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D7.1- Methodology for Measuring Social Integration

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Abstract: This report aims at providing a methodology for the assessment of MAMEM's impact on social participation and integration of persons with disabilities. It identifies the challenges and repercussions of social inclusion and exclusion of persons with disabilities and defines a portfolio of digital and social inclusion indicators which are relevant and pertinent to them. Further, it suggests statistically validated, robust and mutually consistent metrics for each of the digital and social inclusion indicators. Finally, it proposes a research methodology for monitoring social integration, which unfolds in two stages. In the first stage benchmark data on digital activity and social integration are collected, while in the second stage shifts and changes in the indicators following MAMEM training and usage are monitored and studied.

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Executive Summary

D7.1 performs a literature review on the different aspects of social integration and suggests the methodology and associated indicators that will be used for measuring the impact of MAMEM on the social integration of its patient cohorts.

The proposed methodology seeks to measure social inclusion pre and post usage of MAMEM. It proposes a methodology to reliably measure the impact of MAMEM on indicators that have been validated through research, and to track which digital activities are significantly correlated with the impact of MAMEM on social inclusion.

In addition, D7.1 presents a model for quantifying the impact of MAMEM on social inclusion in a sample of individuals with SCI, NMD and PD disability. This model integrates indicators over three axes of social inclusion outcomes: a) participation and social capital, b) education and employment attainment, c) empowerment and subjective well being.

A set of digital inclusion activities are specified to correspond in each of the aforementioned axes of social inclusion. In the context of the proposed research methodology, in pre and post MAMEM usage measurements, shifts in the social inclusion indicators will be studied and will be evaluated against shifts in the digital inclusion activities.

Finally, based on the literature review on social and digital inclusion indicators, D7.1 explains the research hypotheses that have been adopted in MAMEM and specifies the methodological and research tools that are necessary to quantify social integration.

Abbreviations and Acronyms

API	Application Programming Interface
BCI	Brain Computer Interface
ICT	Information Communication Technology
NMD	Neuro Muscular Disorder
PD	Parkinson Disease
SCI	Spinal Cord Injury
WWW	World-Wide-Web

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1 Introduction

Up to now great effort has been made to enable people with disabilities to become physically integrated in their environments, by widening as much as possible their physical access to life in and out of home (Venter, 2001). However, physically integrating the people with disabilities is very different from integrating them culturally and socially. The objective of MAMEM is to provide the means for people with disabilities, which will allow them to participate in social life around them, to communicate, to develop relationships and fulfilling, productive lives.

MAMEM is meant to be a tool that will reinforce the ability of people with disabilities to exercise control over their life and experiences, by having full access to the richness of digital resources, especially those relevant to health, education, financial independence, and community participation. This social inclusion through the MAMEM platform is meant to offer a sense of personal value and meaning, as well as a sense of reachable prospects towards improving one's self and one's life and social environment. Thus, MAMEM platform is intended to offer the ability to people with disabilities to conduct multimedia authoring and management, so that they may have access to a wide digital landscape of creativity, social networks and relationships.

The MAMEM platform is targeted towards improving computer communication aspects and enabling social interaction and participation in persons with disabilities. This report reviews the literature on social and digital inclusion and proposes the relevant indicators that need to be considered in studying the impact and effects of MAMEM. These indicators will be used in tracking how the usage of MAMEM has improved the way persons with disabilities build relationships and interactions and make optimal use of resources and support systems online.

It describes a methodology through which digital inclusion indicators may be measured before and after the usage of the MAMEM platform, and describes how digital activity consecutively impacts social inclusion and participation. The main result of this deliverable is:

a) The definition of digital and social inclusion indicators and a rationale substantiating their use in the MAMEM evaluation research. The prerequisites for the appropriate specification of these indicators are also described.

b) The description of a set of hypotheses regarding the impact of MAMEM as measured by the digital and social inclusion indicators.

c) The description of methodology through which these indicators can be evaluated.

d) The presentation of the scope, structure and questionnaire tools of the social inclusion research methodology.

In this report, a social definition of disability will first be established as a foundation for the MAMEM impact on social inclusion. According to the social model, disability is a socially constructed experience, rather than solely a matter of a physical impairment. Further, the issues of social inclusion that have been tracked and studied in the relevant literature will be outlined. The notions of social capital and social quality, as fundamental to the experience of social inclusion will be discussed. Digital inclusion will be analysed as a vehicle to social inclusion. The literature on social and digital inclusion indicators will be reviewed and the indicators pertinent to the study of MAMEM impact will be outlined. Finally, research hypotheses will be charted on how the usage of MAMEM influences social and digital inclusion indicators, and a research methodology will be proposed addressing a sample of persons with PD, NMD and SCI disabilities.

2 The definition of disability

The purpose of MAMEM is to succeed in having a profound effect in how persons with disabilities become integrated in the society and have full and continuous access to all the resources and support systems they need, in order to have a fulfilling life and a rewarding sense of self identity. The appropriate indicators that can best evaluate the social effect of MAMEM will have to be grounded on a foundation that defines disability with social rather than strictly medical and/or physical parameters. Indeed, a definition of disability that not only includes, but is based on the social isolation dimension would have far reaching implications. It means that disability is no more a product of the physical dysfunction, but of the social and emotional isolation that this dysfunction causes. Once this isolation is minimized, then the significance of the physical dysfunction in curbing options and opportunities also becomes minimized. The social model will, thus, be used here, to define disability and to serve as a compass in specifying the social inclusion indicators.

2.1 The precedent of the medical model of disability

For a long time the medical model prevailed in considerations of disability. Rimmerman (2013) presents an analysis of this model as one where disability is conceived of as part of a physical incapability and/or illness process, as an abnormality and as an individual tragedy. The medical model emphasizes the deficit of the person, often assigning descriptions like: “unable”, “incapable” or “unproductive”. In the context of the medical model, people with disabilities have been viewed by society as officially exempted and excluded from the mainstream. The core terms used as indicators for disability within the medical model, according to Rimmerman’s analysis, have been “impairment” and “handicap”. Impairment has been defined as, for example, the loss of a limb, or the presence of a dysfunctional limb, organ or body part. “Handicap” has been interpreted as loss or reduction of one or more functional abilities (mainly related to self care). According to the International Classification of Impairments, Disabilities and Handicaps (ICIDH) published by the World Health Organization (1995), the medical definition of disability is based on four principal events: (1) something abnormal occurs within an individual; (2) someone becomes aware of this occurrence; (3) the performance or behavior of the individual may be altered as a result, and (4) and finally, the awareness itself, of the altered performance or behavior to which this gives rise, may place this person at a disadvantage relative to others. This succession of events, from an internalized to an external experience, culminates in the person experiencing their disability as a social disadvantage, in terms of loss of functionality, restriction or ability to perform an activity in the range considered normal for other people, or a limitation or prevention of the fulfilment of a role that is normal (depending on age, gender and social and cultural factors) for that individual.

The impact of the medical model of disability is far reaching:

1) It impacts **self identity.** Seale (2001) notes that delimited identity among people with disability may be an outgrowth of the medical model, and the perception of “handicap” or “impairment” becomes a self fulfilling prophecy as to what is believed to be possible, when it comes to social

participation, to establishing relationships, personal, social and employment interactions.

2) Moreover, the medical model impacts the **motivation to strive** and work against any possible hurdles that create challenges in social participation. Riddell, Baron and Wilson (2001) postulate that people with disabilities often have a limited range of identity characteristics to choose from, in forming their self concept, because of societal labels and ascriptions stemming from the medical model. This inevitably affects the life choices and future aspirations of people with disabilities.

