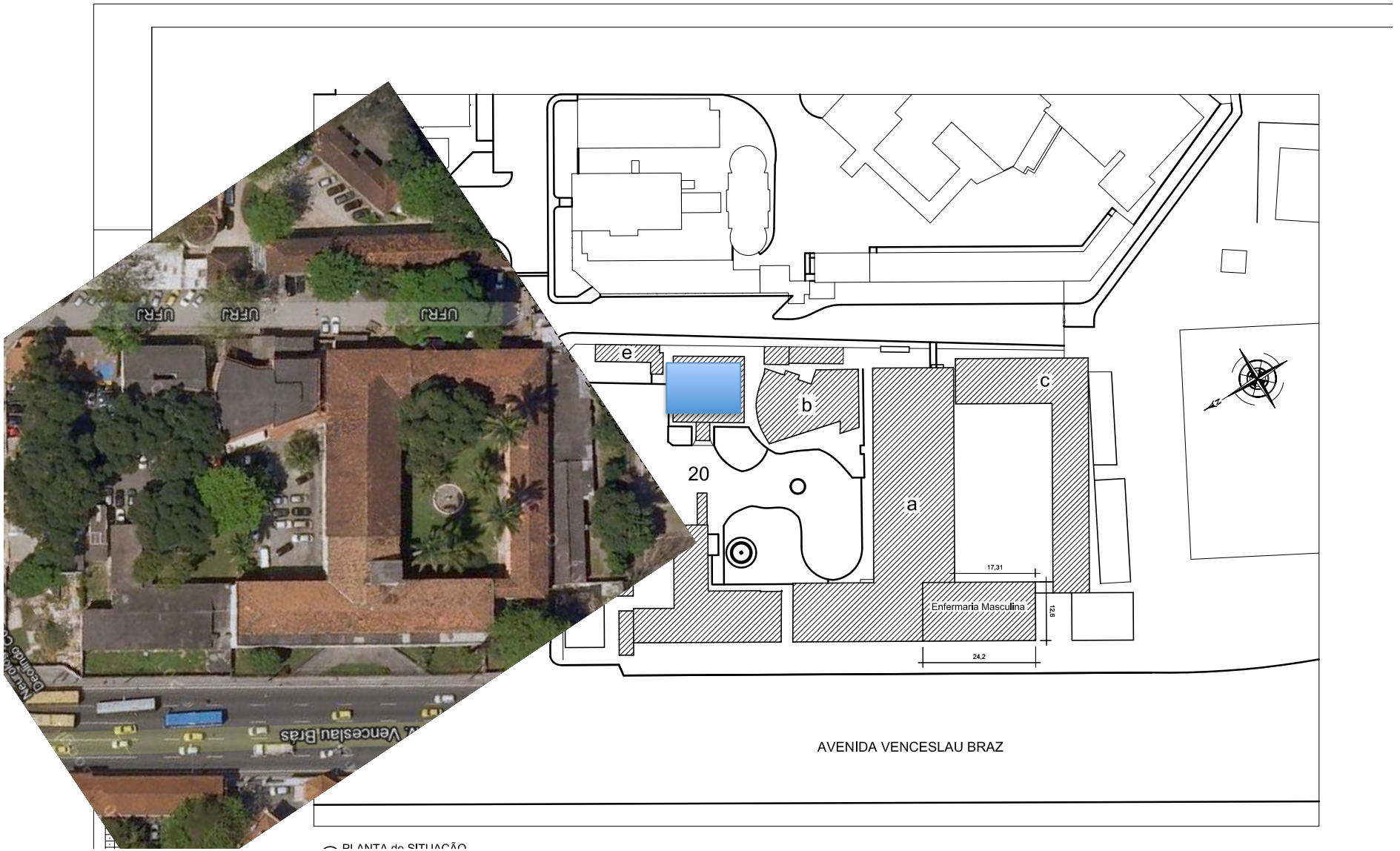

UNIVERSIDADE DO BRASIL
BUILDING A DATABASE PROTOTYPE
Laboratory of Neurocience and Rehabilitation
Institute of Neurology Deolindo Couto (1946)
Federal University of Rio de Janeiro
Neurologia
FINEP
FAPERJ
CNPq
NEUROMAT/FAPESP

Mission: To consolidate at the Institute of Neurology Deolindo Couto (INDC) of the Federal University of Rio de Janeiro a multidisciplinary team to investigate brain reorganization after lesions of the sensorimotor system.

