# Guidelines for Participatory Design with People Living with Mild Acquired Cognitive Impairments

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*Abstract* –Mild Acquired Cognitive Impairment(s) (MACI) are called invisible impairments. This invisibility of symptoms makes that researchers often overlook people with MACI. This is the case in the field of Participatory Design (PD). In this paper, we investigate how to involve people with MACI in designing together digital solutions meant for them. Hence, how to involve people with MACI in Participatory Design. Considering the lack of literature in PD focused on MACI patients, we conducted a borderer investigation of the literature and derived a set of guidelines proposed by PD practitioners for involving people with cognitive impairments in PD. We have collected data on conducting PD with MACI patients from two empirical cases as part of two projects in a rehabilitation hospital in Norway, which offers specialized rehabilitation to people with MACI. We conducted 5 PD workshops with three different workshop outlines. Seventeen people with MACI participated. We present a detailed list of reflections-on-action for each workshop outline. We discuss the reflections with findings from the literature and conclude with a list of guidelines that researchers and designers should consider when involving people with MACI in conducting PD. The paper aims to attract the attention of PD practitioners to the MACI user group with the possibility of expanding the guidelines list in the future.

*Keywords-Participatory Design; Mild Acquired Cognitive Impairments; Guidelines.*

## I. INTRODUCTION

There is an increase in chronic diseases in our aging society, and technology is considered as one of the means to cope with the increasing number of people living with chronic conditions. A notable case is individuals with Acquired Brain Injury (ABI) affecting cognitive capacities. For this user group, the use of technology has become a fundamental part of their daily lives by providing a wide range of useful services and tools to use at home, work, or anywhere else. This paper expands on previously reported results on how to involve people with ABI in designing new technologies that can facilitate their everyday life challenges [1]. Intensive research is ongoing regarding technologies that support patients with moderate or severe cognitive impairments (i.e., [2][3][4]). However, less attention had been paid to people suffering from mild cognitive impairments after an Acquired Brain Injury (ABI), even though mild acquired cognitive impairments are a critical global public health problem and listed among the major causes of permanent impairments [5][6]. In this paper, the abbreviation "mild acquired cognitive impairment(s)" (MACI), coined from Eghdam, Scholl, Bartfai, and Koch [7], will be used to refer to these

people. Note that this is not an official abbreviation for the clinical condition. MACIs are usually described as invisible impairments and might include problems with memory, attention, executive functioning, language, and fatigue. People suffering from MACIs typically have a very challenging daily life, given the invisible nature of the condition.

An essential factor for the design of new technologies that can assists MACI people is their involvement in the design of these solutions that will be used by them in the future. User participation constitutes the core of Participatory Design [8]. PD is that design approach that promotes the involvement in the design process of everyone that will be influenced by the newly designed technological solution. Thus, new technologies aiming to assist individuals who have had an ABI would, from a PD perspective, require people with MACIs to be involved in the design process. However, involving people that have cognition problems to envision future solutions or discuss abstract terms is challenging. PD researchers should consider how to promote involvement and participation. The research question we raise in this paper is *What should be taken into consideration when conducting Participatory Design with people with MACIs?*

PD has, in decades, been concerned with marginalized groups and research on how to involve people with dementia, aphasia, amnesia, cognitive impairments, elderly, etc. in the design of new solutions. While the case of people with MACI is different from these diseases, some symptoms are similar. Thus, a look into the existing literature and how other researchers have described guidelines for working with user groups similar to MACI is relevant for building preliminary knowledge. In this paper, we initially present a summary of guidelines for involving people with cognitive impairments in PD projects. The guidelines are from a systematic literature review conducted by the authors of this paper. The findings were cross-checked and refined with the findings of a literature review of conducting PD with people with dementia by Hendriks, Truyen, and Duval [9].

Further, we present two empirical cases of conducting PD with MACI people. We take a reflective practitioner analysis approach to derive a set of reflections for involving MACI people in PD. These reflections, which emerged from the empirical data from 5 workshops with a total of 17 MACI patients as participants, have been further cross-analyzed with the list of guidelines found from the literature. The cross-analysis is also influenced by the literature on MACI people, their symptoms, and advice for leaving with cognitive challenges from medical practices. We have concluded with a list of guidelines for conducting PD with MACI people.

We contribute by expanding the knowledge of conducting PD with a special user group like MACI people who represent a huge share of the society [6] and can benefit from technology to facilitate their daily life. Moreover, we contribute by bringing the attention of the PD researcher to this user group, which due to the "silent" characteristics of the disease, are usually forgotten or overlooked and left alone to fight a challenging daily life.

The next section gives a more detailed overview of the user group, the symptoms they have, and some suggestions from the medical perspective on how the MACI people can adapt their life to the cognitive challenges. This is followed by a section on what PD is and why it is relevant to conduct PD with MACI people. We present a detailed summary of guidelines deriving from previous research on conducting PD with people with cognition challenges as part of our background literature. Further, we describe our methods for collecting the data and analyzing it, followed by the empirical material from two projects done with MACI people. We describe three workshop outlines applied in 5 PD workshops in the two projects. A list of methodological reflections [10] follows each workshop outline. We further analyze and discuss the findings from the empirical cases with the data from the list of guidelines coming from the literature review. In conclusion, we present a set of guidelines for conducting PD with MACI people.

## II. MILD ACQUIRED COGNITIVE IMPAIRMENTS AND THE IMPLICATIONS IN A PERSON'S LIFE

In this section, we first describe what it means for a person to live with MACIs. Further, we define what cognitive rehabilitation is and how this service is offered in a rehabilitation hospital in Norway, where we conducted our research.

### A. What does it mean to live with Mild Cognitive Impairments (MCI) after Acquired Brain Injury (ABI)?

Cognition is the individual's capacity to acquire and use the information to adapt to environmental demands [11]. However, cognition can be challenged, and cognitive impairments can surface [12]. Cognitive impairments may be associated with cognitive decline due to aging, more-serious decline as dementia, or can be the consequence of an ABI. The latest is the category of patients involved in this study.

ABI is brain damage acquired after birth. The causes of ABI can be from non-traumatic brain injury (i.e., stroke, brain tumors) and traumatic brain injury (i.e., accidents, falls). It can affect cognitive, physical, emotional, social, or independent functioning. The consequences can vary from mild to severe [13]. We specifically focus on those people who have been affected in mildly their cognitive functioning. Eghdam, Scholl, Bartfai, and Koch [7] and Nilsson, Bartfai, and Löfgren [14] use the term Mild Acquired Cognitive Impairment(s) (MACI) "*to describe a subgroup of patients with mild cognitive impairment(s) (MCI) who are expected to reach a stable cognitive level over time. This patient group is generally young and have acquired MCI from a head injury*

*or mild stroke*" (ibid). As this is similar to the user group we are interested in this paper, we borrow their terminology.

Cognitive impairments often persist after the ABI, and they can significantly affect an individual's abilities to perform everyday tasks, fulfill previous roles, and maintain personal-social relationships [14][15][16][17]. Thus, people's life becomes challenging, based on the severity of their injury. These people can experience difficulties in cognitive and emotional processing while having no or limited movement disorders and being independent in self-care [14][18]. Cognitive impairments after a brain injury can cause the following problems to people:

- They can feel a lack of energy for doing many things within a specific time frame.
- They can face problems with memory, which can be related to working memory or long-term memory. This creates difficulties in remembering and learning new things.
- They can face problems to keep the attention and concentrate on a specific issue and be able to eliminate the other unimportant information around them.
- They can face a reduced tempo of performing activities and engaging only those activities that are relevant to them.
- They can face a reduced multitasking capacity. The person becomes very tired if s/he has to manage too many activities at the same time.
- They can face an increased response time due to a slower process of thinking.
- They can face difficulties to start or initiate something, sometimes caused but a lack of motivation.
- They can face challenges in making mental changes from one topic to another.
- They can face difficulties in stopping, which relates to impulsivity, overactivity, and difficulties in controlling unwanted or inappropriate responses.
- They can face a reduced understanding of oneself, which involves a reduced ability to perceive one's own mistakes, to take into account the impression one makes on others, or to assess a social situation accurately.
- They can face thinking specifically and taking everything literally. This can also be associated with a loss of the ability to plan, look ahead, and think purposefully.
- They can have difficulties with using language and communicating, such as not finding a word, repeating the self in a conversation, having difficulties in making a point in a conversation, mixing words, or having difficulties in understanding humor or irony.
- They can face difficulties in processing the information received, solving problems, and executive functioning.
- They can face changes in how they engage in social life and social communication.

(the list presented above is a translated summary from [19][20])

The list of cognitive challenges that can be faced by patients that have had an ABI and suffer cognitive impairments shows how heterogeneous this user group is. In MACI people, these symptoms are mild, and the person in most cases continues having an active life, working or participating in social activities, running a house, or following hobbies. However, their life is not the same [21].

The symptoms of MACI patients mentioned above have similarities with other user groups as dementia and amnesia when memory problems are present, aphasia when communication problems are present, executive functioning, memory, attention, reduced tempo, and slow reactions are elements that are also associated with getting old. Moreover, problems with problem-solving can be similar to other cognitive impairment that patients have had from birth.

In the following subsection, we will describe the case of cognitive rehabilitation as the setting on which we conducted our research. In this paper, we have used interchangeably different variations to refer to people living with MACIs, such as "people with MACIs, MACI people or MACI person". Instead, from now on, we will use "patient(s) with MACIs, or MACI patient(s)" to refer to people with MACIs who are patients in a rehabilitation institution, which is the setting of our study. Moreover, in some cases, we will use the term patient(s) even when referring to the home context because people with MACI have a chronic disease, which makes them chronic patients in a rehabilitation context. When we describe our case, present the findings, and discuss them, we use the term "patients" as it better represents our participants. Instead, when we present the final guidelines, we refer to MACI people in general in any setting where they can be involved in designing new technologies useful to them.

### B. MACI Treatment – Cognitive Rehabilitation

"*Cognitive rehabilitation can be defined as a learning experience aimed at either restoring impaired higher cerebral functioning or improving performance in the real-world using substitution or compensation techniques*" [16]. Cognitive rehabilitation is offered in specialized rehabilitation institutions. The cases presented in this paper are related to two projects that we did in collaboration with the Department of Cognitive Rehabilitation (DCR) of Sunnaas rehabilitation hospital in Norway.

Sunnaas offers multidisciplinary rehabilitation to people with complex functional impairments following illness or injury. We focused only on the cognitive rehabilitation process. The rehabilitation at the hospital (inpatient) is carried forward by a multidisciplinary team that helps the patient to define realistic and attainable rehabilitation goals and then define, in collaboration with the patient, a set of interventions that the patient should do for achieving the goals. The goals and respective interventions make a rehabilitation plan. The rehabilitation plan is imprinted in the "Goal-Plan" document. This Goal-plan is at the core of the rehabilitation process in the hospital. It helps to coordinate the activities that both the patient and the multidisciplinary team get involved in during the patient's hospitalization period. In every activity at the hospital, both the multidisciplinary team and the patient should refer to the Goal-Plan. For the team, the Goal-Plan resides in the hospital Electronic Medical Record system. Instead, for the patient, the Goal-Plan is a printed paper document. The patient continues with the rehabilitation plan at home and returns to the hospital after 2-6 months for short follow-up and further adjustments of rehabilitation goals. A more detailed description has been presented in Becker, Kirmess, Tornås, and Løvstad [22].

