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International Telecommunication Union

How e-Science Can Help to Solve Pressing Societal Challenges:

Fostering A Global Effort to Develop a Worldwide e-Infrastructure for Computational Neuroscientists to Fight Alzheimer's Disease

JOINT CONCLUSIONS

Following the outGRID workshop 'How e-Science Can Help to Solve Pressing Societal Challenges: Fostering a Global Effort to Develop a Worldwide e-Infrastructure for Computational Neuroscientists to Fight Alzheimer's Disease' held on 20 February 2012, representatives from European, Canadian, Indian funding agencies, WHO and ITU sat together with neuroscientists, ICT scientists and e-infrastructure providers from Europe, Canada, US, Latin America, India and Lebanon, with the aim to draw conclusions from the discussions held during the workshop regarding Alzheimer's Disease and Related Disorders (ADRD) research, and with a special focus on coordinating e-infrastructure support and related funding. This report aims to serve as a common background report for all interested parties.

The meeting took place at the ITU premises in Geneva on the 21st February 2012 and was chaired by the European Commission. For the list of participants, see below. The agenda included:

1) Current Context in Alzheimer's Disease and Related Disorders (ADRD) Research and Funding
2) Current Problems, Needs and Challenges
3) Conclusions and Recommendations
4) Follow-Up Actions in Relation to the ITU

1) CURRENT CONTEXT IN ALZHEIMER'S DISEASE AND RELATED DISORDERS (ADRD) RESEARCH AND FUNDING

Burden of ADRD: The increased and increasing human and financial burden of the ADRD affecting demography and transition especially in developing countries was recognized. Research on ADRD needs ICT to effectively address early diagnosis, prevention and treatment of ADRD, allowing for collection, sharing, comparison of large image datasets and related variables for a more effective and comprehensive response to ADRD globally.

ADRD Research Context: The paradigm shift in some research areas such as imaging studies, where unprecedentedly large datasets are publicly available, requires that new working environments be developed. Distributed computing (grids or cloud computing) and High Performance Computing are a key component of such environments in order to address the emerging need for user-friendly access to data, analysis pipelines and computational resources.

Current Political and Financial Context: The current international political and financial context is favourable for ADRD, as shown by new initiatives to address the disease such as the JPND[1] issued February 2012 in Europe, the Sarkozy Plan to Fight Alzheimer's Disease in France[2], the ICRSAD[3] of the CIHR[4] in Canada, the NAPA[5] in the US, the proposals for the new Framework Programme in Europe and the inclusion of a Brain Grid in the NKN[6] in India. In the recommendations to the 65th World Health Assembly on the Prevention and Control of Non-Communicable Diseases (New York, 19-20 September 2011), it was recognized that 'mental and neurological disorders, including Alzheimer's disease, are an important cause of morbidity and contribute to the global non-communicable disease burden, necessitating provision of equitable access to effective programmes and healthcare interventions'. See also WHO (2012)[7] and WHO (2012)[8].

Depth of Scope: Group participants agreed on the use of ADRD (Alzheimer's Disease and Related Disorders) term; the term was preferred over the term Alzheimer's Disease or the term Alzheimer's Disease and Related Dementia so as to include asymptomatic cases and all forms of dementia, including vascular dementia, mixed dementia and fronto-temporal dementia, thus broadening the definition. (Dementia is the complex of clinical cognitive and behavioral symptoms that represent an observable decline from the patient's usual and customary level and a deficit in social and occupational functioning). It was considered that the field has to remain open to other areas of brain research while remaining focused on Alzheimer's disease.