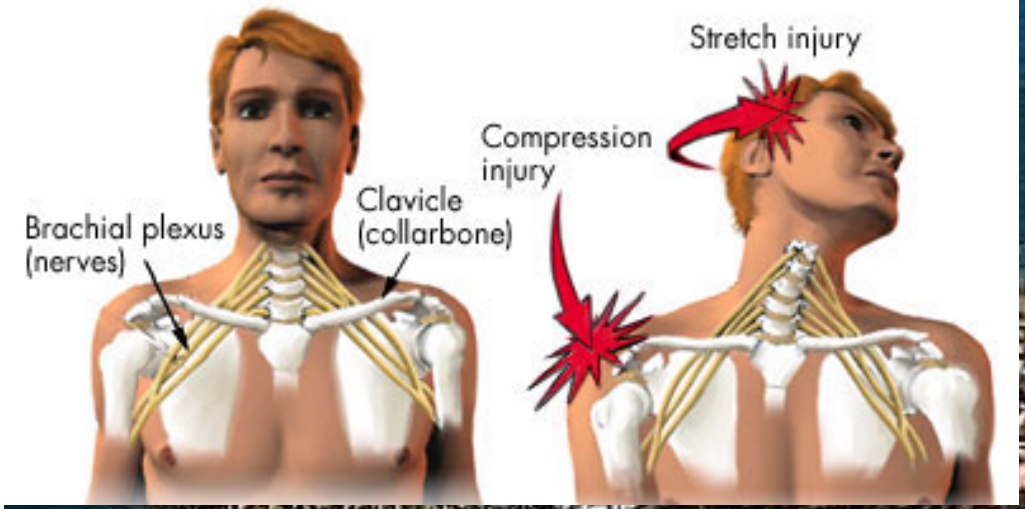


CORTICAL REORGANIZATION AFTER BRACHIAL PLEXUS LESIONS

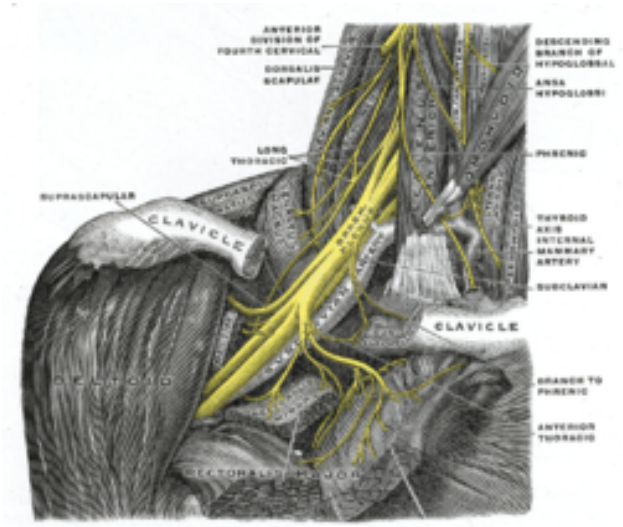
EVALUATIONS

- Functionality
- sensititivity
- Pain
- Life quality/post traumatic disorder
- muscular force
- upper limb kinematics
- TMS
- EEG
- MRI

SURGERY TO REINSTATE MOTOR FUNCTION

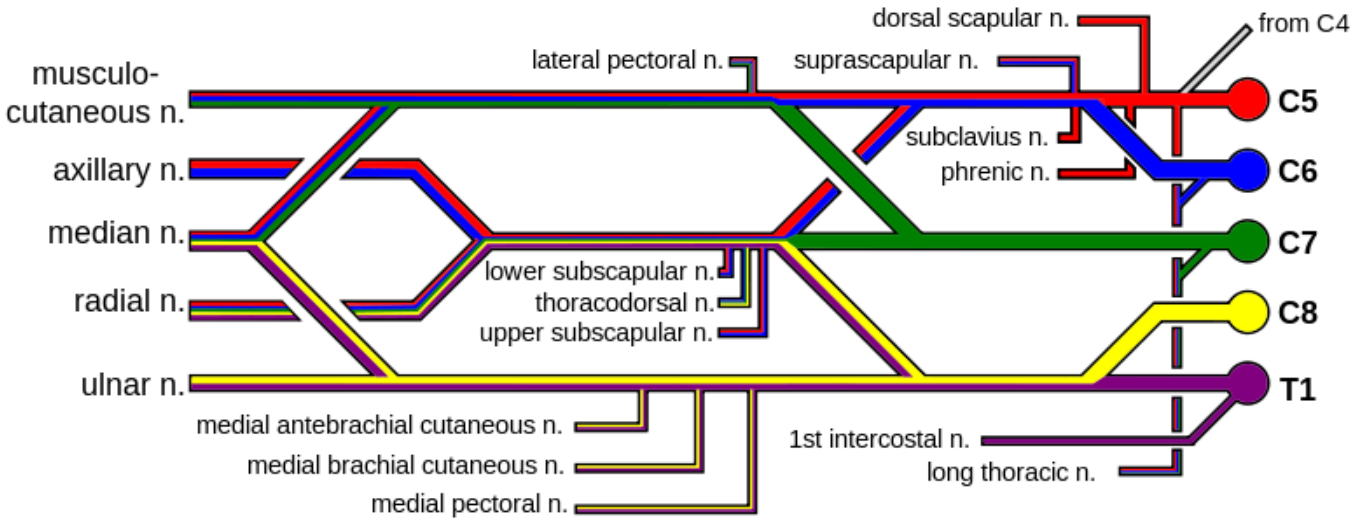


Goals for the next two years:



Wikipedia, brachial plexus

- Build a virtual databank
- Investigate cortical plasticity through EEG, TMS, MRI
- Develop mathematical modeling of cortical reorganization
- **Rules of cortical plasticity?**



BRACHIAL PLEXUS LESION PROJECT
DATABASE CONSTRUCTION: OUR WISH LIST

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Juliana Maia
Paulo Leonardo Tavares
Jose Fernando Guedes
Maria Luiza Rangel
Samuel Frare
Talita Pinto

Marcos V. Barbosa
Maria Lucia Marujo

- A new set of formularies aiming to fully describe the patient's clinical evolution (rendered anonymous)
- Complementary evaluations and exams archiving
- Detailed labeling and proper stocking of eeg, tms, fMRI, stabilometric and kinematic data (this encompasses raw data and data analysis programs) interfacing with patient's evaluations
- Approval by the local ethics committee
- Open access trough registration

From the scratch…….