2.2 The social model

The social model of disability has called for a paradigm shift. That is, a shift from disability being viewed as an individual's impairment to considering disability as a socially constructed experience. The social model arose in response to the shortcomings of the medical model. It was Nagi (1991) who first departed from this medical definition of disability and sought to establish an alternative one. He was the first researcher who disagreed with the assumption that the presence of impairment was enough to determine disability. According to Nagi, disability is an "expression of a physical or a mental limitation in a social context, a gap between the individual's capabilities and the demands created by the physical and the social environment". Nagi added the social perspective by stating that disability refers to "social rather than just organismic functioning" (Nagi, 1991). In this sense, according to Nagi's interpretation, disability can be defined in terms of the functional limitations it produces relative to the demands posed by the environment. According to Jaeger and Bowman (2012, pp.17 – 25) persons with disabilities could be identified by the presence of two unifying and interrelated factors: 1) They have an on going physical or mental condition that society considers unusual; 2) They face discrimination and exclusion as a result of having a condition that society deems unusual and this condition prevents them from accessing opportunities. For Masala and Petretto (2008) the term disability includes environmental, structural and attitudinal barriers that impinge upon the lives of people with physical impairments. These barriers include, for example, the lack of access to education, lack of access to sought after information, to communication and support systems, to employment and income options. The social perspective "makes it possible to see disability as the effect of an environment hostile to some bodies and not others, requiring advances in social justice rather than in medicine" (Siebers, 2001, p. 738). Beliefs and functions that marginalize and disempower persons with disabilities can then be seen as impediments to living to the fullest of their abilities. Under the social perspective, discrimination against individuals with disabilities, which is sometimes identified as "disablism", is viewed as similar to sexism, racism, homophobia, and ageism as oppressions of particular groups based on social, political, and economic forces (Abberly, 1987).

2.3 The implications of the disability models for MAMEM

The goal of MAMEM is to contribute in achieving a major shift in the "incapability" paradigm that has coloured the disability experience up to now. It seeks to provide people who experience functional, physical limitations, with a full access to opportunities for social interactions, cultural participation, knowledge expansion and employment prospects.

MAMEM purports to offer a solution to the inaccessibility or exclusion from the digital landscape, and to offer an answer to the way the design of current electronic devices make it tiresome and even painful to access the digital world and the digital opportunities for social participation.

3 Social Inclusion

3.1 Social inclusion definitions

A pertinent definition of social inclusion addresses not only social participation and an adequate share of available resources, but also participation in the determination of both individual and collective life chances (Stewart, 2000).

By contrast, social exclusion is the process in which individuals or entire communities of people are systematically blocked from (or denied full access to) various rights, opportunities and resources that are normally available to members of a different group and which are fundamental to social integration within that particular group (Silver, 1994). Social inclusion, the converse of social exclusion, is affirmative action to change the circumstances and habits that lead to (or have led to) social exclusion. Relevant to disability, the World Bank defines social inclusion as the process of improving the ability, opportunity, and dignity of people, who may be disadvantaged on any basis, to take part in society (World Bank, 2013). And the digital landscape offers a very wide span of social interactions in a very compact form.

3.2 Social inclusion and social capital

Social inclusion generates social capital, that is, resources accrued to individuals by virtue of their access to contacts, connections and linkages. Putnam (1995, p.67) defines social capital as the "features of social life – networks, norms and trust – that enable participants to act together more effectively to pursue shared objectives". Social capital recognizes the importance of networking as a viable asset. Therefore, people who can expand their networks and use them effectively are considered as having social capital (Bourdieu, 1986). In fact, social capital can be described as an aggregate of the actual or potential resources that are linked to the possession of an enduring network of relationships of mutual acquaintance and recognition (Ostrom, 2009). It may exist only in practical terms (i.e., in material and/or symbolic exchanges, which help to maintain them), or it may be socially instituted and guaranteed through a family, a class, a school. Moreover, it can be "virtual" social capital, through online networks. The digital environment is the widest possible incubator that can generate such "virtual" social capital. People who can access information and who can interact with this information will eventually evolve to be more resourceful and more creative in producing their own solutions and in improving their own life (Ostrom, 1999). Social capital and social inclusion/social exclusion are significant concepts in human services but their interrelationship remains largely unexplored. They may overlap or be used interchangeably to refer to the interface between material, personal and social assets, resources and society (Daly and Silver, 2008).

3.3 Forms of social capital

Paxton (1999, 2002) and Putnam (2000) first proposed the definition and measurement issues of 'bonding', 'bridging' forms of social capital.

Bonding social capital relies on strong ties between people. It is inward focused and characterized by homogeneity, loyalty and exclusivity. Bonding social capital has a significant downside, as a

tightly knit homogeneous community might be one intolerant of individual diversity, asphyxiating to live in and exclusionary to outsiders (Baum, 1999). With regards to people with disability it can be hypothesized that this type of social capital provides a sense of belonging and a sense of security.

Bridging social capital, links diverse groups and people. It is characterized by weak ties, has an outward focus and is likely to foster social inclusion. It is commonly recognized that this form of social capital is useful for finding employment (Stone et al., 2003). As employment is key to many conceptions of social inclusion (Stewart, 2000), it can often mean the difference between 'inclusion' and 'exclusion' for some people and especially those with disabilities.

Vertical social capital is often distinguished from **horizontal social capital** by virtue of the connections being made within a hierarchical structure to government and other institutions, while horizontal social capital (bonding and bridging capital) develops within and between communities. Vertical social capital provides a community's institutional integration and, together with horizontal forms of social capital, equates to an inclusive and cohesive society (Berkman, 2005). With regards to people with disability, access to vertical social capital (over and above horixontal social capital) even just online, can be instrumental to health and quality of life prospects, because vertical capital provides access to sophisticated medical care and possibly financial resources to support it.

3.3.1 Social inclusion and social quality

Beck et al. (2001) have proposed an additional overarching conceptual framework of "social quality", defined as: "The extent to which citizens are able to participate in the social and economic life of their communities, under conditions which enhance their well-being and individual potential". Social quality as defined by Beck et al. is a wider concept that incorporates social inclusion. Social quality is associated with four specific benefits:

1. Social–economic security (protection against unemployment, poverty, ill health and other material deprivations).
2. Social inclusion (equal access to supportive infrastructures, labor conditions and collective goods).
3. Social cohesion (the availability of social networks, equal access to services).

Social quality, defined thus, is relevant to people with disability, in that their speed, agility and efficiency in accessing supportive infrastructures, goods and resources may well be strengthened or hampered relevant to their ability to access the internet effectively.

3.3.2 Social inclusion indicators related to disability

Research on social inclusion and social exclusion of people with disabilities is fairly new. Most of the new studies offer selective relative indicators to measure the gaps between people with and without disabilities.

One of the most comprehensive efforts in examining indicators of social inclusion among people with disabilities was carried out by Kessler/NOD (2010). A series of surveys were conducted

comparing their status to those without disabilities using ten indicators such as employment, income, education, healthcare, access to transportation, socializing, dining out in restaurants, attendance at religious services, political participation and life satisfaction. The primary purpose of this research was to measure the size of the gaps of these indicators between people with and without disabilities. Large gaps were observed in employment, household income, access to transportation, healthcare, socializing, dining out in restaurants and satisfaction with life. Most of the unemployed attributed their restricted patterns of participation to the lack of adequate financial resources, accessible transportation and encouragement from community organizations. The fact that the survey was conducted during a significant economic downturn might explain the low employment rate, poverty and reduction in consumption. Beyond that, findings indicate that employment and community participation patterns may reinforce each other and serve as useful vehicles for promoting social integration for people with disabilities into their communities.

According to the U.K. Office of National Statistics (Labor Force Survey, 2007), about half of the people with disabilities do not work compared to 20 per cent of people without disabilities. Unfortunately, even people with disabilities who are employed have significantly lower incomes than their non-people with disabilities peers. In addition, they are more likely to work in lower skilled and low-paying jobs.

The UK Labor Force Survey of 2007 showed that about a 25 per cent of people with disabilities at working age had no qualifications compared to 11 per cent of people with no disabilities. Young people with disabilities were twice as likely not to be in any form of education, employment or training as their non-disabled peers (15 per cent opposed to 7 per cent), while at the same time the percentage of jobs requiring no qualifications was decreasing. In the sample of people with disability used in the context of the D6.1 (D6.1, MAMEM Consortium 2015), about one in three participants had an income from employment, and not from a pension or from family support.

Azaiza et al. (2006) examined whether employment was positively correlated to social participation and sought to identify the perceived barriers using a random national sample of 597 non institutionalized, working-age Israelis with disabilities. Core findings indicated that employed people with disabilities were significantly more integrated into social and civic activities than the unemployed. While most of the unemployed attributed their restricted patterns of participation to the lack of adequate financial resources, accessible transportation and encouragement from community organizations, the employed reported lack of time as their main barrier. The above findings suggest that employment and rich community participation patterns may reinforce each other and may serve as a useful vehicle for promoting social integration for people with disabilities in their communities.

