Designing eHealth systems for people with disability: the trade-off between personalization and universality

Elisa Salatti

Mauriana Pesaresi Seminar Series – 21/02/2025

The main problem

Uses of technology in healthcare:

Diagnosis

Monitoring

Data management

Education

Treatments

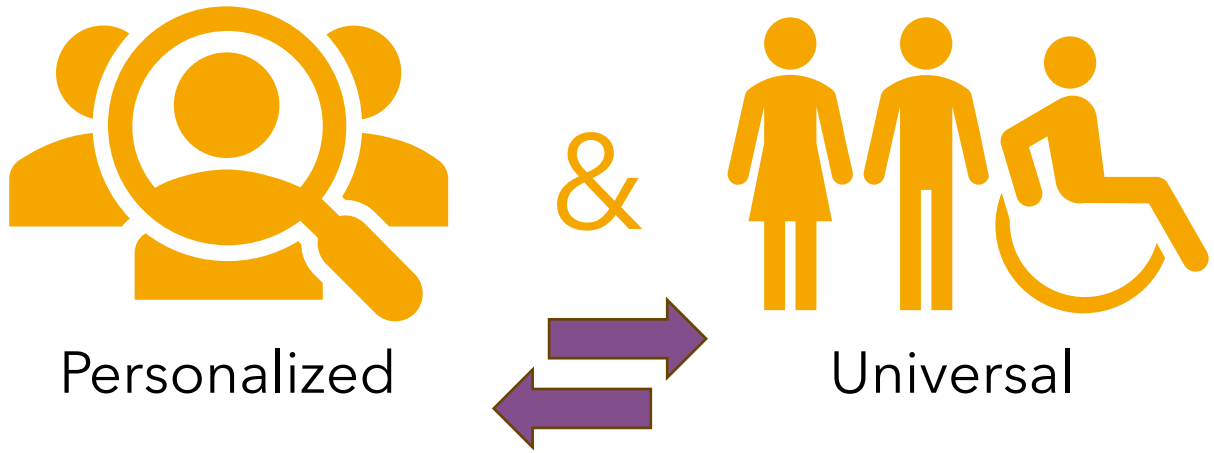
DESPITE THE USE OF TECHNOLOGY,

access to healthcare services is not guaranteed for everyone, especially for people with **disability**[1].

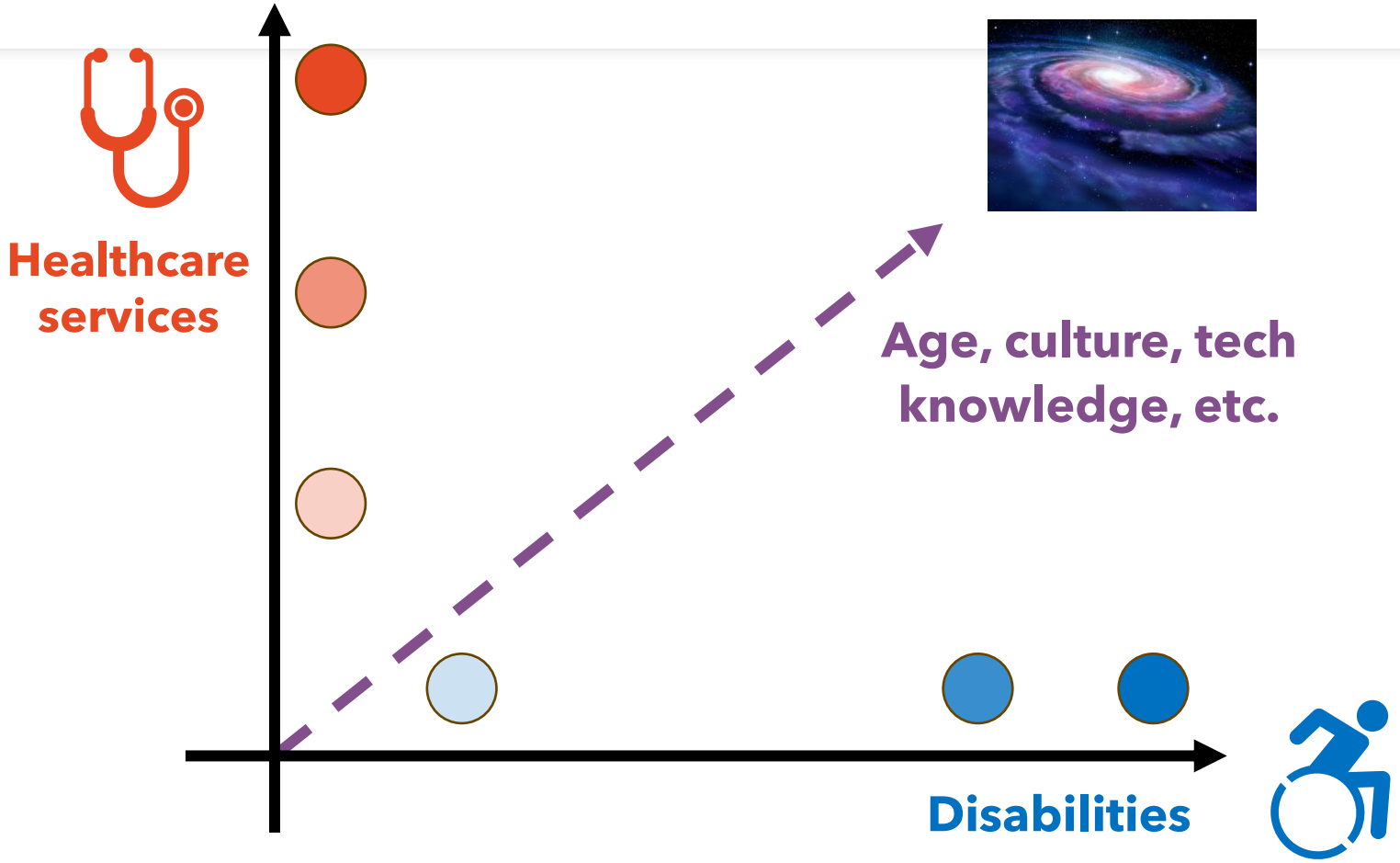
1. World Health Organization. Global report on health equity for persons with disabilities. Geneva: World Health Organization; 2022. Online avaiable: https://www.who.int/publications/i/item/9789240063600.