FICHA DE AVALIAÇÃO NEUROLÓGICA PLEXO BRAQUIAL

• IDENTIFICAÇÃO

Nome:

_____

Prontuário:_____

Tel:_____

Endereço:_____

Naturalidade:_____

Idade:_____ Sexo:_____ Cor:_____

Médico:_____ Fisioterapeuta:_____

Profissão/Atividade:_____

Data Avaliação:_____

• ANAMNESE

– Diagnóstico Clínico: _____

_____

_____

– Q.P.: _____

_____

Q.F.:_____

_____

– H.D.A.: _____

Lesões associadas acidente:_____

_____

Tipo de Cirurgia:

Enxerto: _____

Neurotização:_____

Neurólise:_____

Neurotização e enxertia: _____

Quanto tempo esperou para a cirurgia:_____

Não foi submetido à cirurgia:_____

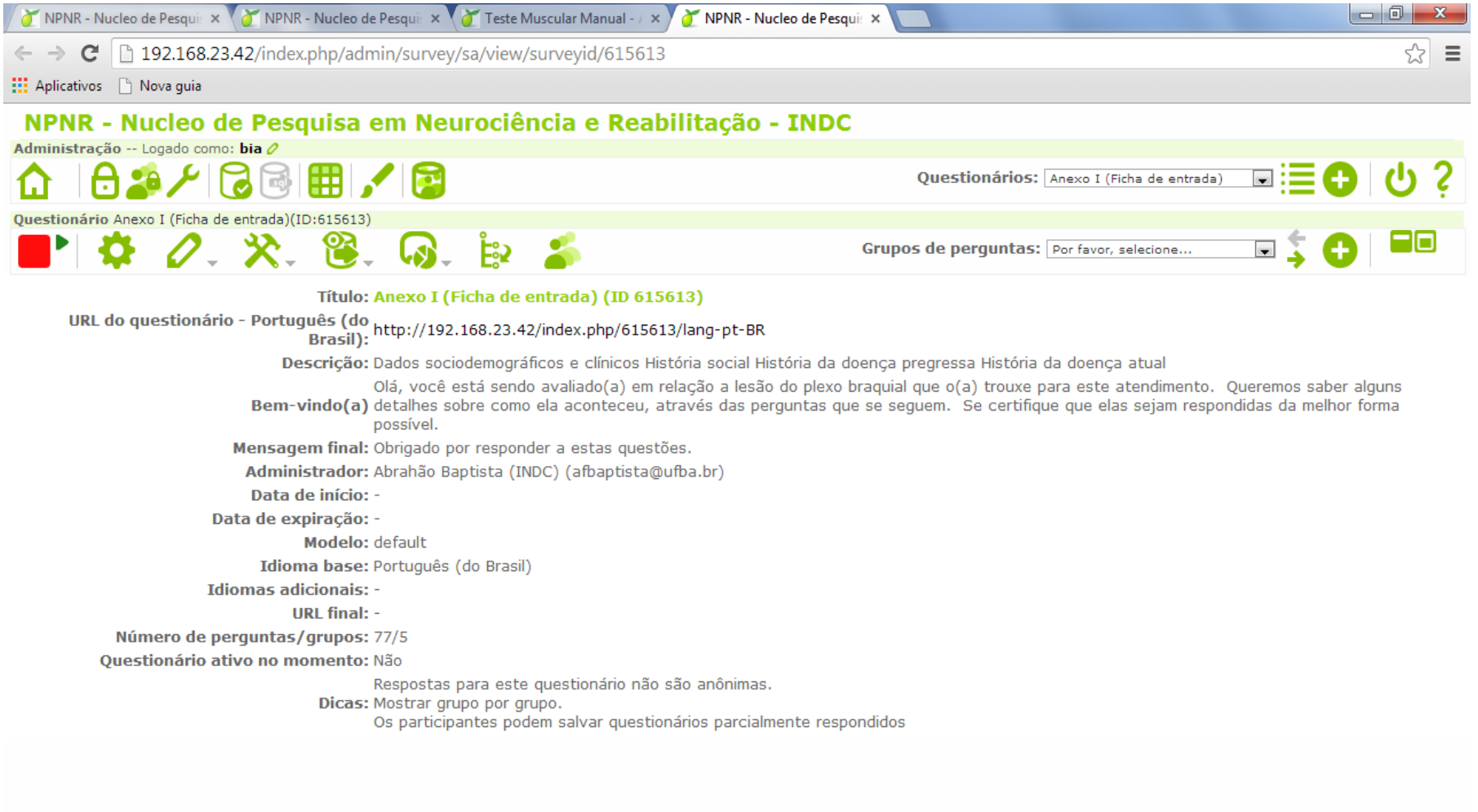
Data da cirurgia: _ Tempo de

Imobilização:_____

– H.P.P.:

Cardiopatia Hipertensão Trauma Diabetes Câncer Cirurgia Ortopédica

❖Step 1) Lime Survey (NEUROMAT, Braghetto and Ribas, July 2013): Training in how to build the forms using lime survey



Anexo I (Ficha de entrada)

Dados sociodemográficos e clínicos
História social
História da doença pregressa
História da doença atual

