MEDINFO 2023 — The Future Is Accessible J. Bichel-Findlay et al. (Eds.) © 2024 International Medical Informatics Association (IMIA) and IOS Press. This article is published online with Open Access by IOS Press and distributed under the terms of the Creative Commons Attribution Non-Commercial License 4.0 (CC BY-NC 4.0). doi:10.3233/SHTI231152

# Teaching Module to Train Students in the Participatory Design of Digital Technologies for Disability Assistance

Adrien UGON<sup>a;b,1</sup>, Corinne ISNARD BAGNIS<sup>c</sup> and Sylvia PELAYO<sup>d</sup>

<sup>a</sup>Laboratoire d'Informatique de Paris 6, CNRS, Sorbonne Université, Paris, France. <sup>b</sup>ESIEE-Paris, Gustave Eiffel University, Marne-la-Vallée, France

<sup>c</sup>Nephrology Department, Groupe Hospitalier Pitié-Salpêtrière, APHP Sorbonne University, Paris, France

<sup>d</sup> Univ. Lille, CHU Lille, ULR 2694 - METRICS, Health Technology Assessment and Medical Practices, F-59000, Lille, France; Inserm, CIC-IT 1403, F-59000, Lille, France.

ORCiD ID: Adrien Ugon <u>https://orcid.org/0000-0001-8258-5759</u>, Corinne Isnard Bagnis <u>https://orcid.org/0000-0002-1048-6636</u>, Sylvia Pelayo <u>https://orcid.org/0000-0002-0002-1048-6636</u>, Sylvia Pelayo <u>https://orcid.org/0000-0002-0002-0003-2830-2548</u>

**Abstract.** Teaching the principles of participatory design to students mainly interested in digital skills is important because user-centered approaches have become essential in the field of new technologies when we want to guarantee that a product will meet the needs of its end-users. Working with technologies dedicated to the disability assistance was considered to be the right application domain. In 2021, ESIEE Paris, a school training students to become engineers with digital skills, created and opened a new teaching module to learn how to follow the principles of participatory design to improve the quality of a project. This paper describes the organization and the conclusions of this experience after two editions of the module.

Keywords. Disabled Persons, participatory design, teaching

## 1. Introduction

ESIEE Paris is a school in France that trains students to become engineers specialized in digital technologies, some of them being specialized in digital health. A typical curriculum is composed of scientific and technical, theoretical and practical courses, management and human sciences courses to learn how to manage projects or teams, and English courses. The teaching modules are, unfortunately, mostly independent of each other.

Michael J. Muller and Sarah Kuhn defined, in 1993, "Participatory design [to be] a democratic process for design (social and technological) of systems involving human work, based on the argument that users should be involved in designs they will be using, and that all stakeholders, including and especially users, have equal input into interaction design" [1]. In all fields of application, the design of digital technologies in

<sup>&</sup>lt;sup>1</sup> Corresponding Author: Adrien UGON, Health, Energy, Environment department – ESIEE Paris - 2 boulevard Blaise Pascal - BP 99 93162 Noisy-le-Grand CEDEX • FRANCE / email: <u>adrien.ugon@esiee.fr</u>.

an industrial environment, and research, is now based on this type of approach, the only one that guarantees that the technological product meets the needs of the end-users.

Recently, discovering innovative ways to teach, especially in the health field, has gained importance [2]. Several approaches have been conducted to teach co-creation principles to university students [3,4]. Working on team projects appears to be the best way to implement the co-conception principles.

In addition to purely scientific and technical courses, the need to train students in participatory design methodologies has thus emerged. Indeed, following the principles of participatory design by working on a team project, by keeping the scientific and technical quality, was considered to be the right way to work on it.

The field of disability was considered an excellent area of application because it is both known, but very unfamiliar to most of the students. People with disabilities have their own needs, their own constraints, and their own preferences, which are often ignored by able-bodied people. In order to work on a new technology that addresses a disability-related issue, it is absolutely essential to meet and interview people with disabilities and to work with them throughout the whole design process. Following the principles of participatory design for the conception of tools for disabled people has proven to be efficient in several projects [5-7].

