EUROPEAN PAEDIATRIC TRANSLATIONAL RESEARCH INFRASTRUCTURE

Webinar – Patient and Public Involvement and Engagement in child health tech development

Francesca Fedeli, Fightthestroke Foundation

5/3/2024

Family engagement in research and development – The case of children with Cerebral Palsy

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Artificial Intelligence in Cerebral Palsy
AINCP

#fightthestroke

Agenda

- FightTheStroke Foundation
- Family engagement in research and digital therapeutics
- Mirrorable
- AINCP
- MirrorHR
- Take home messages

AINCP

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FightTheStroke Foundation

Since 2014 we've built a movement of more than 1000 families in Italy and established worldwide alliances, starting from our lived experience with a child with a disability of Cerebral Palsy

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Being represented: from the first child with CP on a TED stage to 17M of people in the world like Mario

Watch it online at: https://www.ted.com/talks/roberto_d_angelo_francesca_fedeli_in_our_baby_s_illness_a_life_lesson

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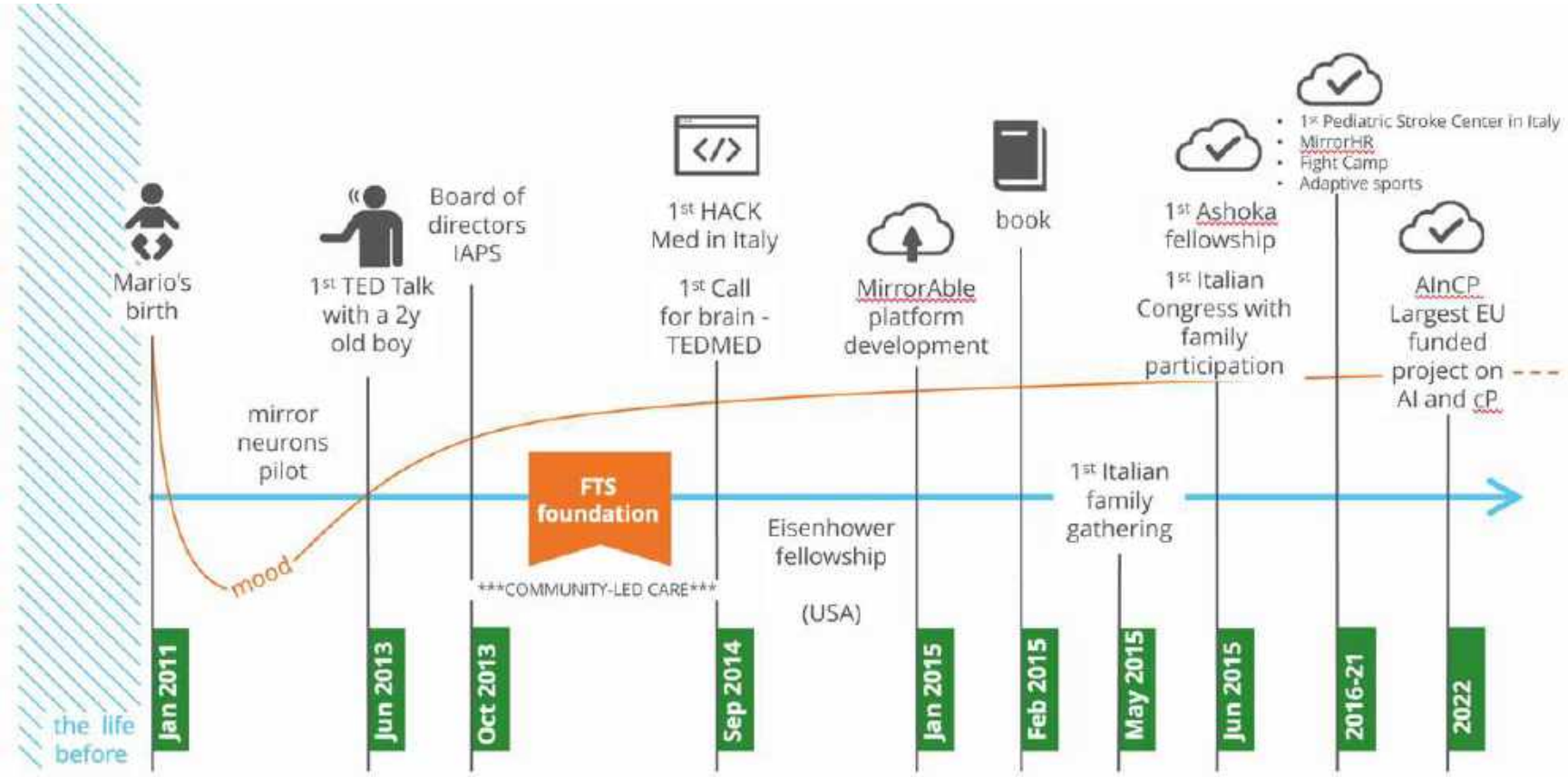
FightTheStroke story of participation in Responsible Research and Innovation



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The reason why behind Mirrorable 1st Tele-rehab Platform based on AOT

The stroke
23/01/2011

A huge problem.

A weak solution.

