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Communication assessment in people with PIMD. Evaluating the use of the INSENSION Questionnaire – Longform (InQL)

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Abstract: This paper aims to evaluate the use of the INSENSION Questionnaire – Longform (InQL) and to present several options of data analysis based on the results of a first study conducted using the InQL. The current version of the questionnaire was tested with the caregivers (relatives and support professionals) of 21 individuals with profound intellectual and multiple disabilities (PIMD). For each test person the questionnaire was filled in by two caregivers. The results are presented exemplarily to show the potential of the InQL as well as to discuss critical aspects. The extracted results show the questionnaire's aptness to provide detailed insights into the means of communication of a specific individual with PIMD as well as various possibilities of data analysis. The implied multiperspectivity of the InQL allows analysing the content from different points of view. These benefits for the field of practice are complemented by those for research illustrated by the concept of the Global PIMD Atlas. For further improvement as well as for validation purposes the InQL is now in revision.

Keywords: PIMD, assessment, diagnostic, communication, Global PIMD Atlas

INTRODUCTION

People with profound intellectual and multiple disabilities

Within research and literature there are many different terms used when dealing with people with profound intellectual and multiple disabilities (PIMD) leading to a certain complexity due to different or unclear descriptions regarding the characteristics of these types of disabilities as well as disagreement about who belongs in this specific category (Nakken & Vlaskamp, 2002; Nakken & Vlaskamp, 2007). Although it is "argued that there cannot be an absolute separation of this specific target group from other adjoining groups" (Nakken & Vlaskamp, 2007, p. 83) a first approach of defining the group of people addressed in this paper is made hereafter in order to avoid misunderstandings. People with PIMD cannot be described as a homogeneous group because, firstly, they can be differentiated according to the cause of their disabilities, which can be a pre-, peri- or postnatal trauma or a specific genetic syndrome (Nicklas-Faust, 2011). Secondly, people with PIMD differ regarding their functional, communicative and behaviour related competencies (Nakken & Vlaskamp, 2007). In most cases, PIMD come along with a profound intellectual disability "characterized by significantly below average intellectual functioning

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and adaptive behaviour that are approximately four or [sic] more standard deviations below the mean (approximately less than the 0.003rd percentile)" (World Health Organization, 2019). Typically, this intellectual disorder is accompanied by neuromuscular and sensory impairments (Petry, Maes, & Vlaskamp, 2005). People with PIMD often communicate on a pre-symbolic level using unconventional behaviour signals like specific body movements or vocalisations in order to express their needs (Bellamy, Croot, Bush, Berry, & Smith, 2010). Due to the fact that these signals are highly individual, the number of those interaction partners who are actually capable of understanding and appropriately reacting to these signals is very restricted. In most cases, these interaction partners are limited to close reference persons (e.g. parents) (Forster & Iacono, 2008; Jansen, van der Putten, & Vlaskamp, 2017).

All these characteristics lead to a high dependence on others in nearly all areas of life across their whole life span (Axelsson, Imms, & Wilder, 2014). Therefore, quantity and quality of their individual support is crucial to enable activity and social participation (Maes, Lambrechts, Hostyn, & Petry, 2007; Petry & Maes, 2006).

Broader context of the study: the INSENSION project

The INSENSION project focuses on people with PIMD by developing an ICT system. This system is able to recognize and interpret meaningful non-symbolic behaviour signals of this target group. For this purpose, it puts these signals into the context of what happens around a specific individual at the time of a given behaviour. This enables the needs of this person for use by assistive applications. The platform uses advances in computer vision and audio signal analysis to recognize facial expressions, gestures, vocalizations and physiological parameters. Further on, similar techniques are used to understand the context of the behaviours (e.g. other persons or objects), additionally extended by readings from ambient sensors to monitor, inter alia, temperature or noises. A combination of these methods for automatic analysis of data acquired from the primary user – the person with PIMD – using cameras, microphones and relevant Internet of Things devices, constitutes the intelligence of the system to be created. This working cycle is visualized in Figure 1.