Our research problem

How can we use technology to help people with disability access to quality healthcare services?



Universal in n-dimensions



Universal accessibility of healthcare services

The World Health Organization has defined a global standard for accessibility of telehealth services[2].

Different frameworks and models can be used to guide human-centered, iterative development processes of eHealth[3], like the the CeHRes Roadmap 2.0.

No specific toolkit/method/framework for universal design for eHealth.

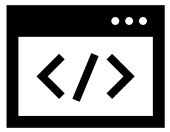
2. World Health Organization (2022). WHO-ITU Global Standard for Accessibility of Telehealth Services. Available at: https://www.who.int/publications/i/item/9789240050464 .
3. Kip, H., Keizer, J., Silva, M., Beerlage-de Jong, N., Köhle, N., & Kelders, S. (2022). Methods for human-centered eHealth development: a narrative scoping review. *Journal of Medical Internet Research*, 24. doi:10.2196/31858.

Access to…

…healthcare services

eHealth

Design



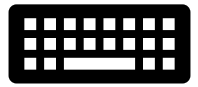
Develop

Evaluate

…technology

Accessibility

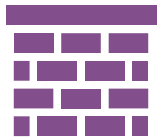
Usability



Assistive technologies

Breaking down the problem

Why do people with disabilities not access healthcare services?

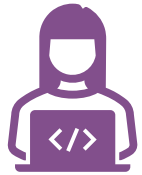


Weaknesses in the healthcare system

Geographical inequalities, cultural and linguistic barriers

Economic issues

Broad spectrum of disabilities



Level of technological knowledge

Different types of medical care

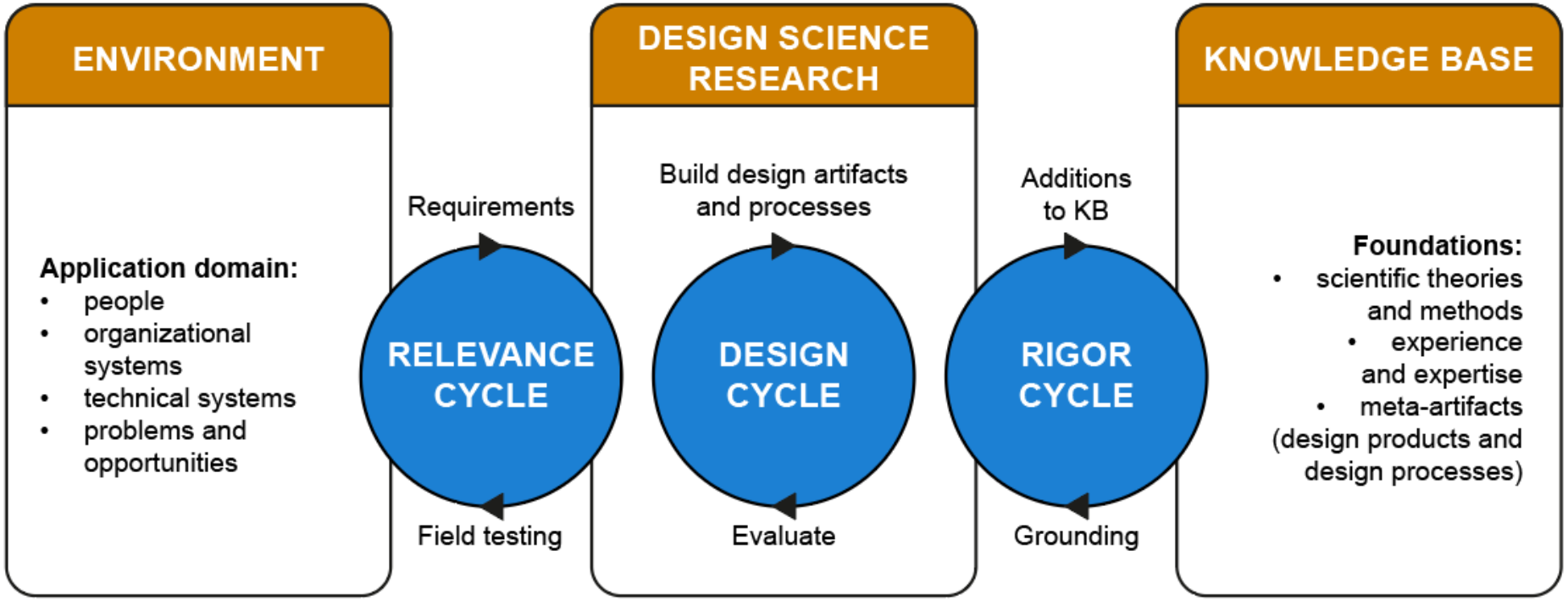
…

Don’t forget our problem: personalization AND universality

Systems design in scientific research

A brief introduction

The Hevner model



4

Designing computer systems for people with disability requires **interdisciplinarity**.

4. Hevner, A. R. (2007). A Three Cycle View of Design Science Research. Scandinavian Journal of Information Systems, 19(2), 87-92.