This article aims to present the course on participatory design of digital technologies dedicated to disability situations, as it has been held at ESIEE Paris since September 2021, and to make an assessment after 2 editions. Section 2 will describe the organization of the module in different sessions; section 3 will provide some examples of the work done by the students. Strengths and weaknesses will be discussed in section 4. Finally we will conclude.

# 2. Methods

The module about the participatory design of digital technologies for disability assistance was created and opened for the beginning of the schoolyear 2021. This module was selected by student choice from a list. It could be followed by up to 26 students. It lasts for 30 hours and can be composed of lectures, tutorials, practical work, project or any other teaching activity.

#### 2.1. 2021-2022 Schoolyear

The first edition of the module was organized in 9 sessions.

The first session was a one-hour introduction to the process, objectives and speakers of the module. A list of disability-oriented digital projects was presented corresponding to 2 types of diseases: renal disease and neurodegenerative diseases, especially Parkinson disease. Students were asked to get together in groups of three persons and choose one of the proposed subjects. The objective of the work to be carried out was to present the user-centered design methodology followed to meet a need through a given technology.

In the second session, an expert in user-centered approaches presented some projects that failed when they were brought to market, because they were designed without following the co-design principles. The objective of this session was for students to realize that it is not enough for a product to be very good scientifically and technically to satisfy users. In the third session, a nephrologist explained how the patient-physician relationship has evolved over the last few centuries and even more so in the last few decades. Now, the patient is at the heart of a care pathway, involved in the decision, he/she benefits from therapeutic education sessions.

In the fourth session, alumni who now manage teams with hundreds of health professionals came to share his experience, accompanied by two physicians. The objective of this session was to explain to the students that it is not so simple to discuss a project when you have different cultures and professions. After that, all students had to present their work in a 3-minute oral presentation to make sure that they had started the right way. The objective of this oral presentation was to correct students who would have started on their own assumptions without working with patients partners.

During the fifth session, students were taught about nephrology and dialysis, for them who had chosen a project about renal disease. Then students were taught about methods to use to follow the co-conception principles. Examples of successful projects were provided.

Then, in the sixth session, a professor of physical medicine and rehabilitation, head of his department in a big hospital in Paris, gave a lecture on the history of disability and on his medical specialty.

In the seventh session, students could listen to the testimony of two patients suffering from a chronic renal disease, one of them being at the hospital at the time of intervention.

In the eighth session, a patient being diagnosed of the Parkinson disease for four years testified to his story; another patient, suffering from a rare disease and having been in diagnostic errancy for decades has explained how she believes in artificial intelligence to collect real-life data and making possible the diagnosis of future generations.

In the final session, students had to present orally their work in a 5-minute oral presentation. During this presentation, the students had to convince a jury composed of patients, doctors, ergonomists and engineers that their technological solution followed the principles of participatory construction and allowed everyone to be satisfied by the solution presented. Each member of the jury had to put 2 grades: the first grade evaluated the respect for each project, of the participatory design principles; the second grade was more subjective and evaluated the personal satisfaction with the product presented. The solution had to satisfy the patients, the physicians, but also had to be scientifically and technically robust and convincing.

In total, during the first edition, the students had the opportunity to discuss with 11 speakers, and get from each of them information that could be support for the design of their product.

At the end of the first edition of the module, a debriefing meeting was organized. The session was considered to be a success, but there were some improvements to be done:

- Even if the testimonies were very interesting, they did not facilitate the exchange between students and patients/physicians. This was enhanced by the fact that students felt ashamed and illegitimate to ask questions.
- The focus on renal disease was too restrictive for students who were mostly interested in digital applications.
- It was necessary to provoke exchanges between students and stakeholders

# 2.2. 2022-2023 Schoolyear

On the basis of the conclusions of the first edition, the organization of the second edition, at the beginning of 2022-2023 schoolyear was modified and followed the following steps.

- The first half of the module was essentially the same as the organization of the first edition.
- The first session was still an introduction with a presentation of projects.
- The second session was dedicated to the presentation of projects having failed when brought to market.
- The third session was about the evolution of the patient/physician relationships, but was led by both a nephrologist and a patient suffering from a chronic renal disease.
- In the fourth session, methods and successful examples about the userscentered approaches were provided. This lecture was followed by the midterm oral presentation, to make sure of the relevance of their work at the early stages of the project.
- The next sessions were different.