Rehab proposals at that time:

1. No evidence based
2. No saliency for the patient
3. No goal directed
4. No targeting the whole family
5. Late discovery→late intervention
6. Extensive treatments
7. No peer learning
8. No availability out of the hospital
9. No data gathering = no relevance for science and industry
10. Not specific, neither effective

Many system pains.

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From a prototype to an effective solution for the whole ecosystem

Sept 2016	Oct-Dic 2016	Jan-April 2017	May 2017-2018
Design	Development	Pilot	Results analysed and published
>50 kids enrolled, **20** families tested, **0** drop out, **280** therapies, **169h** of analysed data (video, emotions, motor), **100%** thinks it's easy to use			• **+26%** motor perf. • **100%** adherence • **+10%** PAM • **+50%** costs saving

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Key success factors for a co-designed solution

EXPERIENCE IN THE ASSESSMENT

EXPERIENCE IN THE TOOLKIT

EXPERIENCE IN THE USABILITY

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Sharing back to increase community knowledge

DEVELOPMENTAL MEDICINE & CHILD NEUROLOGY — ORIGINAL ARTICLE

Efficacy of a home-based platform for child-to-child interaction on hand motor function in unilateral cerebral palsy

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Published online

ABBREVIATIONS

AOT	Action observation treatment
FMA	Fugl-Meyer Assessment
FMA-UE	Fugl-Meyer Assessment for upper extremity

AIM To evaluate the feasibility and effectiveness of an action observation treatment (AOT) home-based platform promoting child-to-child interaction to improve hand motor function in unilateral cerebral palsy (CP).

METHOD Twenty children (14 males, six females; mean age 6y 7mo, standard deviation 1y 7mo; range 5y 1mo–10y 6mo) with unilateral CP underwent 20 sessions where they had to observe and then imitate a wizard performing dexterity-demanding magic tricks; a child-to-child live video-session to practise the same exercise then took place. We assessed hand-motor skills with the Besta Scale, neurological motor impairment with Fugl-Meyer Assessment for upper extremity, as well as spasticity, muscle strength, visual analogue scale, and global impression

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clinical validation of **A**rtificial **IN**telligence for providing a personalized motor clinical profile assessment and rehabilitation of upper limb in children with unilateral **C**erebral **P**alsy

Call: HORIZON-HLTH-2021-DISEASE-04

Type of Action: RIA

Acronym: AINCP

Grant Agreement: 101057309

Project starting date: 01 June 2022

Project end date: 31 May 2027

Project duration: 60 months

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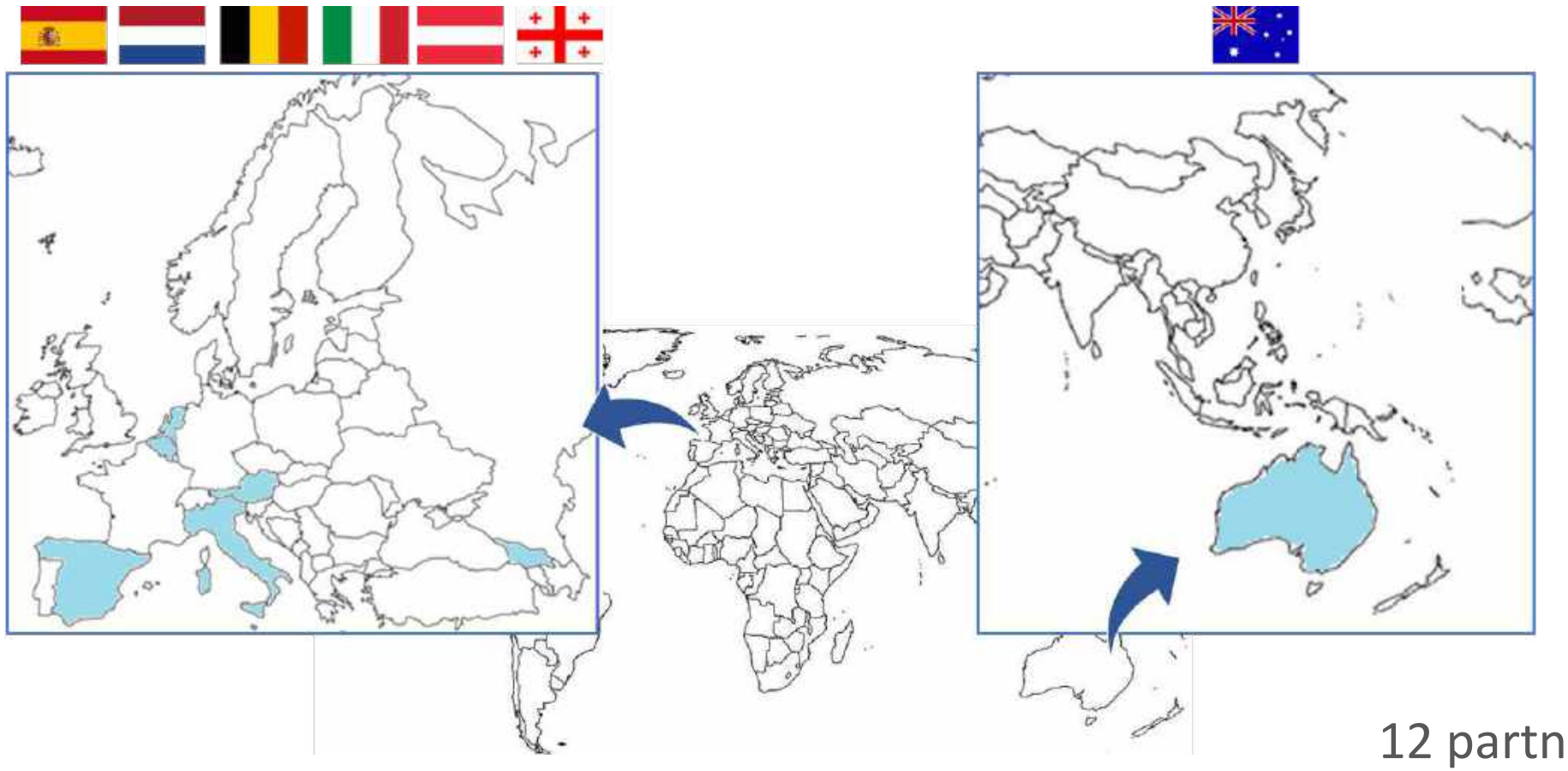
AINCP



