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Contribution of clinical data to the design of assistive systems

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Abstract. The objective of our work is to adapt a new user-centered design (UCD) methodology in the field of design of assistive systems for multiple disabilities people who live in specialized care homes. We have adopted a specific approach by integrating clinical data interpreted on these people with multiple disabilities by medical and social staff. This is a new approach to remedy their difficulty in identifying and/or expressing their needs for assistive technologies. We will show through a case study how these clinical data have enabled us to design high-fidelity prototypes for communication and environmental control devices.

Keywords: User Centered design; interaction technique; multiple disabilities; clinical data; ecosystem

1 Introduction

User-centered design (UCD) is a design approach where the specific needs, expectations and characteristics of end users are taken into account at each step of the product design process. The standard ISO 9241-210 [1] (See Fig. 1) has defined the steps for implementing this approach. It is based on the hypothesis that end-users are best placed to express their needs, participate in the design, evaluate and use the interactive system, until the needs and requirements expressed by users are met. The relevance of the UCD is well established [2]. However, expressing needs is quite impossible for end user with communication difficulties. In addition, there is an emerging stream of consideration of deficiency characteristics in the design process. Several approaches have been studied to involve people with disabilities in the design process and to consider disabilities data. These approaches are reported in the related work section of this article

The aim of this article is to illustrate how clinical data and the profile of the person with a multiple disability impact the prototyping phases of the user-centered design

method. To answer this question, we will describe the implementation of the user-centered approach, focusing on the clinical data acquisition scales and how we used them in the prototyping phases. We will illustrate this approach with a case study for a person with multiple disabilities. We will end our article with a discussion on the consideration of clinical data in the UCD process.

2 Related works

In the context of the design of assistive technology systems, User Centered Design (UCD) tools and methods may not be appropriate [3] for the participation of people with multiple disabilities. The team of Antona et al. [3] evaluated a set of methods and techniques according to two main criteria: (disability and age) and a set of sub criteria (sensory, motor and/or cognitive impairments). Each of the methods is then qualified as “✓Appropriate”, “■ Needs modifications and adjustments”, and “☒ Not recommended” (See table 1). Ritter et al. [4] proposed a human-centered approach based on how human capacities are affected during direct interaction with the interactive system itself.

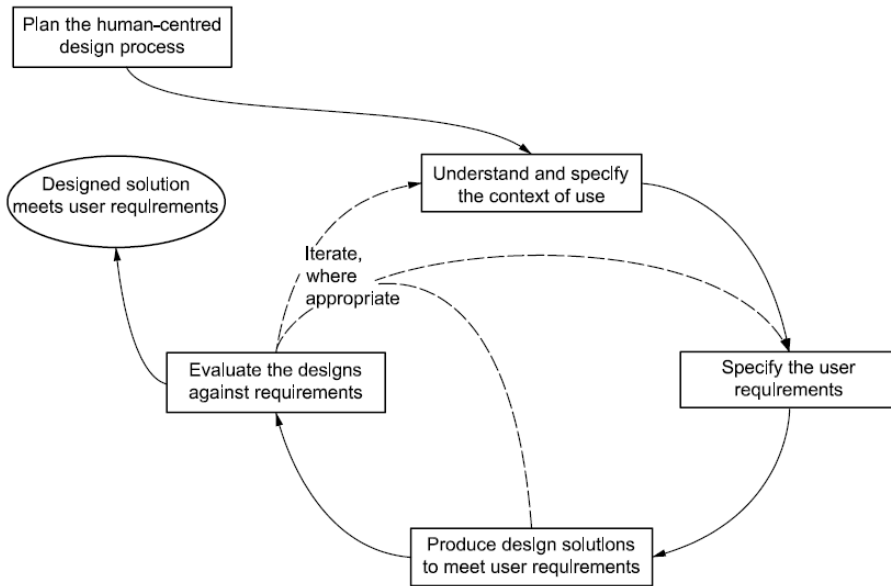


Fig. 1. Interdependence of user-centered design activities according to ISO [1].