Get the requirements

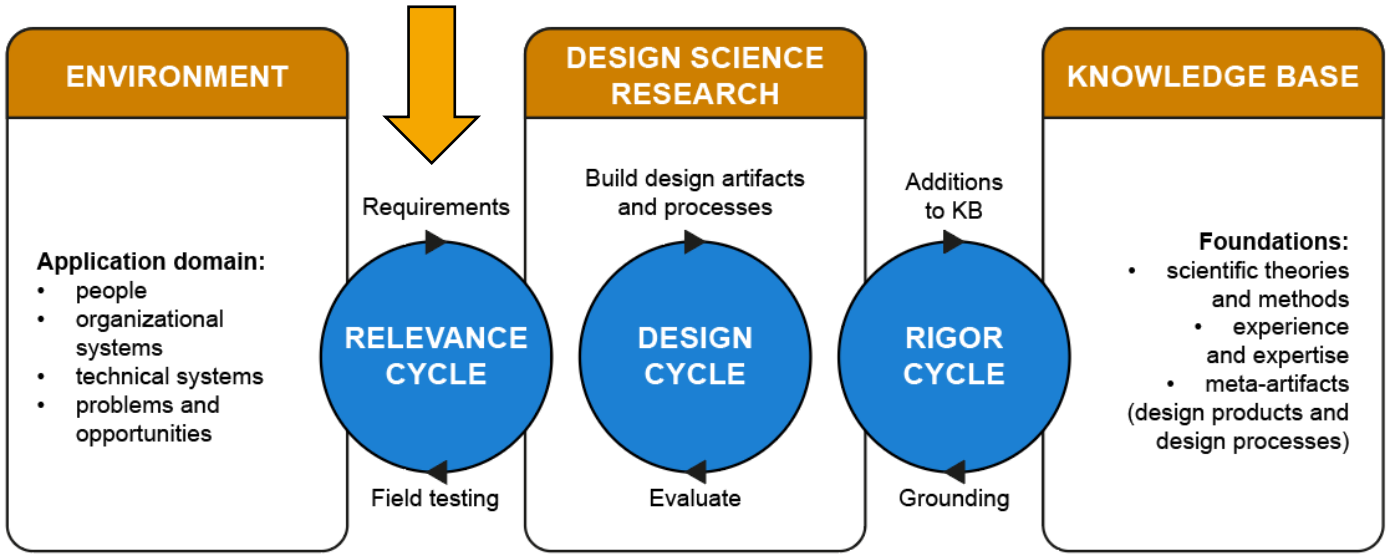
Participative design.

Involve all the stakeholders since the beginning:

- patient
- medical staff
- relatives
- caregivers

Goal: understand the real needs to get the real requirements.

Possible problems: get the data.