História de Doença Pregressa

* **HAS**

Sim Não

* **Diabetes**

Sim Não

* **Disfunção hormonal**

Sim Não

* **História de fratura?**

Sim Não

* **Já fez alguma cirurgia ortopédica?**

Sim Não

* **Fez alguma cirurgia de nervo?**

Sim Não

* **Doença reumática**

Sim Não

* **Cardiopatia**

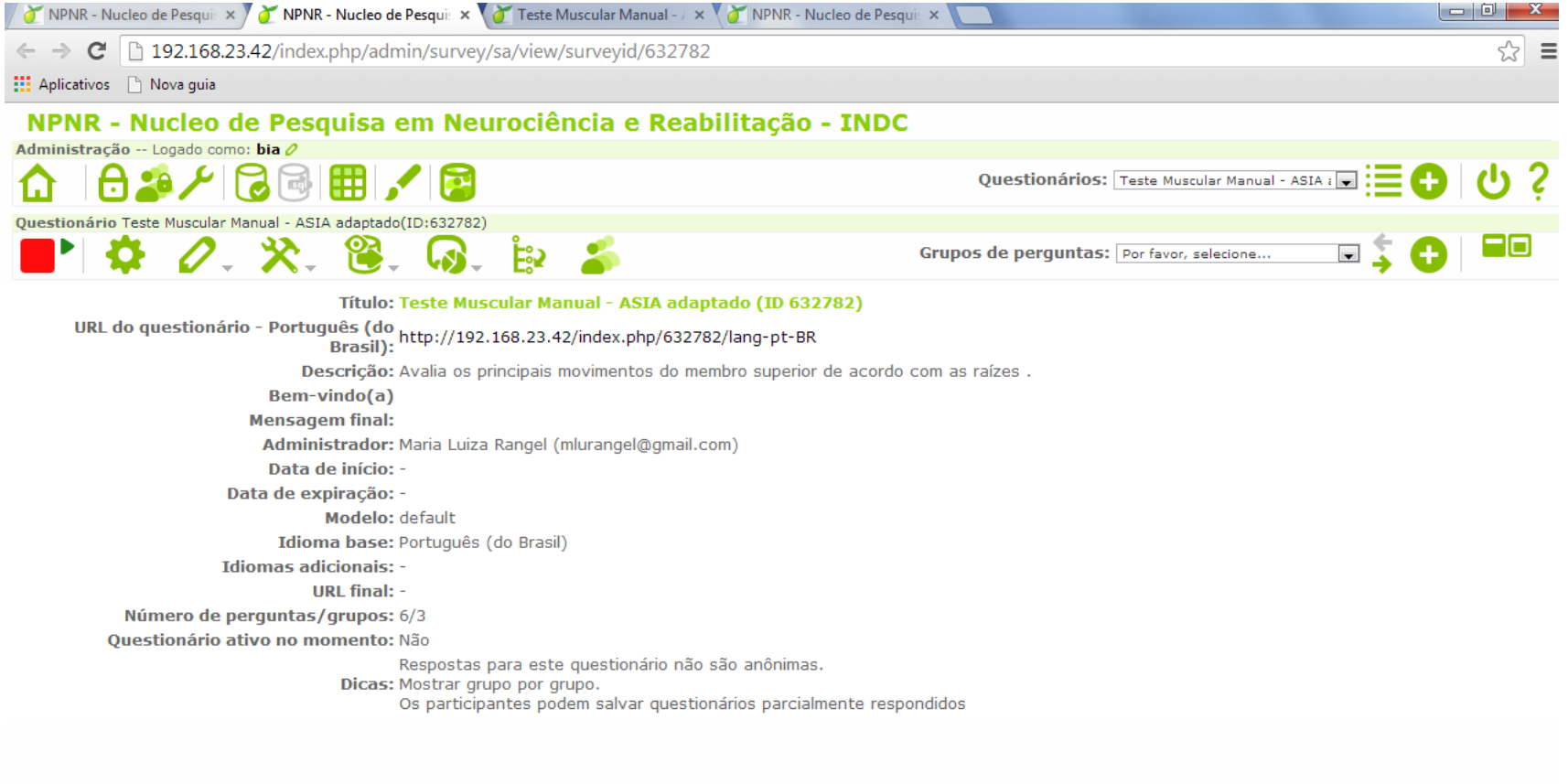
Sim Não

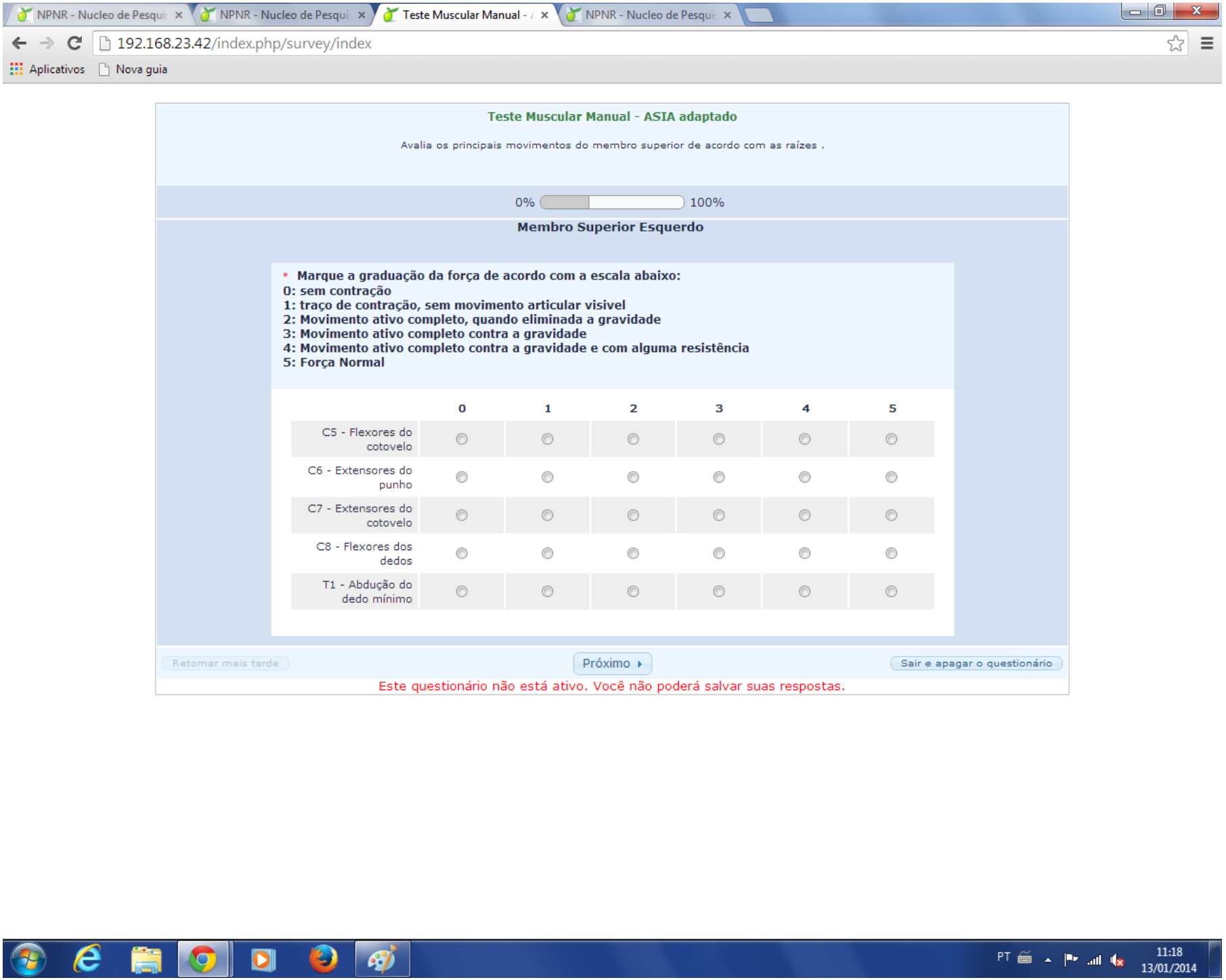
* **História de vertigem**

Sim Não

* **História de tontura**

Outros indicadores


NPNR - Nucleo de Pesqui
NPNR - Nucleo de Pesqui
Teste Muscular Manual -
NPNR - Nucleo de Pesqui
192.168.23.42/index.php/admin/survey/sa/view/surveyid/632782
Aplicativos
Nova guia
NPNR - Nucleo de Pesquisa em Neurociência e Reabilitação - INDC
Administração -- Logado como: bia
Questionários: Teste Muscular Manual - ASIA a
Questionário Teste Muscular Manual - ASIA adaptado(ID:632782)
Grupos de perguntas: Por favor, selecione...
Título: Teste Muscular Manual - ASIA adaptado (ID 632782)
URL do questionário - Português (do Brasil): http://192.168.23.42/index.php/632782/lang-pt-BR
Descrição: Avalia os principais movimentos do membro superior de acordo com as raízes .
Bem-vindo(a)
Mensagem final:
Administrador: Maria Luiza Rangel (mlurangel@gmail.com)
Data de início: -
Data de expiração: -
Modelo: default
Idioma base: Português (do Brasil)
Idiomas adicionais: -
URL final: -
Número de perguntas/grupos: 6/3
Questionário ativo no momento: Não
Dicas: Respostas para este questionário não são anônimas.
Mostrar grupo por grupo.
Os participantes podem salvar questionários parcialmente respondidos


NPNR - Nucleo de Pesqui