As part of the rehabilitation plan, different kinds of rehabilitation therapies, customized to each patient's needs, are applied. Some suggestions of rehabilitation techniques for working with patients that have had an ABI retrieved from the literature are:

- When communicating with an MACI patient, it is important to give her/him time, use short and concrete sentences, be clear, and try to receive confirmation that s/he understood what was said. Moreover, it is relevant to pay attention to how the patient feels that day.

- In order to increase understanding, remembrance, and better communication with MACI patients, repetition is necessary.

- Giving patients more time to do things or discuss is another strategy suggested. Moreover, considering the low capacity and high level of fatigue, pauses are recommended [19][20].

- In order to improve executive functioning Haskins, Cicerone, and Trexler [23] highlight the Goal-Plan-Do-Review (GPDR) model as helpful. GPDR requires the patients to increase awareness toward a specific goal that they want to achieve, plan carefully on how to achieve this goal, do the activity, and evaluate that after.

- In order to improve memory deficiencies, Haskins, Cicerone, and Trexler [23] describe different techniques which are in analogy with a "divide and conquer" approach where a bigger task is divided into smaller steps, and these steps are used to train by repetition. Considering that memory is fragile, an errorless approach in the rehabilitation techniques is used [18]. This aims to teach the patients only the right things so s/he might not risk preserving the error instead of the right information. Visual cues are also considered useful in helping to train memory deficits [24]. Cicerone et al. [25] suggest using references from patients' daily life because it is easier and more likely to remember the information when it is silent and personally meaningful.

The techniques mentioned above were both presented as in individual therapy sessions or group therapies. Patients with MACIs can find group therapies specifically helpful when it comes to discussing their problems and expressing more about their story in front of other patients with similar challenges. Now that an overview of the patient group symptoms and the rehabilitation process which s/he goes through has been presented, we further describe PD and how that might be relevant for this user group.

### III.     PARTICIPATORY DESIGN

PD was established at the end of the 1970s to democratize both the working life and the design process of new information technologies [26]. PD emphasizes the idea that

those who will be affected by the design of new information technologies or digital artifacts, should get involved and have a say during the design process of these technologies [27]. PD considers users "domain experts" of the realities in which they live, so they must undertake the role of the designers [27].

In Routledge Handbook of Participatory Design, Simonsen, and Robertson [8] define PD as:

"*a process of investigating, understanding, reflecting upon, establishing, developing and supporting mutual learning participants in collective "reflection-in-action". The participants typically undertake the two principal roles of users and designers where the designer strives to learn the realities of users' situation while the users strive to articulate their desired aims and learn appropriate technological means to obtain them.*"

At the core of PD is the idea of genuine participation in decision making. Genuine participation stands on a political rationale where the voice of marginalized groups is heard in the decision making that will influence them. Thus, designing technologies for patients with MACIs require their participation in the design process. Their marginalized voices in a paternalistic healthcare system where the patient follows what the doctors say should be raised and heard. By applying PD, these patients can have a say and genuinely participate in the design of new technologies, which will be used by them.

Moreover, as we describe above, MACI is a silent condition and often overlooked. This makes this group marginalized for the technologies that have paid more attention to more severe cases. We use the general term "technology(s)" because, in every technology type, digital solutions, tangible solution, ICTs (Information and Communication Technologies), etc. people that will be influenced by the new technology should be involved in its design. Moreover, different technologies can help MACI patients in different situations. For example, a tangible alarm button can be used in the case of a fall. Instead, an application can be designed to serve as a calendar.

PD is applied as a set of general principles that should be adapted to the specifics of the project. One of the principles of PD is "equalizing power relations". Thus, PD is concerned with questions such as "whom we may risk leaving out of the design space, how we can act upon such challenges and how to provide for alternative perspectives on participation and democratization" [28], and finding ways to give voice to those who may be invisible or weaker in organizational power structures [29] and beyond, thus building a democratic process.

Greenbaum and Kensing [29] point out that democracy is often propagated as a concept that is assumed to happen by itself. However, it requires educated and engaged people acting on their own interests and in the interests of the common good. Another principle of PD is mutual learning, where both designers and users should learn from each other

in the design process. Learning also is cognitively demanding. Thus, the requirement for active participation and mutual learning poses a requirement for people to have a certain level of cognition. The number of people who live with cognitive impairments is high. To have a truly democratic process, we should not risk leaving this user group out of the design process.

Greenbaum and Kensing [29, pp. 33-34] have listed tools and techniques among the principles in PD. Different tools and techniques are used by designers and researchers to involve users in the design process. The designer should reflect which tools and techniques fit her/his user group and then adapt them with the practice at hand [30]. Choosing the right techniques and tools is as relevant as challenging when the focus group of the research is people who suffer cognitive impairments. A technique's goals, structure, and participation model can pose cognitive requirements to the participants. Some aspects of these requirements are fundamental to the activity (for example, a group discussion must involve communication), while other aspects are flexible (communication can be verbal, gestural, etc.). This flexibility can suggest ways in which a technique may be modified or adapted to people's cognitive abilities. However, what tools and techniques are chosen in a PD project would influence the true level of participation of the users in the design process [29].

### A. Participatory Design with people with ABI

In PD, the active participation of people with disabilities in designing new technologies has been discussed significantly in conferences and workshops. Dementia patients or specific severe clinical conditions affecting cognition have been in the focus of many publications (examples [31][32][33][34]). Regarding the mild cognitive impairments, extensive research has been done with old adults or people with intellectual disabilities. However, little research has been conducted specifically on patients suffering from MACI [1] [35].

Augstein, Neumayr, Ruckser-Scherb, and Dielacher [36] have designed an interactive tabletop in the rehabilitation setting of people after an ABI by using a PD approach. However, they have involved in the design rehabilitation specialist as proxies of people that have had an ABI.

More research has been conducted with people that had a stroke. Balaam et al. [37] and Threatt et al. [38] have described some cases of involvement of stroke patients in the design process. However, this involvement is mostly in terms of interviews and observations and further during testing. The design is handled either by the designers or designers and clinicians together. The involvement of clinicians in design is as well described in Faria and Sergi Bermúdez [39]. Instead, Magnusson et al. [40] describe a case where stroke patients are involved in focus groups and as well in co-design workshops were brainstorming, and body-storming techniques are used.

Table 1. List of guidelines for conducting PD with people with cognitive impairments

| No. | Guidelines | Reference |
|---|---|---|
| DG_PP1 | Get the consent of the participant on various moments throughout the research process | [9] |
| DG_PP2 | Communicate about project goals without intermediaries | [9] |
| DG_PP3 | Give yourself enough time for general practicalities | [9] |
| DG_PP4 | Get to know your target group, try to understand their cognitive deficit and become sensitive to their needs and situation | [9][41][42] |
| DG_PP5 | Assess abilities through standardized tests | [4][9][43] |
| DG_PP6 | Recruit and plan well in advance | [44] |
| DG_T1 | Involve users in design in appropriate and familiar environments<br>• The location should hold an appropriate social status<br>• The choice of location should take into account the deficits of the participants and ensure easy access to the meeting room<br>• Using the person's home might help to make the participant feel at ease | [9][45][46][47] |
| DG_T2 | Adapt the language to participants | [2][9][41][44][48][49] |
| DG_T3 | As the verbal might be a problem, make use of non-verbal elements such as visual stimuli like photos of objects or physical artifacts (notes, etc.) | [9][50][51][52][53][54] |
| DG_T4 | Use distinctive contextual cues (like nametags) | [4] |
| DG_T5 | Consider the fidelity of the tools used to design<br>• Consider using physical artifacts | [4] |
| DG_M1 | Consider activities that facilitate challenges in envisioning future solutions<br>• Boost sharing personal experiences [9][41][44][46][55][56]<br>• Support the building of IT literacy [57]<br>• Provide more hands-on activities and collective prototyping [55][58][59]<br>• Use visual cues [41][42][55][59]<br>• Make use of fictional characters in different scenarios [60]<br>• Try to avoid appealing to the person fantasy; avoid too much choice [9] | [2][9][42][44][48][54] |
| DG_M2 | Consider activities that facilitate challenges with abstract concepts<br>• Explain technological concepts in an easy-to-understand way [41]<br>• Consider the fear of sketching [61] abstract ideas<br>• Let the designer do the sketches if needed as a start for discussion [62] | [41][50] [59] |
| DG_M3 | Involve people in designing valuable solutions, real purpose, interesting | [9][44][63] |
| DG_M4 | Plan activities to surpass challenges in continuity<br>• Using a document design history or summary documents of each session | [41][43][51][64] |
| DG_M5 | Use previously known activities and natural tasks | [9][55][59] |
| DG_M6 | For each activity create a relatively open artifact and brief | [48] |
| DG_M7 | Provide alternative activities so to engage all participants<br>• Adapt methods so that it will take into account the difficulties in the comprehension and production of language, both verbal and textual<br>• Adapt methods so that it can overcome impairments of memory<br>• Facilitate participants to stay on track based on their individual needs | [9][48][50][65][66] |

| No. | Guidelines | Reference |
|---|---|---|
| | • If working in a group, modify the method considering the different impairments each member of the group is facing<br>• Consider the possibility of organizing individual participatory design sessions<br>• Consider personalization and individuality for each patient | |
| DG_M8 | Consider activities that can be flexible and empathic to adapt to the needs of the group:<br>• Activities that can help create a friendly environment [44][46][67]<br>• Activities that can boost participants self-esteem and confidence [52][68]<br>• Activities that can include elements of playfulness [42][52][55] | [9][42][49][50][54] |
| DG_F1 | Researchers should clearly explain the purpose of events and the role of the participants | [9] |
| DG_F2 | To enclose personal info from the facilitators will boost participants confidence and make it easier to share things | [9][69] |
| DG_F3 | Incorporate Structure and Review in activities<br>• It is important to foresee enough time for participants to get to know each other, repetition and constant reviewing of the different research/design phases | [2][9][43][46][54][59] |
| DG_F4 | During a participatory design session, try to minimize distraction and keep participants on focus | [9] |
| DG_P1 | Consider a one to one or group work in a PD session<br>• Try to overcome the challenge of working in groups [70]<br>• Try to diminish the risk of the designer strong position [45]<br>• Try to overcome deficits by pairing persons with different deficits into one subgroup [9] | [9][54][71] |
| DG_P2 | Carefully decide the session duration and number of participants<br>• In people with dementia [9] suggests working in small groups | [2][9][46][52] |
| DG_P3 | Involve caregivers as support in conversation with participants<br>• Third-party involvement [56][59] | [2][9][41][51][59] |
| DG_P4 | Involve caregivers as domain experts in the design process | [41][51] [72] |
| DG_P5 | Eliminate usability problems with the carers of the patients<br>• Specialist are relevant in generalizing solution [51]<br>• Use persons who do not suffer from a deficit to get rid of general design problems [2][9] | [4][9] |
| DG_P6 | Promote the involvement of family members; However, the involvement should be associated with a critical attitude | [73][74] |
| DG_A1 | Try not to over-analyze the utterances of the participants | [9] |
| DG_A2 | Be critical towards the representativeness of the participants | [9] |

*B. Participatory design with people with cognitive impairments*

Research in PD with people with cognitive impairments is not novel. Researchers have been conducting PD with people with dementia, aphasia, amnesia, stroke patients, or in general, in older adults' populations, etc. for more than two decades. A set of workshops focused on people with cognitive impairment has been taking place in conferences [33][73][74][75]. Moreover, a considerable number of papers had been published [4][9][33][44][76]. The papers are mostly focused on describing and analyzing single PD projects and deriving implications for involving people with cognitive impairments in the participatory design process. Hendriks, Truyen, and Duval [9] present a broad review of conducting PD with people with Dementia and list a set of guidelines for participatory design together with persons with dementia. In their review, they have looked into PD projects with other user groups that have similar symptoms as persons with dementia such as amnesia, aphasia, and elderly. We build on their findings and expand them further with some findings from a literature review that we conducted in January-June 2019. The findings from the literature review are presented in Table 1.