12 partners
from 7 countries

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Our goal is to design an economical, ethical, sustainable decision-making process for delivering a personalised and validated approach, focused on the care, monitoring and rehabilitation of Upper Limb in children with Unilateral Cerebral Palsy

Our approach

AINCP uses a multidisciplinary approach, where all project collaborators (clinicians, data scientists, physicists, engineers, economists, ethicists, small medium-sized enterprises, children and parent associations) work closely together in building the solution.

www.aincp.eu

Unilateral Cerebral Palsy

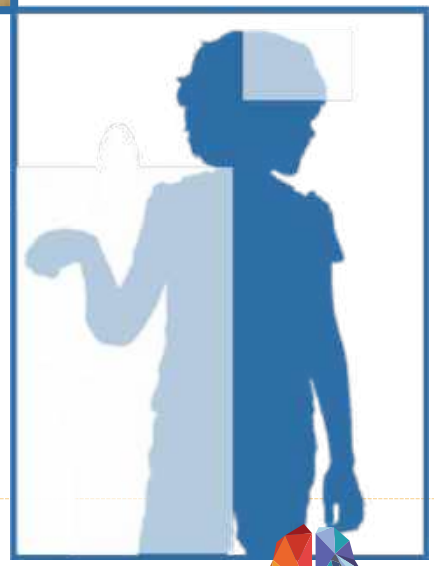
- the most frequent motor type:

  30-40% of children with CP

- up to one child in 1,000 live births

In Europe:

- every year 5,050 new cases
- about 55,000 subjects in developmental age (0-18 years) live



Main target of rehabilitation:

- Upper limb

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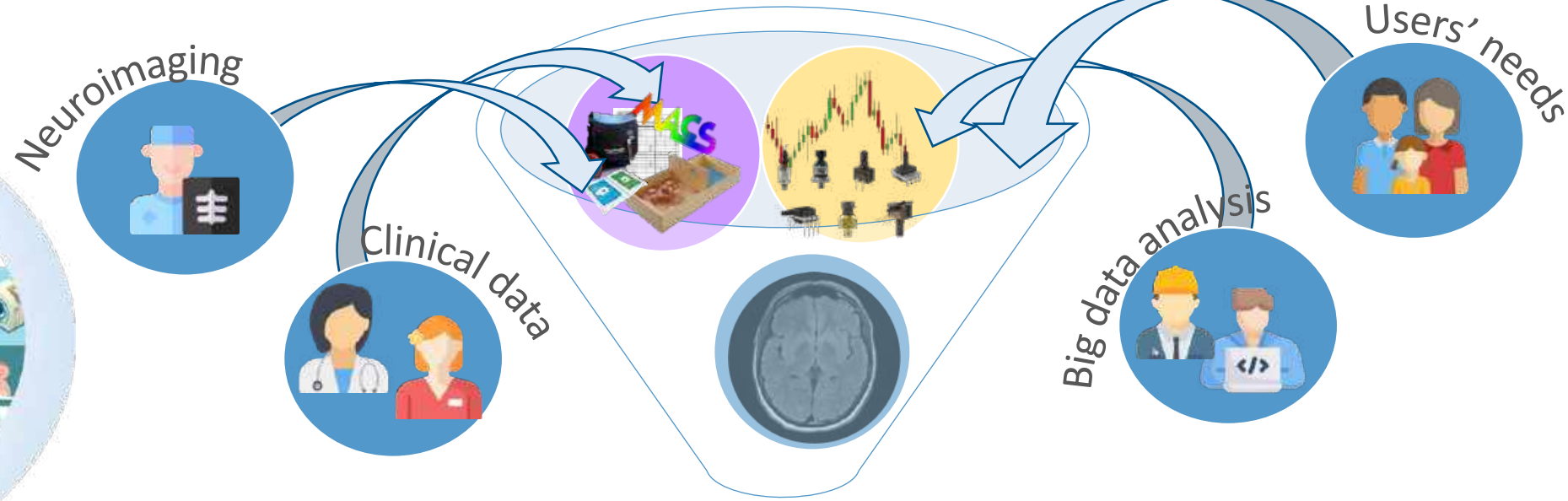

