



GLOBAL PIMD ATLAS

including communication assessment in people with PIMD

Torsten Krämer, Meike Engelhardt, Peter Zentel, Teresa Sansour, Michał Kosiedowski

Contents

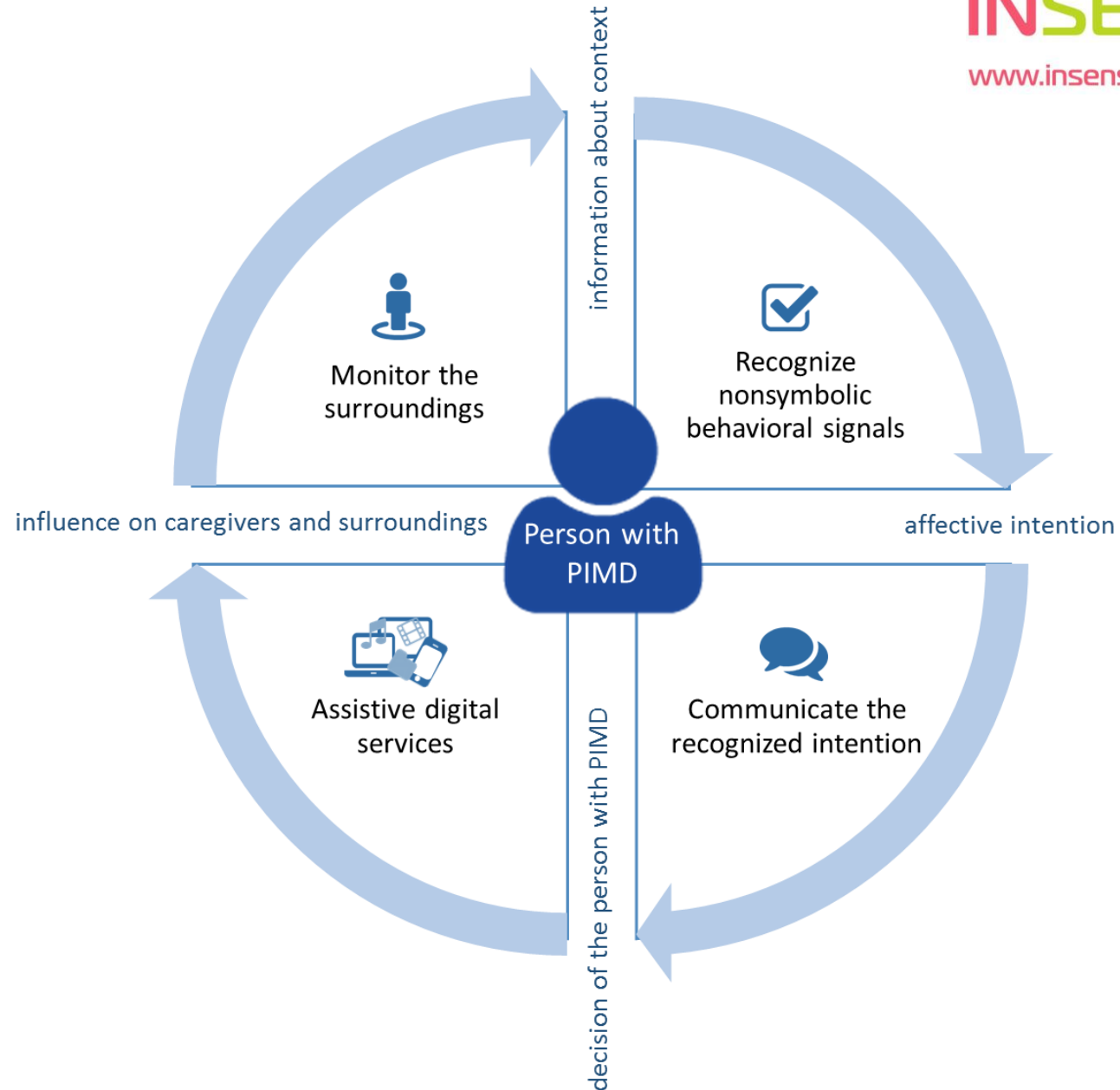
- EU-project *INSENSION*
- Assessment of Communication
- **Idea of the *Global PIMD Atlas***
- Exemplary results
- Summary