[1] Joint Programming in Neurodegenerative Diseases,

[2] http://www.plan-alzheimer.gouv.fr/IMG/pdf/plan-alzheimer-2008-2012.pdf

[3] International Collaborative Research Strategy on Alzheimer's Disease and Related Dementias

[4] Canadian Institutes of Health Research

[5] National Alzheimer's Project Act

[6] National Knowledge Network

[7] Global burden of mental disorders and the need for a comprehensive, coordinated response from health and social sectors at the country level, World Health Organization, Documentation, 10th meeting, 20 January 2012, EB130/SR/10 http://apps.who.int/gb/ebwha/pdf_files/EB130/B130_R8-en.pdf

[8] Strengthening noncommunicable disease policies to promote active ageing, World Health Organization, Documentation, Eighth meeting, 19 January 2012, EB1307SR/ http://apps.who.int/gb/ebwha/pdf_files/EB130/B130_R6-en.pdf

2) CURRENT PROBLEMS, NEEDS AND CHALLENGES

Lack of Harmonization: Participants stressed the problems that arise from the diversity in defining indicators, diagnostic criteria, tools and data collection methodologies not only for ADRD but in the field of health and medicine in general.

Availability and Re-usability of Data: Enormous amounts of locked-up data exist. Researchers do not systematically make their data available to others, and even when the data is available it is most often unusable by other scientists than those who collected them. This is especially the case for data collected on a small scale which 'die' soon after publication. Poor re-usability results in enormous waste of resources. Open access is needed not only for data but also for the tools used to process them.

User-Friendliness of Technology: There are technological and operational barriers to accessing data and e-infrastructure services. Specific effort should be devoted to lower entry barriers to computing solutions and improve the potential long delays in uploading data onto the grid due to local networking environments. Usability studies should be the norm.

Legal and Privacy Issues: Privacy, policy and infrastructural- related issues in clinical and research settings are very challenging given the huge diversity on IPR (Intellectual Property Rights) and require additional efforts to be solved.

Digital Divide: Inequalities in knowledge, access and use of Information and Communication Technologies can hamper global collaboration efforts. Customized approaches to developing a global e-Infrastructure for ADRD need to be deployed. For this purpose, countries are separated in 3 types: 1) Type 1 countries with high access to and use of ICT 2) Type 2 countries with lower development in the field of distributed e-Infrastructures for computational biomedicine, although generic infrastructures exist such as high capacity networks, high-performance computing centres, or traditional imaging laboratories. In type 2 countries, specific technical solutions are lacking, though developing and thus giving sufficient latitude for manoeuvre to foster interoperability is possible. 3) Type 3 countries are regions where even basic generic infrastructures are lacking. Typically, these countries are devoid of high-bandwidth networks, high-performance computing centres, and traditional imaging facilities. These are generally, but not necessarily, low-income countries.

3) CONCLUSIONS AND RECOMMENDATIONS

The group participants agreed on five recommendations as set below. They also discussed that while maintaining the focus to the specific ADRD issue, the same platform technology, computing tools, networks, archives, software can be, with adjustments, used to tackle other health issues

and diseases so that the experience gained is useful for other scopes. This initiative can act as a role model to be applied to more fields.

Maintaining a scope for personalized health and a holistic approach were proposed, based on ICT supporting massive processing of imaging, behavioural, clinical and genetic data and harmonized, multi sector acquisition. As such, images should be made available within an integrated and multidimensional approach towards health, expressing the ambition to have a platform of "personalised medicine" with ADRD being one of the applications. 'Health e-child' was mentioned as an example interlinking multidimensional clinical and imaging information.

Global Effort Needed: The participants emphasized the need for a truly global effort in the area of e-infrastructures for ADRD, bringing together and coordinating national efforts throughout the world. Although there are significant programmes already underway in Europe, USA and Canada, these need to be further strengthened and supplemented by much stronger efforts by developing countries where ADRD growth is expected to be the highest and which will therefore be disproportionately affected by ADRD.

The need to build on and integrate with existing initiatives worldwide to avoid reinventing the wheel and creating a new stand-alone infrastructure was agreed upon. The enabling action of the JPND programme was considered to be very relevant for a global initiative. The annual WSIS[9] Forum co-organized by ITU, where different stakeholder groups from across the world come together to discuss ICT-related topics including global e-health infrastructure, was thought to be an appropriate forum for reviewing these issues.