Get the knowledge

1 Get reqs. | 2 Grounding | 3 Prototype | 4 Expert review | 5 Real world tests | 6 Share

Accessibility

Tools

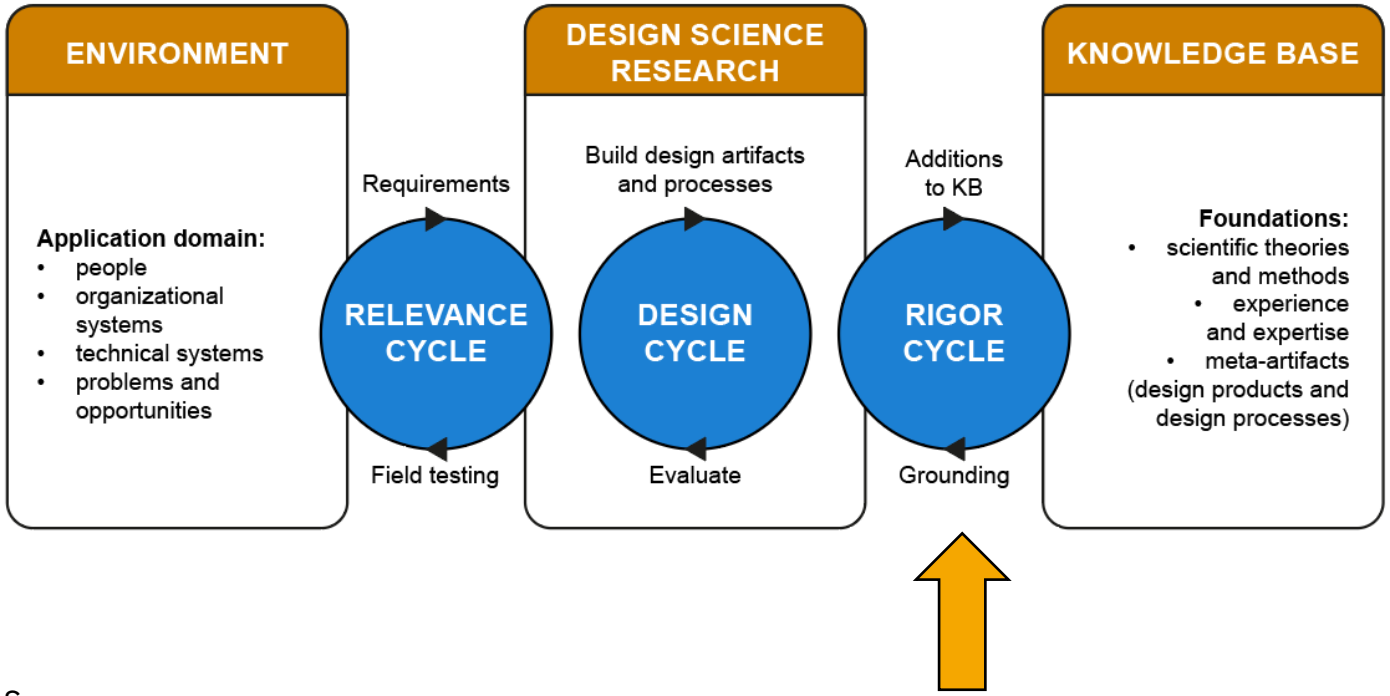
Guidelines

Methods

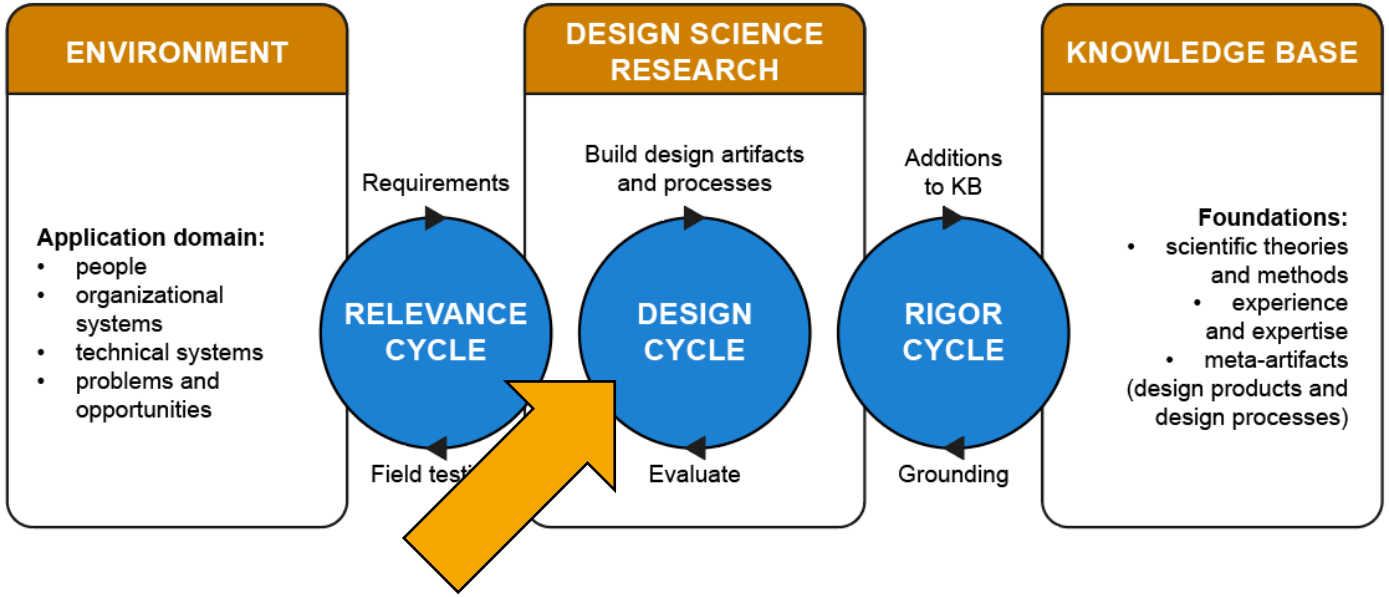
State of Art

Regulamentations

(e.g. **GDPR**)



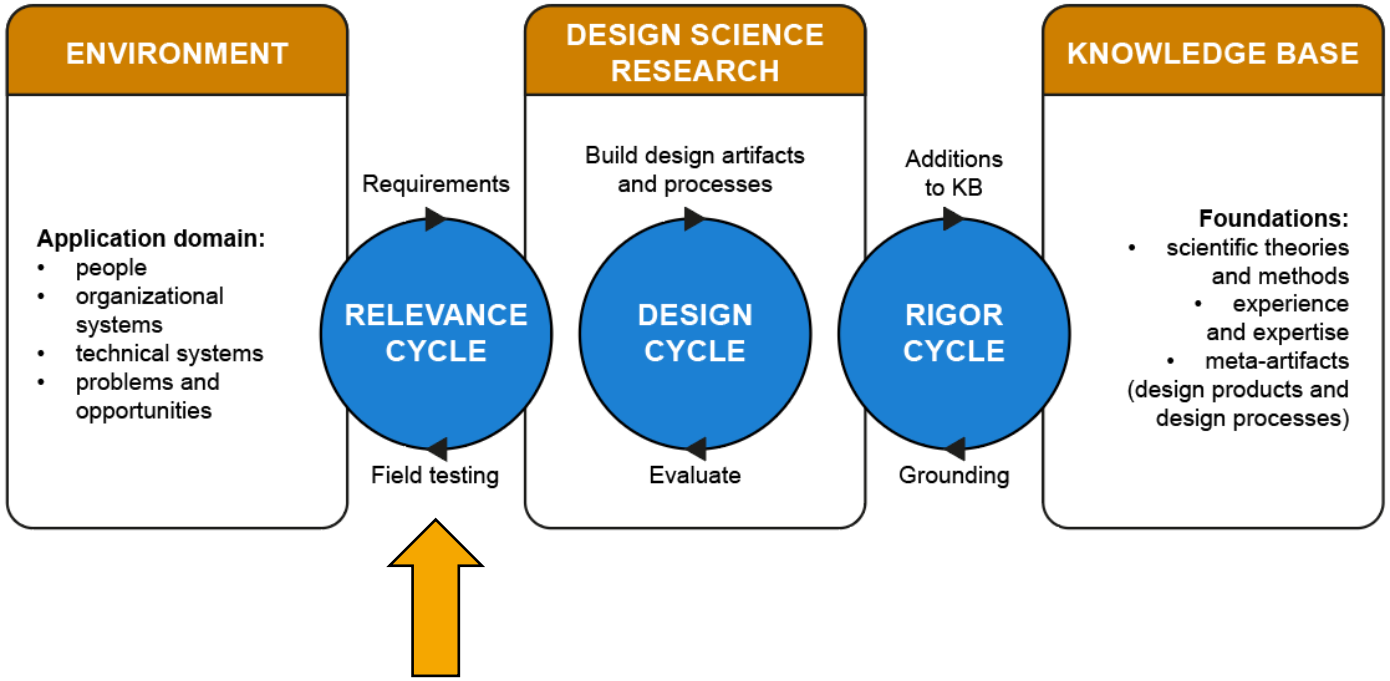
Design and develop prototypes



Test in the real world

Problems in testing systems for people with disabilities[5]:

- small sample size (stats. analysis, between/within groups design, etc.)
- communication between subjects and researchers
- moderate or unmoderated tests? natural or uncontrolled environment?

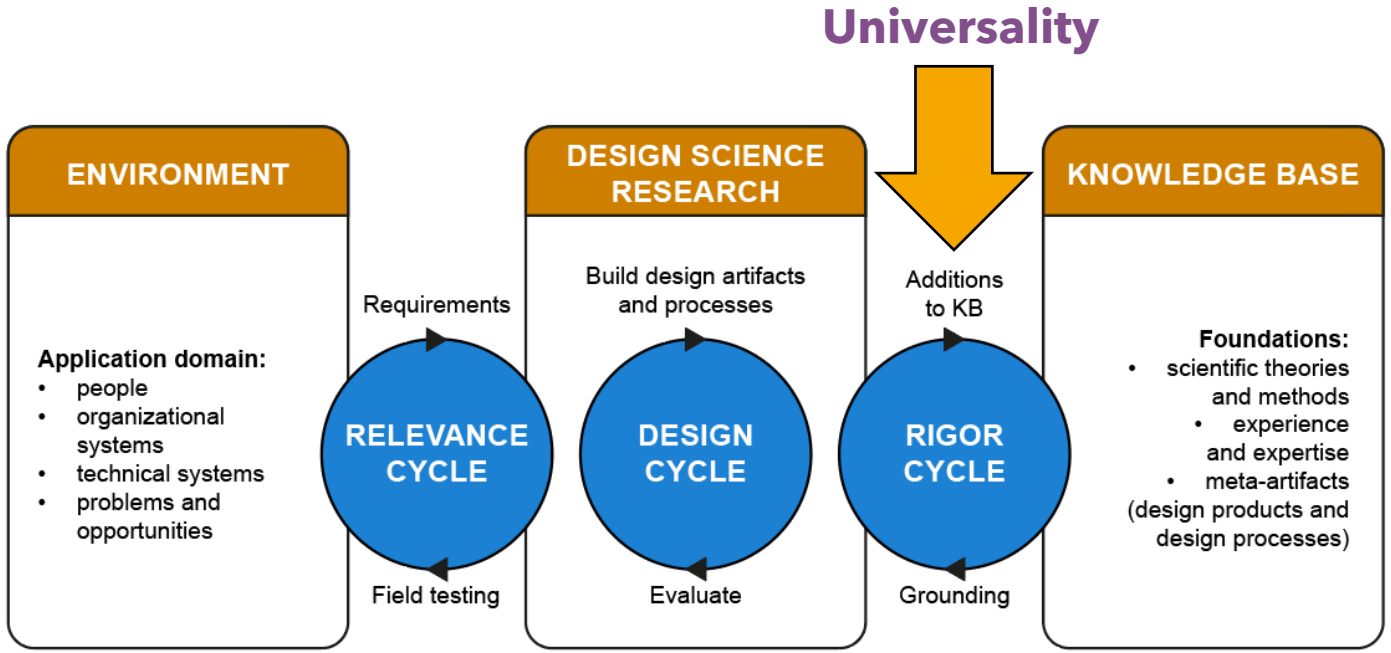


5. Lazar, J., Feng, J. H., & Hochheiser, H. (2017). *Research Methods in Human-Computer Interaction*.

Our goal

Develop systems to **help** patients with disabilities **access quality healthcare services**.

Create and **share new knowledge to the research community**.

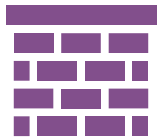


Back to the healthcare problem

Let’s analyze it

Breaking down the problem

Why do people with disabilities not access healthcare services?