As stated above, as a research question in this paper, we investigate what a researcher should take into consideration when conducting PD with people with MACIs. However, as mentioned above, the number of publications specifically related to this user group is low, and only a few other

publications refer to PD with stroke patients. Hence, in order to have a broader overview of how to conduct a PD project with our user group, we did a systematic search in the literature of conducting PD with people with any kind of cognition challenges considering the similarity in symptoms.

We limited our search to the ACM and Springer databases since they are the main publishing venues for conferences and journals in design. We initially planned to investigate publications in specific conferences. However, in order to mitigate the risk of leaving out any relevant publication, we decided to expand the search generally for the two databases. We used several search terms in both databases. The constant search term was "participatory design" or "codesign" (and variations of it), qualified by more specific searches for user groups that experience cognitive impairments such as older adults, people with dementia, aphasia, cognitive decline, brain injury, and stroke.

Moreover, we added search terms that relate to the symptoms that people with cognitive impairments face, such as memory, attention, and tiredness. The search gave us an extensive set of papers. After removing duplicates, we ended up with 326 papers in ACM and 146 in Springer. The initial phase was to read through the abstract and quickly scan the papers' headings if there was any part that was dedicated to PD or the design process. Based on this, we decided if we needed to read the paper further. From the first scan, we decided to read 105 ACM papers and 38 Springer papers thoroughly.

After this, we discarded papers found to be out of scope. Some because they did not explain a specific case of participatory design with people facing some form of cognitive impairments, some for just mentioning a PD process without additional information, and somewhere the design process was not a true participatory design process with the involvement of users as partners in design. We concluded the selection with 105 papers. We classified the papers into Technology papers (18); Methods papers (49); PD practice papers (28) - in which the PD process and the tool developed were explained; and General PD challenges papers (17) - focused more in a conceptual discussion of what implications and what concepts are important on co-designing with people with disabilities. It was not a precise positioning of the papers in one of the categories mentioned above, and some could belong to all. However, each paper was assigned to only one category based on the paper's main contribution.

To analyze the data from the literature review, we were guided by content analysis and grounded theory approaches [77]. The content analysis starts by assigning specific descriptors to blocks of text in the collected data, a process called "coding". The coding can be emergent or a priori. The emergent coding is the core of the grounded theory approach, and the codes emerge from the data under review. Apriori coding involves the use of an established theory or hypothesis to guide the selection of codes. These categories might come from previously published work in related areas, or own prior investigations of the topic at hand.

We started by openly coding our data. Codes that described similar guidelines were grouped into concepts. Concepts were further grouped into categories (axial coding). Throughout the coding process, both authors of the paper were engaged in intensive discussions to find meaningful codes or concepts (i.e., topics).

To compare the results and refine and enrich our emergent codes, we used apriori coding in the second round of analysis. The apriori codes used derived from Hendriks, Truyen, and Duval [9]. Moreover, Hendriks, Truyen, and Duval [9] have categorized their guidelines. We preserve these categories and introduce a set of guidelines and actions to take for each guideline suggested by different authors (cross-checked with the guidelines from Hendriks, Truyen, and Duval [9]) for each of the categories.

In Table 1, we have listed guidelines for conducting PD with people with cognitive impairments, and group these guidelines into the following categories: Preparation (coded as DG_PP), Tools (coded as DG_T), Moderator (coded as DG_F where F stands for the facilitator, inspired by [78]), Methods (coded as DG_M – instead of methods we will refer to this category as Techniques inspired from the Simonsen, and Robertson [8]. We save the letter M in coding as the letter T has been used for the Tools category already) and Participants (coded as DG_P) and Analysis (coded as DG_A).

## IV. METHODS

In this section, we initially present the data collection method, followed by the method used for analysis.

### A. Data collection

The study aims to define a set of guidelines for conducting PD together with people with MACI. For defining the guidelines, we build on two empirical cases where we conducted PD with people with MACI.

In the first case, the aim was to redesign the Goal-Plan document used as a central document of patient rehabilitation at the DCR. The redesign aimed to make the document more useful for the patients during their rehabilitation.

Table 2. A summary of activities on how empirical data was collected

| | Workshops | Participants | Recordings | Facilitators | Reflection-on-action | Preparation meetings |
|---|---|---|---|---|---|---|
| Workshop Outline 1 | Workshop 1 | 4 patients | 1h:10m | 2 | Facilitators + clinical representatives | 3 |
| Workshop Outline 2 | Workshop 2 Workshop3 | 4 patients 2 patients | 1h:10m | 2 2 | Facilitators + clinical representatives | 2 |
| Workshop Outline 3 | Workshop 4 Workshop 5 | 2 patients + 3 staff 5 patients + 5 staff | 1h:45m | 2 2 | Facilitators | 2 2 |

We participated in the project as researchers pursuing our aim of investigating how to involve MACI patients in PD and designers to help the DCR to redesign the Goal-Plan.

Different methods and techniques can be applied in PD projects to involve the users in design. In the PD handbook, Brandt, Binder, and Sanders [30] describe a set of techniques that emphasize different parts such as telling, making, and enacting or the possible combination of these. We decided to involve MACI patients in PD workshops as our method of investigation. Workshops give the possibility to evaluate different traits of user involvement in the design, thus giving us the possibility to explore more on MACI patients and how to conduct PD with them. In a workshop, several techniques can be combined.

For redesigning the Goal-Plan project, we worked together with a project committee with representatives from the multidisciplinary team at the DCR. We prepared and conducted three workshops with a total of 10 participants. All three workshops were audio recorded. Moreover, after the workshops, a reflection meeting was conducted between facilitators and clinical representatives to discuss the workshop and the participants' engagement. The first author kept notes from these meetings electronically.

The second case is a continuation of the first case. The aim is to design a digital Goal-Plan that can be used by patients and staff in the process of defining rehabilitation goals and keeping track of the goals throughout the time that the patient is at the DCR. Thus, the digital tool would work as an enhancement or substitution of the current paper document. Two workshops with people with MACI, where a total of 7 patients and 7 multidisciplinary team members participated, were organized as part of the project.

The authors of this paper were involved in the project as researchers and designers. Both authors worked in the preparation of the workshops. The first author was as well a facilitator in the workshops. Both workshops for this digitalization of the Goal-Plan project were audio-recorded, and the reflections from the workshops were as well audio recorded. A summary of the data collection is presented in Table 2.

### B. Analysis

To analyze the experience of conducting PD with people with MACI, we build on Schön's [79] approach of the reflective practitioner. Schön describes two types of reflections:

Reflection-in-action is undertaken in the indeterminate zones of practice. The reflective practitioner "*thinks up and tries out new actions intended to explore the newly observed phenomena, test tentative understandings of them, or affirm moves invented to change things for the better. What distinguishes reflection-in-action from other kinds of reflection is its immediate significance for action.*" ([79, pp. 28-29]). Referred to as a reflective conversation with the situation.

Schön's use of the term reflection-on-action refers to the process of making sense of an action after it has occurred. It serves to extend one's knowledge base.

The two PD projects described in Sections V and VI have involved both reflections in action and reflection-on-action.

Some reflections for the first case (Section V) have already been presented in a previous publication [1]. Those reflections were made before the literature review. The reflections presented in this paper have been refined further due to the findings in the literature review.

The analysis was conducted in two parts. Initially, for each of the cases, the authors, based on the experience of conducting PD with MACI patients, made a list of reflections on each of the workshops. The list of reflections for the three workshops in Case 1 started in June 2018 and was published in March 2019 [1]. However, we expanded the list of those reflections in January-February 2020, where additional elements of the workshops or the preparation phase were listed as reflections. For Case 2 and its two workshops, the list of reflections was made in February 2020. The reflections list is what Schön [79] defines as reflections-on action. The reflections on action presented in this paper are the ones from the perspective of the facilitator in the PD sessions and not through an evaluation of the sessions from the patients' perspective.

We present the reflections for each workshop outline because the same outline had mostly the same reflections. If there were different reflections among workshops in the same outline, we have made sure to capture and include it in the reflections by referring specifically to the workshop.

The second part of the analysis was the refining of the reflections drawn on existing literature guidelines for conducting PD with people with cognitive impairments. The initial reflections list for each workshop outline was put in an excel sheet where each reflection was inserted in a different column. Instead, in the rows, we listed the guidelines found in the literature (as in Table 1). Figure 1, the under excel sheet, shows this part of the analysis. We started a qualitative "correlation analysis" based on reflections and interpretations. We initially went through the guidelines from the literature and analyzed which of our reflections from the empirical cases were compatible with specific guidelines found in the literature. Some of the guidelines in Table 1. helped the authors reflect on topics we had taken for granted in the initial reflective analysis, leading to updates in our reflections' lists.

Moreover, a second round of reflective interpretative qualitative "correlation analysis" was undertaken. Again, we read through the guidelines from the literature and analyzed which of the reflections were compatible with them, leading to further refinements of the reflections list.

In the third round, we started grouping our list of reflections based on the categories that we had in the guidelines from the literature in Table 1. These categories are borrowed from Hendriks, Truyen, and Duval [9], and are Preparation, Tools, Techniques, Facilitators, Participants, Analysis. We present the reflections for each workshop outline divided into each of these categories.

In the fourth round of analysis, we created a new version of the excel file and created separate sheets for each of the categories, as shown in Figure 1, the top excel sheet. The reflective interpretative analysis in this phase led to a set of guidelines for conducting PD with MACI patients, emerging from the literature of PD guidelines with people with

cognitive impairments and the experience of conducting PD with MACI patients in two projects.

The correlation analysis was also influenced by the characteristics of cognition challenges that the MACI patients have and the suggestions coming from rehabilitation theories, as described in the "Cognitive Rehabilitation Manual" [23]. The final list of guidelines for conducting PD with MACI patients is included in this paper's discussion.



Figure 1. Visualization of the excel sheet used for the analysis and the smaller sheet of analysis for tools guidelines for conducting PD with MACI patients

## V. CASE 1: REDESIGNING THE GOAL-PLAN

Above we presented the cognitive rehabilitation process in a hospital in Norway. The structure within the hospital, which is specialized in cognitive rehabilitation for patients with MACI, is the DCR. One of the primary working documents at the DCR, as explained above, is the Goal-Plan. Intending to empower the patient, the DCR wanted to redesign the layout of the document so it would fit more patients' needs and consequently make the patients make more and better use of the document during their stay at the hospital. We will refer to this project in this paper as "the redesign project".