Several research studies have proposed adaptations of the implementation of the UCD method. The works [5], [6], [7] and [8] showed that the participation of people (family, medical and social workers, etc.) close to the end users was beneficial in the design of prototypes meeting their needs. Guffroy et al [8] defined the concept of ecosystem, which represents this whole human environment (professional and sometimes family caregivers). Roche et al [9] proposed AMICAS (Innovative

Methodological Approach to Adapted Systemic Design), which aims to take into account the analysis grids (context, profiles, and characteristic action situations) of people with multiple disabilities by matching them with the situations of use in order to identify which tasks users can perform and describe the difficulties encountered.

Table 1. Summary of User Requirements Elicitation Methods [3].

User Requirements Elicitation	Disability				Age	
Methods and Techniques	Motion	Vision	Hearing	Cognitive/ Communication	Children	Elderly
Brainstorming	✓	✓	■	■	■	■
Direct observation	✓	✓	✓	✓	✓	✓
Activity diaries and cultural probes	■	■	✓	■	■	✓
Survey and questionnaires	■	■	■	☒	■	■
Interviews	✓	✓	■	☒	■	■
Group discussions	✓	✓	■	☒	■	■
Empathic modelling	✓	✓	✓	☒	☒	☒
User trials	■	■	■	■	■	■
Scenarios and personas	✓	✓	✓	✓	✓	✓
Prototyping	✓	✓	✓	✓	✓	✓
Cooperative and participatory design	✓	✓	✓	■	■	■
Art-based approaches					✓	✓

Other work shows the importance of disability [10] or health [11] data to develop ontologies. These are used to design, for example, adapted systems for generating therapeutic programs [10] or for the adaptation of assistive technologies [11]. It is in this trend towards taking clinical data into account that our approach to the design of communication assistive devices for people with multiple disabilities is based, for whom the evaluation and characterization of their capacities can be difficult and can evolve over time. We are planning to implement this methodology for the design of OUPSCECI assistive technologies (AT) for communication and environmental control. The OUPSCECI AT consists of a virtual interface (see Fig. 6, Fig. 7) and a control box for the interaction devices (see Fig. 5).

3 Implementation of the CCU approach

The study population concerns adults and children with motor and severe mental impairment, associated with various disease (behavioral disorders, sensory disorders, (no or little written and/or oral language), hosted by a specialized care homes (SCH) or by an institute for motor skills development (IMS). According to the professionals involved, these residents suffer from social isolation and loneliness, a sense of powerlessness and a reduced self-image. They need assistive technologies to communicate with their ecosystem. In addition, this population is composed of people who have difficulty expressing their needs due to the nature of their disability. The abilities of the residents in the sense of ICF (International Classification of Functioning) [12] are constantly evolving (worsening of disabilities, appearance of associated disorders, etc.). This potential change in capabilities confronts us with two challenges: the adaptation of user requirements and the adaptation of assistive technology to meet the changing needs. To address these challenges, we have implemented the UCD ap-

proach of ISO 9241-210 [1] in which we will demonstrate the importance of observational methods, including the contribution of both clinical scales and ecosystem expertise in all stages of UCD (see Fig. 2.) for people with multiple disabilities.