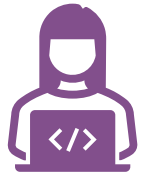


Weaknesses in the healthcare system

Geographical inequalities, cultural and linguistic barriers

Economic issues

Broad spectrum of disabilities



Level of technological knowledge

Different types of medical care

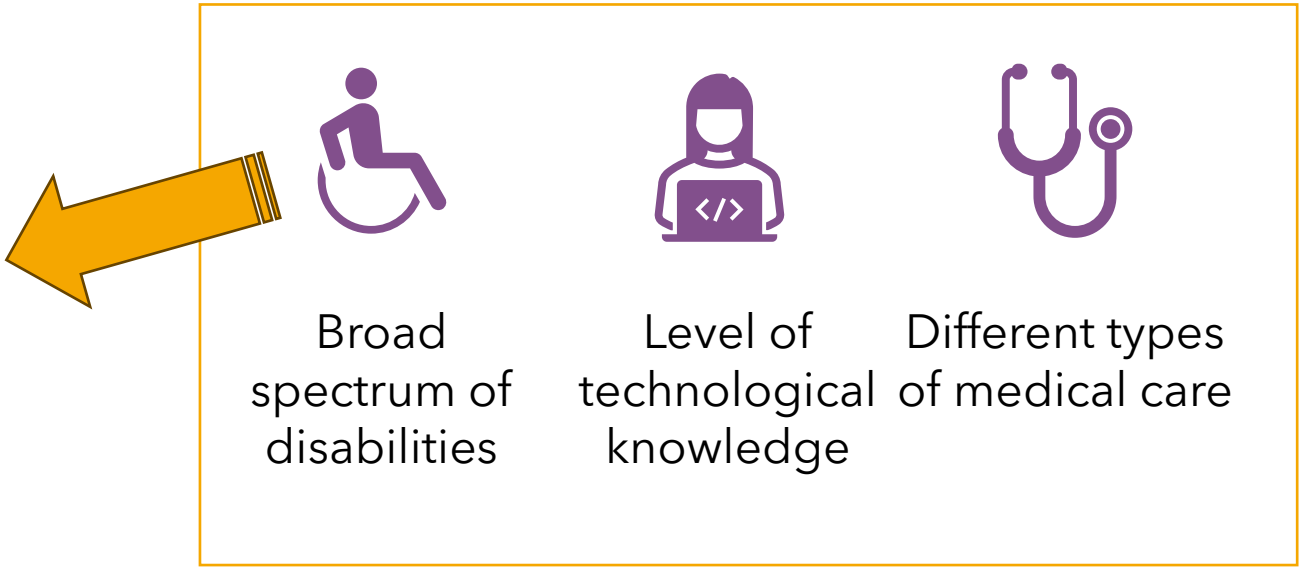
…

Don’t forget our problem: personalization AND universality

Breaking down the problem

Let's choose the one to focus on:

Autism Spectrum Disorder (ASD)



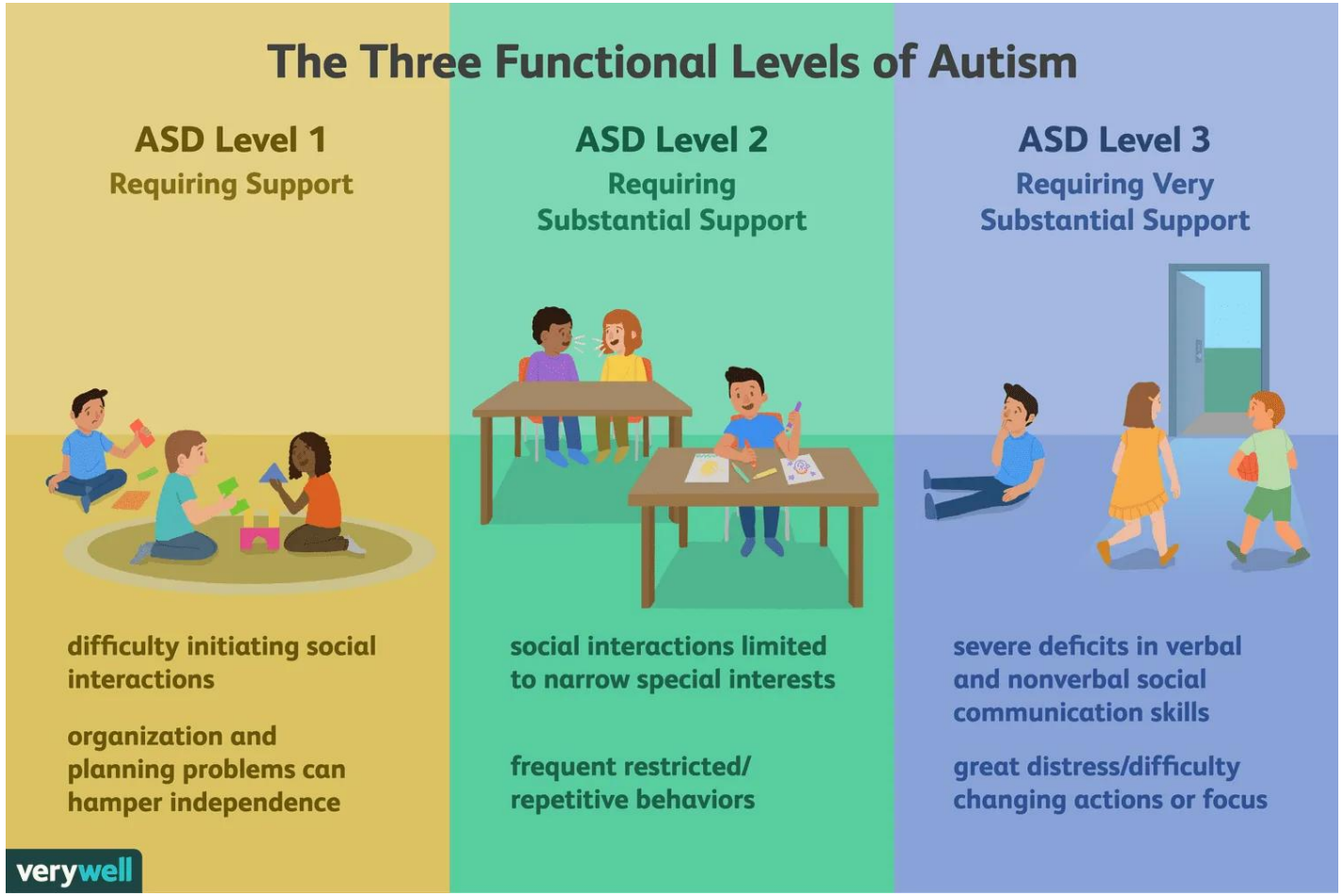
The ASD

Autism Spectrum Disorder (ASD) is an early-onset neurodevelopmental disorder that has a significant impact on individuals' lives.

People with ASD often have problems with communication and social interactions and exhibit restricted and repetitive patterns of behavior.