As stated above, the authors were involved in the project in the role of researchers and designers to investigate patients' needs and, together with the patients, redesign a new version of the Goal-Plan that would fit those needs. Both authors worked in the preparation phase and the reflective analysis presented in this paper, and the first author participated and facilitated the workshops described below.

In collaboration with a project committee with representatives from the multidisciplinary team at the DCR, we prepared and conducted three workshops with the patients. The title of the workshops was: Redesign the Goal-Plan: A patient's perspective. The workshops aimed to get an understanding of what experience the patient has had with the Goal-Plan and discuss ideas on how to redesign that document so that patients can integrate it more in the activities during their rehabilitation period at the hospital.

In total, ten patients participated. In the first two workshops, patients that had been at the hospital for more than a week were invited, so they were familiar with the document to be redesigned. Four patients participated in the first two workshops. In the last workshop, only two patients participated, who were back at the hospital for their follow-up week, six months after their discharge. We were two

facilitators – the first author in the role of facilitator and designer and as well one representative from the hospital who had an experience of working with this patient group but was not their direct therapist at the DCR. We refer to this second facilitator as a "knowledgeable third party" [1].

Below we describe the preparation process for the workshops and present and reflect on two workshop outlines

### A. Preparation

In the preparation phase, we collaborated with a multidisciplinary team at the DCR. This team was assigned as a leading committee for the project, and we refer to it in another publication as the multidisciplinary project committee.

The committee was compounded by therapists who had high expertise in working with MACI patients. We refer to these people as "domain experts".

In order to facilitate the collaboration in the planning phase, prior to workshop 1, the first author conducted a PD workshop with the multidisciplinary project committee. The aim was to introduce the committee to some of the techniques used in PD and also for the first author in the role of researcher and designer to learn more about the user group. The workshop was initially seen with skepticism from the committee members, but once they understood the aim, they expressed that it was useful to learn about the PD approach and be able to contribute to *"design"* better workshops to enhance MACI patients' engagement.

Based on an agreement with the project committee and some shared editing iteration, the DCR staff members gave patients before the workshop a consent form, including an invitation to the workshop and a description of the project. The consent form was written in a very simple language to make it easier for the patient to follow. However, it was a detailed and consequently long description, to make sure that all the ethical issues were covered.

The project committee members tried to recruit their patients, asking if they would be interested in participating in the project. The patients that showed interests were then presented with the project invitation and the consent form. We were aware that the description might be excessive for the patient and could make her/him neglect reading it carefully. To make sure that the patient understood the consent form, one of the staff members at DCR spent time with the patient (that had expressed the willingness to participate) before the workshop, going through the document, and provide further explanations where needed. The workshop time was included in the participant's weekly plan. This is a calendar document where all the activities of a patient at the hospital are listed. The participants said that listing the workshop in the calendar helped them remember.

Regarding ethical concerns, we decided together with the committee that no personal patient data would be recorded. However, the sessions would be audio recorded so we could analyze the data later. The data collected through recordings are considered not anonymous (they are identifiable data), so they would be stored carefully in a safe location. In accordance with the project agreement, all digital data was stored in a personalized folder at the hospital servers.

During the first workshop, we noticed that some patients did not have a clear idea of what they had committed and needed a reminder. Thus, before workshops 2 and 3 in the morning of the workshop day, the nurses at the DCR talked with the patients again, to make sure the patients understood the scope of the project and were reminded and more prepared for what they were participating in later in the day. This was especially useful for patients with memory problems.

Moreover, we decided to conduct the workshops in environments that were familiar for the patients at the unit and would be adequate not to distract the patient and influence in their attention.

### B. Workshop Outline 1

We organized Workshop 1 in two parts.

The first part was "storytelling". The title was "Sharing your experience". We invited participants to talk about their experience with the Goal-Plan. Moreover, we provided participants a whiteboard with a print out of the old Goal-Plan was set in the middle and sticky notes in different colors. The patients could use those to write down keywords to facilitate remembering what they had to say when their turn would come.

In the second part, we challenged participants to think, "How would they want their Goal-Plan to look like" and design the idea afterward. The technique chosen was drawing and discussion.

For the second part, we removed the Goal-Plan and gave each of the participants a white sheet of paper, where they could design their ideal Goal-Plan.

The first author led the session. The second facilitator was facilitating the communication with the patient when that was needed.

### C. Reflections-on-action

In this subsection, we present a set of reflections-on-action from workshop outline 1. Reflections are grouped based on the categories borrowed from Hendriks, Truyen, and Duval [9] and also used in Table 1 above. The reflections are presented as insights on best practices or problems we faced based on a look back on our experience while conducting PD with MACI patients. We refer to these reflections again in the discussion section when we analyze these reflections from a theoretical perspective and conclude with a set of guidelines for conducting PD with MACI patients. Numbering the reflections has no specific meaning, but it useful to refer to after in the discussion.

Preparation

- WO1_1 – Involving domain experts in planning the PD process for the MACI patients resulted in arranging a workshop which was enjoyable for the participants and provided the researchers with relevant information. Moreover, for a researcher or designer would be very difficult to gain deep knowledge of the patients' needs in the timeframe of a project. Thus, having in the planning team, the domain experts facilitates having a broader perspective for the patient group and planning better.

- WO1_2 – Having a PD introduction to the project committee compounded by domain experts helped the mutual learning and made the planning easy. We, as designers and researchers, learned more about the user group, their needs, and challenges. During the mutual learning period, the first author had in situ conversations with the domain experts about the patients and how to design with MACI patients. Relevant tips and literature were exchanged in the conversation. Moreover, the domain experts gained new knowledge about the PD techniques and gave more specific recommendations on the activities that could be adequate or not for the workshop participants.

- WO1_3 – Explaining the consent form individually and verbally to the patients that had shown interest to participate in the workshop helped in increasing their understanding of the workshop's aim and how the data would be collected and stored. The lack of a verbal explanation would have caused one of the participants not to understand what was signing for. The person was diagnosed with dyslexia.

- WO1_4 – The project committee facilitated the recruiting process. The patients were already in the hospital unit, so it was easier to invite them to participate. However, in order to establish a relationship with the hospital and receive permission to conduct research in the DCR, it was a long process. In this process, we had two significant gatekeepers that supported us.

- WO1_5 – Planning was done well in advance, but the recruiting process was mostly done on a one week before notice. This because the persons invited were at the hospital, which was easily accessible for the authors. However, the process was limited in time because the persons would be patients at the hospital only for five weeks. Moreover, the domain experts suggested that even if recruited well in advance there is a risk that the patient might forget about the workshop date or in another scenario, the change in his/her condition from one week to another can influence them to drop the participation (some can feel too tired, not motivated, etc.).

Tools

- WO1_6 – Involving the DCR patients in a workshop at the hospital, which was a familiar environment for the patients, created an easy-going atmosphere. We used a room the patients had been in before for some of the activities at the hospital. Moreover, the room was easily accessible to everyone.

- WO1_7 – We distributed the materials on the table. The participants liked to look through these carelessly distributed workshop materials on the table, but they did not use any of them. Any of the four participants did not embrace the unstructured and open way of presenting materials.

Techniques

- WO1_8 – The participants did not use the sticky notes at all in the first part. They instead expressed themselves verbally and shared their stories easily with the others—three of the participants engaged in talking about their

stories and their Goal-Plan in the first part. Instead, writing down in sticky notes, the main points in their story was difficult, and the participants seemed uncomfortable to do. Thus, the facilitators dropped the idea and instead investigated more through in situ questions. One of the participants was more reluctant to share his stories. After the workshop, we found that the participant's cognitive impairments had influenced his ability to articulate himself.

- WO1_9 – The fear of white paper, the blank page syndrome [31][32], was made visible in the second half of the workshop. The participants were good at articulating their needs verbally, but they were not able to create a visual image of their needs and consequently design ideas. Participants received the white paper and felt uncomfortable to write something on it. Instead, they started telling the facilitators what they wanted to have in a new version of the Goal-Plan. Both facilitators, ones noticing the hesitation, immediately reacted and suggested the participants to not focus on the white paper but more telling us their ideas about a new Goal-Plan. All the participants received the white paper with them, and only one of the participants came back the next day with a design suggestion and talked personally to the first author. Joyce [33], in her dissertation, discusses the role of open options in creativity and finds how the openness of the design space can constrain creativity. That is what we experienced with the MACI patients.

- WO1_10 – Realizing the hesitation on writing in the sticky notes and designing on the white paper, both facilitators abandoned the writing and drawing idea and started bringing up the questions of the workshop as discussion points to elicit ideas and needs from the patients. This flexibility toward the participants' needs and comfortability made it possible to end the workshop with some interesting data from the participants and, most importantly, have an enjoyable session for the participants, which expressed the enjoyment to the facilitators.

- WO1_11 – The broad approach of the workshop was distracting for the participants. Opening the workshop by asking the participants to talk about their experience with the Goal-Plan resulted problematic. It made them focus more on their goals and their specific problems rather than the main project aim, the Goal-Plan layout. Noticing the distracting reaction that the initial more general questions about the Goal-Plan created, the facilitators started asking the participants more specifically about the Goal-Plan layout. This resulted in participants being more focused on the main aim of the workshop and giving feedback specifically for the issue at hand. In the planning phase, the domain experts warned facilitators about the patients' willingness to tell their story and the possibility of getting distracted and get lost in detail. We experienced this with our participants. The presence of the second facilitator contributed in improving the communication and bringing the participants in focus.

- WO1_12 – The participants had different MACI, which meant they had different cognitive challenges. This required that within the aim of the workshop to adapt to each of the participants' cognitive needs. We noticed that two of the participants were more focused on discussing personal goals than contributing to the layout of the document. Thus, to them, we started asking more specific questions with short, clear sentences. Instead, one participant was more reluctant to share his stories. Thus, we tried to ask indirect questions so the participant could start sharing some ideas, and also, we were careful not to push the participant out of the comfort zone.

- WO1_13 – The aim of the project concerned the participants directly. Thus, they were interested in contributing as much as possible. One of them expressed that the contribution to designing a new Goal-Plan would help maybe not them directly but others after them in their rehabilitation. The same participant had discussed the workshop in the evening with the kin, and they had together designed something in the white paper.

- WO1_14 – Building on the participants' personal experience and opinion resulted in being a positive experience because the participants where used at the hospital to share their stories with different therapists. Moreover, talking about the Goal-Plan from their experience created an environment that was friendly and boosted the participants' self-esteem as there was no right or wrong answer.

- WO1_15 – A thorough review of the literature about the patients' clinical condition as well as observing the patients in the unit, made clear that it is a very special user group. The committee suggested focusing on the patients' abilities and how to strengthen those abilities during the workshops. The staff highlighted the patients' willingness to share their stories and express themselves both through words and as visual imagery.

- WO1_16 – Based on the committee expertise, the optimal workshop duration would be 1 hour, divided into two parts, each of 20-30 minutes with a 5-10-minute break in between. In this way, it would be possible to have the patient concentrated all the time without fatiguing him/her. This was the case during the first workshop. The activities in each part lasted enough to not be overwhelming for the participants. The participants seemed happy after the workshop.

- WO1_17 – Creating a friendly environment with coffee and biscuits and long breaks was stated as a positive trait of the workshop from the participants. The had the possibility to talk more with each other and with the facilitators during the break. However, the participants knew each other from before as they had been involved in group therapies. This created a friendly relationship between them and, from our interpretation, influence positively during the workshop by boosting the participants' willingness to share their opinions and experiences.