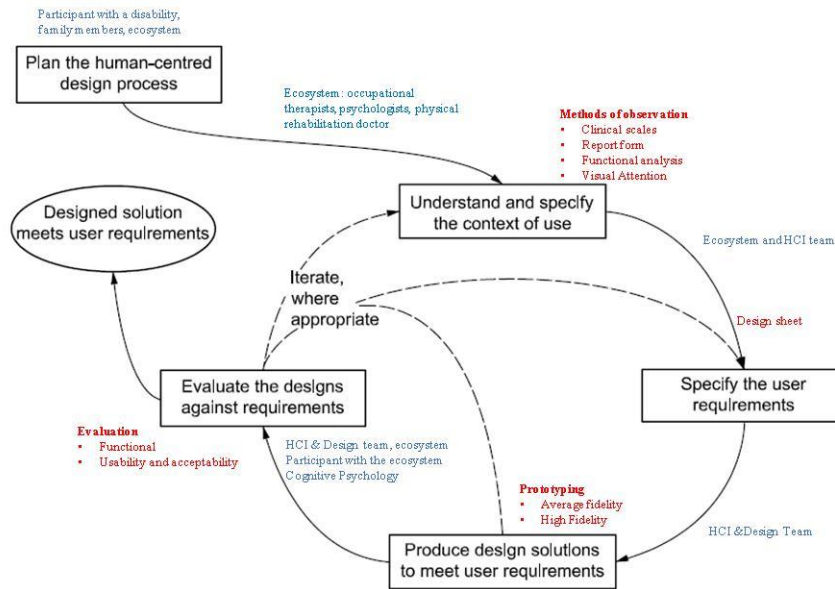


Fig. 2. Interdependence of user-centered design activities according to ISO with the role of the ecosystem (in blue) and the role of the data used (clinical data) or produced (design sheet) (in red).

3.1 Understanding and specificity of the usability' context

For this study population, a set of observational tools was used by occupational therapists, psychologists and a psychology student with the objectives of assessing motor, communication, memory span, visual attention, reasoning and learning skills. This set of tools is composed of:

- The Corsi's test [13]; It measures the person's visual-spatial memory span; this will allow us to define the level of depth (sub-menu of the virtual interface) of the assistance system;
- The ComVoor tool [14]; It allows us to evaluate the perception and representation of stable mode of communication (objects, images, pictograms and written). For our design issue, the ComVoor tool makes it possible to define which form of communication is most suitable and at which level of meaning attribution the communication can be implemented;
- The ECP (Polyhandicap Cognitive Skills Rating Scale) [15]; It measures cognitive abilities (attentional, communicative, learning, reasoning and spatio-temporal) as well as social, emotional and autonomy abilities for people with multiple disabilities. For design purposes, the ECP scale makes it possible to define the complexity of the inter-

face (e.g. number of items per menu level, which mode of communication, etc.) according to the learning and reasoning abilities of the person with multiple disabilities. During the evaluation phase, the ECP will also aim to qualify the evolution of social and emotional skills during the appropriation phase of the assistive technologies;

- A clinical rating scale for the flexion-extension of long fingers using the Kapanji scale [16]; this scale gives recommendations for the choice of the interaction device according to the flexion and extension skills. This measurement is supplemented by an indication of the grip force estimated by an occupational therapist as well as recommendations (type of switch recommended, body parts allowing interaction, ergonomics of tablet setting on the wheelchair and so on).

A functional analysis grid completes these measures. This grid is an adaptation of the ABC (Immediate Antecedents, Behavior, and Consequent Context) behavior functional analysis grid [17]. It aims to describe the modalities of communication behavior, to understand the context, in which the participant's communication and/or interaction behavior appears, as well as its nature and modality, and then the responses provided by his ecosystem. Moreover, the grid allows the identification of daily activities and interests and will eventually allow the specification of the functionalities of the CECI (Environmental Control and Integrated Communication) high-fidelity prototype that will be designed with the SoKeyTo design platform [18]. The Fig. 3 illustrates how the clinical data are used to provide the design sheet.