High personalization of the care from the diagnosis to the rehabilitative treatment

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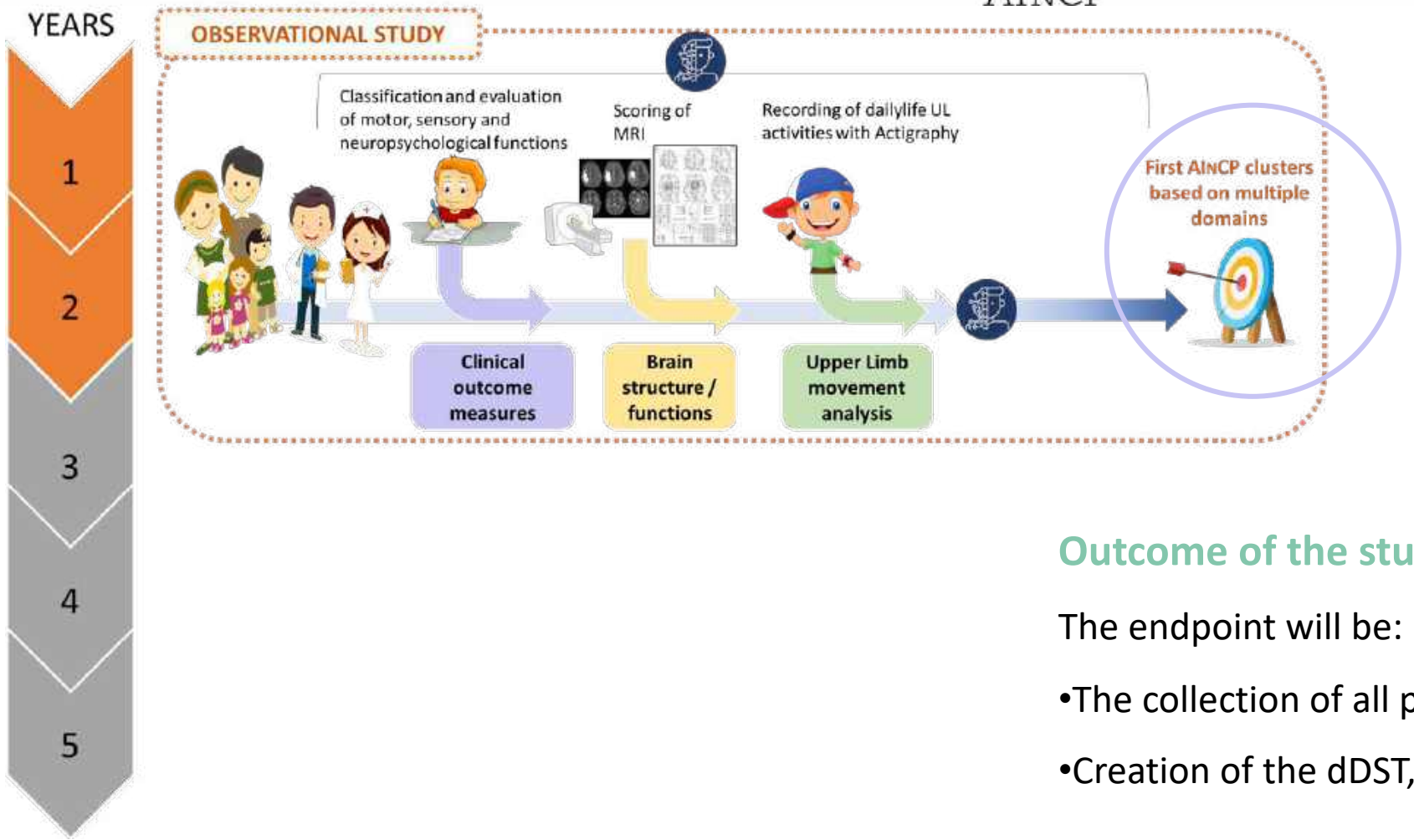
AInCP observational study



Outcome of the study

The endpoint will be:

- The collection of all planned measurements
- Creation of the dDST, by means of AI and Big data analyses