Facilitators

- WO1_18 – Having as a facilitator, a "knowledgeable third party" improved the communication process for those participants whose communication ability was affected by brain injury. Discussing the issue of facilitators with members of the committee, we

considered an extension of the workshop team by someone from the clinical side that knows how to work with the patient group but is not directly involved with the participating patients. The committee suggested a member from the Learning and Mastering Center at the hospital, which was specialized in providing patients with a deeper insight regarding their health. The member might have met the patients during other activities around the hospital but was not part of the DCR staff and not directly involved with the patients. The involvement of a person that fulfills this requirement as a facilitator in the workshop was very useful in smoothing the communication and boosting the participants' contribution.

- WO1_19 – Facilitator's challenges of not being fluent in the Norwegian language created a fun atmosphere that helped the participants to feel at ease and not be shy to highlight their challenges. Moreover, as a facilitator keeping up with a positive and humble attitude helped the facilitators to communicate with the participants better. Facilitators were speaking on a slow tempo and not in a feeling of rush. Moreover, facilitators used a simple language and showed respect for the participants' knowledge and experience with their situation.

- WO1_20 – The broad approach of the workshop diminished the direct participants' contribution to the design of the Goal-Plan document. Thus, the facilitators had to intervene to help the participants get back on track and focus them on the aim of the workshop.

Participants

- WO1_21 – The number of facilitators should balance the number of participants. We decided that two facilitators (the first author having design skills and the knowledgeable third-party having domain knowledge) would be sufficient in a workshop with four participants. This saved the balance during the workshop. The participants were in the majority, so they were not put in the spotlight, which could have created stress. However, having one leading facilitator helped to keep the focus in one direction.

- WO1_22 – The committee suggested that the maximum number of participants per workshop should be around 4 or 5. In this way, the participants would feel more comfortable and have the right space to share their stories and opinions. Indeed, that worked well in workshop 1 with the four participants. Each of the participants had a dedicated time to express her/himself.

- WO1_23 - Recruiting MACI patients at the hospital through domain experts made the process of recruitment easy. Moreover, the domain experts served as the gatekeepers for involving in the workshops MACI patients based on the standardized tests that the patient has had at the hospital.

Analysis

- WO1_24 – We conducted a reflective analysis with the two facilitators and representatives from the DCR. Analyzing the findings in an interdisciplinary group helped in making a better sense of the participants' behavior during the workshop (reflected in this paper)

and their feedback (integrated into the new Goal-Plan design). The assessment of the participants at the hospital and knowing their diagnosis was useful in triangulating the findings and make out meaning from them.

After the first workshop with workshop outline 1, we reflected on the things that did not work perfectly during the workshop, and we made another plan for the next workshop. This leads us to workshop outline 2.

### D. Workshop Outline 2

The workshop was organized as an updated version of a future workshop, as presented by Jungk and Müllert [80]. Future workshops have been widely used in PD. The aim is to make people critically discuss a current situation and then envision possible improvements for the issues critiqued in a fantasy phase. After a phase of envisioning any solution, it comes to the realization phase. In the realization phase, feasible solutions based on what the technology allows are discussed further. We ideated an updated version of the future workshop, as presented below.

The workshop was divided into three parts.

In the first part, the participants got a version of the old Goal-Plan printed out. Next, to each of the fields in the document, we added two icons, thumb up and down. We asked the participants to mark with thumb up those fields that they considered important for their rehabilitation. After choosing to thumb up or down, the participants were asked to share their choices with the others and tell a little bit why they decided so. The aim was that the participants could discuss the choices among each other and maybe build on the ideas of each other. To structure the discussion, the knowledgeable third-party facilitator started going from one field to another and asking participants for their choice. Thus, it made it easier for the participants to follow and contribute to the discussion.

In the second part, the participants were asked to try to rewrite the fields (words used in the document) that they found important, in a way that they thought would be easier to understand and read. The participants were suggested to add additional fields if they thought they would be important in the Goal-Plan. Again, they had to work initially on their own and then present their suggestions to others. The other participants could ask questions or comment. The facilitators asked questions to enable the participants to articulate more of their needs and sometimes ask questions to understand better what the participant meant, to not risk misinterpretation during analysis.

The third part was called "rearrange". In this part, the participants were asked to rearrange the fields of the document which they had selected and rewritten in the first two parts. They could arrange the document as they wanted, add new fields or, change the structure of the document. At this point, participants could use the template of the old Goal-Plan or get a white sheet and design on it individually. Colored sticky notes and pens were provided.

In the third part, the participants were also provided with some examples of designs made by the multidisciplinary project committee in the workshop with the designer. Participants could have a look at those sketches for a short

period for inspiration. This exemplars' aim was to help participants surpass the white page syndrome.

The same workshop format was used in the third workshop, where two patients that came back for a follow-up week participated. The only change was that in order to customize the discussion for these two participants and adapt to their experience, we focused mostly during the workshop on how the continuity of the rehabilitation plan could be achieved when the patient leaves the hospital.

### E. Reflections-on-action

In this subsection, we present a set of reflections-on-action from workshop outline 2. Reflections are grouped based on the categories borrowed from Hendriks, Truyen, and Duval [9] and also used in Table 1 above. Here we do not have any reflections in the category "Analysis", so this category is not included below. The reflections are presented as insights on best practices or problems we faced based on a look back on our experience while doing workshops 2 and 3 with MACI patients. Here we include only reflections that were additional in workshop outline 2. The reflections from workshop outline 1 had already been taken into consideration before planning workshop outline 2.

Preparation

- WO2_1 – In workshop 2, we found that repeating the information about the workshop and the participation for the patients that had committed to participate and were suffering from memory problems resulted in them being more focused during the workshop and more prepared on what they were going to discuss. The nurse, as in workshop 1, had a meeting with the prospective participants to help them understand the consent form. In addition, the nurse talked again with the patients in the morning before the workshop to remind them about the workshop. This brought a more engaged and wider feedback from the participants during the workshops.

Tools

- WO2_2 – Distributing the sticky notes and the colored pens in an organized way in each of the parts of the workshop was noted to stimulate the participants to engage with the tools. They did not have the hesitation to chose among the tools because they had a structured set of tools for each part of the workshop.

- WO2_3 – Having the Goal-Plan in a printed version in front of each of the participants individually as part of the workshop toolkit, helped them be more engaged with it. Participants could customize the printed piece of paper as they wished – they owned it. Moreover, using the workshop tools to collect data facilitated the interpretations. For example, we could count how many thumbs up or down were related to a field in the Goal-Plan.

Techniques

- WO2_4 – We implemented a task-oriented approach in the workshop. Each of the parts was framed as a clear task that would serve a specific purpose. Participants liked this approach. They engaged in significant discussions with each other and the facilitators. Moreover, they started building on the ideas of each other. If someone brought up a new idea that would also trigger a discussion among other participants.

- WO2_5 – We observed aiding the participants through specific cues such as marking thumb up and thumb down in the Goal-Plan, made it easier for them to starts the discussion and elicit their ideas. The usage of thumbs up and down was associated with more personal stories and individual opinions about why a specific field in the document was relevant or not. So, having a structured way where to start the discussion was useful in helping the patients to build up ideas and relate those to personal experiences. The cues included in the tasks facilitated participants' ideas and discussion. This created the opportunity for the facilitators to ask more questions to elucidate the meaning of participants' ideas.

- WO2_6 – Having a narrower scope of the PD session helped participants to stay focused and contribute significantly. While these reflections are not new, they appear very important in the case of patients with MACI.

- WO2_7 – In the critique phase of the future workshop, we did not organize a real critique session. Instated, we asked what the participants liked and what the participants thought needed to be improved further in the current Goal-Plan. Providing both the thumb up and down options enabled the patient to think that some things need to be improved, but at the same time, that there are other things that are extremely relevant and need to be preserved. This was useful to keep participants' good feelings and not expose them toward a negative mindset. Thus, considering ways of using positive rhetoric that can elucidate a critical perspective from the MACI patients in workshops is very relevant.

- WO2_8 – The second part of the future workshop is the fantasy phase. It was clear from the first workshop that the MACI patients could not produce much information while moving directly to the fantasy phase (hesitation of the white paper). Thus, before jumping to the fantasy phase, we introduced a transition phase by asking participants to rewrite some of the fields in the Goal-Plan that they thought could have been written better for them. Rewriting aided participants to start envisioning a better solution for the Goal-Plan but still be connected to the things that they knew, meaning to the Goal-Plan that they had seen many times. In another publication [1], we refer to this as "the teaser of future envisioning". The teaser is a simple known task that helped participants in transitioning toward the fantasy phase of the workshop and be able to design a new version of the Goal-Plan either by rearranging the old one or by designing in a white paper. The white paper syndrome was defeated, and participants could come up with design suggestions for a new version of the Goal-Plan. Figure 2 shows some of these design suggestions provided by patients.

- WO2_9 – The use of exemplars in the "rearrange" part of the workshop, might lead and influence participants' ideas. We were skeptical about the usage of these exemplars, but we wanted to observe what their influence could be and how the patients would react toward that. However, screening participants' designs did not reveal a noticeable influence from the exemplars presented. Based on our reflective analysis the reason the exemplars did not influence the design ideas was that they were presented to participants in the last part of the workshop, and participants had already built up a mental vision of their Goal-Plan in the previous phases. Moreover, we exposed the exemplars only for a short period and explained that they were supposed to be triggers for possible options of how a Goal-Plan could look like. Integrating exemplars was inspired by research through design and Gaver's work with the ludic design [81][82][83]. Looking at the amateur designs from the staff inspired MACI patients participating in the workshops to get the colored pens and sticky notes, and start designing, overcoming the fear of the white paper. However, this is a very delicate usage, and more investigation is needed.
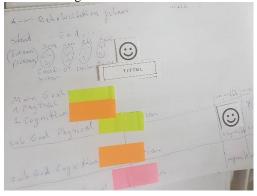


Figure 2. Workshop 2 - Patient's design suggestion

Facilitators

- WO2_10 – Providing structure and review helped participants to give more ideas and articulate their thoughts more deeply. The knowledge third party going from one field of the Goal-Plan to another to ask if the participants had marked that with thumb up and down facilitated the initiation of the discussion among participants. Moreover, asking additional questions helped participants to express their ideas better.

Participants

- WO2_11 – In the third workshop, the two participants were of different natures. One of them was more expressive, and the other more reserved. Hence, the facilitator had to make sure that both were getting the same time and attention by providing the same time and attention to both participants.
- WO2_12 – Participants with different backgrounds but similar cognition levels seemed to work better with each other. This was noticed, especially in workshop 2. The four participants had different MACI but more or less similar functional level. This helped in keeping up at the same speed and feeling motivated by each other.
- WO2_13 – We noticed that participants were comfortable with the group work. They were used in working in groups, from previous group therapies at the hospital. Many showed during the workshop confidence point to another patient on things they thought were similar. Moreover, we noticed that some participants who had different ideas from the group felt confident enough to share them with others. Especially if the idea they had was related to a story in their life. However, the situation was different in workshop 3 when one of the participants was perceived as influencing the ideas of the other. Facilitators had to intervene through more strategic questions to retrieved more hidden ideas. A helpful thing was that each of the participants had to work initially on their own and then discuss with the others in the group in its own turn. This helped in preserving the individuality of opinions.
- WO2_14 – Participants that were present in workshops 2 and 3 had a milder ACI (acquired cognitive impairments). Thus, they could contribute better in giving feedback on design details as well.