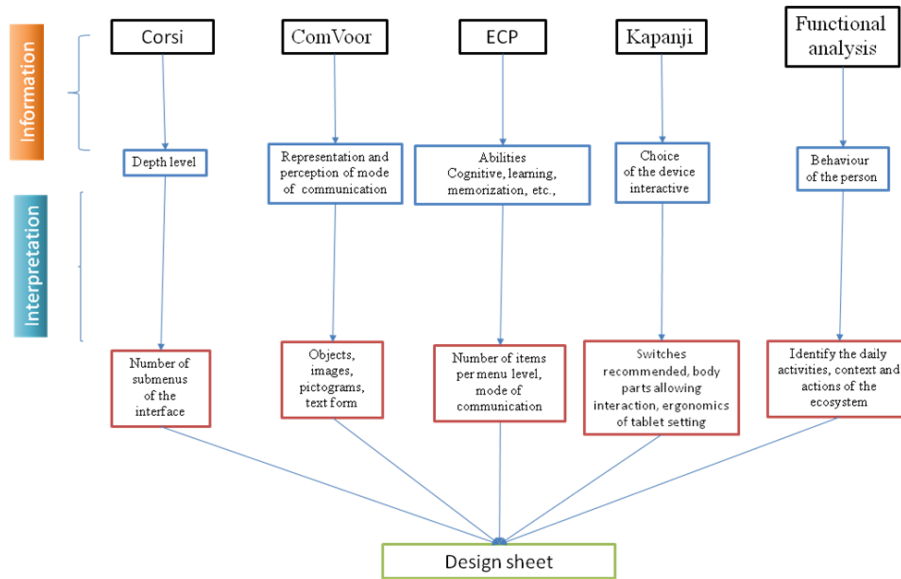


Fig. 3. Clinical data and their use in providing specifications.

3.2 Specifying the user' requirements

For the 9 study's participants, three focus groups were set up. Each of them determines the needs for 3 participants living respectively in 2 SCH and one IMS. The objective of these Focus Groups was to be able to interpret the information provided by the evaluation scales and translate them into needs and interface features. These Focus Groups consisted of a psychologist, an occupational therapist, two Master 1 students (psychology and Human Computer Interaction) and three senior HCI researchers. The medico-social staff previously interpreted the scale information to present their functional recommendations and the HCI researchers proposed interaction specifications (interaction modes, interaction techniques, user feedback, interface layout, etc.). Arbitration was made on the proposals between the two fields of expertise in order to arrive at a needs sheet for the specification of assistive technologies that is best suited to the needs and abilities of the person with multiple disabilities.

3.3 Prototyping of OUPSCECI virtual interfaces

From the requirements sheet established, high-fidelity prototypes have been made using the SoKeyTo platform [18], which allows to define the features of the virtual interfaces. These are the size, shape, icon returns and interaction techniques, the number of items and the number of levels in the interface. The versions of the first and second level of the virtual interfaces are submitted to the occupational therapist for testing and feedback to the design team until approval. A videoconference between the psychologist and occupational therapist and the three HCI designers takes place every two weeks. The various design specifications are arbitrated during these progresses of the discussion. The HCI and designers and the medical-social team meet in focus groups on request within the establishments. We propose to illustrate the steps of the UCD of participant P1.

3.4 Prototyping of the control box of interaction devices

The diversity of people with motor disabilities means that they need access to a computer with several types of devices. In relation to this diversity and the results of the assessment scales, occupational therapists were asked to have the option of using either a joystick, touch and/or ON/OFF switches for validation. Based on this, we developed a prototype circuit board (see Fig. 4) in order to be able to connect these three types of interaction devices. The interest of this control box is to allow the occupational therapist to refine these device choices and their settings for the person with a disability. That is to say, to be able to test other interaction devices and to configure them by means of software. This device is composed of a Teensy 3.2¹ micro-controller because it implements touch input pins that allows touch interaction for people with little strength.