The fifth session started with a group work on disability. By groups, students had to search for information on different issues faced by people with disability. After that, the professor of physical medicine and rehabilitation, head of his department in a big hospital in Paris, gave a lecture on the history of disability and on his medical specialty.

The main difference with the first year was the organization of the 3 next sessions (sessions 6, 7 and 8), during which panels were organized. Each of the three sessions was organized the following way: it started by two 45-minute panels, led by students, who had to prepare the questions. In each panel, patients, physician, ergonomists and sometimes engineers answered the questions. With these panels, we reached the objective of provoking an exchange between students and patients. At the end of the panels, the students had one hour to ask questions to the participants of the panel, and also to other scientific experts, to get information and make sure of the quality of their product.

In total, the students had the opportunity to discuss with 23 speakers, and make each of them a stakeholder of their product.

# 3. Results

In the first year, twelve projects were presented by students; ten projects were realized in the second year. Most of them were evaluated as very good or excellent by the jury. One of them was about the use of virtual reality for the relief of phantom limb pain. A first version used a bicycle. The idea was given up after that amputees explain that cycling requires an expensive prosthesis that recent amputees affected by phantom limb pain have not yet acquired. Students changed so that the amputee can evolve in a calm and reassuring environment, cool, allowing forgetting the pain of the phantom limb. Figure 1 illustrates the virtual reality environment designed by the students. This project was awarded in two different competitions.



Figure 1. Screenshot of the "virtual reality" world designed by the students.

# 4. Discussion

The teaching module is very promising. It will continue to evolve in the years to come. There are still some issues to be addressed for students to work on a team project, relying on the principles of participatory design, with a high scientific and technical quality. 30 hours is a very short time to achieve the expectations. Moreover, some essential issues should be addressed in the project to be more realistic: the security of the data and the ethics issues should be considered; a market study should be added, One more challenge is to have in mind that all students do not have the same interest and knowledge in the health field, and to provide to each of them the adequate content.

### 5. Conclusions

From the point of view of both students and teachers, this module is a real success. The students manage to provide a quality project that meets the expectations. They are very grateful to have the opportunity to work with physicians, disabled people, and other experts on a same project. The lessons learnt in this module are used in next teaching modules.

## References

- Muller MJ, Kuhn S. Participatory design. Commun. ACM; 1993 Jun;36(6):24-8, doi: 10.1145/153571.255960.
- [2] Sivarajah RT, Curci NE, Johnson EM, Lam DL, Lee JT, Richardson ML. A Review of Innovative Teaching Methods. Acad Radiol. 2019 Jan;26(1):101-13, doi: 10.1016/j.acra.2018.03.025.
- [3] Konstantinidis EI, Petsani D, Bamidis PD. Teaching university students co-creation and living lab methodologies through experiential learning activities and preparing them for RRI. J Health Inform. 2021 Feb;27(1): 1460458221991204, doi:10.1177/1460458221991204.
- [4] Høiseth, M, Forshaug A. Design students' take on co-design in health: reflections from learning and education perspectives. Proceedings of the Design Society. 2021 Aug;1:1083-92, doi:10.1017/pds.2021.108.
- [5] Konnerup U. Engaging People with Aphasia in Design of Rehabilitation Through Participatory Design: A Way to Learn what They Really Want. Stud Health Technol Inform. 2017 Jan;233:148-57, doi:10.3233/978-1-61499-740-5-148.
- [6] McNeilly P, Macdonald G, Kelly B. Rights Based, Participatory Interviews with Disabled Children and Young People: Practical and Methodological Considerations. Compr Child Adolesc Nurs. 2021 Apr;1-10, doi: 10.1080/24694193.2021.1874078.
- [7] Andrews EE, Powell RM, Ayers KB. Experiences of Breastfeeding among Disabled Women. Women's Health Issues. 2021 Jan;31(1):82-9, doi: 10.1016/j.whi.2020.09.001.