Araten – Bergman and Stein (2014) studied 274 participants with self-reported disabilities who completed a questionnaire containing measures of individual social capital, community participation, well-being, and background data. Employed participants reported significantly higher levels of social capital and were more integrated in various in and out of home activities than their non-employed counterparts. Moreover, employment status was found to have a significant contribution to how subjective well-being of participants varied. MAMEM might prove

instrumental in allowing people with disabilities to make the most of employment and/or income opportunities in the online market and job spaces.

Having a disability shapes a person's psychological state, being influenced by external events (the way one interacts with people and is included) and internal events (how one thinks and feels about oneself, as in terms of a disability, and in terms of self identity and self esteem). Gill (1995) has suggested that people with disabilities tend to share certain personality traits:

- Accepting human vulnerability and recognizing the need to help others.
- Handling uncertainty and unpredictability.
- Finding the humor in disabilities and the problems caused by them
- Managing multiple tasks simultaneously
- Being highly oriented toward future goals and possibilities
- Being very sensitive to closure in personal communication
- Being flexible, creative, and inspired in situations of limited resources or nontraditional modes of operation.

Clearly, many of these traits are helpful in dealing with the unique everyday life experiences of a person with a disability. Though not every one with a disability will possess all of these characteristics, many people with disabilities have developed some or all of these traits as a means of surviving and thriving in society. MAMEM is anticipated to reinforce and strengthen these qualities, and to facilitate their expression, by offering persons with disabilities a much wider spectrum of personal expression, participation and interaction.

4 Digital inclusion as a vehicle of social inclusion

4.1 The digital barrier among people with disabilities

As proposed by the social model of disability, it is not just the physical impairment that is relevant, but most importantly the consecutive socially constructed limitations in asserting an independent life and socially fulfilling roles and interactions (Rimmerman, 2013). One such limitation is that of being excluded from digitally available resources and connections. Seale, Draffan and Wald (2010) define digital exclusion as a phenomenon whereby marginalized individuals are not able to access and meaningfully participate in the same learning, employment, social, volunteer activities as others who have access to and use of digital devices like computers and smartphones.

Moreover, the design and structure of digital devices has consistently neglected the specific needs of persons with disability (Goggin & Newell, 2000; Kanayama, 2003; Ransom, 1994). This has meant that unless provided with specific assistive technologies, many persons with disabilities are significantly excluded from digital environments (Stephanidis & Savidis, 2001). At this point, extensive usability testing is performed on digital devices to ensure an easy, convenient, and accessible user experience. However usability tests are not enough in considering the needs of persons with disabilities (Keates & Clarkson, 2003). As digital technologies and the world wide web continue to become more important in everyday life, equal access to digital devices will continue to grow in significance. Until the needs of persons with disability become a regular, on going consideration at the root of software and hardware development, MAMEM development focuses on being a fully accessible, agile and efficient link with the digital space.

4.2 Linking digital advantage with social advantage

The relationship between access to and use of computer and smartphone devices and social inclusion is not circumstantial. Studies show a causal relationship between social and digital exclusion. Anderson (2005) is one of the few researchers to have addressed this issue through a longitudinal study, however, he showed that other factors outweigh the importance of the use of digital communication devices in influencing quality of life. Secondly, interventions that introduce digital communication devices (by educators, policy makers, NGOs, etc.) are often poorly recorded and evaluated. While academic research has progressed towards recording different levels of engagement with technology, it approaches the issues from a pure “user”–“non-user” perspective. Moreover, there is very little theoretical development regarding the exact nature of the links between digital and social exclusion. While social exclusion definitions have been written up and discussed intensively by sociologists and economists, however, they are rarely linked to similar measures for digital exclusion. The results of a study into “Social Disadvantage and the Information Society” by the Oxford Internet Institute (Helsper, 2008) point out that there is a strong, statistically significant association between the social disadvantages an individual faces and their inability to access and use digital services. Those who are most deprived socially are also least likely to have access to digital resources such as online services. Those who suffer deep social exclusion are up to seven times more likely to be away from the Internet than are those who are socially advantaged.

4.3 Literature review on digital inclusion indicators

4.3.1 Indicators of digital / ICT usage

Bradbrook and Fisher (2004) advocate the '5 Cs' of digital inclusion:

1. **Connectivity:** access to software, which, in this case, will become greatly facilitated by the use MAMEM.
2. **Capability:** the skill that an individual develops with digital technologies (and the skills of their social environment respectively).
3. **Content:** both accessing and generating content.
4. **Confidence:** feeling self confident in digital and internet spaces.
5. **Continuity:** establishing rewarding and efficient digital habits and routines, on an ongoing, continuous basis.

Indeed, continuity, is related to Dutton's (2007) idea of the Internet and other digital technologies as part of the infrastructure of everyday life. Digital technology becomes part of the tapestry of life moment by moment, across locations and across time. Digital technologies capture connections, expressions, interactions, tasks, carried out over multiple interconnected screens. Anderson (2005) describes how digital inclusion often fails to incorporate this idea of continuity especially in groups that are vulnerable to social exclusion because of physical constriction and isolation. People tend to 'dip in and out' of technologies such as the Internet, depending on their physical and/or everyday circumstances. However it is one thing to "dip" in an out of the digital environment and another thing to be altogether excluded from it because of disability. Surveys (Dutton and Helsper, 2007) show clearly wide differences between fully engaged users, the in-out users, and those who have never used the Internet. In the literature, three patterns of digital participation are discussed: 1) the usage gap, 2) the second level digital divide, and 3) digital inclusion.

The usage gap: Van Dijk (2005) has argued that access problems of digital technology gradually shift from material access, to skills and usage access. When the problems of material access have been solved, and ownership of digital devices is secured, the problems of skills and uses come to the fore. Van Dijk proposed defining digital skill not only as the skill to operate computers and network connections, but also as the skill to search, select, process and apply information from and interact with a superabundance of sources and the ability to strategically use information and networks online to improve one's position in society. They are called instrumental, informational and strategic skills respectively.

The second level digital divide: The term became popular in the late 1990s describing those with or without access to information and communication technologies. It became popularized in OECD reports (2001). Hargittai (2002), Correa, (2008), also refer to this as the production gap. The second level digital gap is the one that separates the consumers of content on the Internet from the producers of content (Reilly, 2010). New applications have made it possible for anyone with a computer and an internet connection to be at minimum in interaction with others, and at best a creator of content, yet the majority of user generated content available widely on the Internet,

like public blogs, is created by a small portion of the internet using population, and people with disabilities are even further from this contribution (Reilly, 2010). The "emerging digital differentiation" conceptualizes digital divides as recursive, and thus dynamic phenomena (van Dijk, 2002; van Dijk and Hacker, 2003). If gaps close at one stage, they open at another. For example, if Internet usage gaps are bridged, Internet skill gaps or internet content generation gaps show up.

It will be important to track the ease in which the people with disability will trust MAMEM and will persist in their effort to make optimal use of it and even "exhaust" its potential to ease and facilitate their use of the Internet.

"Digital inclusion": Crandall and Fisher (2009) see digital inclusion as a prerogative of the twenty first century. They claim that digital inclusion goes beyond access to computers and the internet for all, regardless of physical, cognitive or financial ability. It means technological literacy and the ability to access **not only** relevant online content but **also** services, resources and opportunities. Hache and Cullen (2009) extend the definition by arguing that digital inclusion is the process of democratization access to ICT. The authors claim that digital inclusion should be seen as a wagon to social inclusion that ensures individuals and disadvantaged groups, like people with disabilities, have access to, and skills and self confidence to use ICTs and are therefore able to participate in and benefit from electronic mediated growing knowledge and information society. The above point out that the concept of digital inclusion needs to be considered side by side with social inclusion in a cause and effect relationship. The measurement of social inclusion needs to be statistically evaluated and indeed correlated with digital inclusion.

In the case of MAMEM, it will be important to track the extent to which MAMEM becomes an enabler of social relationships, by making it possible for people with disabilities to extend their network of contacts, to come across new opportunities for learning or for income, and to experience a sense of belonging to a community, despite their physical constraints.