¹ <https://www.prjc.com/teensy>

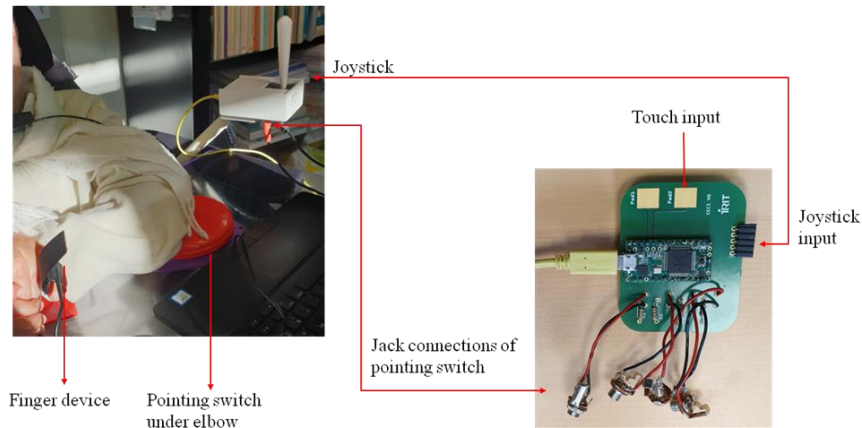


Fig. 4. Control device system architecture.

On this microcontroller we have connected a joystick and four jack type connections. These allow up to four switches to be connected. This option makes it possible to connect a maximum of four contactors depending on the residual movements of the person (palm of the hand, finger, head movement, etc.). Our device has been developed with the open-source Arduino language.

4 P1 CASE STUDY

4.1 Profile of P1

P1 is an adult person with cerebral palsy, without written and oral expression. P1 uses a foot control device, with five switches, to control his electric wheelchair (see Fig. 5). He has athetotic movements in his upper limbs but there are fewer of them at foot level. The movements that P1 can control are:

- On the right with switch above the buttons of movement of the wheelchair: 30 press of the button per minute;
- On the left with switch on the footrest on the left of his left foot: press of the button per minute.

Currently, he communicates using a paper's notebook, designed by the medico-social staff of his place of live. It is used with a third person who slides his finger over the various pictograms in the communication notebook to help him express his needs. The choice of the pictogram is validated by the nodding of your head. These pictograms are listed according to eleven categories: feelings, body, grooming, clothing, family, questions, activities, objects, colors, SCH personnel and life events.

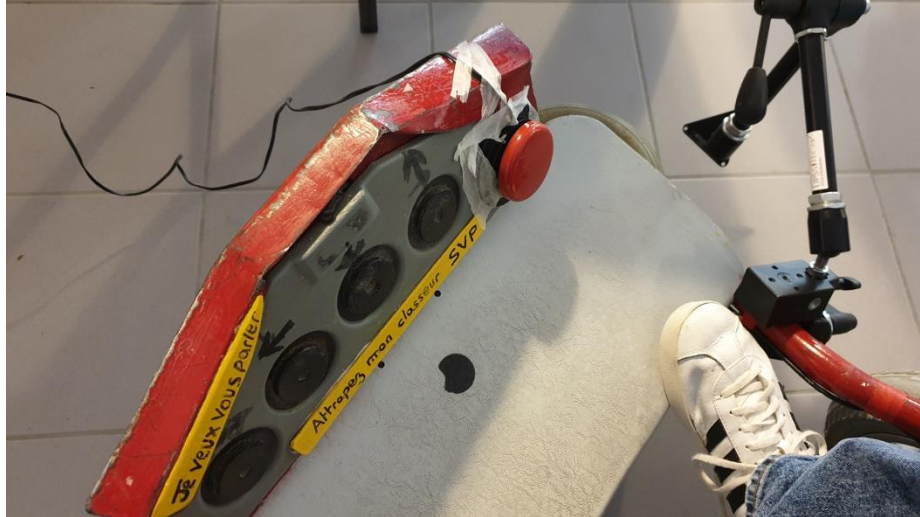


Fig. 5. Control device for the P1 chair and the OUPSCECI interface. The four grey buttons are used to control the wheelchair and the two yellow markers for "*I want to talk to you*" and "*Please grab my communication notebook*". The last red ON/OFF switch on the right end will be used for the virtual OUPSCECI interface of P1.