Good coordination between funding agencies is necessary. It was agreed that the mechanisms of joint calls should be explored to fund the development of global e-infrastructure and other agreed international priorities whereas joint reviews by funding authorities were suggested with the aim to produce best practices, learn from past experience and feed into future developments and funding orientation.

The expected global effort and the anticipated federation of interoperable platforms will dramatically improve the current situation. It was recommended to create a working group to evaluate how international collaboration in federating e-infrastructures and platforms can be effective by selecting use cases to illustrate that:

- The gain in statistics by collecting much more input datasets will lead to a measurable gain in accuracy of important measurements on ADRD.
- Benefiting from much higher CPU power will allow greater in depth testing of existing and new models.

[9] http://www.itu.int/wsis/index.html

- The access of neuroscientists from developing countries to the federation of interoperable e-Infrastructures will completely change their perspectives with regards to their current – limited – investigations.

e-Infrastructures: e-Infrastructure for ADRD is seen as an example of the general need for global e-infrastructures. Global ADRD research needs to be supported by a federation of interoperable platforms accessible by all researchers worldwide. The platforms need to flexibly combine computing resources – cloud, grid or High-Performance Computing – while providing a level of abstraction that shields the user from the complexities of the underlying computational infrastructure. As such, user-friendliness of e-infrastructure services and tools is considered key for attracting a larger number of users who are exposed to attractive commercial sector solutions whereas usability studies are recommended to design and deploy new solutions.

The infrastructure needs to be interoperable in the form of globally federated platforms open to (suites of) tools, algorithms and applications. As the e-infrastructure will be based on distributed computing networks with computing resources (nodes) located across multiple countries and continents, network interoperability is therefore a key determinant to this effort success.

The funding agencies have a key role to play in ensuring the development and sustainability of such federated platforms, which need to combine existing e-infrastructures like C-BRAIN[10], N4U[11], DECIDE[12] and LONI[13], link them with more generic e-infrastructures such as EUDAT[14], PRACE[15] and EGI[16], and allow for emergent infrastructures to hook in, such as the one to be developed in India under the National Knowledge Network[17]. High bandwidth connectivity across the cooperating regions, to be ensured through international collaboration between the NRENs[18], DANTE/GÉANT[19], TEIN[20], RedCLARA[21] and other actors is a condition for the above.

Open Access: Joint research efforts supported by an interoperable federated e-infrastructure require sharing of data among the researchers, and therefore an open access policy in all

[10] http://cbrain.mcgill.ca/

[11] http://neugrid4you.eu/

[12] https://www.eu-decide.eu/

[13] http://www.loni.ucla.edu/

[14] http://www.eudat.eu/

[15] http://www.prace-ri.eu/?lang=en

[16] http://www.egi.eu/

[17] http://nkn.in/

[18] National Research and Education Networks http://en.wikipedia.org/wiki/National_research_and_education_network

[19] http://www.dante.net/

[20] http://www.tein2.net/

[21] http://www.redclara.net/index.php?lang=en

participating countries is strongly recommended. Open access extends not only to scientific data but to all elements necessary to ensure the availability and reproducibility of research results, including software. All data should be published in a form that is reusable by others. Data traceability is feasible and would allow knowing what people have done with data and resources and give credit for data 'ownership'. In regards to privacy, policy and infrastructural-related issues and the huge diversity on IPR internationally, the ITU can contribute in harmonizing data collection and use world-wide.

Interoperability and Standards: The need for standardization was stressed to ensure interoperability in sharing not only data but anything that connects to the data production and processing including computing tools, applications, methods, software, metadata, workflows across different platforms and even communication (i.e. protocols/APIs[22]). The participants pledged to develop a federated data framework to promote sharing and integration, where necessary through the development of standards. However, participants also agreed that standardization may in some cases be constraining and should be weighed against a potential loss of scientific creativity.