NPNR - Nucleo de Pesqui
Teste Muscular Manual -
NPNR - Nucleo de Pesqui
192.168.23.42/index.php/survey/index
Aplicativos
Nova guia
Teste Muscular Manual - ASIA adaptado
Avalia os principais movimentos do membro superior de acordo com as raízes .
0%
100%
Membro Superior Esquerdo
* Marque a graduação da força de acordo com a escala abaixo:
0: sem contração
1: traço de contração, sem movimento articular visivel
2: Movimento ativo completo, quando eliminada a gravidade
3: Movimento ativo completo contra a gravidade
4: Movimento ativo completo contra a gravidade e com alguma resistência
5: Força Normal
0
1
2
3
4
5
C5 - Flexores do cotovelo
C6 - Extensores do punho
C7 - Extensores do cotovelo
C8 - Flexores dos dedos
T1 - Abdução do dedo mínimo
Retomar mais tarde
Próximo
Sair e apagar o questionário
Este questionário não está ativo. Você não poderá salvar suas respostas.
PT
11:18
13/01/2014

OUTPUT LIME SURVEY

❖Step 2 (jun/Dez 2013): forms digitalization

1) Admittance (personal information data, kept separately)
2) Clinical evaluation (experimenter+ neurosurgeon+ physical therapist)
3) Acute, Post surgery (experimenter+ neurosurgeon)
4) Longitudinal evaluation (experimenter+ physical therapist)
5) Laterality (Odfield), Balance (Berg), Pain (DN-4), **DASH**
6) Other forms (specifics)

Phantom limb sensation, PTSD, Depression

Predictive task, Rhythm Complexity, Narakas

THE **DEVIL** OF certitude

❖ **Step 3 (Dez 2013, Braghetto and Menezes)**:

CREATING a virtual protocol to categorize, classify and properly evaluate longitudinally brachial plexus injured (BPI) patients.