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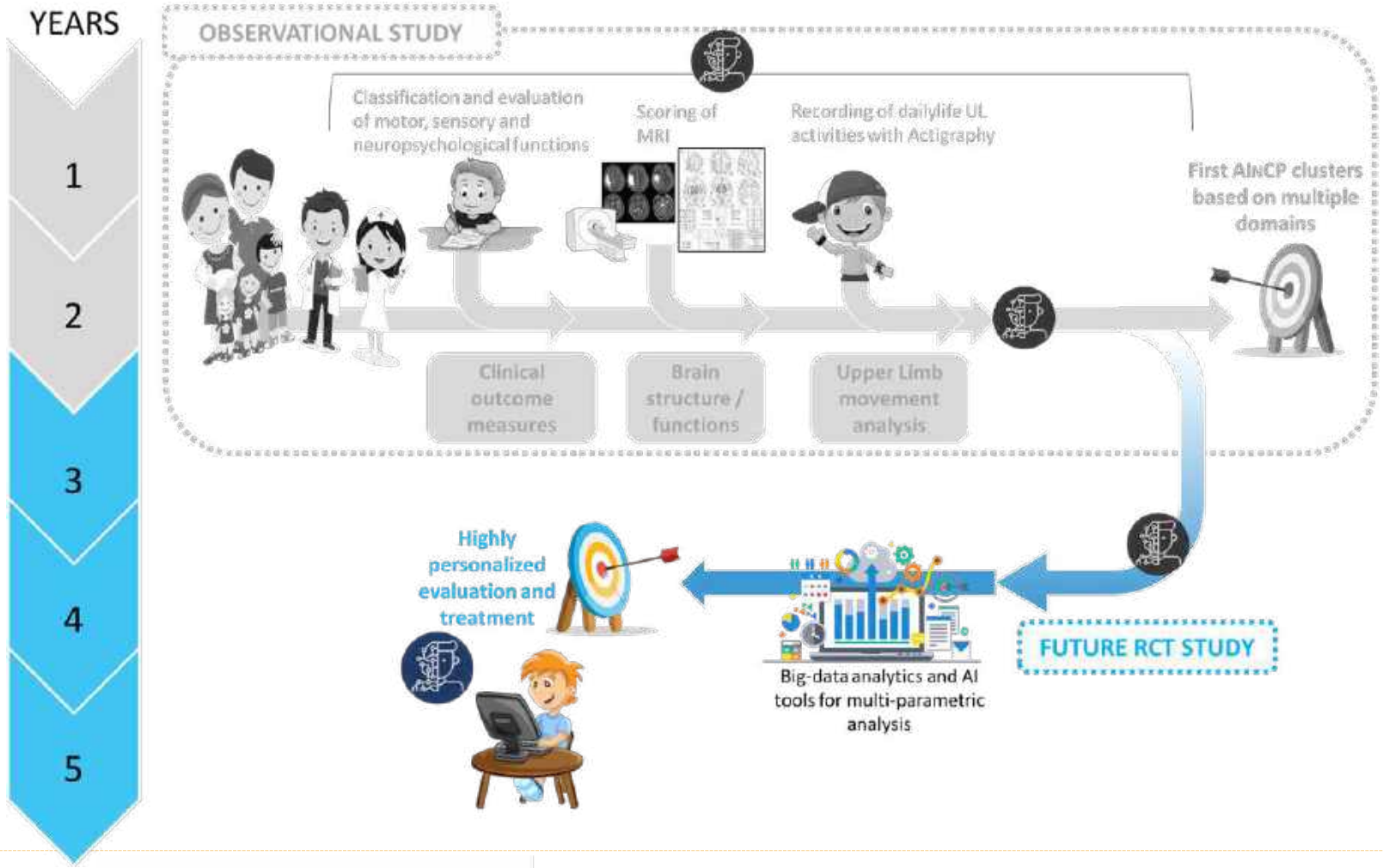
AInCP experimental study

→ Creation of highly personalized rehabilitative models



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AInCP

wearable

Upper limb movement analysis

MRI

Neuroimaging/ Neuroplasticity

clinicians

Clinical outcome measure

At home

diagnostic

dDST

rehabilitation

rDST

theranostic

tDST

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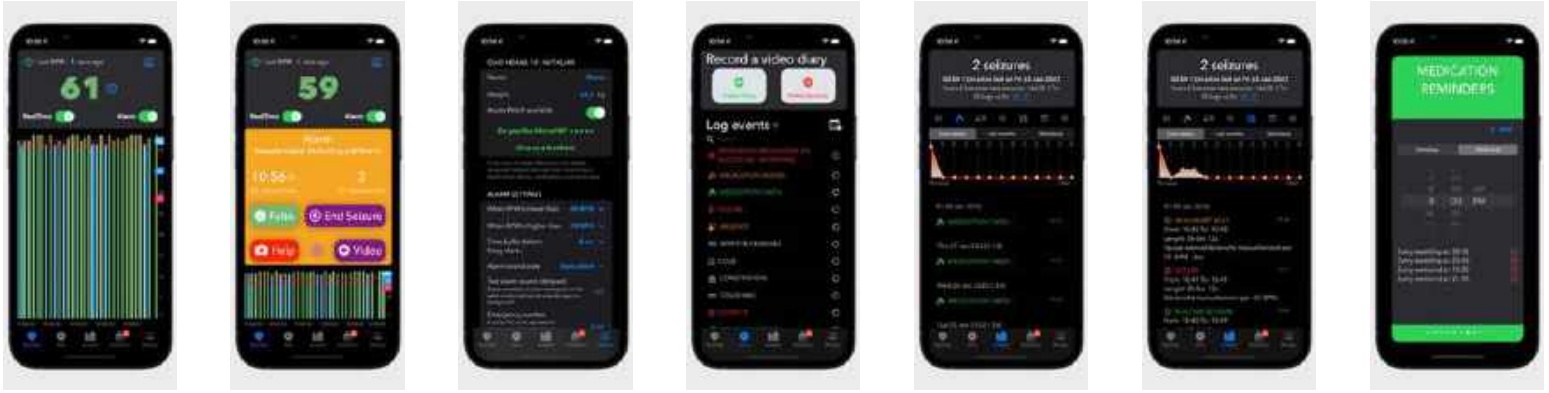
MiRRORHR
Seizures
Heart
Diary
TAGGING
ML
CAREGIVER
PARENT
FAMILY
KID
DOCTOR
DATA
RESEARCH