4.2 Needs Sheet

The request of P1's ecosystem is that his paper's communication notebook should be integrated into the digital interface, in which there will also be a home automation part (music management, television control, access to his calendar), functionalities identified in the functional analysis grid.




Table 2. Specification sheet.

Scales	Interaction components	Features	Choice made
Kapanji	Device	Control device	Foot pedals
		Physical selection 1 to 1	Yes
Kapanji, functional analysis	Interaction techniques	Scanning strategies	Yes, Read direction
		Pointing technique (finger, stylus, mouse)	No, none
		Validation principle	Yes, button push
ComVor, Corsi, ECP, eye tracking	Visual representation	Layout	Line/column (affordance of the paper communication notebook)
		Item number	6 or 9 per screen

ComVor, ECP	Feedback	Icon Shape	Rectangular with Highlighting edge
		Icon size	5 cm x5 cm
		Color preference	Primary
		Object characterization capability	Yes
		Maximum number of levels	5
		Visual	Ye
		Textual	No, no mastery of language
Functional Analysis, eye tracking	Device setting	Sound	Yes
		Multimodal	Yes
		Tablet under windowxs	Anywhere, preferentially in the visual field, at a distance

Table 2 illustrates how the information from the various clinical scales impacts the specifications for prototyping. For example, the ComVoor tool informs us about the categorization capacity and the ECP about its learning capacity: this translates into the fact that a given screen will be composed of a maximum of twelve pictograms relating to a topic and seven navigation pictograms in the OUPSCECI virtual interface (see Fig. 6, Fig. 7). Similarly, the value of the Corsi test indicates that we should not go beyond five screen pages (submenus), but this should be confirmed during the interface appropriation phase for P1. The ComVor and Corsi tests advocate highlighting the contours of the pictograms (of the line, column or only pictogram of the line, column) in order to distinguish them from the others. On the other hand, validation tests carried out by the occupational therapist have shown that it is preferable to validate the selection when releasing the switch.

4.3 High-fidelity prototypes

We have designed two versions of the high-fidelity prototype (V0 and V1) of OUPSCECI's virtual interface with the platform SoKeyTo. The first prototype was composed of only three rows and three columns (See Fig. 6, as illustration) for each interface level. The selected pictograms were those of its paper's communication notebook. The last line was made up of navigation pictograms (previous , next , and return to topic selection ). The scanning strategy was a line/column scanning strategy with a scanning speed of 3,5 seconds. Validation was effective when the button was pressed with the right foot of P1. However, the choice of the foot

to be used for navigation and pictogram selection is not yet defined. This choice will require pressure and release tests in real situations during the appropriation phases of OUPSCECI. Table 3 reports advantages and disadvantages depending on the pressure foot after preliminary trials carried out by the occupational therapist. In addition, tests to determine the foot for which movements are best controlled should also be carried out in real conditions. The first trials conducted by the occupational therapist led to discussions and modifications to take into account his cognitive and motor abilities in next versions of the OUPSCECI virtual interface.