The next step will be to associate such functional descriptors to physiological measures collected in specific experimental contexts.

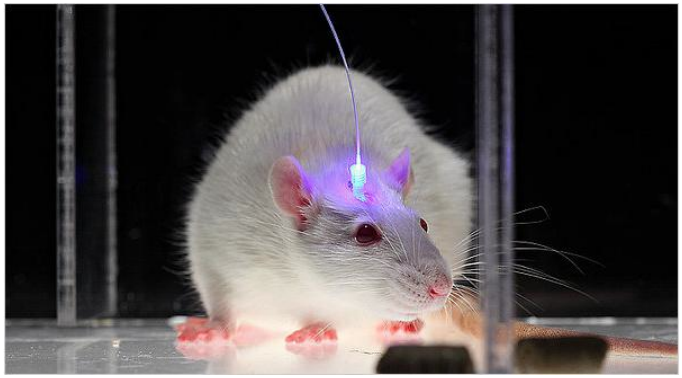
These data shall constitute the first open access database In BPI.

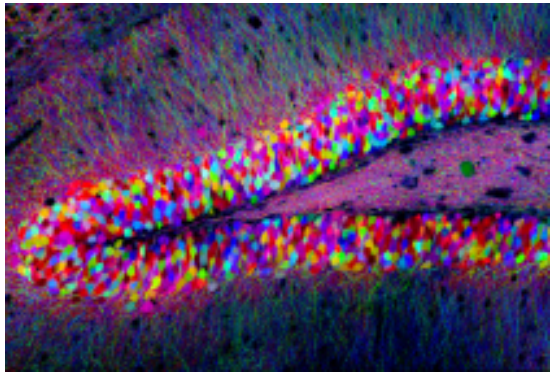
Progama anonimizacao

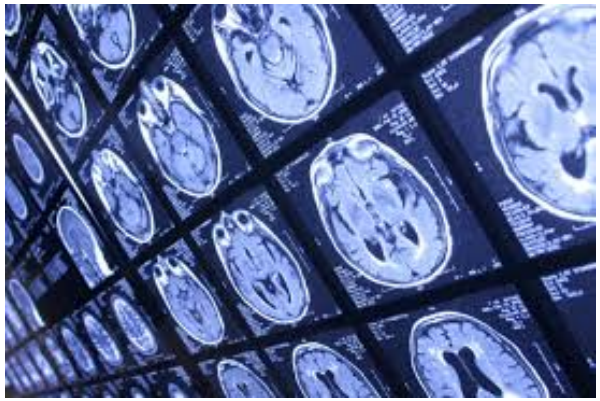
Fill the electronic formulaires

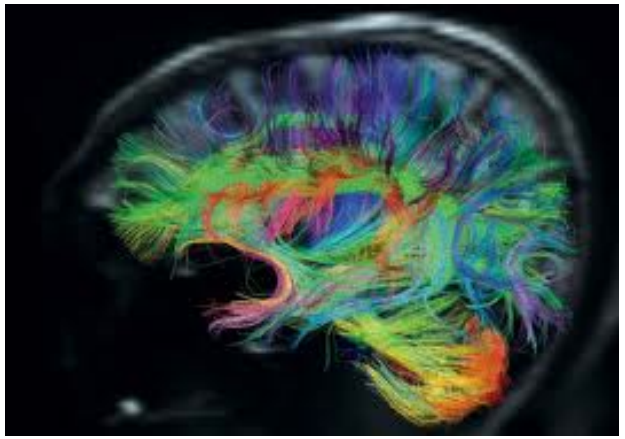
WHY CONSTRUCTING A DATABASE WITHIN NEUROMAT?