4.3.2 Indicators of digital / ICT use impacting social inclusion

Access and use of digital devices provide an opportunity for people with disability to communicate and interact with others and gain a sense of equality and inclusion. Bowker and Tuffin (2002) interviewed people with disability to explore the meaning of "choice to disclose" in online media. They found the flexibility of online media provided control over people with disability's disclosure of impairment, an opportunity not typically available in real world social interactions. They could communicate through online media, without the element of their disability becoming disclosed, and without it becoming an element in interaction and communications. The authors described this as "normalization". The affordance of "normalization" enables people with disability to be included and treated as equal by their non-disabled peers.

The D6.1 (D6.1, MAMEM Consortium, 2015) findings showed that people with PD, SCI and NMD disabilities often take longer to use typical software like Word, Email, Skype. Moreover, they often tire easily and they may engage in online activities for less time than intended, because of fatigue. The sheer difficulty in using digital devices allows no "choice to disclose". They carry their

"disability identity" online as well, by virtue of being slower than an average user. MAMEM promises to speed up and ease the use of digital devices, thus offering people with disability the option of "normalisation", described by Bowker and Tuffin (2002).

Online communities have shown to be a success for those with a disability (Bradley and Poppen, 2003). Based on a one-year follow up questionnaire, their study indicated that those communicating with the help of ICT discovered a new sense of friendship and show significantly reduced isolation. People with disability find online self-help groups and blogging important for feelings of inclusion. McClimens and Gordon (2009) conducted a study in which people with intellectual disability were introduced to, and trained in writing blogs over six meetings. The authors stated that the participants experienced a new form of inclusion and empowerment when able to express and share their thoughts and feelings online.

The intention for MAMEM is to solve a core issue that people with disabilities have currently (even when they are willing and able to communicate digitally and to establish online relationships and networks), which is the ability to overcome the physical constraint of fatigue that results from having to use muscle operated devices. Today, policy makers are becoming more and more determined to make physical public spaces accessible to people with disabilities. Appropriate elevators and ramps can be found in most public buildings. Digital public spaces are just as real. However, up to now, policy makers are not taking into account the barriers created by muscle operated digital devices, in people whose muscles are not as functional any more. We need to perceive WWW as a space to which every human has a right to full and unencumbered access. We need to approach the digital environments as having equal importance to physical environments, in the social and emotional well being of a person. MAMEM purports to address the issue of full and unencumbered access to the digital world, for people with disability.

Access to information and services through websites, which in other contexts are hard to obtain or are unavailable, gives people with disability a sense of inclusion in society as a whole (Parsons et al., 2006). Closely related to access to information and inclusion is a sense of empowerment. For people with disability, empowerment can be provided by the use of computers and the Internet (Renblad, 2003), which facilitates them to make their own decisions. With the help of information and communication technology, people with disability can have access to information needed to make decisions or acquire a sense of control over issues that concern them. Moreover, the digital and online landscapes may enrich the overall quality of life for people with disability and enhance their physical, emotional and social adjustment, through social interactions, employment and volunteer work opportunities (Stewart, Hansen and Carey, 2010).

Shpigelman (2014) notes the impact of online participation on psychological well - being. Participation in social networks is associated with psychological well - being (Steinsfiel et al., 2008; Valkenburg et al. 2006). Lee (2011) found a positive correlation between social network activity and subjective well being in students with disabilities. Thus, empowerment and subjective well being are important indicators of digital inclusion.

Finally, people with disability may experience movement impairments, and physical social

isolation, yet MAMEM intends to facilitate their ability to make choices and decisions in the digital environment, where movement does not play a role, neither impedes one's options and opportunities. As long as the digital environment is readily and easily accessible, and MAMEM means to address exactly this issue.

4.3.3 Key insights from ICT use among individuals with SCI, NMD, PD and implications towards developing indicators

In the context of task D6.2 (D6.2, MAMEM Consortium, November 2015) research was conducted among a sample of individuals with disabilities caused by: a) spinal cord injuries b) Parkinson's disease and c) neuromuscular disorders. Interviews were conducted with regards to computer use. Below we summarize some of the results that are mostly related to the objectives of this deliverable.

Usage of electronic devices (desktop, laptop, mobile):

All participants in the sample (N=53) of the D6.2 (2015) study were users of digital devices, and many of them were users of multiple screens (owning a tablet and/or smartphone in addition to a desktop/laptop computer). In fact, the study showed that the persons with disabilities in the sample (N=53) used digital devices extensively, from a mean of 4,34 hours per day (PD patients) to a mean of 6,05 hours per day (NMD patients).

It was shown that across all three samples of SCI, PD and NMD patients, the digital devices were widely used for social participation (Facebook, forums), communication (email, Skype) productive activities (writing, editing), recreation (movies, etc.) and on line study. Therefore, the individuals in the sample were avid users of social opportunities online.

The implication here is that digital communication (Facebook, forums, email, Skype, etc.) is an important vehicle of online social inclusion and participation and will be included in digital indicators. For all of the participants in the study, their digital activities were a significant part of their day, and in fact it they were part of their daily routines and habits.

All respondents fulfilled 4 of the 5 Cs of Bradbrook and Fisher (2004). They achieved Connectivity, Capability, Confidence. A smaller number were able to generate content. Continuity was a major challenge for several participants, since the digital engagement generated fatigue and even pain, so they would have to curtail the time they were online or involved with the computer.

Importance and contribution of electronic devices to the life of the people with disabilities:

Moreover, when the participants in the sample were asked as to the relative importance of their digital activities, the wide majority assigns highest importance first to communication, and then to social participation and then to recreation, productive activities and study online. The above findings validate the importance of digital social participation and interaction, and a possible link with the perceived sense of a normal social life of people with disabilities individuals.

All three samples (SCI, PD, NMD participants) agreed on the following core contributions of digital device use in their life: educational attainment and interpersonal interactions, followed by work and employment status/potential. The above are validated as indicators correlated to the usage of

digital communication devices and the Internet.

Self evaluation of social life:

This research confirmed the hypothesis that the social life of people with disabilities is impacted as a result of the disability. However, as shown in Table 1, a significant part of respondents across the three samples stated that they have a normal life or only restricted in energetic aspects like dancing.

Percent who responded with the following statements in the question: How is your social life affected by your disability?	SCI patients (N=15)	PD patients (N=19)	NMD patients (N=19)
My social life is normal	40.0%	36,8%	5,3%
No significant effect on my social life apart from limiting energetic aspects like dancing	26,7%	36,8%	73,7%
TOTAL	**66,7%**	**72%**	**79,0%**

Table 1: D6.1 Self report on social life

It can be hypothesized that the daily usage of digital communication devices, which was the case with all the research participants, may have to do with the relatively high percentage of people in the sample, who express that their social life is normal or limited only as to energetic activities like dancing. This may well explain to some extent the relatively high perception about their social life "being normal, or only limited as to energetic activities like dancing". It will be interesting to evaluate how MAMEM usage would further impact their quality of social life.

The above findings point out that the digital and social inclusion indicators that will be used in evaluating the impact of MAMEM on social inclusion, need to take into account digital activities that contribute to:

1. Communication and interpersonal interactions
2. Social, online participation
3. Work and employment opportunities and prospects
4. Educational attainment

Moreover, according to the clinical requirements specified in D6.2 (D6.2, MAMEM Consortium, 2015), on the basis of questionnaire answers, the MAMEM platform will have the greatest effect on the patients' computer usage when it reduces pain and fatigue of computer use, while increasing the effectiveness and ease of use. Therefore, these elements need to also be included in the total MAMEM impact evaluation.

Feedback from the caregivers:

D6.1 included the caregivers in the study. The hypothesis was that care givers of people with disability might have a different perspective on how the subjects of the study use the computer and perceive their social life. Indeed, there were several discrepancies in how the subjects themselves responded to key questions, and how their caregivers did.

Consistently, the caregivers described the social life of the people with disability as more constrained than the latter did. With regards to the question "how is your social life affected by your disability" the results of the top two boxes of the Likert scale are summarized in **Table 2**.

	SCI subjects	SCI care givers	PD subjects	PD care givers	NMD subjects	NMD care givers
My social life is normal	40%	20,0%	36,8%	31,6%	5,3%	0,0%
No significant effect (limited energetic aspects such as dancing)	26,7%	33,3%	36,8%	42,1%	73,7%	76,5%

Table 2: D6.1 Top 2 boxes of caregivers' report on social life

It is seems that caregivers are slightly inclined to be less positive about the subjects' social life. It can be hypothesized that they evaluate against their own healthy frame of reference.