MirrorHR: the first epilepsy research kit built together with Microsoft, giving back data ownership to the patients



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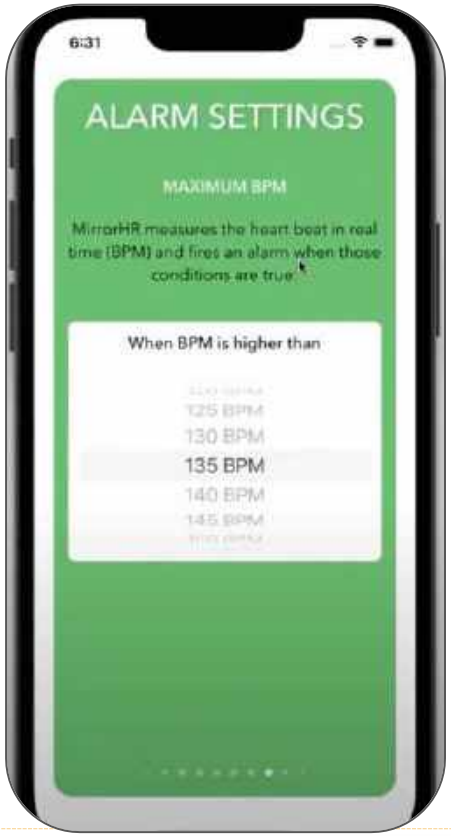
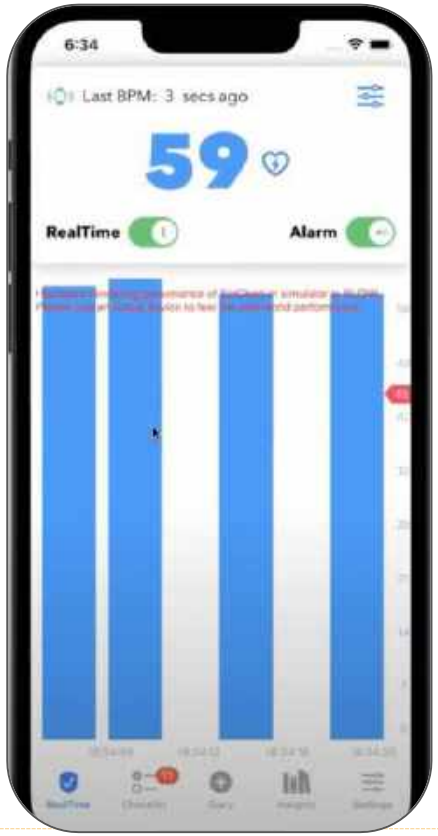
Goal #1: Give Users a Peace of Mind at Night

- 70% of seizures are indicated by a spike in heartbeat

- Set the minimum and maximum bpm thresholds

- The application will monitor the user's heartrate throughout the session





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No Crisis: Click this button for false alarms

Help: Contacts local emergency responders

End of Crisis: Press this button when seizure is over to end the session

Video: This option allows caregivers to record the seizure to share with doctors

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Seizure with no early intervention: x-axis in in **hours**

Seizure with early intervention: x-axis in in **minutes**

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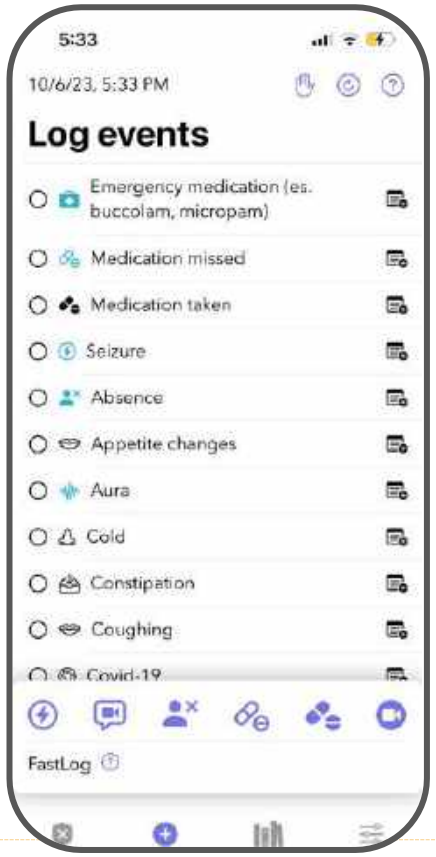
Goal #2: Provide an Online Symptom Tracker