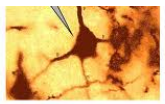
Sao Paulo, January 21th, 2014





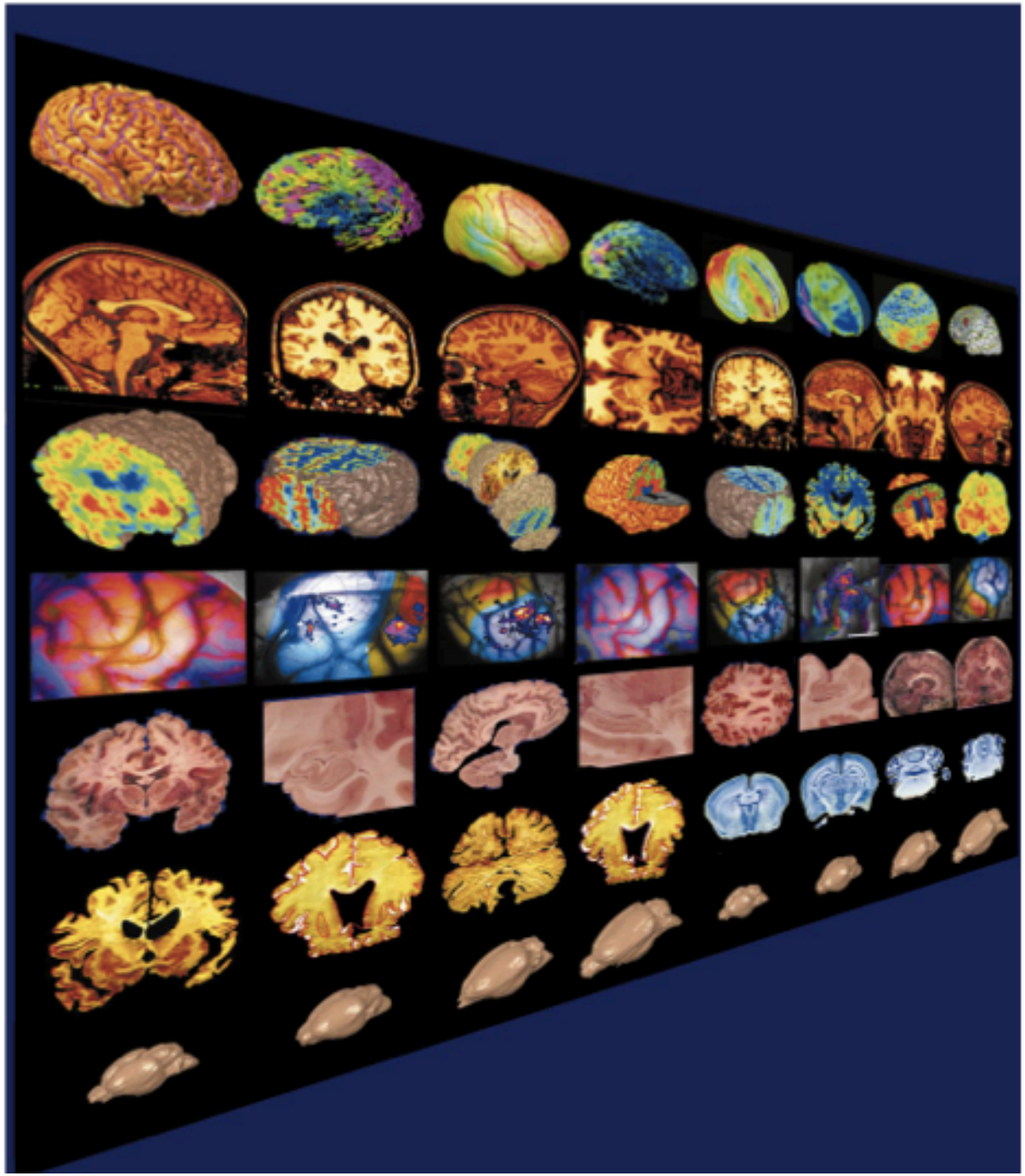


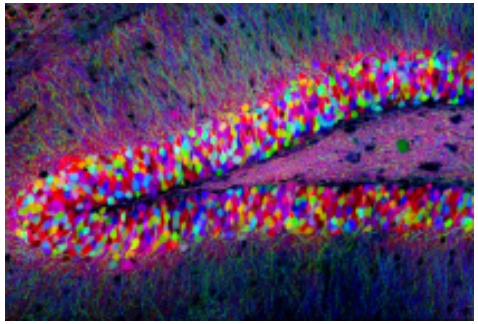




Databasing the brain

Progress in neuroscience might be faster if researchers shared their results in a network of databases. But the technical challenges are huge, and reaching a consensus on what to archive won't be easy, says Marina Chicurel.





Big obstacles:

- Reaching a consensus on what is worth including in databases*.
- The technical difficulty of collating and relating disparate types of information (anatomical, electrophysiological recording, images, etc);
- The reluctance of researchers who have traditionally guarded their results jealously to embrace data sharing.

*“Tackle the devils early in the game,” says David Choi. “The devils include the possibility of prejudice overly influencing future thought, essentially by controlling the shape of the database or the priority given to certain data over others”.

commentary

Should the neuroscience community make a paradigm shift to sharing primary data?

Stephen H. Koslow

The author outlines the pros and cons of data sharing for neuroscientists and argues that continued progress in the field will depend on a cultural shift toward making primary data freely available. He argues in favor of distributed databases to maximize the efficient use of data.

Table 1. Pros and cons of sharing primary data.

Against sharing primary data	Response
No one else can understand the complexity of my data.	This can be overcome by including the relevant experimental conditions and variables in the database.
If someone else analyzes my data, they may come up with a different answer, disproving my perspective.	The true answer is what we are pursuing, and by considering different perspectives on the same data set, we will come closer to reality.
Someone else may find something new in my data that I did not see.	Finding something new in an existing data set will increase our scientific knowledge without the unnecessary effort and cost of repeating the entire experiment.
It is my data that I worked very hard to collect, and no one else has the right to it.	Publication of the study already implies that its results and conclusions are to be shared. If these are to be evaluated in detail, readers should have access to the primary data on which they are based. In most cases, sharing primary data also serves the interests of the organizations that fund the research.
I have not finished analyzing my data, and I will make it available once my analysis is complete.	A published paper suggests that the experimental data have been substantially analyzed; thus sharing at this point would seem appropriate.
I cannot trust or understand the data produced in another laboratory.	Currently we all try to understand data from other laboratories whenever we read the scientific literature; this influences our own future experimental and theoretical pursuits. Having the complete data set available for re-analysis would increase experimental efficiency.

Sharing data

Why?

- The power of brain databases could catapult the field to new levels of research and discovery.
- Continued innovation and expansion in brain data sharing is supported by efficiency and economy in terms of both experimental power and real dollars.
- The need for large scale science to understand the brain.

How?

- Clearly it is not realistic at present to create a single database that can store all these types of information.
- A more practical approach is to establish a variety of smaller-scale initiatives, in which individual neuroscientists work with information scientists to create databases relevant to their own research.

