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# Global Atlas of People with Profound Intellectual and Multiple Disabilities

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## Abstract

When it comes to providing solutions capable of increasing self-determination of individuals with disabilities, PIMD – profound and multiple intellectual disabilities, seems to be one of the biggest challenges. As a multidisciplinary team of researchers, we have an ambition of designing a technological platform based on recent advances in ICT that will assist people with PIMD in using digital services and applications that facilitate their communication with others and allow them to directly influence their living environment. Designing this system – the INSENSION platform, requires us to collect comprehensive information on the target end users. Due to the fact that the PIMD population is relatively small we are able to only involve about 15 individuals with PIMD in our project works. That is why we introduce the Global PIMD Atlas which is an online platform to collect information on people with PIMD and share it within the community involved in studying PIMD and supporting these people. In this paper we present how we designed such a repository and argue how it could be used to get better understanding of the characteristics of this population group and in consequence to provide new, better solutions to support them.

## Keywords

profound intellectual and multiple disabilities, assessment, communication, artificial intelligence, data repository

## Introduction

Individuals with profound intellectual and multiple disabilities (PIMD, also referred to as PMLD – profound and multiple learning disabilities) are defined as having a profound intellectual disability (IQ below 20) combined with severe neuromuscular physical and frequently sensory impairments (Petry, Maes, & Vlaskamp, 2005). Additionally, many individuals with PIMD have medical problems such as epileptic seizures or respiratory problems (Axelsson, Imms, & Wilder 2014). Due to these complex impairments, they depend on others in more or less all aspects of daily life among the whole life span. Hence, the quantity and quality of individual support is decisive for their functioning and participation (Maes, Lambrechts, Hostyn, & Petry 2007). The limited self-determination is due to the fact that these individuals usually communicate on a preverbal and pre-symbolic level. This prevents them from utilizing possibilities created by various forms of Alternative and Augmented Communication (AAC), ranging from both non-electronic and low to high tech tools. Lack of mobility is an additional factor limiting their opportunities to influence their living environment.

### *The Insension Platform*

Providing a change to the situation of people with PIMD and their ability to communicate with others and increase their self-determination has been the basis of our concept to create the INSENSION platform. The INSENSION platform is a personalizable intelligent system enabling interaction to individuals with PIMD by means of digital services. This platform is aimed at using the advances in modern Information and Communication Technologies (ICT) to unobtrusively recognize non-symbolic behaviors signals of a given person with PIMD and translate them into intentions based in the context of the life situation happening around that person. More precisely, the platform targets recognition of meaningful facial expressions,

gestures, vocalizations and relevant physiological reactions, and combining these with the information about the context and knowledge on the given individual. This in consequence shall enable them to communicate with others including unknown persons via dedicated ICT-based communication applications or to influence their living environment through such simple technological applications as having their favorite music played. We tackle this challenge of designing and developing an ICT system within the INSENSION project that is funded by the European Union through the Horizon 2020 research and innovation program.

### *The Global PIMD Atlas*

The development of the INSENSION platform requires from us to take account of high individualism of its end users. Nevertheless, our goal is also to include as many capabilities into the system as possible, so that it can support recognition of the needs of the specific person with PIMD out-of-the-box where possible. Hence, it is necessary to collect as much information on the target end user population as possible. Due to the fact that people with PIMD are a relatively small population group in any given, constituting about 0.01% of the total country population, collection of such data on a significantly large test group of people is logistically difficult. Therefore, we proposed to create a repository, which would enable collection and access to the information on PIMD population for investigators from around the world. This kind of repository would be similar in concept to a number of other repositories that have been created in the recent years. One of the most renowned repositories is The Cancer Genome Atlas which collects data on a number of types of cancer (Tomczak, Czerwinska & Wiznerowicz, 2015). Other such repositories include, among others, the Human Connectome Project (Marcus et al., 2011) or the Autism Brain Imaging Data Exchange, with its leading idea: “towards a large-scale evaluation of the intrinsic brain architecture in autism” (Di Martino et al., 2014).

The repository containing information on people with PIMD, created as part of the INSENSION project, has been launched as the Global PIMD Atlas (also referred to as Global PMLD Atlas). We discuss details of how it was constructed in the next section of this paper.

## **Discussion**

### *Genesis of the Global PIMD Atlas*

The goal of the INSENSION project is to create a technological platform that is capable of linking non-symbolic behaviors to personal intentions of people with PIMD. This objective requires to equip this system with means to properly recognize these behaviors on the one hand and means to understand the context of these behaviors on the other. The former allows recognizing the nature of the current reaction of the end user, such as demand, comment or protest (Rowland & Fried-Oken, 2010). The latter allows then to distinguish between, for example, protesting to different situations such as presence of a specific person or the air temperature being too low. That in consequence creates the possibility to communicate the intention of the person. If the person expressed a demand, for example, the current situation needs to be prolonged. In case of an expressed comment social interaction needs to be engaged and if the person showed signals of protest the current situation must be changed. That communication may be directed at both: other people (e.g. asking the person mentioned above to leave) and specialized ICT applications (e.g. by switching on the heating system controlled by a smart room application).