## VI. CASE 2: DESIGNING A DIGITAL GOAL-PLAN

In June 2019, as a joint collaboration among our research institution and the DCR of the rehabilitation hospital, we started "The interactive Goal-Plan" project. The project aims to develop a digital version of the Goal-Plan, which can support the patients to take more control over their rehabilitation at the hospital and outside it. We will refer to this project in this paper as "the digitalization project".



Figure 3. Participants working in pairs patient-therapist during workshop 5

The aim of supporting the patient to take more control over her/his rehabilitation starts with the patients deciding themselves what they would like to have in a technological tool designed for them. This philosophy of the hospital is compatible with the PD principles. Thus, a PD process started in January 2020, where the authors of this paper in the role of researcher and designers were involved in two PD workshops organized respectively 22nd of January and 5th of February 2020 at the rehabilitation hospital premises with patients with MACIs and staff from the DCR. These workshops will be described below.

*A.    Preparation*

In this project, a multidisciplinary project committee was created again. The first author in the role of the designer and researcher worked in close collaboration with few representatives from the DCR. One member of the DCR, which was involved directly with the patients, was in charge of the recruitment and deciding on a venue and time suitable for all. The planning of the workshops was done in collaboration among the authors of this paper and an Occupational Therapist (OT) that had been working at the DCR before but was now in other duties at the hospital. This person had been a crucial person in the first case described above. Thus, she had created knowledge about the design process and the PD principles previously. As she was not directly involved with the patients but had high expertise in working with the patients, she represented the "knowledgeable third party" in this project. A more elaborate plan was made considering the experience of the facilitators and the lessons learned from the first case.

For workshop 4, the plan was to recruit 5 patients. However, only two patients responded positively to the invitation. The workshop was planned to have a room that could support groups working in pairs, but the room available had only one single long table. We needed to be flexible to the positioning of the participants, so not much noise was created and distract the patients. Workshop 5 was planned for the 29th of January, but we needed to postpone it due to a small number of patients willing to participate. Workshop 5 was organized in a room called the "Idea Lab" suitable for bigger group workshops.

Participants in this case workshops were patients and DCR staff members. Hence, we prepared two invitations and consent forms in order to make the call more personalized. The consent forms this time were shorter and more precise. It had a clear part highlighted in colors where the aim of the workshop and each of its parts were presented. This was followed by a description of how the data collected would be handled. The one-page invitation resulted in being easier for the patients to read through and understand. The "knowledgeable third party" mentioned above contributed substantially to writing the consent form. Moreover, together with the designer (first author), they drafted the workshop description and presentation. The presentation was planned to stay on the screen, and the written material was distributed to the participants as a cue for understanding better the tasks in each of the parts.

*B.    Workshop Outline 3*

In workshop 4, two patients and three therapists from the DCR participated. The workshop was called "My Interactive Goal-Plan – Defining goals", and the aim was to envision and discuss requirements for a digital tool that can support the patients to be more involved in setting their rehabilitation goals during their first week at the hospital. The workshop was planned to have three parts. The duration of the workshop was planned for 1.5 hours, with each part having 25 min and 10 min break between parts. We ended doing only the first two parts in 1.5 hours because more general preparations took

time, such as sitting in the right place, explaining the tasks, and showing examples.

The first part consisted of a set of cue cards with possible functionalities for a digital Goal-Plan. Each of the patients' participants had a set of cue cards in different colors. The participants had to read the cue cards individually and chose among the set of cue cards, those cards that involved functionalities that they liked. There were no limitations in the number of cards to choose from. Participants were also given empty cards so they could add more functionalities if they wanted.

As a second task of the first part, participants were asked to choose the five most favorite cue cards. These five cards should be presented later to the other participants in the workshop. After presenting the five cards chosen to the other participants and telling them why the person thought the card was relevant, all participants had to discuss in the group and agree on a set of five cards that all thought were the most important functionalities to have in a digital Goal-Plan that could support them in defining their rehabilitation goals. In the workshop in parallel with the patients' table, we had a table of therapists (staff members) from the DCR doing the same tasks. The set of cue cards that they had was targeted to therapists needed and desired functionalities in a digital Goal-Plan that could support their work in facilitating patient's rehabilitation.



Figure 4. Storyboard created from one of the patient-therapist teams in workshop 5

The second part of the workshop required each of the patient participants to work in pairs with one from the therapists. The task the duo patient-therapist had was to make a story. The story would be on how the digital tool, which had the functionalities the patients and therapists had concluded in the first part as the most desirable ones, would be implemented in the processes at the DCR.

A paper storyboard was given to each of the pairs. The storyboard was divided into three parts to help the patient and the therapist to think about the activities the patient does alone, or activities the therapist does alone or activities they do together. A set of animated pictures picturing an animated fictional patient in specific moments at the hospital, home, or at the outpatient clinic was provided to the patient and the therapist as facilitating cues to make possible the creation of the storyboard. Facilitators told that if participants wanted, they could as well draw, or in case that they wanted to represent some functionalities of the digital tool, they could

just paste in the storyboard one of the cue cards of the first session.

The last task was to provide the patient and staff with some choice of technology layouts such as phone, tablet, PC, and some cut out of possible icons and ask them to try to design the interface of the digital solution. However, the time spent in the first two parts did not create the opportunity for doing the last part, so we dropped the idea.

In the workshop, two facilitators participated - the first author and the "knowledgeable third party". Differently from the first case, the "knowledge third party" in this case was not only facilitating the communication but was as well in charge of leading specific sessions together with the first author - designer. The patient workshop was facilitated by the knowledge third party and the staff workshop by the first author. In the second part, each of the facilitators had to lead one of the pairs workshops, sitting on the two opposite corners of the table. We had one therapist more participating in the workshop. Hence, one of the therapists in the second part worked on the tasks alone in order to not shake the balance in the pair's groups.

Workshop 5 had the same outline. This time knowing the limitation in time, we scheduled only the first two parts of the workshop and gave time to other practicalities. The workshop was called "My Interactive Goal-Plan – Owning my rehabilitation". The workshop aimed to discuss how a digital tool can contribute to support the patient to be more in control and involved in her/his rehabilitation process after the patient has defined the goals. 5 patients and 5 therapists from the Sunnaas DCR participated. Two facilitators participated. A third person was involved in supporting materials distribution and making sure that everything was in place while the two facilitators were leading the sessions.

### C. Reflections-on-action

In this subsection, we present a set of reflections-on-action from workshop outline 3. Reflections are grouped based on the categories borrowed from Hendriks, Truyen, and Duval [9] and also used in Table 1 above. The reflections are presented as insights on best practices or problems we faced based on a look back on our experience while conducting PD with MACI patients. Here we include only reflections that were additional in workshop outline 3. The reflections from workshop outline 1 and 2 have already been taken into consideration before planning workshop outline 3. The following reflections are focused only on the MACI patients. Even though the DCR staff members participated in the workshops together with the patients, their involvement in the process is out of the scope of this paper.

Preparation

- WO3_1 – Dividing the tasks of reDCRitment and planning as described above helped in doing better planning because more time was dedicated to discussing the workshop outline and refining how the tasks in each part would be represented. Moreover, the person in charge of reDCRiting had more time available to dedicate to explain to the patients that had expressed their will to join the workshop, the aim of the workshop, and why their participation would be relevant.

- WO3_2 – The involvement of a knowledgeable third party in the planning of the workshops was relevant for formulating better the workshop aim considering her expertise in the patients' group and the process of rehabilitation. Moreover, her engagement helped in formulating better invitation and workshop description that was suitable for the MACI patients and their challenges in communication.

Tools

- WO3_3 – Adding a written material given to participants during the workshop facilitated the information processing for them. Participants that had difficulties in understanding the requirements in each part of the workshop read what the task was about in the material written as a manual step by step with clear bullet points. The printed material helped them stay focused and have a higher level of understanding of the tasks.

- WO3_4 – Having short sentences and in a simple language suitable for the participants improved understanding and engagement. Moreover, the material was given in Norwegian. This helped the patient understanding and reduced the level of fatigue that speaking and reading on a foreign language can require.

- WO3_5 – Using low fidelity tools like the paper printouts in cue cards or in the animated images made it easier for the MACI patients to contribute to the workshop. The paper tools provided participants with the possibility to rewrite and move around based on their needs. Moreover, there was no fear that a card or a visual image was destroyed as we had a bunch of extra print outs ready to be distributed on needs.

Techniques

- WO3_6 – Cue cards facilitated the process of envisioning a future solution. The patient could agree or not with the hints mentioned in the cue cards. Sometimes an explanation of the cue cards information was needed. In that case, the facilitator would tell a little bit more on what was the aim behind those cards. Having initial cues helped to bring on participants' attention things that they might have forgotten on their own. Moreover, working on the cards and refining the ideas of the cards was expressed from the participants to be easier than having to initiate the thoughts themselves.

- WO3_7 – The openness of the cue cards gave the possibility to the patients to add their personal experiences. Some of the participants gave the cards other meanings based on their understanding and will. Thus, having cue cards not too detailed opened the opportunity for the participants to not just agree with the cues but be able to customize them, as shown in Figure 5.

- WO3_8 – Participants expressed that they found the project relevant and interesting for them and for other patients with MACIs in need or rehabilitation. This was

the main reason they had committed to participate. Moreover, as stated above, most MACI patients are still working, and they are familiar with the notion of workshops. One of the participants was working on service design and was very familiar with the techniques used.

- WO3_9 – During workshop four, considering the time spent on the previous tasks, both facilitators agreed to drop the third part of the workshop. After the workshop, both facilitators expressed that the participants needed a long time to read the cue cards and discussing them. This had created a delay in the previous tasks. Moreover, both facilitators noticed during the workshop, that the tempo of information processing was slower for some participants. Thus, providing them with the time they need is relevant to take into consideration.

- WO3_10 – In the second part of the workshops, we had created a fictional character for the storyboard. In both workshops, we saw that patients' participants were not influenced by this fictional character that we called "Anna". They quite often referred to this character as "me" – "I am the one in the story".

- WO3_11 – The second part of the workshop outline was more demanding than the first one. Participants had to discuss on the cue cards, make sense of them together (patient and therapist) and then make a story. These tasks put a high burden on cognition. However, the usage of the visual cues in the animated form facilitated the envisioning of the future solutions made more concrete in the case of the storyboard. The visual images enhanced creativity and sparked ideas for the story. Patient participants and therapists enjoyed having the visual cues and, as in the case of cue cards, took the freedom to interpret these visual images as they wished. Moreover, in this part, we introduced participants with an example of the storyboard created by the facilitators. Participants had the exemplar as inspiration and did not look at it in detail. However, the exemplar helped them envision what they had to do in the task.

- WO3_12 – Structuring the storyboard and how to build the story helped in making an abstract idea more concrete and the story more approachable for the participants, both patients, and therapists. The duo patient-therapist could divide the activities as instructed in the storyboard. Moreover, the structured way of creating the storyboard served for initiating a discussion on what activities the patients would like or should do alone and as well in which activities during their rehabilitation they can or should interact with the therapist. The structured way of thinking, and building the storyboard facilitated the patients' contribution to the workshop.