EU-PROJECT *INSENSION*

Research project *INSENSION*

Financing:	EU-Project (Horizon 2020)
Period:	01/2018 – 12/2020
Consortium:	International & interdisciplinary
Target group:	People with PIMD
Objectives:	ICT platform enabling persons with PIMD to use digital applications and services ➡ Enhancing the quality of their life ➡ Increasing their ability to self-determination

The concept of the *INSENSION* system



ASSESSMENT OF COMMUNICATION

The *INSENSION* Questionnaire – Longform (InQL)

Hall et al. (2008) & Vos et al. (2012)

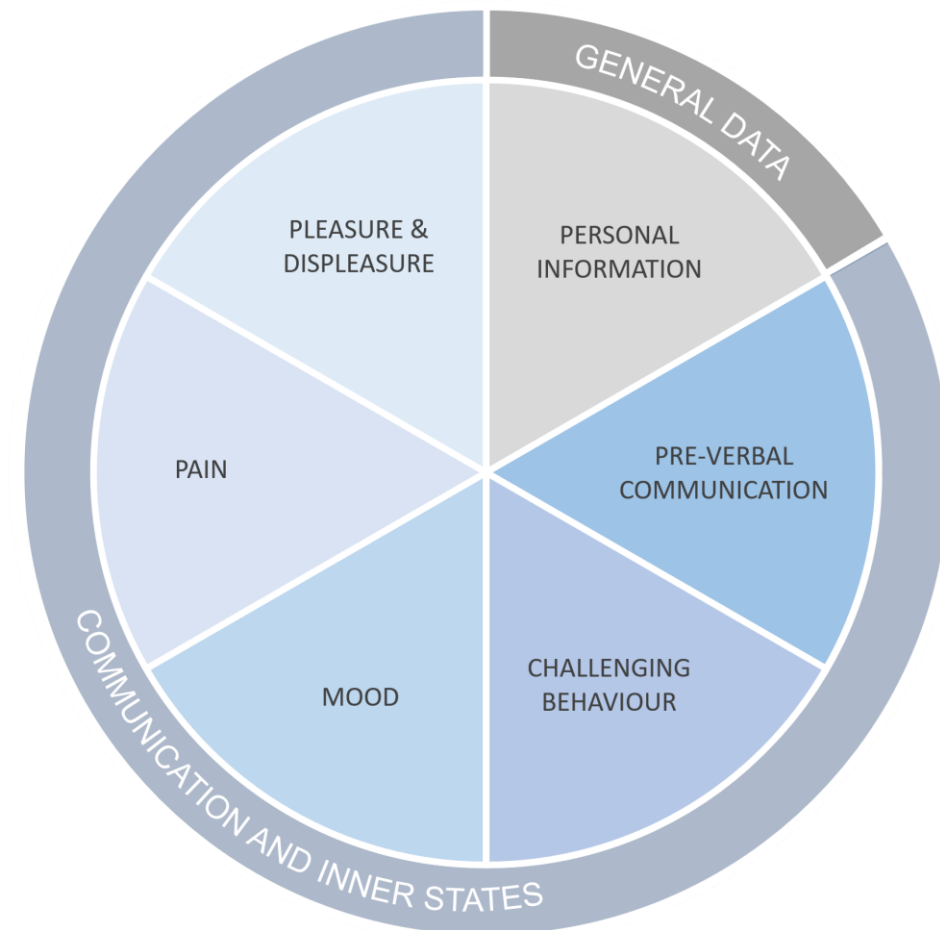
Preverbal Communication Schedule (PVCS)
by KIERNAN and REID (1987)

Aberrant Behavior Checklist (ABC)
by AMAN & SINGH (2017)

Mood & Anxiety Semi-structured Interview (MASS)
by CHARLOT et al. (2007)