Moreover, the differences between the evaluations of care givers and the evaluations of the people with disabilities in the D6.2 sample are bigger when it comes to reporting what kinds of activities are performed with the computer. Some indicative discrepancies are summarized in **Table 3**.

	SCI subjects	SCI care givers	PD subjects	PD care givers	NMD subjects	NMD care givers
Social participation (Facebook, etc.)	54,5	63,6%	57,9	57,9%	94,7%	88,2%
Productive activities (writing, editing)	72,7%	36,4%	52,6%	21,1%	73,7%	52,9%
Communication (email, Skype, etc.)	72,7%	45,5%	78,9%	73,7%	100%	82,4%
Study (online courses, articles, etc.)	63,6%	27,3%	47,4%	36,8%	84,2%	58,8%
Games	9,1%	45,5%	31,6%	21,1%	31,6%	52,9%
Recreation	81,8%	81,8%	42,1%	31,6%	42,1%	70,6%

Table 3: D6.1 Subjects' and care givers' reports on computer usage

The above findings show fairly big discrepancies in the reported use by the subjects themselves and by their care givers. There are two possible hypotheses that may explain the discrepancies:

Hypothesis 1: social desirability bias: Computer use for games and recreation is consistently reported to be higher by the NMD, SCI caregivers, than by the NMD, SCI subjects themselves. It

may be that the subjects offer self reports driven by the need for social approval. The social desirability bias refers to the tendency of survey respondents to offer answers that will be favourably viewed by others. It can take the form of over reporting “good” or “socially approved” behaviour (van de Mortel, 2008). The SCI and NMD participants under reported computer usage for gaming and recreation and over reported usage for on line study. By comparison, their caregivers over reported gaming and recreation activities and under reported online study activities. PD subjects, who tend to be older in age, may have less affinity to gaming, and thus their self report of gaming and recreation computer usage was more aligned to that of their caregivers. It is interesting to note that all three subject groups (people with NMD, SCI, PD) state much more intense usage of online study and communication, than their caregivers. It can be hypothesized again, that subjects may view these activities as more socially acceptable. It can be hypothesized that reporting on line study activities is more in line with a socially acceptable self image, than, for example, gaming and recreation activities. The fact that some activities are consistently over reported **across all three D6.1 subject groups** and some activities are under reported across all subject groups, versus the evaluations of care givers, indicates that this hypothesis may be valid.

Hypothesis 2: caregiver awareness of computer usage: An alternative hypothesis is that caregivers are less aware and less attentive of the type of activities that the people with disabilities they care for engage in, online. Thus, they may not be able to provide as accurate reports of computer usage. This hypothesis generates the question, again, why are some activities over reported by care givers and others are under reported, against the evaluations of the subjects themselves.

The implications for MAMEM evaluation: During MAMEM’s clinical trials computer usage will be monitored with specialized software, and therefore, computer use will be validated in real life conditions. Thus, the monitored computer usage data will be studied against the self reported data, to validate any possible social desirability bias, in the self reports of subjects in D6.1. Two points need to be considered: a) The discrepancies described above validate the need to have both subjects and caregivers provide feedback before and after the usage of MAMEM; 2) The MAMEM evaluation process has to take into consideration the social desirability bias and make provisions that the research will elicit as honest responses as possible.

Should a social desirability bias be validated in the next research phase of MAMEM usage, then the implications for the development of MAMEM are far reaching. The use of MAMEM would allow people with disabilities more privacy and more independent use of the computer. This privacy could mean becoming more independent from care giver approval. It could also mean the freedom to engage in sensual activities online, if they choose so, without fear of well wishing care givers breaching the privacy of such activities.

5 The proposed indicators

On the basis of the above literature review two sets of indicators need to be defined: **1) Social inclusion indicators,** which indicate social outcomes.**2) Digital inclusion indicators,** which indicate digital activities which are hypothesized to be related to the social outcomes. Ultimately, these two sets need to be integrated into one research methodology that will be employed in assessing the impact of MAMEM on the social inclusion of people with disabilities.

5.1 Overview of an integrated set of social and digital inclusion indicators

A portfolio of social and digital indicators is proposed that is founded on a triangle of three main axes: **a) The Education and Employment indicator axis, b) The Participation and Social Capital axis, and c) The Empowerment and Well Being axis**. Each of these axes will have to be evaluated through both social inclusion indicators and digital inclusion indicators. The three axes are to be treated as an integrated system alongside respective digital indicators, as presented in Figure 1.

In this context, the three axes of social inclusion indicators will be used to measure social inclusion **shifts and outcomes** experienced by the person with disability, following usage of MAMEM. The digital inclusion indicators will be used to measure specific **online activities** that are hypothesized (on the basis of the literature review) to be linked to these outcomes. Therefore, by measuring both social and digital inclusion indicators the research among SCI, PD and NMD individuals will verify the extent to which social inclusion outcomes are impacted by the change MAMEM brings to its users in facilitating their online activities.

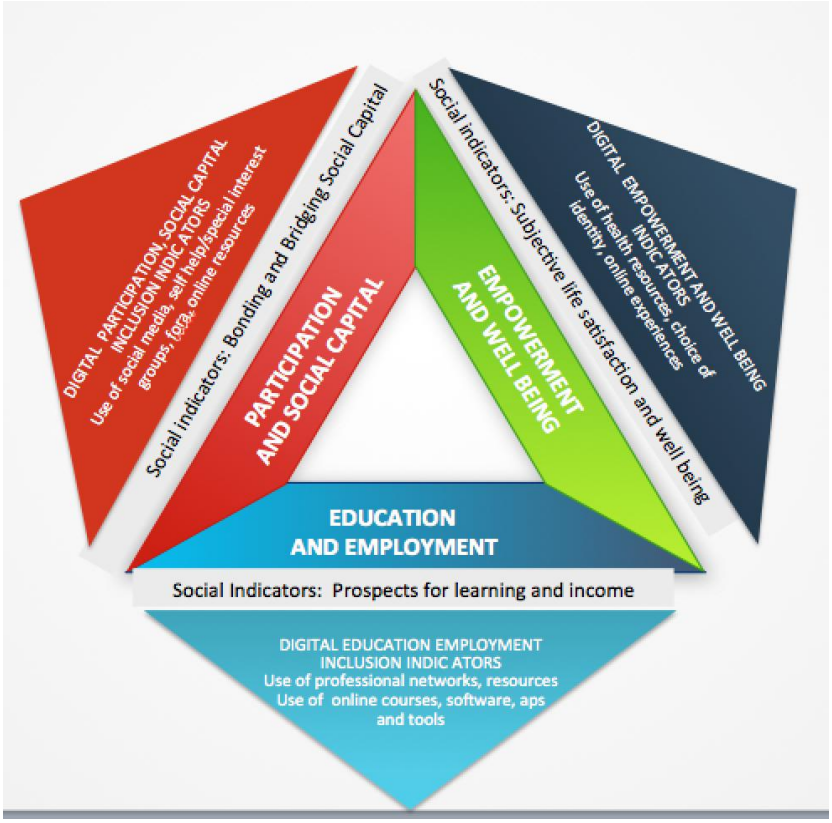

Figure 1: An integrated system of social and digital inclusion indicators

5.2 The social inclusion indicators

Atkinson and Marlier (2010) propose the following principles in establishing single indicators for measurement:

- An indicator should identify the essence of the problem and have an agreed normative interpretation
- An indicator should be robust and statistically validated
- An indicator should be interpretable in an international context
- An indicator should reflect the direction of change and be susceptible to revision as improved methods become available
- Three principles concern the portfolio as a whole:
    - The portfolio of indicators should be balanced across the different dimensions
    - The indicators should be mutually consistent
    - The weight of single indicators in the portfolio should be proportionate.