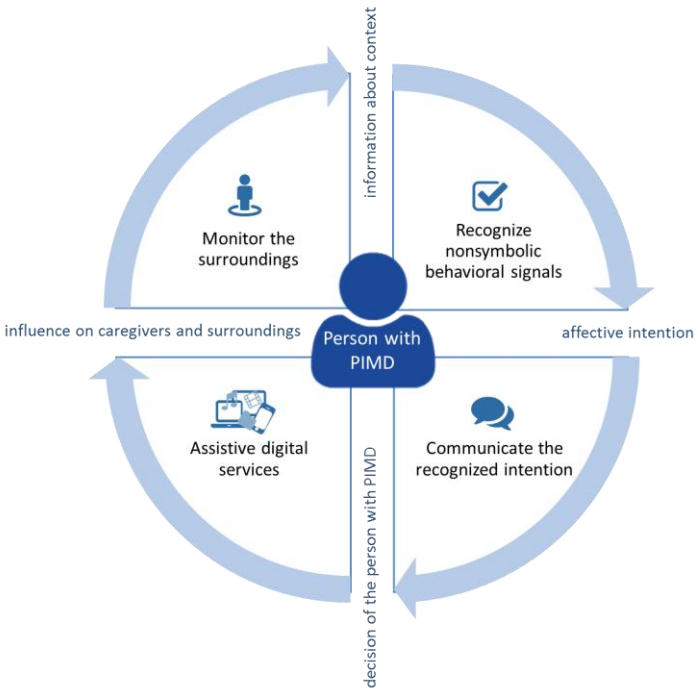

Figure 1: Working cycle illustrating the concept of the INSENSION system.

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To be able to recognize meaningful non-symbolic behaviour signals of a particular person with PIMD a standardized way of assessing these behaviours as well as their potential meaning in various contexts was needed. Therefore, the INSENSION Questionnaire – Longform (InQL) has been developed and will now be described in the following section.

METHOD

INSENSION Questionnaire – Longform (InQL)

The attempt of approaching the target group by demonstrating, among others, some specific characteristics concerning their communication abilities leads to the following question, which served as a starting point in the INSENSION project: *How do people with PIMD express their needs?* Of course, the outlined heterogeneity does not allow a general answer to this question but rather implies an individual approach. Therefore, an assessment of communication skills and the expression of inner states in the form of a paper-based questionnaire was created based on a preceding international review of literature and diagnostic instruments. For this review, three commonly used online bibliographic databases were considered (PubMed, PsycINFO and ERIC) using search terms regarding the target group combined with ("AND") diagnostic as well as communication terms "OR" terms related to inner states (oriented towards Adams & Oliver, 2011; Bunning, Smith, Kennedy, & Greenham, 2013; Nakken & Vlaskamp, 2007; Wessels & van der Putten, 2017). complemented by commonly used key words. The review included results between 01/1973 and 12/2017 yielding all in all 2436 publications which were reduced to a final number of 39 after applying inclusion criteria (relation to target group or another similarly vulnerable group; relation to diagnostic procedures dealing with the expression of inner states or communication skills; text written in English) and removing doubles. The results were complemented by renowned German-speaking as well as recently published tools.

These publications suggested contentwise clustering leading to the elaboration of fundamental diagnostic areas (right part of Figure 2), which need to be covered by the questionnaire in order to answer the above-mentioned key-question. These areas can roughly be divided in two parts, which then split up into further subcategories:

General Data (grey part) cover *Personal Data* (e.g. age, gender) as well as *Medical Status & General Competencies* concerning motor skills, mobility, visual and hearing skills among other things. *Additional Information* like preferences or dislikes as well as important rituals and routines are also part of this questionnaire.