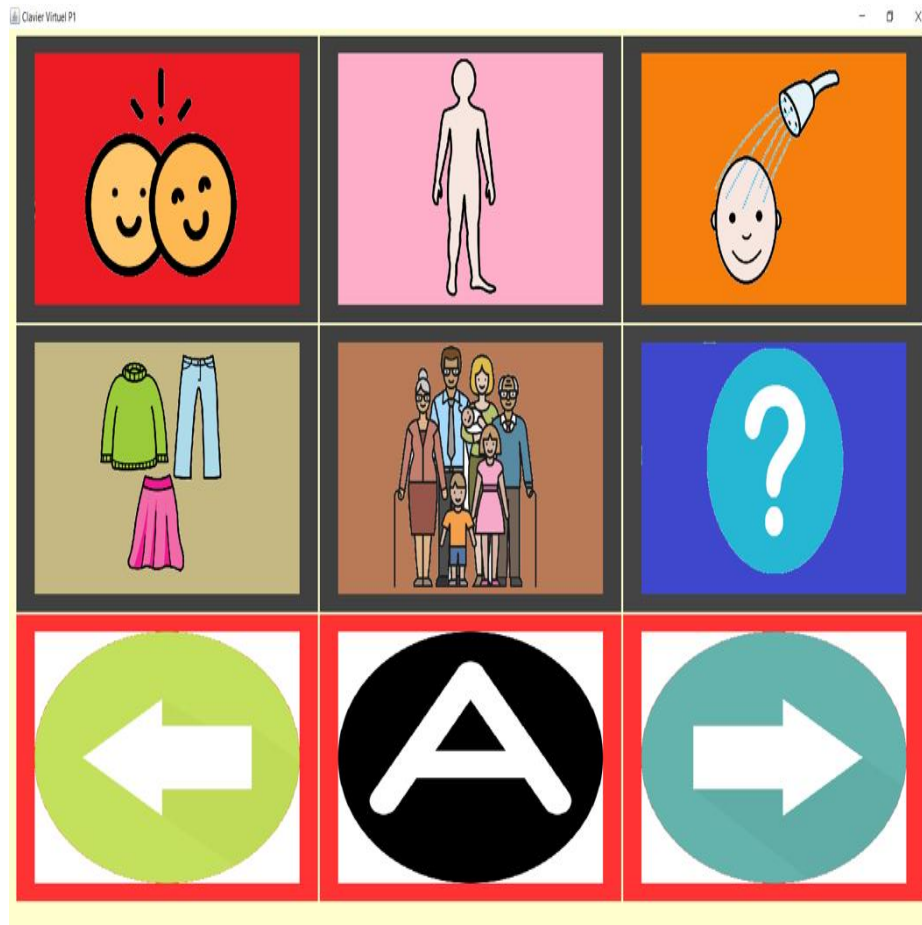
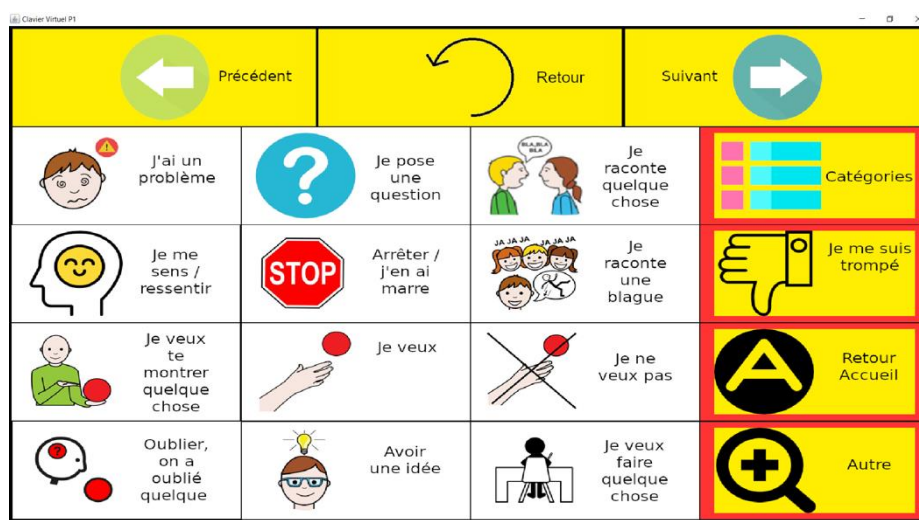


Fig. 6. Example of the OUPSCECI virtual interface of P1 (version 0).

Table 4. Advantages and disadvantages depending on the pressure foot.