Spectrum: while all people with autism share certain difficulties, the way and intensity of these difficulties vary greatly from person to person.

People with ASD are often more likely to use technology compared to the general population.



Breaking down the main problem

Broad spectrum of disabilities

Level of technological knowledge

Different types of medical care

Let's choose the one to focus on:

Dentist

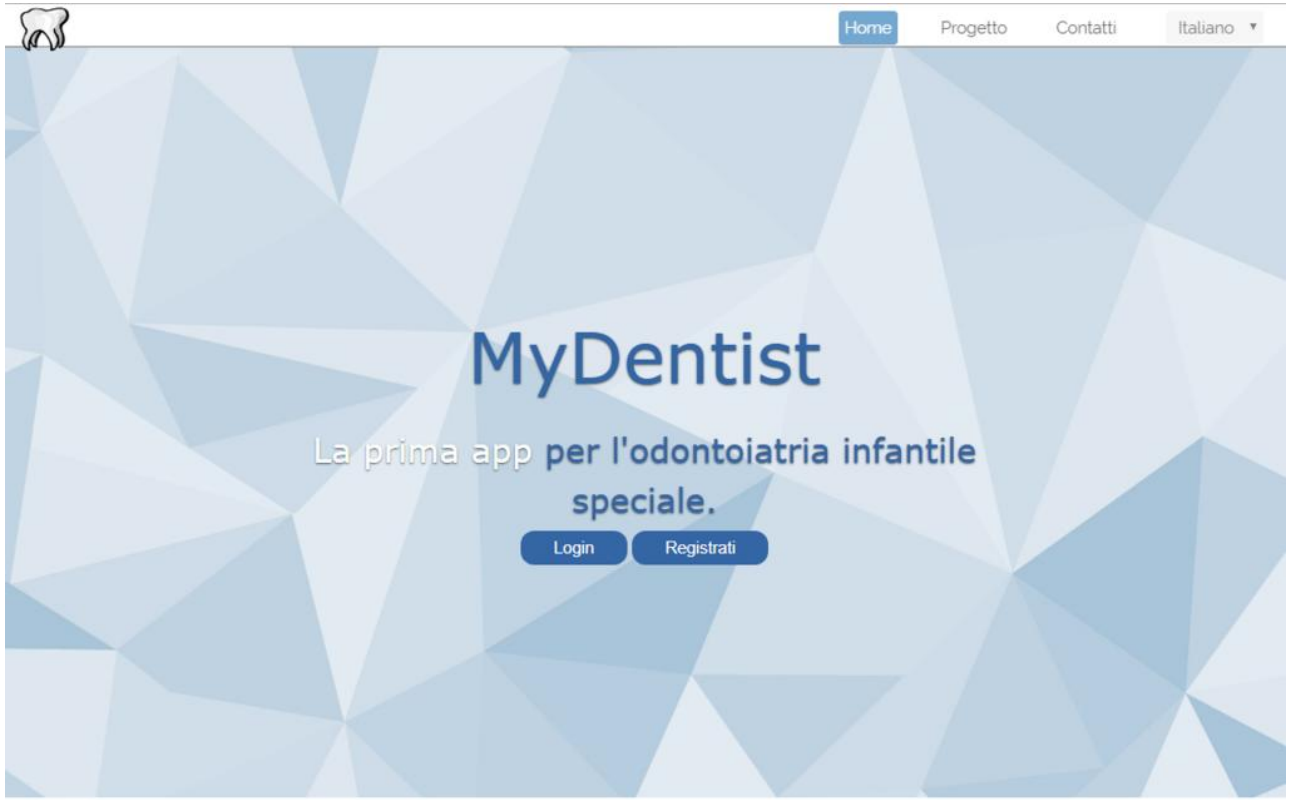
MyDentist - Example of use cases

Heathcare access problem

Children with ASD **perceive sensory experiences differently** than neuro-typical children, which makes it extremely **difficult for them to accept unfamiliar environments and contexts**.

High level of stress/anxiety -> no collaboration.

Dentist often forced to administer **complete sedation even to provide basic dental hygiene**. [6]

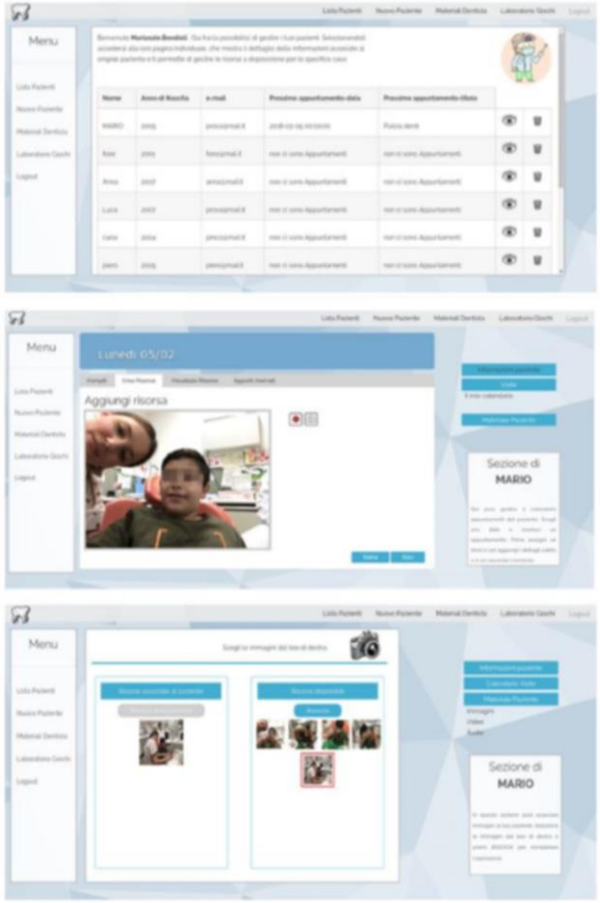


6. M. Bondioli, M. C. Buzzi, M. Buzzi, S. Chessa, L. Jaccheri, C. Senette, and S. Pelagatti, "Guidelines for research and design of software for children with asd in e-health," Universal Access in the Information Society, vol. 23, pp. 1909–1930, 07 2023.