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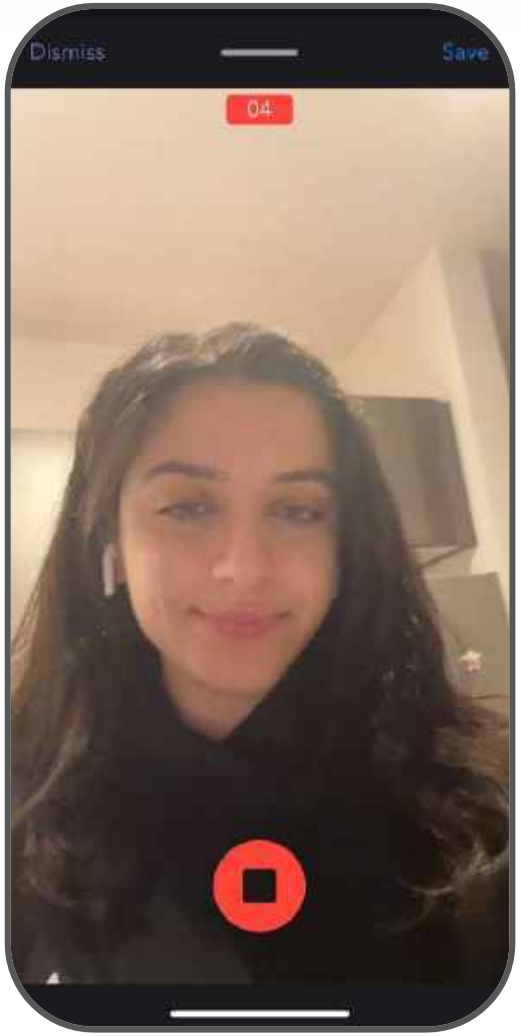
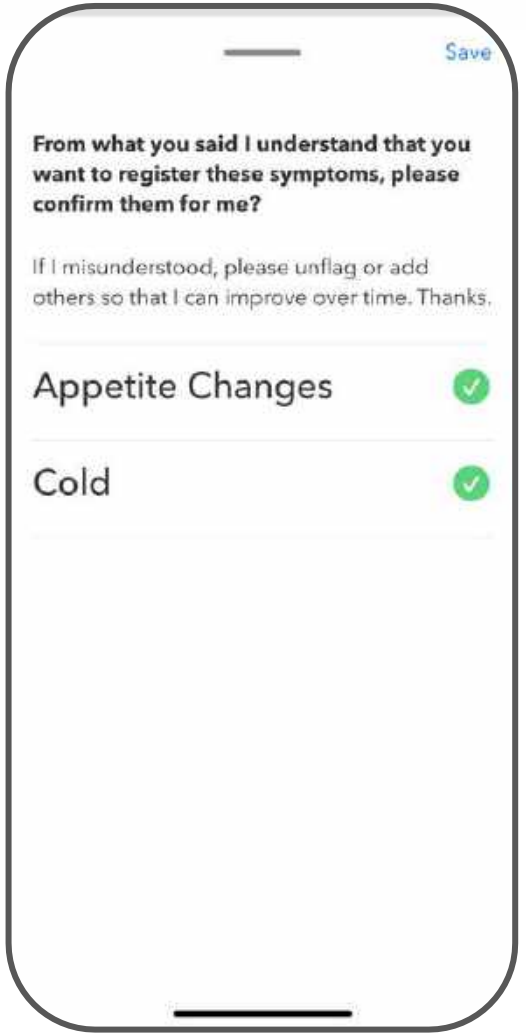


"Today I had a bit of a cold and some appetite changes."



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Goal #3: Foster Research Initiatives

Use Machine Learning to Predict Seizure Trigger

Our goal is not to predict seizures, rather to reduce the **frequency** and **severity** of them.

Figure 1 reveals the correlations between symptoms and seizures on a sample subset of data.