In accordance to the above, the proposed portfolio of indicators is summarized in **Table 4**:

INDICATOR	RATIONALE AS TO SOCIAL INCLUSION OUTCOMES	VALIDATION
Bonding social capital	It measures strong ties between people, and it will be used to measure the impact of MAMEM in facilitating and fostering its users to develop stronger ties with people and communities on line.	Baum (1999)
Bridging social capital	It measures how MAMEM has impacted the ability of its users to conduct useful interactions online, and to attract useful resources or solutions, by connecting with people or groups.	Stewart (2000)
Personal empowerment	This indicator will measure shifts in the sense of isolation, access to self help tools, and in the sense of control over issues at hand	Shpigelman (2014)
Subjective well being	This indicator will measure how MAMEM impacts the experienced sense of well being, and satisfaction with life, via facilitating digital social participation	Beck et al. (2001)
Employment opportunity prospects	Social and communities opportunities profile (SCOPE)	Azaiza (2006)
Education attainment prospects	This indicator will measure shifts in access to educational resources via the use of MAMEM	Kessler/NOD (2010)

Table 4: Social inclusion indicators

5.2.1 Research tools for the evaluation of social inclusion indicators

Various research scales and tools have been developed in order to measure social inclusion indicators. In the context of evaluating the impact of MAMEM a set of research tools is proposed and summarized in **Table 5**. For each of these social inclusion indicators, effort was made to isolate the optimal research tool, ensuring that it fulfills the Atkinson and Marlier (2010) indicator criteria.

INDICATOR	RESEARCH TOOL	VALIDATION OF TOOL
Bonding social capital	Internet social capital scales	Williams (2006)
	Name Generator	Burt (1984)
Bridging social capital	Internet social capital scales	Williams (2006)
Personal empowerment	Shpigelman online experiences	Shpigelman (2014)
Subjective well being	Warwick Edinburgh Mental Well Being Scale	Beck et al. (2001)
Employment opportunity prospects	Social and community opportunities profile	Huxley et al. (2012)
Education attainment prospects	Social and community opportunities profile	Huxley et al (2012)

Table 5: Research tools per social inclusion indicator

In the following we will briefly discuss about the research tools mentioned in Table 5.

Internet Social Capital Scales:

This tool will be used to evaluate digital social inclusion. Williams (2006) worked on the Social Capital Scales in order to measure the relationship between the use of new, virtual environments, and social interactions. Specifically, Williams wanted to evaluate online social capital as opposed to offline, and study distinctions and differentiations between these two. His tool includes a bonding and a bridging subscale, and items from these two subscales will be used to measure the social participation indicator of social inclusion. According Appel et al. (2014) the Internet Social Capital Scales have weak validity unless used in a specific context. In their case they specified the questions directed to a student sample mentioning the name of the university (Rutgers), and in that case the validity of the scales rose significantly. Using the statements of the Internet Social Scales with specificity to MAMEM use is thus indicated.

A series of Internet Social Capital Scales items will be included in an interview questionnaire, and will be evaluated on a Likert scale. The Internet Social Capital Items in the questionnaire are summarized in **Table 6**.

BONDING SUBSCALE	RATIONALE
There is a person(s) online that I can turn	Items that measure digital

to for advice on important things that concern me	communication as a means to access emotional or other resources
When I feel lonely there are people online I can talk to	
There are people I interact with online would give me support or help if I needed it	
BRIDGING SUBSCALE	**RATIONALE**
Interacting with people on line makes me feel like a part of a larger community	Items that measure digital communication in terms of participation, interaction and connection
I come in contact with interesting people all the time	
Interacting with people online makes me want to try new things	

Table 6: Internet Social Capital Scale research items

The Social and Communities Opportunities Profile:

This tool will be used to measure education and employment indicators of social inclusion. Huxley et al. (2012) developed and widely tested the Social and Communities Opportunities Profile (SCOPE). The short version of this scale includes two subjective scales: perceived opportunities and satisfaction with opportunities. It also includes objective opportunity and participation items. Domains covered include leisure time, housing, work, finances, safety, education, health, and family and friends. There is also a 121-item long version which includes a subjective well-being scale that is similar to quality of life questions, but the long version proved less acceptable to test participants than the shorter version. The Social and Communities Opportunities Profile scale was developed using concept mapping for a model of social inclusion with objective and subjective factors, showing how opportunities and choices relate to material domains. The scale has good construct validity as measured by associations with participation and social capital measures.

We perceive that the sub scales of a) perceived opportunities and b) satisfaction with opportunities of the Social and Communities Opportunities Profile are relevant in evaluating the impact of MAMEM with regards to education and employment as a social inclusion indicator. Through these two sub scales we propose to investigate whether the users of MAMEM applications feel that their education and employment prospects and opportunities have increased following more extensive use of digital technologies with the aid of MAMEM. We propose to use these two scales, specially adapted to the needs of the people with disabilities.

In the interview questionnaire, a series of Internet Social Capital Scales items will be included, along with a series of SCOPE items, adapted so as to be relevant to the life conditions of persons with disabilities. The items that will be included in the study are summarized in **Table 7**.

SCOPE ITEMS	RATIONALE
Exploring employment and income options	Explore access to opportunities online, in a series of areas, and more specifically in the area of employment, income, learning and professional, health resources.
Developing business ideas	
Finding customers	
Learning and developing new skills	
Meeting like minded individuals	
Belonging to professional resource groups	
Finding health information and resources	
Asking for support/help from experts and/or mentors	

Table 7: Social and Communities Opportunities Profile research items

The Warwick-Edinburgh Mental Wellbeing Scale:

It measures positive affect, psychological functioning and interpersonal relationships. Mental wellbeing is more than the absence of mental illness, and the scale covers only positive aspects of mental health. A measure of mental wellbeing was chosen in preference to a measure of mental ill health, in order to correspond with the increasing emphasis on promoting positive mental well being. The tool is an ordinal scale consisting of 14 positively phrased statements rated on Likert scales. This scale has demonstrated high internal consistency, construct validity, discriminant validity, and test-retest reliability across a range of populations (Bartram, Yadegarfar, Sinclair, & Baldwin, 2011; Clarke et al., 2011, Tennant et al., 2007). This tool is included in the study because the sense of well being is an important indicator of personal empowerment, shown to be an important and relevant outcome of social inclusion. The items of the Warwick – Edinburgh scale to be used in the research are summarized in **Table 8**.

WARWICK – EDINBURGH SCALE ITEMS	RATIONALE
Over the past few weeks I have been feeling optimistic about the future.	The specific items point out can be expected to measure a general state of well being and confidence.
Over the past few weeks, I have been feeling useful.	
Over the past few weeks I have been feeling confident.	

Table 8: Warwick – Edinburgh Scale research items

Shpigelman Facebook experiences:

Shpigelman (2014) conducted a study with persons with disabilities focusing on the potential of social network sites to empower individuals. The study used a series of questions on the goals and outcomes around using social networks and Facebook in particular, and some of these questions validated that social networking sites offer a strong sense of participation and inclusion. A number of the items used in that study are particularly suitable to measure how MAMEM can encourage active participation in social media and digital online platforms. Such items are presented in **Table 9** and they will be adapted so as to cover digital rather than specifically Facebook experiences.

SHPIGELMAN SOCIAL EXPERIENCE ITEMS	RATIONALE
Over the last few weeks I have been able to meet new people on line	Digital indicators will separately measure social participation and social activities. These specific items are intended to measure perceived social engagement and feelings related to social interactions.
Over the last few weeks I have particularly enjoyed not just reading but also writing content	
Over the last few weeks I have been able to find people online that I am (sexually) attracted to	
Over the last few weeks I have been able to find friends online that I might meet face to face	

Table 9: Shpigelman social experiences research items

5.3 The Digital inclusion indicators

The digital inclusion indicators are spread over three key areas, namely: **1) digital activities related to participation and social capital, 2) empowerment and well-being, and 3) education and employment.** The specific indicators to be used derive from the findings of deliverable D6.2 (D6.2, MAMEM Consortium, November 2015), which explored extensively the usage of digital communication devices among a sample of persons with SCI, PD, NMD types of disability. The indicators that will be employed reflect the "5 Cs" of digital inclusion, which are: connectivity, content, continuity, confidence and capability. The specific digital inclusion indicators to be used are summarized in **Table 10**.