Information on Communication Skills and Inner States (blue parts) gather data on how the particular person with PIMD expresses his/her needs. The level of *Preverbal Communication* provides information on the person's communication skills focusing on (non-symbolic) behaviour signals. *Challenging Behaviour* plays an important role in people with PIMD due to the increased prevalence, the manifestation in genetic syndromes and the communicative character of these behaviours (Poppes, van der Putten, & Vlaskamp, 2010). Following the aim of improving the quality of life of people with PIMD, knowledge about their way of expressing Inner States like the current *Mood*, *Pain*, *Pleasure & Displeasure* is required to be able to react adequately and provide suitable support.

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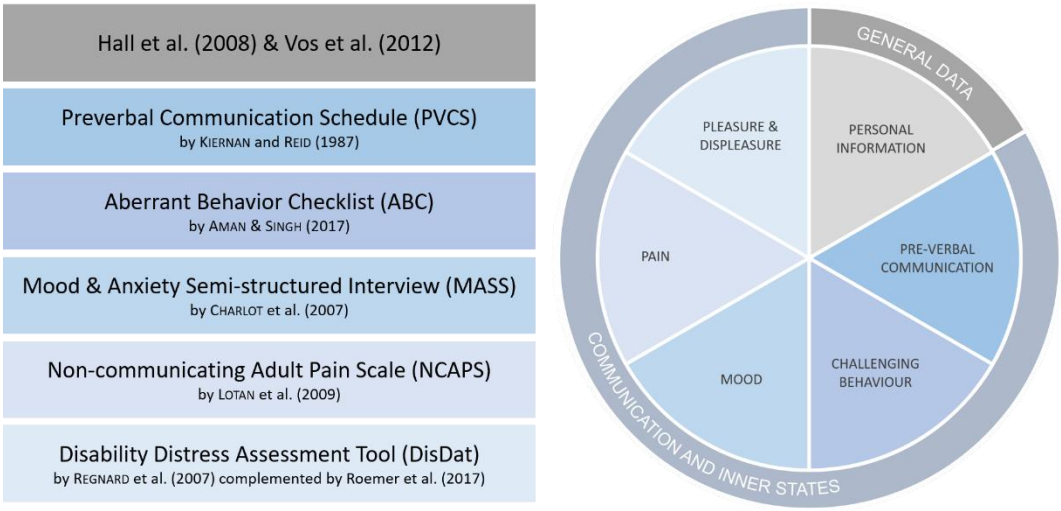

Figure 2: Content of the InQL.

In order to select one diagnostic tool for each area all 39 publications were analysed according to these criteria:

(1) The number of items as well as the anticipated duration for passing the test should not be too extensive due to the fact that each single tool will be complemented by others covering further diagnostic areas.
(2) The publishers or authors must permit the upload of the diagnostic tool (or at least parts of it) within the scope of the Global PIMD Atlas (see section *Benefits for research: Global PIMD Atlas*).
(3) The items of the diagnostic tool should fit contentwise the characteristics of the target group (or at least after minor adaptations).
(4) The items of the diagnostic tool should fit all age groups.
(5) Full-text including all diagnostic material must be available.
(6) The diagnostic tool should be evidence-based.

The left part of Figure 2 illustrates those sources, which served as reference points for the InQL coloured according to the diagnostic area they belong to. Not all of these tools were taken one to one but were partly modified for meeting the above listed criteria. The additional texts served as further orientation.

The InQL works as a proxy report since direct questioning of the target group itself often is not possible (Nolan, 2016; Vos et al., 2012). Due to the implied subjectivity of a proxy report (Andresen, Vahle, & Lollar, 2001), it is recommended to have the questionnaire filled in by at least two different reference persons who know the individual with PIMD for at least six months interacting on a regular basis (e.g. parents, teacher). All in all, the InQL covers 39 pages including all test instructions of the six sub-questionnaires (see left part of Figure 2). Regarding the scope as well as the fact that some items require direct testing with the person with PIMD (e.g. imitation skills) a completion in stages according to the division in sub-questionnaires is intended and reasonable. The InQL will be accessible on the website of the INSENISON project (www.insension.eu).