To achieve the goal described above, a key activity we undertake is to understand what non-symbolic behaviors the INSENSION system should recognize and how the context of these behaviors is constituted so that the system can follow it. Such information is today used by close direct support persons (DSP) of people with PIMD, including parents and professionals. It is

often collected within communication passports such as Personal Communication Passport (Millar 1997; Millar & Aitken 2003). We adopted this concept and defined the so called Electronic Communication Passport (ECP). The ECP is a machine-readable electronic document, structured to record all information on an individual with PIMD that helps us to construct an ICT platform like INSENSION on the one hand, and allows this platform to use that information to configure itself automatically to work for the given individual with PIMD on the other.

We use the ECP to record information on the representatives of the target end users. These come from the population under care of the non-governmental care organization from Poznań, Poland – Stowarzyszenie Na Tak. Na Tak maintains care facilities for all ages of people with PIMD, starting with a kindergarten, through a school up to a care center for adults. In total about 15 persons with PIMD that communicate on a pre-symbolic level so far, attend these facilities. While they are a perfectly suitable user group for our research and development works, from whom we learn a lot about the requirements towards the INSENSION system, we nevertheless realize that an insight into a significantly larger user group would help us to make the INSENSION platform easily adaptable to the needs of an individual end user. To this end, it is important to equip the system components responsible for recognizing various non-symbolic behaviors. The larger the libraries of gestures, facial expressions and vocalizations used by the PIMD population are integrated into these components, the richer the capabilities of the system will be out-of-the-box. That is why, we strived to enable the ECP within a web-based repository to enable the collection of relevant information on people with PIMD with whom we do not have direct contact, by those who maintain such a contact as researchers or DSP. Due to the fact that such a repository could be collecting information on individuals with PIMD residing in any

location around the world and that we believe it should be shared by the community involved in this information collection, we named this repository The Global PIMD Atlas (the Atlas).

### *Comprehensive Assessment of People with PIMD*

As we have mentioned in the previous subsection, the Atlas uses the concept of ECPs to collect and store relevant information on people with PIMD. This is adapted from the known communication passports such the mentioned Personal Communication Passport. While the latter was the inspiration for defining the ECP, it is important to note that the Personal Communication Passport does not attempt to incorporate all available information on a person. It provides an efficient way of sorting and presenting important facts about the person in an accessible manner by giving a short overview of the specific individual in terms of needs, likes, dislikes and behavioral issues. Hence, it prevents a communication breakdown between persons with intellectual disabilities and their caregivers (Sajith 2018).

Therefore, within the ECP we went beyond the initial idea of this kind of passport. It incorporates not only little basic information but provides a holistic representation of a specific person with PIMD. The tool is based on a comprehensive assessment system that includes the main characteristics of a person, concerning general data (personal data, general competencies, additional information on (dis)likes, routines, etc.), and specific data on both communication and inner states (preverbal communication, mood, pain, (dis)pleasure and challenging behavior), which should be identified by recognizing individual vocalizations, facial expressions, gestures and physiological data. This comprehensive assessment system is planned to be based on the known assessment tools such as surveys oriented towards Hall, Arron, Sloneem, and Oliver (2008) and Vos et al. (2012) concerning the collection of information on personal data, general competencies, additional information, the Communication Matrix by Rowland and Fried-Oken

(2010) for collecting information on (pre-verbal) communication, the Mood, Interest and Pleasure Questionnaire (MIPQ) by Ross and Oliver (2003) for collecting information on mood, the Non-communicating Adult Pain Scale (NCAPS) by Lotan, Moe-Nilssen, Ljunggren, and Strand (2009) for collecting information on pain, and Disability Distress Assessment Tool (DisDat) by Regnard et al. (2007) for collecting information on pleasure and displeasure or distress.

### *Technical Construction of the Atlas*

As we already mentioned the Atlas is a web-based repository of information collected with the use of the ECP concept. Therefore, the system for the management of this repository contains two major elements: the data repository module and the online access application. In this subsection, we discuss how they were constructed. At the end of this discussion, we also point the attention of the reader to the ever important issue concerned with the security of all information collected within the Atlas.