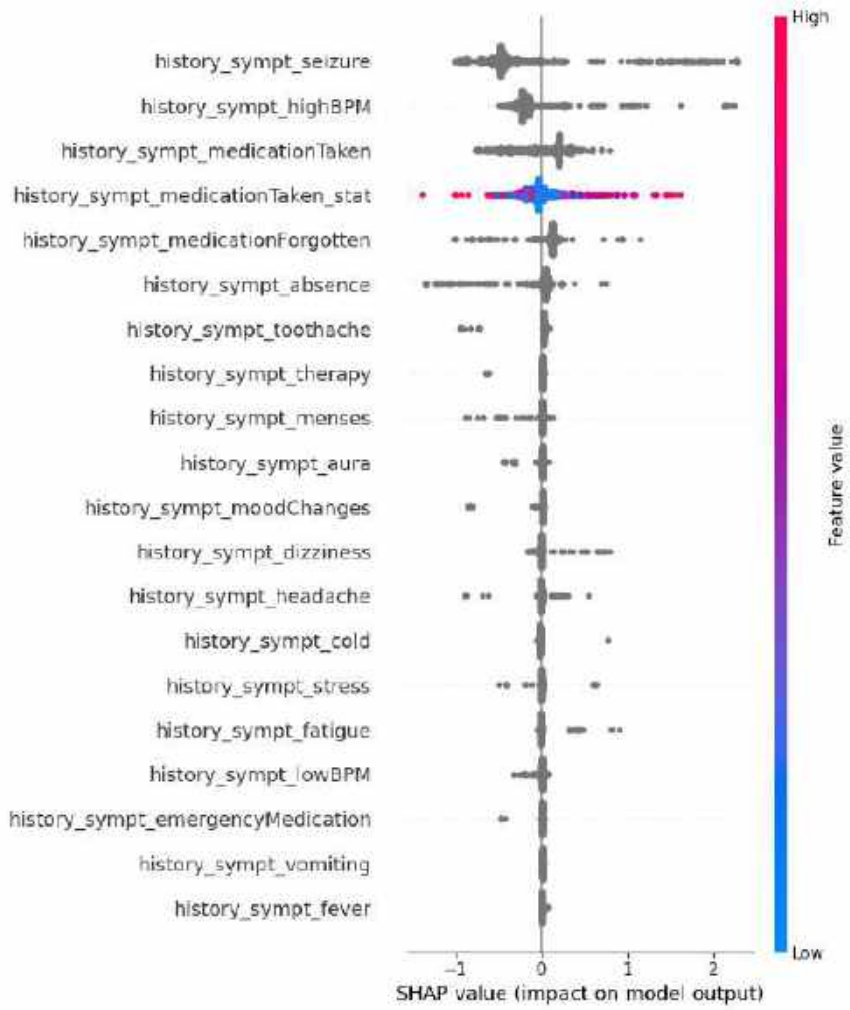

Figure 1

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Where We Are:

- 4,000+ downloads from the app store
- Available in 21 languages
- Users in 61 countries
- 4,000 seizures logged
- 70,000 symptoms logged
- 25,000,000+ bpm measurements

- Majority of users located in Europe, Middle East, and Asia
- Minimal presence in America due to high cost of advertising

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Why co-creating, since the beginning?

- Time saving
- Cost saving
- Rewarding
- Higher scores of Patient Activation Measure imply higher compliance
- More shared knowledge imply less misunderstanding
- Care effective

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Allyship in research: how to make it happen

RESEARCHERS

- Do not display disability as a punishment
- Clean up your ableist language
- Do not presume, get rid of bias, do not steal hope
- Start finding solutions together from the beginning
- Show me the data
- Recognize mutual competences, don’t be afraid to say ‘We don’t know’
- Active and continuous listening to changing habits

CAREGIVERS

- Improve health literacy level
- Avoid conspiracy theories and fake news sources
- Rely on communities for peer experiences sharing
- Get rid of not evidence-based treatments
- Share reliable sources of data with your doctors
- Recognize mutual competences, don’t ask a neurologist for and advice on children books
- Do your homework

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Some references

AMA Journal of Ethics®
Illuminating the Art of Medicine

MEDICAL EDUCATION
JAN 2024

Aspiring to Disability Consciousness in Health Professions Training

Lydia Smeltz, Susan M. Havercamp, PhD, and Lisa Meeks, PhD, MA

Abstract

Lack of disability-competent health care contributes to inequitable health outcomes for the largest minoritized population in the world: persons with disabilities. Health care professionals hold implicit and explicit bias against disabled people and report receiving inadequate disability training. While disability competence establishes a baseline standard of care, health professional educators must prepare a disability conscious workforce by challenging ableist assumptions and promoting holistic understanding of persons with disabilities. Future clinicians must recognize disability as an aspect of diversity, express respect for disabled patients, and demonstrate flexibility about how to care for disabled patients' needs. These skills are currently undervalued in medical training, specifically. This article describes how integrating disability consciousness into health professions training can improve health equity for patients with disabilities.

Table. Recommendations for Creating Disability Conscious Medical Education

Theme	Recommendations
Recognize diversity of disability	• Include a variety of disability types. • Consider the balance between education focusing on a specific subset of disability (eg, physical disability) and education focusing on a broader representation of different disability lived experiences. • Include intersectional identities in the curriculum.
Move beyond medical model	• Define ableism and its manifestations at the individual, institutional, and societal levels. • Include the social model of disability in teaching. • Utilize disability studies and disability justice principles.
Develop respectful curiosity	• Acquire the skills to ask questions that advance trainee knowledge of how to provide patient-centered care.
Prioritize continual engagement and learning	• Integrate a longitudinal curriculum across preclinical and clinical years. • Utilize a variety of teaching formats (eg, standardized patients with disabilities, patient panels, home and community visits). • Leverage existing knowledge and resources.
Center disabled people	• Engage with people with disabilities. • Hire disabled people as teachers. • Include disabled faculty on high-level curricular committees. • Continually seek feedback from disabled people.

Source: https://journalofethics.ama-assn.org/article/aspiring-disability-consciousness-health-professions-training/2024-01?fbclid=IwAR3wyuBTkqhmi21fTfyoVWm39DC-SiPZO-3ynUIp1zzaHuuSsAKmKW3kAU4

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Restablishing asimmetries allows building trust and frictionless relationships:

that's how we're working together as families and people with disabilities engaged in research and development of child health tech!

Still eager to know more about our movement?
https://www.fightthestroke.org/

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