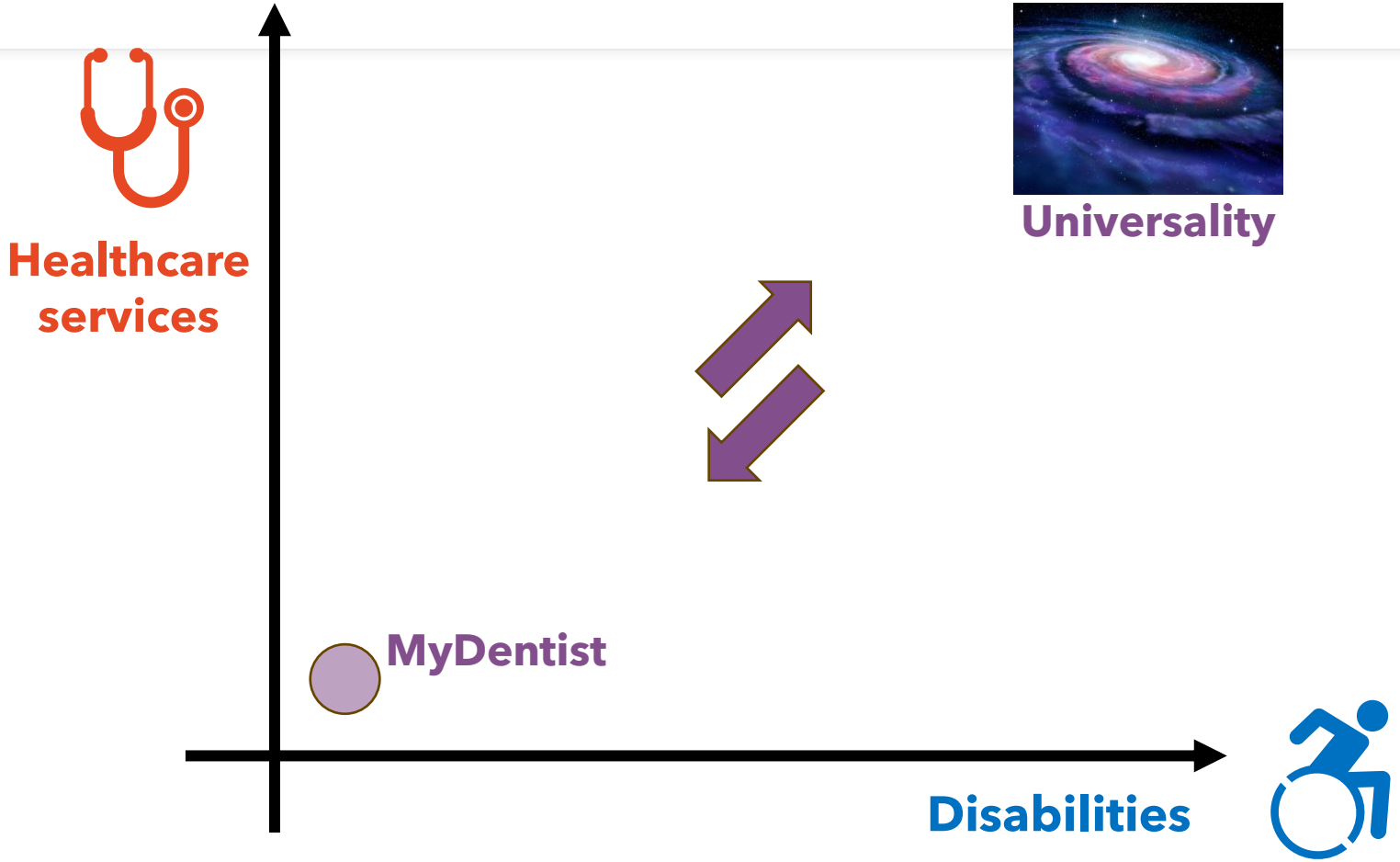
MyDentist - Example of use cases

Goals:

- **reduce anxiety** during visits
- **teach correct behaviors** both at the clinic and at home
- **motivating them to maintain adequate oral health**.



Personalized…



… but we have lost universality!

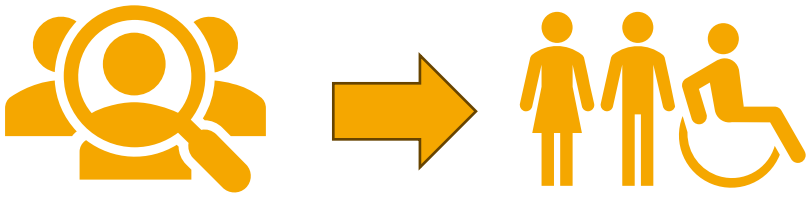
How can we reach it?

We can use different approaches

Making use cases?

Unfeasible

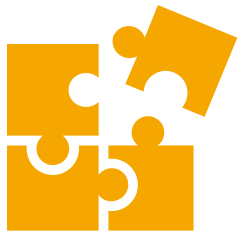
From personalized to universal



Create a toolkit

Methodologies, functionalities or even components (!)

Possibly universal and adaptable.



e.g. GDPR compliance

What else can we do to achieve universality without losing personalization?

(Q & A time)