### **Data Storage**

The Atlas is a repository of ECPs of multiple persons. While an ECP is a machine-readable structured document, it is nevertheless useful that it is also readable by humans. This is because information that is stored with ECPs can potentially also be utilized by other systems and applications than the INSENSION platform and the Atlas. This may include, for example, applications utilizing ECPs in pedagogical scenarios, where the DSP browse information stored within them to gather information relevant to a given pedagogical scenario. Therefore, we analyzed existing standards for data storage and exchange in digital form that make the information readable not only by machines but also by humans. We looked into such standards as XML –Extensible Markup Language (Harold 1996), JSON - JavaScript Object Notation (Bray

2017), REBOL – Relative Expression Based Object Language (Goldman & Blanton, 2000) and Gellfish (Van Ranssen, 2005).

Our final choice lied with JSON, which is a subset of version 1.2 of YAML - YAML Ain't Markup Language (Ben-Kiki, Evans & Ingerson, 2005) and is often used for asynchronous client-server communication, including browser-server. This makes it easily usable within systems designed in accordance with the RESTful paradigm (Richardson & Ruby, 2007). This choice was also connected with the fact that constructing ECPs as JSON documents makes it very easy to create a non-relational database for storing this data with the use of the MongoDB database system (Banker, 2011). This way we were not required to perform any additional tasks concerned with designing the data storage such as, for example, designing the database schema. As a document-oriented database platform MongoDB provides all necessary functionality to store and manage ECPs out-of-the-box. The only functionality added on top of MongoDB is a REST API enabling to access and manage the data storage. This API includes methods for the management of ECP data, the management of individuals whose data is stored and the management of the data storage users, which means users who can enter and download the collected data.

### **Access Application**

This API mentioned above is utilized by the web-based application that constitutes the user interface of the Atlas enabling access to the information collected with the data storage. This web-based application has been implemented using the Java programming language. It is thought as means for the registered researchers to add pseudonymized data collected from people with PIMD using online data forms and a way to browse all the data stored within the Atlas. That is why the access application allows to manage a pool of individuals with PIMD related to a given

researcher, which means individuals for whom the given researcher provided or aims to provide data to the Atlas, to enter assessment data with the use of the survey tools and to browse the data. Due to the fact that the whole assessment survey is relatively lengthy, it must be noted here that the access application allows to save a draft incomplete record. The Atlas has been also equipped with the multilinguality capabilities to facilitate its usage by interested communities in various locations.

### **Security of Information**

The Atlas aims to collect data that are sensitive and require special attention as to their security and appropriate measures for authorizing access to them. At the same time, it is expected that the ECPs for a given individual might change as new information is found on these individual or they develop new skills, habits or (dis)likes. Therefore, we proposed that the data are pseudonymized before storing them in the Atlas rather than fully anonymized. The pseudonymization is done in such a way that each individual on whom the Atlas holds information is given a random unique identifier. The person or organization that enters the information on that individual must be capable of linking that identifier to a real person on his or her own. This way we ensure that none of the Atlas users other than those that know the given individual with PIMD, and nobody from outside of the Atlas users community, can link the collected data to a real person. As far as technological security of the data is concerned, it goes without saying that adequate encryption techniques are used for data transmission and storage.

### **Conclusions**

Our motivation for creating a repository that could collect comprehensive information on the population of people with PIMD has been to ensure that the INSENSION system we have been developing had rich functionality capable of supporting a wide range of end users' needs.

However, we also believe that such a repository can be a platform for sharing information on the PIMD population within the community involved in studying this type of disabilities. This can help researchers and practitioners to get better understanding of the characteristics of this group, for example by providing findings concerning the phenotype of specific genetic syndromes or enabling comparisons in terms of specific characteristic (e.g. age, gender, diagnoses (sensory impairment, diseases)). In consequence, new, better methods and tools for assisting people with PIMD can be developed. Such a model works within the medical research community where creation of specialized repositories for collecting patient data related to specific conditions became an often used methodology.

In our opinion, our goal of making the Global PIMD Atlas a platform for sharing information on people with PIMD can be achieved due to the use of an assessment system that integrates well-established tools to collect information about people with disabilities. This system is coded into a carefully structured electronic document – Electronic Communication Passport – based on the ever more popular JSON format. The passports are stored in a database constructed with the use of a database system verified in multiple installations and systems. The Atlas uses a REST-based API to upload and download the data, and a set of web forms allowing to enter and to browse the information. Moreover, we paid careful attention to secure processing of the sensitive data that are collected within the Atlas.

It is also worth noting that our goal is to make the Atlas available to the whole community and we wish the community to influence its further potential extensions and usage scenarios. In this, we see the potential of collaborating with such initiatives as, for example, the Global Public Inclusive Infrastructure and Cloud4All, which work on enabling Internet services to people with limitations resulting from disabilities, age and other issues (Vanderheiden et al.,

2011). This is because we believe that people with PIMD might be able to utilize a range of digital applications and services thanks to a special user interface that we develop in the INSENSION project.

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