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Research Approach

In order to investigate the questionnaire's suitability for filling the prevalent gap concerning adequately sensitive, standardized as well as empirically based diagnostic tools providing useful insights into the communication repertoire of individuals with PIMD (Brady et al., 2012; Brady et al., 2018; Chadwick, Buell, & Goldbart, 2019), this study deals with the following research questions:

- What options of data analysis are provided to the users of the InQL?
- What are critical issues regarding the use of the InQL?
- What are potential benefits of the InQL?
- What consequences for the InQL arise of the results of the study?

Therefore, the current version of the questionnaire was tested with the caregivers (relatives or support professionals) of 21 individuals with PIMD. For each test person the questionnaire was filled in by two reference persons. The process of filling in was monitored by an attendant responsible for observing the raters' way of working in order to fill in an evaluation sheet afterwards.

First details on the composition of the sample (n = 21) gathered by means of the first sub-questionnaire of the InQL dealing with general data is provided in Table 1.

Table 1. Descriptive characteristics of sample (n = 21).

Variables	Descriptive
Age	M = 17.5 (range: 6.2-40.9)
Gender	
Female	33.33 %
Male	66.67 %
Sensory impairment	
Visual impairment	57.14 %
Blind	4.76 %
Hearing impairment	19.05 %
Deaf	-
Motor Skills	
Cannot walk	57.14 %
Can walk with human help	42.86 %
Can walk with walking aid	19.05 %
Can walk independently	23.81 %
Medical problems	
Epilepsy	52.38 %
Cerebral palsy	33.33 %
Other medical problems	85.71 %
Syndrome	42.86 %
Aicardi Goutières Syndrome	4.76 %
Angelman Syndrome	4.76 %
ATR-X Syndrome	4.76 %
Autism Spectrum Disorder	23.81 %
Down Syndrome	9.52 %
Fragile X Syndrome	4.76 %

For anonymization purposes in this particularly small target group, there is no additional information given regarding the sample's geographic or ethnic origin or their economical level.

The conduct of this study was oriented towards common ethical guidelines of the Ethical Committee of the participating institution (Heidelberg University of Education).

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Results

Intraindividual and interindividual Analysis

In this section, extracted results of some test persons are presented exemplarily. The first part focuses on the analysis options regarding inter rater agreement whereas the second part shows conceivable ways of describing the communication repertoire of a specific individual with PIMD. Although the current sample size does limit statistical calculations, the following explanations intend to exemplify the potential of using the InQL.

Figure 3 presents the percentage agreement in the sub-questionnaire "challenging behaviour" of both raters for Person 1 (male, 40.9) in contrast to the results of Person 2 (male, 18.0) illustrated in Figure 4. This part of the InQL does not ask for the frequency of specific behaviours but for the rater's subjective perception to what extent the particular behaviour is experienced as challenging. The more challenging the behaviour was rated the higher the score becomes (Aman & Singh, 1986).

In case of Person 1, there is a quite high degree of correspondence between the two raters, which is not a chance agreement but a moderate one proven by Cohen's Kappa κ = 0.49 (Landis & Koch, 1977).

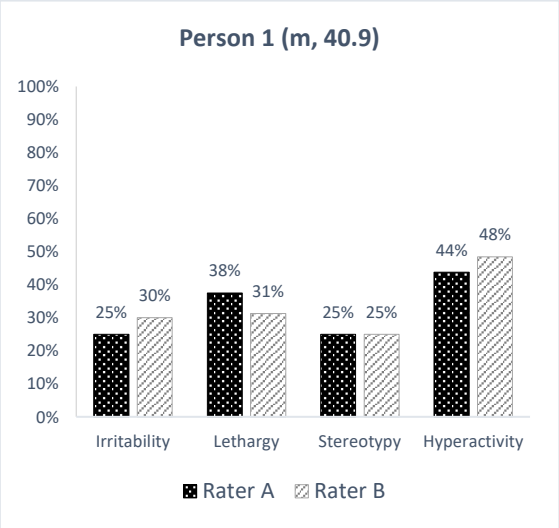

Figure 3. Percentage agreement (κ = 0.49) of both raters in the area challenging behaviour for Person 1.