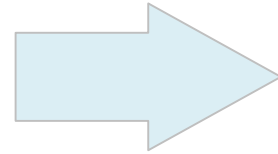
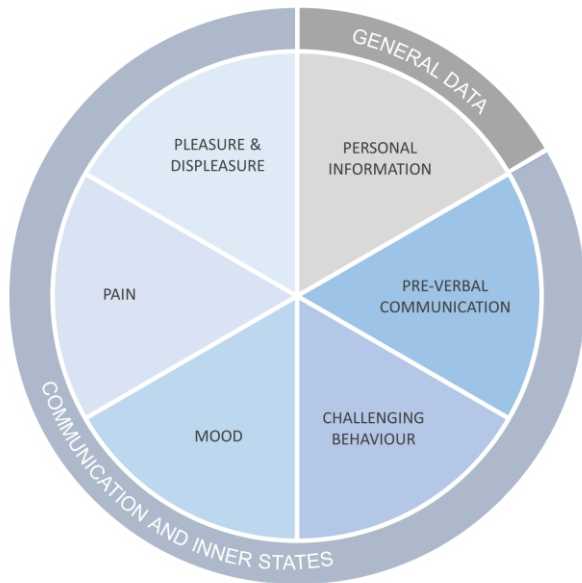
Non-communicating Adult Pain Scale (NCAPS)
by LOTAN et al. (2009)

Disability Distress Assessment Tool (DisDat)
by REGNARD et al. (2007) complemented by Roemer et al. (2017)

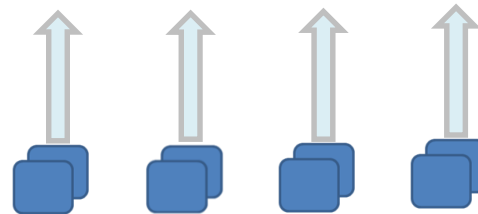


IDEA OF THE *GLOBAL PIMD ATLAS*

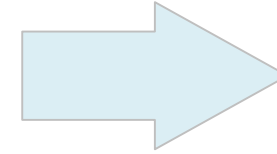
Creation of the InQL



Creation of a global database



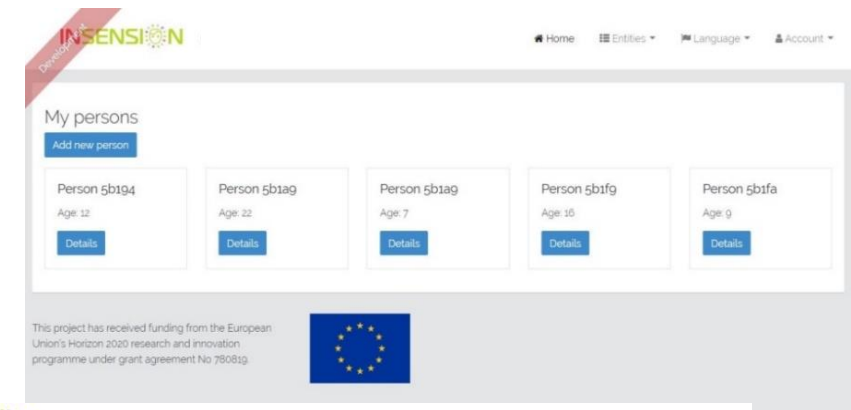
Entering datasets



Various options
of data analysis

What is the *Global PIMD Atlas*?

- **Knowledge repository**
- User interface to a repository which contains a **comprehensive collection of information** on the target group
- **Adding pseudonymized data** from people with PIMD
- **Getting access** to the whole of the collected database



The screenshot displays the 'Information on Evaluator' form in the INSENSI web application. The form includes a 'Type of Relationship' dropdown menu currently set to 'personal caregiver'. Below this is a 'Center' text input field. The 'Medical Status & General Competencies' section contains several rows of information, each with a text input field and radio button options for 'yes (please specify)', 'no', and 'unclear'. The rows are: 'Diagnoses' (e.g., syndromes like Rett-syndrome, autism, intellectual disability), 'Challenging Behaviour' (e.g., stereotypes, self-injury, hitting), 'Perceivable Physiological Parameters' (e.g., fast breathing, sweating, conspicuous muscle tone), and 'Use of Vocalization' (e.g., different sounds).