DIGITAL INCLUSION INDICATORS	DIGITAL ACTIVITIES	RATIONALE Bradbrook and Fisher (2004)
PARTICIPATION AND SOCIAL CAPITAL	Mail exchange Skype SMS exchange Mobile access Social media account	Connectivity Content Continuity

	Frequency of interactions with friends online Participation in groups and fora Content generation	
EMPOWERMENT AND WELL BEING	Gaming Entertainment Access to health related resources, groups, advice, information	Capability (skills)
EDUCATION AND EMPLOYMENT	Participation in e – learning Participation in professional social media Business website owned Client and job search online	Capability Confidence

Table 10: Digital inclusion indicators

5.3.1 Monitoring tools for digital inclusion indicators

In order to measure the digital inclusion indicators we will rely on two monitoring software tools: a) desktop monitoring software, and b) social activity monitoring software. Below we provide some details about the functionality of these monitoring software tools.

Desktop Monitoring Software:

User's activities taking place in the computer will be monitored using a desktop monitoring software. In the context of MAMEM our intention is to employ iSafe Free Keylogger[1], which is a free software that provides a set of features that can be used to monitor user's activities as they operate the computer, at any given time.

More specifically, iSafe Free Keylogger can be used to capture the user's screen at a specified frequency, giving insight about the applications operated by the user. Furthermore, it has the ability to record every keystroke typed, including all special characters, while being language independent as it includes a wide variety of input languages. As a consequence, it is trivial to recognize all visited websites irrespectively of the web browser that has been used to serve these websites. One extra feature that can be applied based on recorded keystrokes is monitoring any kind of chat the user participates to, such as Skype, Facebook or mail clients. In addition, mouse activity can be listed in log files, with every click being stored in these files. Last but not least, iSafe Free Keylogger allows to grant access to input and output devices. All printing processes can be identified and registered, the insertion of a usb drive can also be reckoned and the voice input

[1] http://www.isafesoft.com/free-keylogger/index.htm

from the microphone can be recorded as well. **Figure 2** provides a screenshot for the dashboard view of the monitoring application.

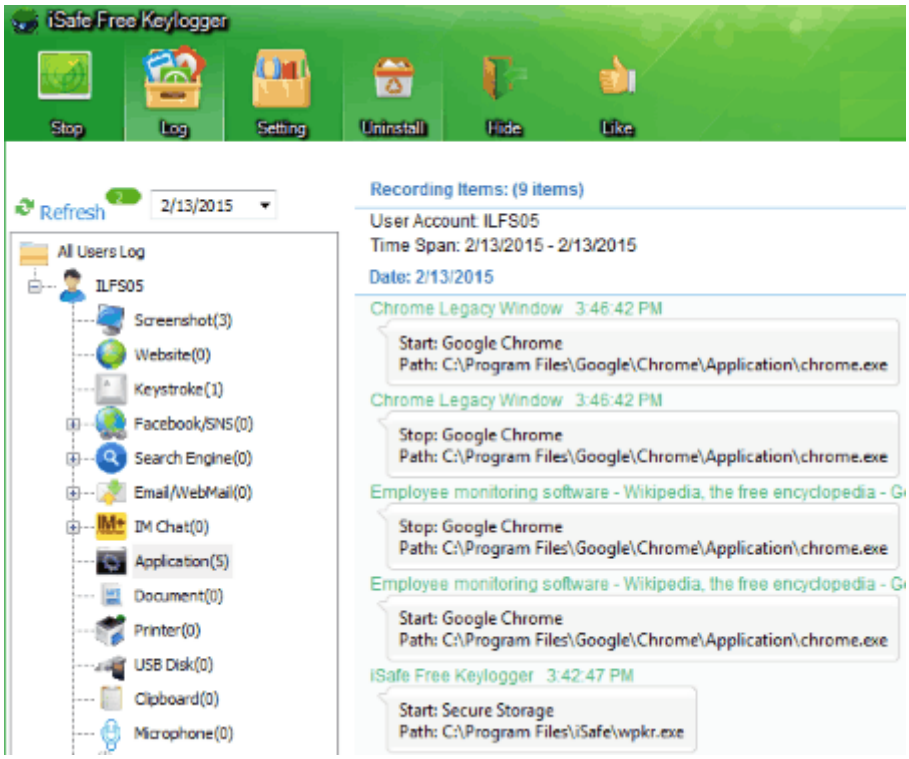

Figure 2: iSafe Free Keylogger Interface

The process of installing iSafe Free Keylogger is straight-forward and allows to easily configure the set of features that will be enabled for monitoring the user's activities. After the installation is completed, the keylogger becomes totally transparent to the user so as to avoid any disturbance.

Social Media Monitoring Software:

We will rely on an easy-to-use web-based tool that enables real-time monitoring and analysis of a variety of popular social media platforms (Twitter, Facebook, Instagram, etc.) in order to track the social activity of our subjects and derive conclusions with respect to their level of social integration.

The monitoring tool is configured to keep track of content that is posted around specific keywords and/or accounts/sources of interest. For instance, these could include a set of keywords that are indicative of a certain topic and a number of accounts that often post messages related to this topic. Having these keywords and accounts in place, we will then be able to browse through a stream of social media items that have been posted in relation to them. Such a stream is illustrated in **Figure 3**, where the tool presents social media content related to the brand "Liebherr" (in this example case the tool has been used for the task of brand monitoring).

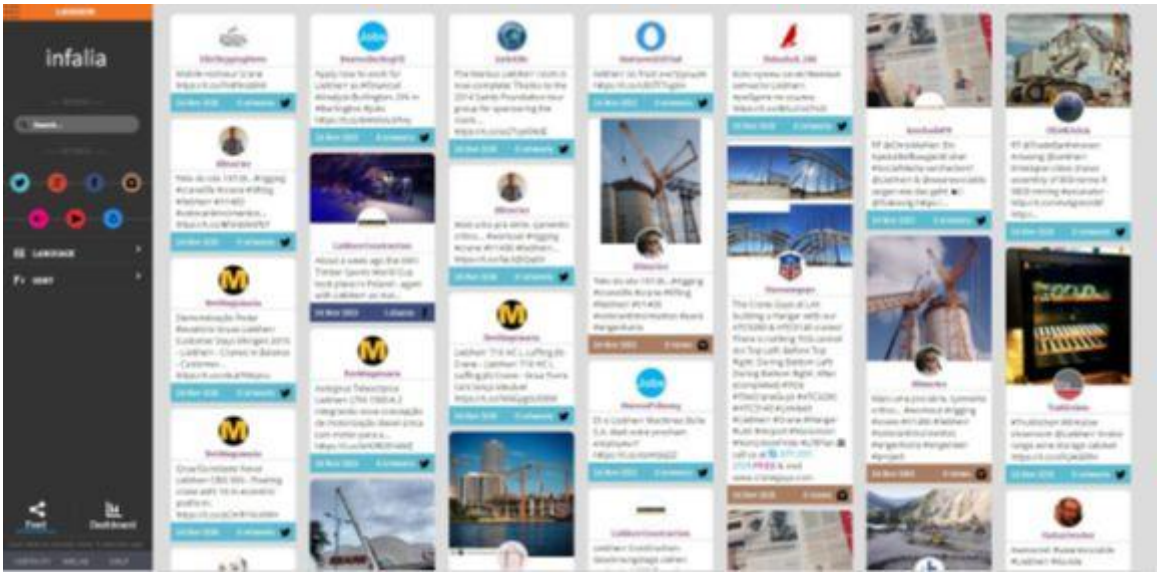

Figure 3: Browsing through a stream ("feed") of social media posts around the brand "Liebherr"

The stream (or feed) view enables users to also filter the monitored items by keyword, source (e.g. show only posts from Twitter), and language, and to also rank them by recency (i.e. first the most recent ones) or popularity (e.g. first the ones with the largest number of retweets).

Browsing the messages that social media users post around a topic or entity of interest is definitely useful for discovering points of view, complaints and positive comments about the topic of interest. However, the real power of the tool is the capability to provide quantitative views and statistics about the monitored content. This is exposed to users through the "dashboard" view, which is illustrated in Figure 4.

The dashboard consists of a number of "widgets", i.e. visualization elements that depict a specific piece of information in an easy-to-grasp way. Each widget or any combination of them can be embedded in a third-party website on demand. The first row of widgets concerns the activity and impact measurement of the monitored topic in terms of activity (number of posts), user base (number of users posting), reach (number of users reached) and endorsement (number of users liking the posted content).

Another widget depicts the contribution of each social media source (Twitter, Instagram, etc.) to the overall activity about the topic. A timeline widget illustrates the activity around the most important keywords over time. Finally, there is a histogram widget that shows the most active users around the topic and a keyword bubble widget that depicts the most important keywords around the topic. Relying on the functionality of the aforementioned tool and making best use of the available widgets we will manage to derive the information necessary to spot any change in the social integration status of our subjects.