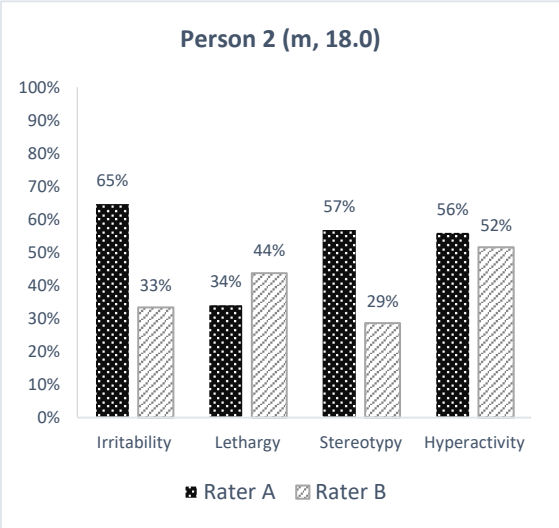

Figure 4. Percentage agreement (κ = 0.01) of both raters in the area challenging behaviour for Person 2.

Concerning another sub-questionnaire (preverbal communication), Table 2 focuses on the inter rater agreement within the total sample. According to the calculated Kappa, in the majority of the sample (61.11 %) the two respondents have a moderate agreement regarding their rating of preverbal communication skills in the particular person with PIMD.

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Table 2. Distribution in total sample (n = 21) regarding calculated agreement of both raters (Landis & Koch, 1977) in the area preverbal communication.

Kappa	Agreement	Part of sample
< 0	Less than chance agreement	-
0.01-0.20	Slight agreement	-
0.21-0.40	Fair agreement	19.05 %
0.41-0.60	Moderate agreement	66.67 %
0.61-0.80	Substantial agreement	14.29 %
0.81-0.99	Almost perfect agreement	-

Regarding the expression of pain, one exemplary result is illustrated in Figure 5 presenting an overview of which behaviour areas are stated meaningful in Person 3 (male, 17.2) by the raters. Therefore, the percentage of those behaviour signals being marked as used frequently in each area was calculated for both raters and summarized in the graphic. Although it does not provide information on the concrete manifestation (e.g. frequency, intensity) of these behaviours, it highlights relevant areas.

Figure 5. Overview of expression of pain in Person 3.

Some parts of the InQL require a more qualitative data analysis due to their structure. Table 3 presents another exemplary result describing the behaviour signals of Person 4 (male, 28.3) in cases of pleasure in comparison to signals shown in cases of displeasure. The description is based on the information given by his professional caregiver only listing relatively clear behaviour signals. Therefore, those behaviours which were marked as being shown in situations of both pleasure and displeasure were not added to the list since they are no clear indicators for the prevalent inner state of the person. This way, an overview of how this specific individual expresses (dis)pleasure is provided.

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Table 3. Description of signals of pleasure and displeasure in Person 4.

Behaviour area	Clear signals of pleasure	Clear signals of displeasure
Vocalisations	volume: medium pitch: medium duration: intermittent murmur	volume: low pitch: high duration: long groaning/moaning
Total facial appearance	laughing smiling	grimace
Appearance of eyes	smiling eyes winking	staring tears narrow
Movement of jaw		grinding
Movement of nose and mouth	tongue movements	mouth tense
Body posture	movement change slumped restless	rigid/no movement tense leans to side
Movement of head	movement change floppy nodding	rigid/no movement withdrawn leans to side
Movement of hands and arms	grabbing hands opened	hands closed
Movement of feet and legs	rigid/no movement	movement change

This section aimed at visualizing possible options of data analysis based on the great amount of information gathered by means of the InQL for both practice and research purposes. Of course, these descriptions represent just examples of what data might be analysed or how this could look like and, therefore, no claim to completeness is risen.