It was also noted that data sharing does not necessarily require a common data standard. A reference model approach should be adopted to act as a 'lighthouse' for the neuroscientific community enabling several derived concrete architectures and a comparison of existing approaches through abstract entities and their relationships. Such a model will help understand the problems faced, the existing global solutions and their context in the aforementioned framework to advance on different levels (e.g. standards, technologies, policies, etc.). A similar approach but not limited to the one developed in the context of the EUDAT infrastructure was suggested, allowing for the use of diverse approaches and standards while at the same time ensuring interoperability and encouraging data integration.

Applying the reference model approach for a longer time bears the potential of harmonizing the use of standards internationally. It has an optional character but is strongly encouraged, especially for future data collection. This approach does not force standards on research communities, but informs about their existence in the field and over time leads to synergies in standardization and an increasing degree of interoperability whereas existing standards are improved, merged, or simply re-used where possible. A certain level of variability is accepted and needed for innovative methods, but should at least be recognized and flagged. Tools such as a dictionary allowing for comparisons or minimal information checklist can be helpful when linked to the activities under the reference model umbrella. In conclusion, a 'partly standardization- partly harmonization' approach is preferred, well-guided by the reference model process of the neuroscientific community.

[22] http://en.wikipedia.org/wiki/Application_programming_interface

Benchmarking: The need to produce benchmarks by which services provided to ADRD researchers can be compared and assessed was recommended, such as a set of well-defined criteria and metrics for objective comparison of platforms, infrastructures and tools. The ITU pledged to explore this issue within its e-health working group. Alternative options proposed include rating of resources by users with the help of social networking tools.

4) FOLLOW-UP ACTIONS IN RELATION TO THE ITU

The participants greatly appreciated ITU's participation in this global effort and asked for ITU's assistance in achieving the above recommended objectives. The participants noted that with ITU's membership of 193 countries, over 700 private-sector entities and over 30 academic institutions, ITU can help with the deployment of infrastructure and applications, promote communication and networking, and serve as an international forum for discussing global policies. Also, ITU's global outreach capacity to mobilize support for this initiative in all corners of the globe would be helpful for the global research community to obtain open access to the world's store of biomedical data.

The items below were recommended as follow-up actions:

1. The group participants prepare a draft set of requirements to be shared with the ITU working groups for feedback. This list of requirements will act as a needs assessment to be circulated to all interested parties.
2. The participating organizations can consider joining the ITU as Sector Members. The academic membership category, open to universities and associated research institutions - many of whom are part of the outGRID consortium - is an affordable avenue for these entities to participate in ITU activities, especially in study groups working on standardization of e-infrastructure. One of the topics of interest could also be ITU's work on cloud computing[23].
3. The participants are also invited to contribute to ITU-T focus groups, e.g. Focus Group "M2M Service Layer" or Focus Group "Innovation and Standards". ITU membership is not a prerequisite for participation in focus groups; focus groups are open to any individual or organization from a country which is a member of ITU and who is willing to contribute to the work.
4. The ITU Secretariat organizes interoperability events, i.e., testing events where engineers meet (either physically or remotely) to test their implementations and whether they conform to the standards.

[23] ITU-T Study Group 13; Working Party 6; http://www.itu.int/net/ITU-T/lists/sgstructure.aspx?Group=13&Period=14

5. The upcoming Joint ITU-WHO Workshop on e-Health Standards and Interoperability on 26-27 April 2012[24] can serve as a forum for the outGRID community to present their objectives.
6. Deputy BDT Director Y. Grin will deliver a speech to the 2012 WSIS Forum in Geneva mid-May; participants are welcome to attend.[25]

[24] http://www.itu.int/en/ITU-T/Workshops-and-Seminars/e-Health/201204/Pages/default.aspx

[25] http://groups.itu.int/Default.aspx?alias=groups.itu.int/wsis-forum2012

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- Rios Alfonso, maatG and GNUBILA
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