Switch on the left foot	Switch on the right foot
Advantages <ul style="list-style-type: none"> - Better control in movement repetition - Fewer unrestrained movements Disadvantages <ul style="list-style-type: none"> - Limit the positioning by the wheelchair's switches - Risk of two presses of the button (wheelchair switch and OUPSCECI application switch) 	Advantages <ul style="list-style-type: none"> - More possibilities for positioning the switch. - P1 prefers the right side because he feels more precise. Disadvantages <ul style="list-style-type: none"> - Less control in the repetition of movements. - More unrestrained movements

**Fig. 7.** Example of the OUPSCECI virtual interface of P1 (version 1).




















In version 1, the interface displayed currently consists of three blocks:

- 1st line (in yellow), navigation pictograms (previous: return to the previous interface of the same pictogram topic; next: move to the next interface of the same topic and back: return to the screen of the 11 pictogram categories;
- 4th column (in yellow), pictogram of choice of the communication theme; pictogram signifying a choice error; return to the first level of the interface with a choice between three pictograms ("I want to talk to you" which is intended to indicate to the interlocutor that P1 wants to talk; "communication" pictograms" and "home automation" pictogram).
- The central block composed of 4 lines / 3 columns is made up of communication pictograms. Table 5 gives the meaning of the pictograms. To facilitate communication between P1 and her caregivers (family and professional) a textual description was added. The navigation pictograms have been moved to the first line for easier access (time saving).

Real-world trials will be required to define whether pressure or release is used as a validation technique to select a pictogram. The muscles involved in each movement (pressure or release) are not the same, so each action does not mobilize the same muscles:

- Validation by release essentially involves the levator muscles of the foot;
- Validation by support requires the mobilization of several muscles and more coordination.

Table 5. Pictograms and signification.

	Previous		I'm felling
	Back		I m tired something
	Next		I'm telling a joke.
	Topics		I want to show something
	I was mistaken		I want
	Home		I don't want
	Others		To forget, to have forgotten something
	I have a problem		Have an idea
	I'm asking a question		I want to show something
	I'm telling something		

These three blocks were chosen because they allow the pictograms to be categorized (navigation, central communication or environment control block, change of topic or mention of an error). This layout has been retained because P1 has characterization capabilities under development. Ongoing tests carried out by the occupational therapist show that the representation of the interface is suitable even if the number of items is greater than initially envisaged by the ECP scale (from 9 to 12 for the central block).

A feedback (red, primary color suggested by ComVor scale) mentions that the pictogram block or the current pictogram depending on the scanning strategy chosen for P1. The text description of the pictogram by means of text-to-speech can be activated. Several scanning strategies (block by block, or row/column) and several selection

modes (row by row and then block by block or block by block) are being evaluated. All these configurations can be modified in the profile file of P1.

5 DISCUSSION/CONCLUSION

Designing assistive technologies for the benefit of a population of multi-disabled users living in institutions involves the implementation of a UCD. Our approach is to integrate clinical data in addition to the needs. Considering the lack of oral or written language, our approach integrates needs expressed by the ecosystem and when possible by end-users himself or herself. The case study presented here has allowed us, through a concrete case, to validate the relevance of this approach and to better understand the contribution of clinical data in the two design phases (*understand and specify the context of use* and *prototyping* phases). These clinical data will also be used by occupational therapists to adapt the assistive technology to daily life. They will be supplemented by data from the log analysis of the use of the technical aid and ecosystem interviews. The real contribution of these data sources will be measured during the phase of appropriation of the assistive technology and its adaptation to the requirements of the person with a disability. Moreover, each participant in our study, depending on his or her degree of autonomy and the evolution of his or her pathological profile, will have specific needs that are likely to evolve over time. This is why, when scaling up (all nine residents), in addition to using clinical data to express needs, we also wish to adopt an agile approach [19] in the development of these technical aids. The next step will be to validate the contribution of clinical data in the design stage by analyzing the phases of appropriation of the technical aids and to write recommendations for the design and configuration for occupational therapists and psychologists.

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