Discussion

Critical reflection

The study revealed several critical issues coming along with using the InQL. Based on the evaluation sheets provided by the attendants monitoring the working process of the raters the following aspects should be taken into account for revision. Regarding usability, the process of completion was very time consuming on average (3,5 hours spread over 1,4 days) due to the detailedness and total scope. According to the attendants' estimations it took about 3,5 hours spread over 1,4 days per questionnaire. Moreover, the feedback also referred to the formulation of some items with regard to competence orientation and comprehensibility. It was noted that the questionnaire's structure including the use of different scales also might increase its complexity potentially resulting in a restricted practicability.

Another critical aspect is related to the results regarding inter-rater agreement. Besides differences in the raters' own perception or the behaviour manifestation in various contexts it is also possible that potential inconsistencies of the items lead to different ratings.

Besides these critical issues, the questionnaire also brings several benefits for both practice and research. Hereafter, potential advantages for both fields are discussed separately.

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Benefits for practice

Of course, diagnostic in general plays an important role in practice building the base for further implications regarding the particular individual. Various options of how this could look like in the case of the InQL are discussed subsequently according to the presented results of this study.

The results regarding inter rater agreement concerning challenging behaviour in Person 2 (Figure 4) show that there are differences in the respondent's perceptions. These results could now serve as a base for discussions on potential reasons for the different ratings by providing structured information for further exchange between the raters. With regard to the evaluation of irritating behaviour and stereotypy, the respondents could discuss whether the discrepancy is reasoned in a subjectively different perception. Furthermore, the particular behaviours could have been shown less in the context of rater B (school scenario) or perceived as less problematic than in the home scenario of rater A. Moreover, rater B could potentially have useful ways of handling or preventing these behaviours worth sharing with rater A. Based on this information the respondents could jointly work out behaviour strategies, e.g. alternative behaviours, for and with Person 2.

Another option of using the results of the questionnaire as a base for fostering concerns the part of preverbal communication. Having identified the person's level of communication development by means of the particular sub-questionnaire, further implications to strengthen the current compentencies as well as to initiate the next level can be derived as explained by Rowland (2013).

The results on the expressions of pain and signals of pleasure and displeasure obtained by the InQL provide insights into the communication repertoire of the respective individual with PIMD but structured differently. Regarding the expression of pain in Person 3 (Figure 5), the raters mainly agree upon relevant behaviour areas. People that are unfamiliar with Person 3 could benefit from this structured information as an orientation to initiate social interaction with him. Table 3 presents more detailed information by listing concrete behaviour signals instead of whole areas, which could support others on reading the person's signals and interpreting his inner state. Of course, the information provided by the respondents cannot replace the process of getting to know each other, but should rather support this interaction. A reflective use of this information is obligatory to avoid a self-fulfilling prophecy and to stay open for own observations and perceptions.

These examples show the wide range of opportunities offered by using the InQL to those working and living with people with PIMD and, consequently, point out the potential value for individuals with PIMD themselves. This is not the only benefit it brings to the field of practice but within the scope of the so-called Global PIMD Atlas the questionnaire can also be of great interest for both practitioners and researchers as presented in the following section.

Benefits for research: Global PIMD Atlas

Within in the INSENSION project, the idea of the so-called Global PIMD Atlas has been developed regarding future research related to INSENSION and the InQL. Subsequently, this concept will be presented in the form of an outlook visualized in Figure 6. As an online knowledge repository available to the community concerned with supporting individuals with PIMD, the Global PIMD Atlas will provide a user interface containing a comprehensive collection of information on this target group. Prospectively, registered practitioners and researchers from all over the world will have the opportunity of adding pseudonymised data from people with PIMD using an online version the InQL. In exchange, they will get access to the whole database for their own purposes (e.g. research studies). Within this process the database as well as the assessment system will be permanently enriched and

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optimized engaging, among others, the research community itself regarding the scope and function of the Atlas.