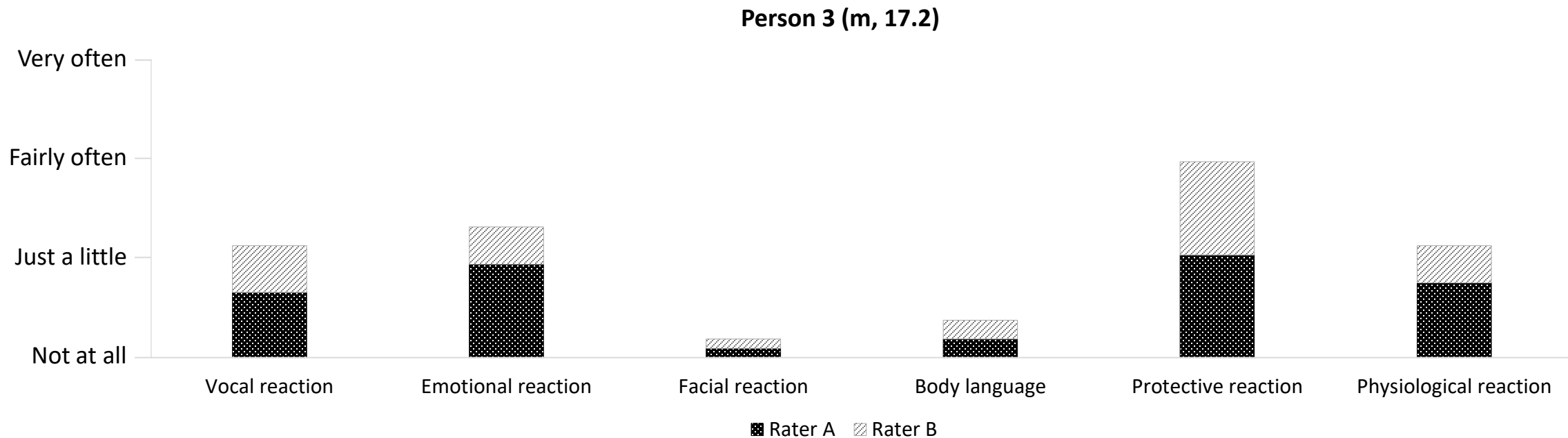
EXEMPLARY RESULTS

Descriptive characteristics of current sample (n = 26)

Variables	Descriptive
Age	M = 21.6 (range: 6.2-67.9)
Gender	
Female	34.62 %
Male	65.38 %
Sensory impairment	
Visual impairment	53.85 %
Blind	7.69 %
Hearing impairment	15.38 %
Deaf	3.85 %
Motor Skills	
Cannot walk	53.85 %
Can walk with human help	46.15 %
Can walk with walking aid	19.23 %
Can walk independently	23.08 %
Medical problems	
Epilepsy	50.00 %
Cerebral palsy	38.46 %
Other medical problems	88.46 %
Syndrome	42.31 %
Aicardi Goutières Syndrome	7.69 %
Angelman Syndrome	3.85 %
ATR-X Syndrome	3.85 %
Autism Spectrum Disorder	23.08 %
Down Syndrome	7.69 %
Fragile X Syndrome	3.85 %
Battled Child Syndrom	3.85 %