When? …

- Upon publication in a web-based mode appropriate security to protect the data from corruption, yet available to scientists on request.

FROM THE EARLY 2000, DATABASE SITES OF INTEREST IN NEUROSCIENCE

Biomedical Informatics Research group (BIRN)
National Institutes of Health (USA)

- Designed as the first national cyber-infrastructure for biomedical research.

- Created in 2001 by the National Center for Research Resources (NCRR), then a unit of the US National Institutes of Health (NIH), BIRN initially was funded for more than $20 million.

- Its purpose: to create a shared, distributed computing framework for databases, data integration, inter-operable analysis tools and data mining software.

http://www.birncommunity.org/

TESTBEDS: EXAMPLES OF TEMATIC CONSORTIA

- Morphometry BIRN to pool and analyze data across neuroimaging sites for potential relationships between anatomical differences and specific memory dysfunctions, led by Bruce Rosen, M.D., Ph.D. of Harvard University, the Massachusetts Institute of Technology and Massachusetts General Hospital;

- Function BIRN to standardize data collection and analysis for multi-site magnetic resonance imaging of schizophrenia patients, led by Stephen Potkin, M.D., of the University of California at Irvine;

- Mouse BIRN to study neurodegenerative diseases by pooling and analyzing multi-scale structural and functional mouse data, led by G. Allan Johnson, Ph.D., of Duke University. The Mouse BIRN subsequently transitioned to the leadership of Arthur W. Toga, Ph.D., of the University of California at Los Angeles.

- Non human primate consortium (NHPRC) to strengthen communications, leverage system-wide resources, and facilitate sharing of information and best practices across institutions. Established in partnership with the National Institute of Health (NIH), the Consortium consists of working groups in the areas of genetics, training, colony management, DNA banking, pathology and behavioral management.

http://www.birncommunity.org/

Brain Research and Integrative Neuroscience Network

http://www.brainnet.net/

The goal of BRAINnet is to expand our knowledge on what constitutes healthy development of the brain across all ages and what goes awry when brain disorders occur.

To accomplish this goal BRAINnet has formed a global consortium of investigators, and provides them with access to multiple types of data acquired from the same individuals.

The immediate goal of access to each set of data is to write a specific paper for peer-reviewed publication. The topic of this paper is approved by the BRAINnet membership working in the same or related areas.

The outcomes sought by BRAINnet are to understand the human brain in all its strengths and fragilities, and to apply this understanding to mental health problems: their causes, treatment, and ultimately their prevention.

In June 2009, data from the Brain Resource International Database has been made available to BRAINnet from:

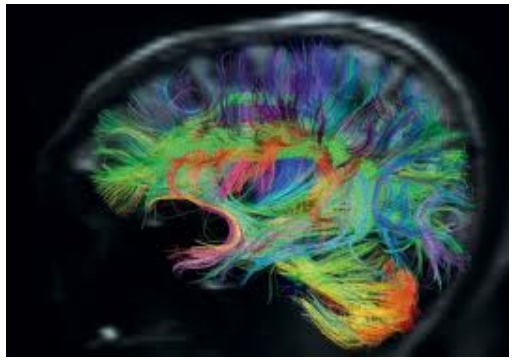
5,000 subjects, with confirmed status as healthy

1,000 subjects with confirmed status as clinical disorder or extreme function:

Major Depressive Disorder
ADHD
First Onset Schizophrenia
Post Traumatic Stress Disorder
Alzheimer's Disease
Mild Cognitive Impairment
Traumatic Brain Injury
Sleep Apnea
Panic Disorder
Anorexia Nervosa
Obesity

The following types of data are available for these subjects, acquired using standardized protocols and platforms:

Screening Questionnaires
General and Emotional Cognition
Brain-Body Functions
Genetics
MRI, fMRI and DTI



ILLES J, LOMBERA S. IDENTIFIABLE NEURO ETHICS CHALLENGES TO THE BANKING OF NEURO DATA. MINN. J.L. SCI. & TECH. 2009;10(1):71-94.

Identifiable Neuro Ethics Challenges to the Banking of Neuro Data

Judy Illes * & Sofia Lombera**

The ethics and policy challenges include:

- Regulating the content of, access to, and use of databases;
- Ensuring that data remains confidential and that informed consent procedures account for future use and commercialization of data;
- Managing unexpected findings, data anonymization, and recontact procedures.

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CONFIDENTIALITY, CONSENT, AND COMMERCIALIZATION

- Identifying information must be removed from data prior to submission for sharing. (Nonetheless, new possibilities for reconstructing facial and cranial features from a brain image make old confidentiality rules about identifying information a particularly vexing problem today).

- Commercialization raises further ethical issues, including preventing exploitation of vulnerable populations, balancing costs and benefits, and avoiding conflicts of interest.

- Research with identifiable samples involves risk of discovery of unexpected and potentially unknown clinical significance, missed incidence, violation of the donor's privacy through discovery, and disclosure of sensitive information (intrinsic harm), or risk of discrimination by disclosure of information to third parties (consequential harms).

- Participants must be told that when samples (data) are used anonymously, they cannot be given specific information about findings related to their samples.

The National Bioethics Advisory Commission (“NBAC”) recommended that IRBs should develop general guidelines for disclosure of results in current or future research when :

(a) the results are scientifically valid and confirmed,
(b) the results have implications for subjects’ health concerns, and
(c) a course of action to ameliorate or treat the concern is readily available.