Facilitators

- WO3_13 – Coordinating 5 patient participants and 5 therapists as participants required more than two facilitators. In workshop 4, the facilitators had the possibility to sit with the therapist and the patient individually and try to ask in-situ questions when needed. Instead, in workshop 5, both facilitators were moving among groups but were not constantly present while the groups were working. Momentos, in which more investigative questions could have been asked, were lost. These were only realized afterward when hearing the recording.

Participants

- WO3_14 – One patient participant in workshop 4 was tired at the end of the workshop. Instead, all the 5 patient participants in workshop 5 stayed overtime and seemed to enjoy the tasks. From this, we want to highlight that MACI patients capacity variates, and in order to involve everyone and not risk tiring the participants, either participant with the same capacity should be grouped together in workshops, or we should design the workshop based on the capacity of the most fragile participant. This can be established before the workshop while knowing the participants' clinical condition.

- WO3_15 – The patients and the therapists participating in the workshops had a good collaboration. They both collaborated into making the story. Some patients initially struggled in the understating, but the respective therapists supported them by explaining the task so the patients could contribute significantly. The involvement of the staff members as participants in the workshop was not to ask them what the patients need in a digital Goal-Plan (the patients can speak for themselves) but to ask them about their share in the digital solution. Sitting a patient and a therapist together in designing a shared digital solution that will be used by them is not a common practice. Thus, in a future publication, we will expand more on how the collaboration in a PD workshop worked between these two user groups.

Analysis

- WO3_16 – Both facilitators conducted a fast round of reflections-on-action after each of the workshops. Facilitators discussed their individual and common impressions about the workshop and highlighted strong points and downsides in each of the sessions that they were in charge. This was audio recorded for future analysis and reflections. Those immediate reflections-on-action were very helpful in refining the list of reflections presented in this paper because the immediate reflections captured feelings and perceptions, which usually are lost when data is analyzed later in time.

## VII. DISCUSSION

In this subsection, we discuss the findings from the reflective analysis from the literature review perspective. We conclude with a list of guidelines for working with people with MACIs for each of the categories initially introduced by Hendriks, Truyen, and Duval [9].

*A. Preparation*

In our experience, the preparation phase was conducted in close collaboration with domain experts. Thus, the experience that we describe is seen from the perspective of involving domain experts and people experienced with specific patient groups for planning the PD process. The literature recommends getting the consent of the participants at various moments throughout the research process [8]. Our participants did not participate for an extended period in the research. In our workshops, we experienced that the consent prior to the workshop was sufficient. Nevertheless, throughout the workshop, both facilitators were closely observing the participants for signs of fatigue or irritation and informally getting approval that the process was going well for each of the participants. An important insight from our study was the need to provide the information described in the invitation and consent form in different forms (verbal, visual, etc.) to the participants and repeat the informing process many times to ensure that the information is processed, and the person is aware of what s/he is committing to (WO1_3, WO2_1).

Another guideline from the literature is to communicate about the project goals without intermediaries [9] (DG_PP2). In our two cases, the domain experts communicated the project goal to prospective participants. Further, during the workshop, the facilitators repeated the project goal as a precaution to assure that all participants were aware about what they were contributing to. When the intermediaries are people that have knowledge about the cognition challenges of the patient group and are experienced and trained in communicating with them, the intermediaries can be an asset in establishing the communication with the prospect participants and explaining the project goals (WO1_3, WO2_1).

Moreover, in analogy to the literature (DG_PP3), we experienced that there was a need to establish an extra time for general practicalities [9]. However, this time could be managed better if the preparation phase was handled by a group of people who are part of the PD project. Dividing the recruiting and planning process among different persons created more space for ideating better the workshops in workshop outline 3 and as well manage better the recruiting process (WO3_1). The literature states that it is relevant to know the target group well [9][41][42] (DG_PP4), know the patients' deficits so you can adapt to their situation. For researchers and designers, a higher understanding of the MACI patients' cognition challenges can come due to the close collaboration with the domain experts – the rehabilitation specialists working with MACI patients in cognitive rehabilitation. They have deep knowledge about the patient group and can contribute to informing designers. However, PD requires mutual learning and applying this perspective to teach domain experts how designers work can help them provide more knowledge about the patient group (WO1_1). In our case, the selection of the participants was made through the clinic. Assessing abilities through standardized tests [9][4][43] (DG_PP5) was helpful in defining the patients' abilities and disabilities, and for us to plan adequately. They were also useful in the analysis. Ability

assessment was not done by the designer but by the healthcare practitioners.

The literature states that it is beneficial to plan and reDCRit participants well in advance (DG_PP6). In the case of MACI patients, we experience that planning well in advance is recommended, especially when the designer leading the PD project is new to working with MACI patients and need to learn more about the patients' needs and situation from the healthcare practitioners. However, the reDCRiting process was done over a short period. This because patients do not stay at the hospital long, and some of them can forget about participation in the workshop if they were reDCRited well in advance. Moreover, patients' condition varies from one day to another (WO1_5). Thus, planning for absent patients is required.

In the preparation phase, we finalized these guidelines for conducting PD with MACI people:
1. Invite the patients and present the information regarding the project in different ways, either text, verbal explanations, images, audio, etc. and make sure to repeat the information several times during the workshops/activities based on the participants' needs.
2. Benefit from the knowledge of domain experts (in this case, the rehabilitation specialists) to recruit and convey the information about the project. They know how to work with MACI people.
3. Plan the PD workshops in collaboration with a multidisciplinary group. Establish mutual learning and make better preparation for the PD process by benefiting from the expertise of everyone.
4. Plan the project well in advance and recruit in a short time. Prepare for absences.

*B. Tools*

The literature emphasizes the need to involve users in design in appropriate and familiar environments, which take into consideration the deficits of the participants [9][45][46][47] (DG_T1). The same is true for MACI patients. The hospital environment was familiar, and the participants had previously been in the areas where the workshops took place (WO1_6). Moreover, these areas at the hospital are designed to offer easy accessibility for everyone. Another important element mentioned in the literature is to adapt the language to the participants (DG_T2). In the case of MACI patients, this is extremely relevant. Our reflections from the workshops (WO3_4) and existing literature [19][20] show the importance of using short sentences and an understandable language when addressing MACI patients.

Regarding tools used during workshops as supporting materials for techniques, we found that sometimes using text might be a problem, and it can be more useful to make use of non-verbal elements such as visual stimuli like photos of objects or use physical artifacts [9][50][51][52][53][54]. In our empirical data, we found that having the Goal-Plan in a printed version served as a stimulus for the participants (W02_3). Moreover, we experienced that MACI patients felt more motivated to use workshop tools if these tools were individualized. The MACI patients worked well in

manipulating the tools provided initially individually and then sharing the outcome with others.

We did not use contextual cues such as nametags as it has been proposed in the literature [9] (DG_T4). This because the participants coming to the workshops knew each other from before.

In our experience, using low fidelity tools part of the workshop toolkit made it easier for the participants to contribute. However, we lack experience with digital toolkits, and further investigation of conducting PD building on digital toolkits is needed. Despite our lack of experience with digital toolkits, we argue that being aware and considering the fidelity of the toolkit [4] used in a PD project should be a priority. This should be carefully considered with regard to patients' abilities tested through standardized tests.

Finally, in WO1_7 and WO2_2, we highlight how the structuring of the tools became relevant for motivating participants' contributions to the workshops. This is compatible with the rehabilitation theories for building structure in remembering things and focus attention [25] and should be taken into consideration when presenting PD tools in workshops.

Regarding tools, we have the following guidelines for conducting PD with MACI people:
1. Involve users in a familiar environment
2. Use distinctive contextual cues in the toolkit materials
3. Consider the fidelity of the tools in relation to patient-specific cognitive challenges
4. Use a simple language with a positive tone
5. Use visual stimuli which are individually targeted
6. Have clear tools for each part of the workshop and have a structured way of delivering the tools.

### C. Techniques

Having clear guidelines and techniques for conducting PD with MACI patients that involves a significantly heterogeneous group is difficult. Moreover, techniques can variate based on the technology to be designed. This may put other requirements in place. Here we highlighted insights from our experience within the two projects and five workshops, and we invite other researchers working with MACI patients to refine and supplement the list.

People with cognitive impairments find it challenging to envisioning future solutions [2][9][42][44][48][54]. In the literature, different ways of supporting the envisioning of future solutions are proposed (listed in DG_M1).

In our work with MACI patients, we have found that a task-oriented approach of activities (WO2_4) and narrow scoping of a session (WO2_6) can help the patient to process a line of information at once and to be able to envision more future usage of the solutions. The fear of using the white paper showed the challenge that MACI people have in envisioning a future solution and how the fantasy ability can be undermined when too many options are presented. Thus, as stated in the literature, trying to avoid appealing to the person fantasy and avoid too much choice [8] is adaptable for the MACI patients as well.

A relevant finding influencing the future envisioning is what we called the "teaser of future envisioning" (WO2_8) in

the workshop outline 2. The aim is not to ask the participants directly to enter into a fantasy phase but use intermediary tasks that can aid the fantasy of the participants. In the literature is emphasized the relevance of making participants share personal experiences as a start for boosting future envisioning [9][41][44][46][55][56]. The teaser of future envisioning should build on personal experiences that make the participants think about the future.

Another important element for surpassing the challenge in envisioning future solution was the usage of cues in the form of written text cue cards (WO3_6) or cue cards with pictures (WO3_11). The usage of visual cues is recognized in the literature [41][42][55][59].

What we found interesting in our workshops was trying out the power of exemplars as a way to enhance creativity (WO2_9). The usage of examples of designs as a means to aid the fantasy of people with MACIs needs more consideration and further study. However, we can state that it was helpful for our participants who had different aspects of MACIs. It aided their creativity by making them think outside of the box. We observed that the exemplars presented in the form of amateur and not finished designs helped the participants relate more to them and feel more confident in designing themselves as they noticed that no finished and polished designs were expected by them.

In [9], using fictional characters has been defined as useful in envisioning future solutions. However, our participants seemed not to be keen on that. They wanted to be represented and talk about themselves instead of a fictional person. This is also related to rehabilitation theories where patients are motivated to accept and embrace their new selves.

In the literature, providing more hands-on activities and collective prototyping [55][58][59] is seen as contributing to participants' ability to envision a future solution. We experienced that for MACI patients, the envisioning process required a break down into smaller activities that could help the patient create a bigger picture by putting the pieces in each smaller activity together. This is similar to the memory rehabilitation theories [25], which suggest breaking down an activity in smaller steps and train each of the steps slowly, adding one step at the time. Using activities that are familiar is as well helpful to consider in techniques with MACI patients similarly to the findings from the literature [9][55][59].

Another challenge that people with cognitive impairments face is abstract concepts [41][50][59] (DG_M2). From our cases, we found that MACI patients also have a fear of sketching and the white paper syndrome, hesitating to draw. Based on this, designing more narrowed down (WO2_6) and structured activities (WO3_12) and tell personal stories or personal opinions (WO1_14) can help in surpassing the challenges of MACI patients with abstract concepts.

We also found that people with cognitive impairments are keener on getting involved in designing solutions that are interesting, valuable, and have a real purpose [9][44][63]. We have highlighted the same point in WO3_8 reflection.