Overview of current means of communication

- Ratings regarding expression of pain



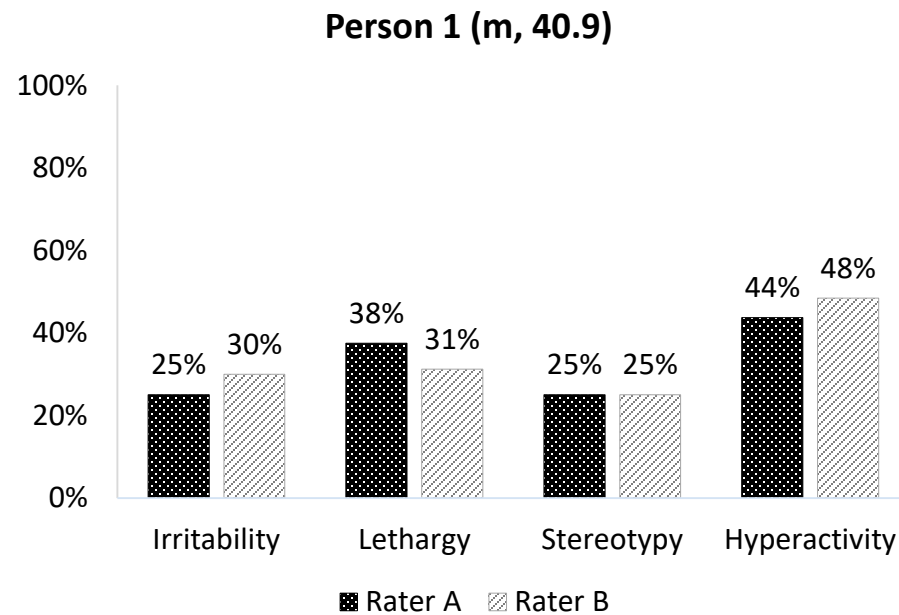
Overview of current means of communication

- Ratings regarding expression pleasure and displeasure

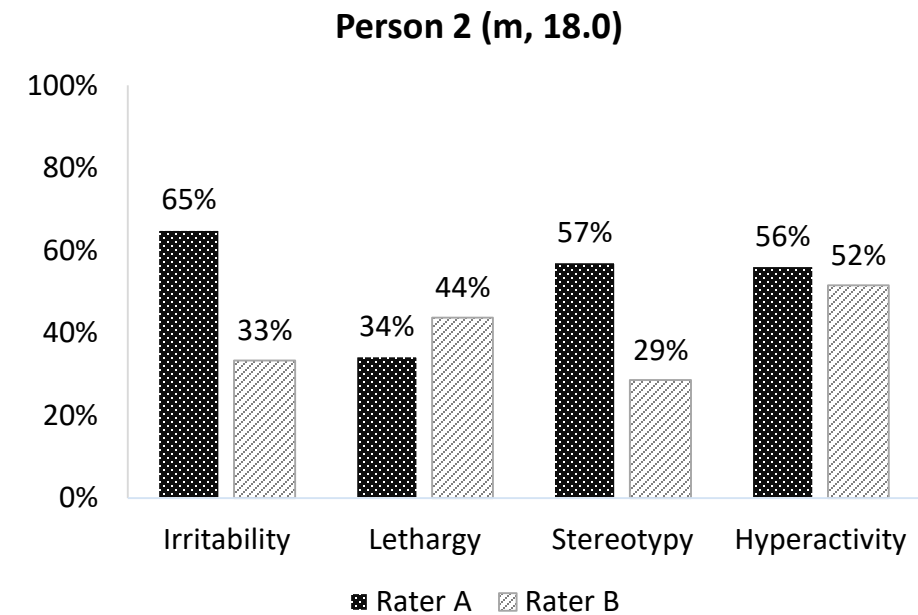
Behaviour area	Clear signals of pleasure	Clear signals of displeasure
Vocalisations	volume: medium pitch: medium duration: intermittent murmur	volume: low pitch: high duration: long groaning/moaning
Total facial appearance	laughing smiling	grimace
Appearance of eyes	smiling eyes winking	staring tears 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

Compare ratings

- Ratings regarding subjective perception of challenging behaviour



$k = 0.49$ (moderate agreement)



$k = 0.01$ (slight agreement)

SUMMARY

Functions of the *Global PIMD Atlas*

- **Overview** of current means of communication
- **Compare ratings**
- **Compare data** of specific individuals
- Track **progress** over time + document changes
- **Report function** via email
- Use data for **own research**

Conclusion

- Secondary product in *INSENSION*
- Great potential
- Steps to pass:
 - Revision of InQL
 - **Collaboration** with community

Thank you for your attention!

www.insension.eu

Contact Info:

Michał Kosiedowski: kat@man.poznan.pl

Peter Zentel: zentel@ph-heidelberg.de

Teresa Sansour: sansour@ph-heidelberg.de

Meike Engelhardt: engelhardt@ph-heidelberg.de

Torsten Krämer: kraemer@ph-heidelberg.de



This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 780819.



Jožef Stefan Institute