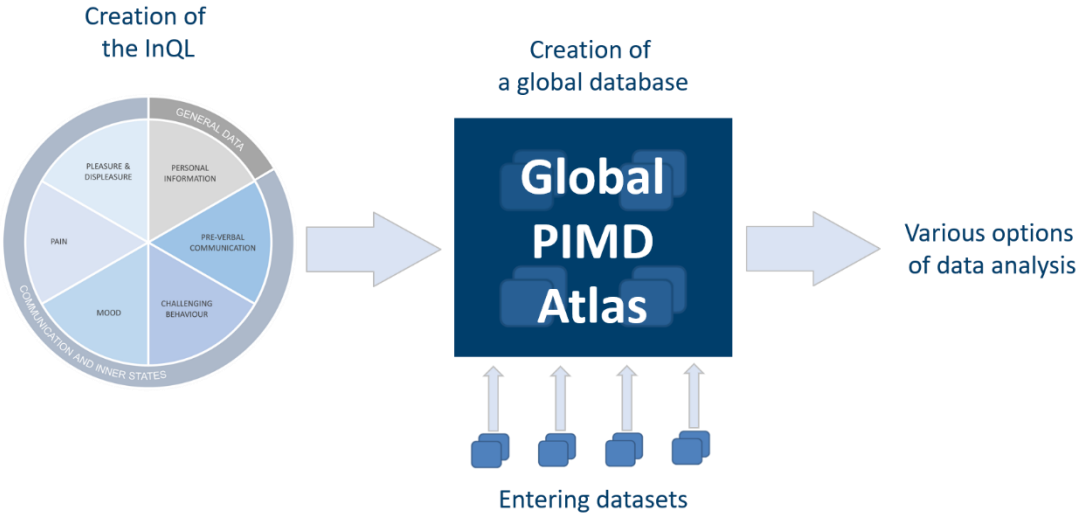

Figure 6. Concept of the Global PIMD Atlas.

An extract of conceivable options the Global PIMD Atlas will provide to its users was already presented in order to show examples of how the stored data could be approached. Users may analyse the information on an intraindividual level comparing areas or focusing on specific sub-areas, comparing the results of different raters or tracking progress over time in order to document changes. On an interindividual level, users may compare the data of an individual to a sample of the Atlas, for example according to age, gender, life situation or diagnoses (e.g. genetic syndrome) as presented in Table 1. In a statistical way, the Atlas will enable the calculation of correlations as well as the evaluation of scientific findings, e.g. regarding the relation of behaviour and communication (Lundqvist, 2013) or behaviour and inner states (Hayes, McGuire, O'Neill, Oliver, & Morrison, 2011).

Consequences for the InQL

The lack of suitable diagnostic instruments in this context requires the development of an assessment tool capable to fill this gap. Therefore, the InQL is planned to be revised according to the results of the presented study. Of course, all mentioned critical aspects as well as positively evaluated issues will be taken into account regarding the revision. For example, one criterion, which was not yet met satisfactorily, is usability. Among other things, creating the online version of the questionnaire like it is envisaged for the Global PIMD Atlas is one way of improving this aspect. Moreover, further studies are required in order to test psychometric characteristics such as reliability or validity. Expert observations of the participants behaviour being compared with information gathered by means of the InQL could be one method of choice.

CONCLUSION

The lack of standardized and empirically based assessment tools for people with PIMD, which do not only focus on one specific area of development, shows the relevance of elaborating a comprehensive diagnostic tool that provides a detailed insight into the

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development and competencies of an individual with PIMD. Covering several important diagnostic areas, the InQL could potentially fill this gap and therefore, further testing is necessary. Although most of the used diagnostic tools were already validated, additional investigations are needed in order to validate the InQL as a whole and including all adaptations against the background of the target group. For further improvement as well as for validation purposes the questionnaire is now in revision.

The enormous benefit this tool brings to the field of practice, especially due to its detailedness, cannot be denied. Moreover, the special potential enabled by the comprehensiveness of the InQL obviously lies in its implied opportunities for research illustrated by means of the innovative and highly promising concept of the Global PIMD Atlas.

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