Another element to consider in deciding about PD techniques to apply with MACI patients is to provide alternative activities that can support all the participants to engage [9][48][50][65][66] (DG_M7). With the MACI

patients, we found that it is important to make an appeal to the individual participants' abilities (WO1_15). Moreover, alternative ways to present the tasks are needed, so it fits the patients' needs. MACI patients experience an increase in the time needed to perform activities. This is called the tempo of performing activities. Adapting to MACI patients' needs in the tempo of activities is very relevant for assuring that patients do not feel overwhelmed and rushed.

In DM_8 we found that it is relevant to consider activities that are flexible and empathic enough to adapt to the needs of the group, for example, activities that can help create a friendly environment [44][46][67], activities that can boost participants self-esteem and confidence [52][68], and activities that can include an element of playfulness [42][52][55]. We experienced that being flexible was required when working with MACI patients. Moreover, serving coffee and biscuits during the breaks helped to create a friendly environment. One of the patients made a video in workshop 5 and shared that with us to express his enthusiasm.

Regarding techniques, we have the following guidelines for conducting PD with MACI people:
1. Having a task-oriented approach where more complicated activities are presented in small steps that build on each other.
2. Having a narrowed scope for the PD sessions and not distracting people with MACIs with general questions.
3. Using cues that can support future envisioning. It is important to consider different ways of presenting the cues. Both text-based and images are useful. The cues should be open so they can offer the possibility for personal interpretations from the participants in the PD workshops.
4. Introduce in workshops "the teaser of future envisioning" and activity that builds on people with MACIs current experiences and ask them to think how these specific experiences can be improved in the future.
5. Take into consideration using exemplars that present examples of what the MACI people are expected to do.
6. Use positive rhetoric when asking for critical opinion. The aim is to not influence MACI people to enter in a negative mindset.
7. Prepare alternative activities that can include all the participants in the workshop independent of their disability.
8. Create a friendly environment by showing empathy and respect toward participants' experience.
9. Involve MACI people in PD projects that are relevant and interesting for them.
10. Structure the activities as much as possible so it can be easier for the MACI people to conceptualize.
11. Try to avoid fictional characters in the design process. MACI people prefer to refer to themselves in the design.
12. Adapt to the MACI people's tempo while conducting activities in a PD session.
13. Be flexible to changes activities, drop activities, repeat the explanation of activities based on the needs, and the requirements of the MACI people involved in the PD session.

## D. Facilitators

The literature emphasizes that one of the facilitators' responsibility is to explain clearly the purpose of the events and the role of the participants [9] (DG_F1). Similarly, this was important with the MACI patients were repeating the aim of the event in a clear language, and having it printed out during workshops 4 and 5 helped the participants stay focused and contribute significantly to the workshops. Moreover, the facilitator should try to appeal to the patients' challenges (WO_10) by highlighting that not everyone is perfect [9][69]. The MACI patients all come from a life without their current disability. Thus, making them feel good by emphasizing that the challenges are common among other people without the ABI can break the ice.

The literature also emphasizes that the facilitators should incorporate structure and review in activities [9][2][43][46][54][59] (DG_F3). They should give time to participants to know each other, have the possibility to repeat, and review parts of the workshops. With MACI patients, this was very relevant. The facilitator should also consider having a slower tempo to adapt to the patients' ability to process information.

Moreover, trying to minimize distraction and keep participants focused [9] (DG_F4) is also a challenging task when working with MACI patients. This can be supported by having more structured and narrowed down workshops where patients have short and clear tasks to perform.

One important finding from our work can be found in WO1_18, the involvement of the "knowledgeable third party" as a facilitator in the workshop. Considering the variations in MACIs, it would be impossible for a designer to be able to have the ability to communicate properly with every variation of cognitive impairment. A person that is specialized for working with MACI patients can support communication. Moreover, in the digitalization project, we saw the knowledgeable third party not only facilitating communication but also leading the PD sessions. This was the result of a long mutual learning process in which the designer and the knowledgeable third party had been involved throughout the "redesign" and "digitalization" projects described above. However, involving the knowledgeable third party and the number of facilitators in a session, in general, should be balanced to the number of participants in order to avoid putting MACI patients in the spotlight.

Regarding Facilitators, we have the following guidelines for conducting PD with MACI patients:
1. Involve a knowledgeable third party as a facilitator for facilitating communication and ultimately leading the sessions.
2. The facilitators should explain clearly the purpose of the events and the role of the participants for each part during the workshop.
3. The facilitators should incorporate a structure in the activities and the review of the activities.
4. The facilitators should enclose some personal information about themselves.
5. The number of facilitators should be balanced with the number of participants so the facilitators can devote more time to each of the participants or participants

groups and ask in-situ questions to uncover meaning in the ideas or provoke new ideas.

### E. Participants

Using participant groups with few members is suggested in conducting PD with people with cognitive impairments [2][9][46][52]. This is also true for MACI patients. A number of 4-5 patients were suggested by the domain experts to be a good group size. The duration of the workshops should be short and adapted to the number of participants involved. Thus, enabling everyone to have a say and to not rush the slow tempo of some of the MACI patients. In DG_P1, the guideline is to consider one to one group work in PD sessions with people with cognitive impairments [9][54][71]. Moreover, Yaghoubzadeh, Kramer, Pitsch, and Kopp [70] state that cognitive impairments could be challenging for working in groups. From our reflections (W02_13), we found that participants had experience and worked well in a group. They were able to build on the ideas of others while still keeping their stand if they had a different opinion. The benefit of group work is also compatible with the rehabilitation theories, where group therapies are considered very effective [24][25][84]. However, we stated that not all MACI patients have the same abilities. When working in groups, it should be the facilitator's responsibility to give the same time, attention, and possibility to everyone.

Another guideline from the literature is to pair persons with different deficits into one subgroup [9]. This aims to surpass challenges in individual deficits by working as a group and contributing each with their abilities. In our experience, we noticed that participants who had different cognitive impairments, but the same functioning level could work better in the same group (W0_12).

The literature also recognizes the involvement of caregivers as support in conversation with participants [2][9][41][51][59]. In our case, we had direct caregivers as participants in the same workshop with the patients. Caregivers have usually been involved in the design process as patients' proxies for patients with some forms of cognitive impairments. MACI patients have the capacity to be involved and speak for themselves. Using caregivers as proxies is useful when the user group being represented in not able to be involved. In the MACI patients' this is not the case. In PD with MACI patients, domain experts can support the process of planning the work with patients and make sense of the patients' needs. Meanwhile, MACI patients can participate in PD activities.

In the digitalization project, an MACI patient and a therapist had to work together in making the storyboard. All seven pairs in both workshops 4 and 5 had a good collaboration. Thus, involving in a PD project as participants, both the MACI patients and the therapists in designing digital solutions can result in a positive experience.

Moreover, the literature discusses the elimination of usability problems with the carers of the patients [4][9] and using persons who do not suffer from a deficit to get rid of general design problems [2][9]. In our reflections, we found that the participants in workshop 2 with a milder ABI had the possibility to contribute more in design details.

The literature also highlights the need to involve the kin and the family in the design [73][74] (DG_P6). We have not experienced this in our cases. However, we want to argue that the involvement of the family members or kin should be done only when it is necessary, and the solution designed involves them as well. One of the patients in the workshop, when asked about family involvement, said: "I should decide if I should involve my family".

Regarding Participants, we have the following guidelines for conducting PD with MACI people:
1. Involve participants in group activities where they can work on their own and together with others.
2. Consider a small number of participants for a short period of time.
3. Involve a "knowledgeable third party" to support the conversation with the MACI participants.
4. Use persons with milder cognitive impairments for exploring design details.
5. Promote the involvement of family members as participants only in the design of the solution that involves them and when the MACI person agrees.

### F. Analysis

Hendriks, Truyen, and Duval [9] suggest that the researcher should try not to over-analyze the utterance of the participants. Moreover, they suggest being critical to the representativeness of participants. These guidelines are also useful when designing with MACI patients. However, from our experience, we suggest that the reflexive analysis can benefit from the involvement of a team from different disciplines. This can also eliminate the problem of over-analyzing the utterance of the participants because a caregiver can take things less seriously than a designer that is new to the patient group.

Furthermore, implementing a structured reflection on the action right after the workshop where the facilitators reflect on the workshop in general, tools, techniques, participants, and their behavior can be very relevant to the analysis later because it captures the feelings at the moment, which often can pass undocumented.

Regarding Analysis, we have the following guidelines for conducting PD with MACI people:
1. Try not to over-analyze the utterance of the participants.
2. Have a critical attitude toward the representativeness of participants.
3. Involve people from different disciplines in the analysis, especially rehabilitation specialist in MACIs.
4. Incorporate a reflection-on-action structure among the facilitators right after the workshop.

### VIII.    CONCLUSION

In this paper, we present a set of guidelines for researchers and designers to conduct PD with people with MACIs. We have initially presented in Table 1 a summary of guidelines drawn from previous studies of conducting PD with people with cognitive impairments. Then, we have presented two PD projects that we conducted with MACI patients and presented a set of reflections from each of the workshop outlines we

have been working with. The reflections have been further discussed in regard to the existing literature, and finally, a set of guidelines for conducting PD with MACI people has been introduced. While the guidelines are the final outcome of the paper, the rich description of the reflections-on-action is also a contribution to PD, which put emphasis on the situated knowledge generated in PD workshops. These rich descriptions in some cases are even more relevant to PD because they represent a story derived from the experience of the PD researcher that has conducted the study and highlight things that are usually overlooked on more formal guidelines. Hendriks, Slegers and Duysburgh [85] state that a good way to go forward on a codesign approach for people suffering from some form of impairments is "*facilitating researchers and designers to share experiences, best practices, lessons learned, and so on ...in the form of method stories*"

People with MACIs compound a significant part of our society. This is increasing with the increase in the tempo of life. People are more in danger of accidents and consequently are at risk of having more accidental brain damage. In people with MACI in many cases, there are no physical impairments. MACI people work, go to school and try to live their life to the fullest. However, their daily life is challenging due to fatigue, memory problems, attention problems, loss of executive functioning, etc. Thus, they need to adapt their lifestyle to their new self and make use of aids to keep up with daily life activities. Technology can help in assisting MACI people.

In designing these new technologies for them, we need to involve the MACI people in design. They can significantly contribute to the design if the right means for enabling their contribution are provided. That is what we want to achieve with this paper.

We contribute by giving PD practitioners a list of guidelines for working with MACI people. Moreover, through these guidelines, we aim to make technologists turn attention to the MACI people and design more supportive technologies for them.

The number of participants involved in our study is small in comparison to the heterogeneity of the MACI people group. Our guidelines are not a final list, and we hope that more researchers will investigate on this user group and expand our lists. These guidelines are in the form of recommendation, and they should be combined based on the situation at hand, in which PD researchers and designers critically reflect on what can be adapted in their specific case and what not and what is the consequence in the PD process if one of the guidelines is not taken in consideration.

In the future, we will continue testing our guidelines in further projects with this user group. Additionally, we want to investigate how to involve more digital tools in designing together with MACI people and how we can involve in the best way possible the MACI people in the co-development of different types of digital tools meant for them, besides the cases presented in this paper. Furthermore, we want to investigate how much are the MACI people willing to participate in PD practices, and where do we, as researchers and designers draw the line.

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