



Review article

Changing requirements and resulting needs for IT-infrastructure for longitudinal research in the neurosciences



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ABSTRACT

The observation of growing “difficulties” in IT-infrastructures in neuroscience research during the last years led to a search for reasons and an analysis on how this phenomenon is reflected in the scientific literature. With a retrospective analysis of nine examples of multicenter research projects in the neurosciences and a literature review the observation was systematically analyzed. Results show that the rise in complexity mainly stems from two reasons: (1) more and more need for information on quality and context of research data (metadata) and (2) long-term requirements to handle the consent and identity/pseudonyms of study participants and biomaterials in relation to legal requirements. The combination of these two aspects together with very long study times and data evaluation periods are components of the subjectively perceived “difficulties”. A direct consequence of this result is that big multicenter trials are becoming part of integrated research data environments and are not standing alone for themselves anymore. This drives up the resource needs regarding the IT-infrastructure in neuroscience research. In contrast to these findings, literature on this development is scarce and the problem probably underestimated.

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1. Introduction

In an estimation of the World Health Organization and the US Institute of Ageing, by 2016 the world population for the first time in history will have more people aged 65+ than people younger than five years (WHO and US National Institute of Ageing, 2011). With this incidence the prevalence of neurodegenerative diseases, such as Alzheimer's and Parkinson's, will increase over the next decades. For 2050 an expected number of 100 million people will suffer from Alzheimer's worldwide (Coleman and Barrow, 2012). This will sum up to a predicted annual cost of 1.9 trillion US\$. According to a study of the European Brain Council, 127 million Europeans were affected by brain disorders in 2004, which cost the health systems approximately 400 billion Euros (Di Luca, 2011). To boost neuroscience research, the European Union increased its funding budget in the 7th framework program for brain research from 10% to 20% (Di Luca, 2011).

This paper addresses the growing IT challenges arising from new research approaches and changing methods applied in the neurosciences within the last ten to 15 years and ongoing. Relevant measures – with regard to the existing and upcoming difficulties – are described which facilitate research projects to produce high-quality research data and to ensure the provision of sustainable databases fulfilling applying regulations. But what distinguishes neurologic disorders from cardiologic or oncologic diseases? And how do these particularities affect the planning, setup, and maintenance of according IT-infrastructures?

One key aspect is the heterogeneity and complexity of symptoms affecting the patients' mental well-being, cognition, motor function, self-perception or self-conception. Thus, the measurement and evaluation of effects resulting from neurologic diseases cover a broad range of instruments and methods. Even conditions like sexual perceptions can meanwhile be observed by analysis of physiological data. Due to this heterogeneity (Balk et al., 2014) holistic approaches are chosen to investigate the etiology of diseases, to assess the morbidity and severity of clinical symptoms and to find biomarkers for prediction and therapy. All this is on the background of changing perceptions of disease definitions and nosologic readjustments, which is focused and stimulated by research approaches dealing with personalized medicine (Murray et al., 2011). Furthermore, this holistic approach affects the use and the applicability of biomarkers that will be based on a whole panel of different measurements and platforms (Filiou and Turck, 2011). For example, genomics approaches like genome wide association studies (GWAS¹) are not enough for identifying biomarkers in complex psychiatric diseases anymore. These approaches must be supported by further research such as epigenomics, phenomics, environmental factors, and neurobiological approaches (Schulze, 2010). This results in more complex study designs and the subdivision of patients into smaller treatment groups, which – for significance reasons – require higher numbers of patients to be included in one study. To make symptoms and conditions measurable and comparable, a broad range of techniques and instruments is used and according results and interpretations need to be handled adequately. Neurologic symptoms are often measured using specific questionnaires to be answered by the patient (such as the Multiple Sclerosis Impact Scale (Riazi, 2002)) or scores assessed by physicians (like the Expanded Disability Status Scale (Kurtzke, 1983)).

A hallmark of psychiatric research is big cohorts with several thousand patients and controls, which can only be achieved through collaboration (Anderson-Schmidt et al., 2013; Sullivan, 2010) of many centers. This also and especially applies for the

Neuropathology. Ethically, the human brain holds an exceptional position (Shen, 2013) and together with the decreasing number of autopsies (Kretzschmar, 2009) the number of brain donations is decreasing. Therefore, large consortia are being built (Bell et al., 2008; Sheedy et al., 2008) to optimally study the brains of affected people. The above described difficulty of measuring “soft” clinical symptoms is a major challenge in multicenter projects (inter-observer variability). The same applies for MRI investigations and for the processing of biomaterial using different devices from various vendors.

Longitudinal studies are required and are already performed (Demiroglu et al., 2012; Warner et al., 2008) since the patients need to be followed up for many years to observe the disease progression, therapy effects, or the change in quality of life. In addition, many mental disorders and degenerative diseases, such as Multiple Sclerosis or Huntington's disease, have an early onset. Chronic diseases affect patients for years and it happens quite often that they result in an early termination of employment and thus add an additional burden to the health system and economy of a country (DeVol et al., 2007). A big issue in longitudinal studies is the discovering of new knowledge and resulting further developments during the study runtime. Hence, the diagnostic clarification grid may change over time, as do instruments or definitions. For example, the diagnostic criteria for Multiple Sclerosis have been revised twice in the last decade (Polman et al., 2011).

How can all these challenges be addressed when building a data infrastructure for clinical neuroscience research today? This paper provides an insight into the state of art for IT-infrastructure in neuroscientific research projects and is a prospect on the upcoming challenges which need to be addressed.

2. Materials and methods

To identify challenges, requirements and solutions for IT-infrastructure for longitudinal research in neurosciences a mixed approach was chosen reviewing literature and analyzing experiences of neuroscience research projects of the last ten to 15 years from 2000 until today.

2.1. IT-requirements for longitudinal and large cohort studies

Neuroscience is one of two key research topics of the University Medical Center Göttingen (UMG²). To identify the IT-requirements for longitudinal research in the neurosciences, national as well as international neuroscience projects of the Department of Medical Informatics were evaluated following Shortliffe's concept of experimental research in medical informatics (Shortliffe, 1983). This means that implementations of solutions are understood as experiments aiming to test which positive and negative outcomes the solution produces. The subsequent design is then a re-design reflecting the results and becoming itself again an experiment. This results in a continuous improvement of approaches, IT-components, and methods.

Since 2001 the Department of Medical Informatics designed, re-designed, operated, and evaluated IT-infrastructures for nine national and international neuroscience projects (see Table 1). These projects are perceived as experimental designs for the given research purpose as they contain different types of data for many studies.

To identify IT-requirements, the research projects and respective IT-components were compared regarding the following questions: (1) How did volume and types of variables in the

¹ GWAS: genome wide association studies.

² UMG: University Medical Center Göttingen.

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