Figure 4: Dashboard offering several statistics and visualizations around the brand “Liebherr” (again the example above is used in an example for brank monitoring)

5.4 Battling the social desirability bias

D6.1 (D6.1, MAMEM Consortium, 2015) findings on computer usage have indicated that the responses of people with disability who participated in the sample differed from the respective responses of their caretakers. The participants with disability understated computer usage for gaming and recreation, and overstated usage for e-learning and studies, while the responses of their caretakers were exactly the opposite. We hypothesize that a social desirability bias may account for the skew in the findings on computer usage across the reports of the two populations. It may be that the participants with disability felt that computer use for studies would project a more positive self image, versus computer use for gaming. We therefore need to explore further how the social desirability bias may be minimized in the MAMEM evaluation process. Typically, researchers try to motivate respondents to provide well thought of and accurate answers in surveys, by stressing the value of the research, the importance of their responses to the research

enterprise, and place direct requests for candid, considered answers. Current research suggests that candid responses can be triggered implicitly, improving data quality very much.

Research in the field of Behavioural Economics points out that honesty of responses increases when it is provoked subtly. Research by Shu et al. (2012) has shown that in a self graded maths test, when respondents were asked to sign at the end of the maths test that their self grading was honest, 79% of them cheated. Signing at the beginning of the maths test reduced cheating to 37%. Signing before instead of after also improved compliance with a tax form, with reporting car mileage and with online sales reporting.

Rasinski et. Al (2005) used what they described as "goal priming" to increase the honesty of answers in a survey. They first exposed the experimental group of participants to a "priming task", that is, series of word puzzles that had respondents choose synonyms to words like honesty, genuineness, authenticity. It was then found that the experimental group consistently lied less in a series of questions on sensitive personal information versus a control group. This study demonstrated that honesty in self – report questionnaires can be increased by simply activating the concept of honesty, even in an unrelated task (see **Table 11**).

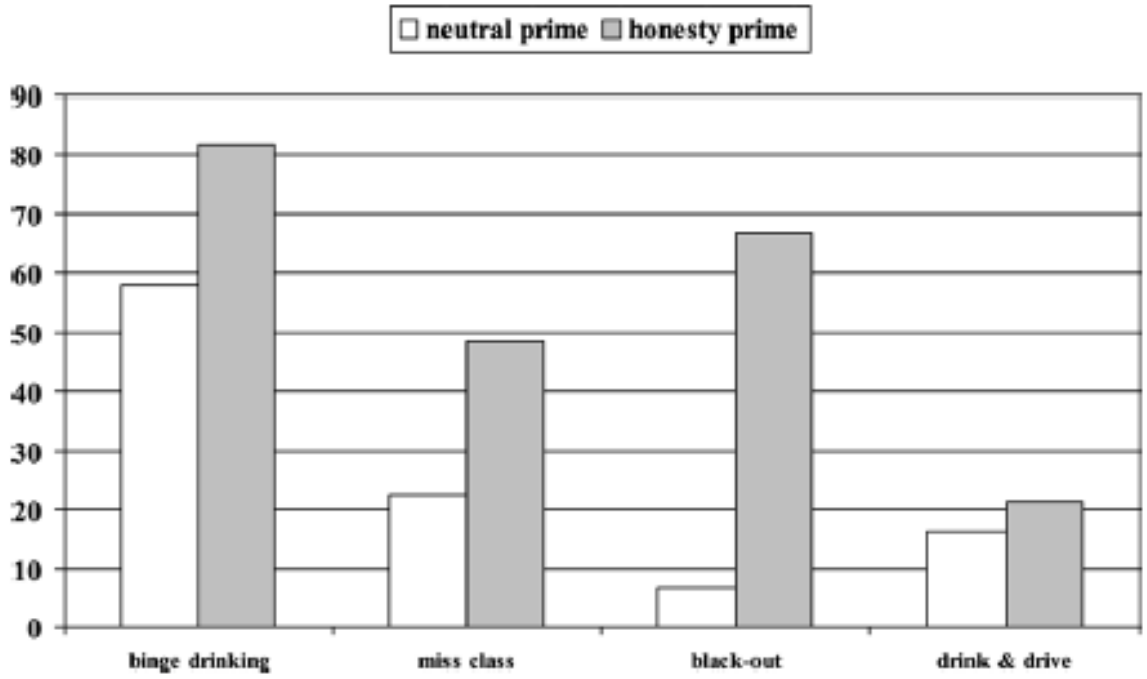

Table 11: Proportion of participants reporting that they have performed each sensitive behaviour by experimental condition of neutral prime and of honesty prime (honesty vocabulary task). Excerpted from Rasinski et al. (2005).

To ensure optimal conditions for respondent honesty, a consent form may include a honesty clause and be signed in advance of the interview. In addition, a "honesty priming task" may be used as well. Pashler's (2013) "task for honesty priming" seems best indicated for this research and is summarized in Table 12.

Honesty priming condition			
Honest	Open	Sincere	Truthful
Secure	Safe	Comfortable	Protected
Common	Frequent	Routine	Average
Genuine	Real	Straightforward	True
Plain	Neutral	Simple	Basic
Correct	Actual	Straight	Accurate

Table 12: Honesty priming condition, Pashler (2010)

5.5 The duration of MAMEM use and its significance

The use of MAMEM for one week only or for a maximum of two weeks as specified in the clinical protocols of D6.3 (D6.3, MAMEM Consortium, 2016), does not guarantee that the platform is given a full chance to prove its impact on the social inclusion of people with disabilities. However, the short duration of use is a limitation that cannot be overcome at this point in time. The social inclusion evaluation research needs to take this short duration of use into consideration, and must employ tools that can provide an adequate measure of the potential of MAMEM to foster social integration, were it to be used on a longer term.

Ethnographic tools can provide qualitative information that can supplement the quantitative data, and can provide rich insights into the potential of MAMEM in generating social inclusion. Zimmermann and Wieder, in 1977, first described the "diary – interview" methodology, within the context of ethnographic research. The diary is not a "retrospective tool" like the interview. In the interview the research participants reflect back on their experiences and extract an average usage opinion. The diary can supplement the interview learnings, by offering feedback on the user experience **as it occurs**, in the user's own articulation. It can capture sentiments, likes and dislikes, obstacles and opportunities regarding the use of MAMEM, enriching our understanding of how MAMEM impacted the digital social integration experiences of the user.

In our case, specific guidelines will be given to the MAMEM users urging them to audio record their feedback, following three of their MAMEM usage sessions. The caregivers will be expempted from audio diaries.

5.6 The research hypotheses

It is hypothesized that the usage of MAMEM will effect changes in the social and digital indicators as these become evidenced in the digital behavior and consecutive reactions of a sample of persons with disabilities. The core hypothesis is that MAMEM usage will tackle the two major barriers to more extensive use of digital devices, which were clearly shown in the D6.1 study, namely, pain and fatigue. The research hypotheses are presented in **Table 13**.

DIGITAL INCLUSION HYPOTHESES	EXPECTED OUTCOME
It is hypothesized that the use of MAMEM will shift digital inclusion indicators: More time spent online More extensive use of software like e mail clients More extensive use of social media	We hypothesize that all indicators of digital inclusion will be impacted, indicating wider use We also hypothesize that there will be a

More active use of social media	learning curve whereby the more familiar the user becomes with MAMEM, the more intensely they will engage in online activities
SOCIAL INCLUSION HYPOTHESES	**EXPECTED OUTCOME**
It is hypothesized that a difference in the social indicator measurements will be evidenced, before and after the usage of MAMEM. We also hypothesize that the social inclusion indicators may take a bit longer to show steeper changes. Though digital inclusion indicators may quickly show the difference impacted by MAMEM, however social indicators are based on deep seated habits and it is possible that these habits need s bit longer to transition.	It is hypothesized that the research participants will report higher participation across the social inclusion indices However, given the fact that they may have to report on the impact of MAMEM only a short while following the training, it is also hypothesized that the impact on social inclusion indicators may not be sharp

Table 13: Research hypotheses

6 Methodology

In this section we will first describe the research scope and rationale. Further, we will define the research sample and specify the research procedure in detail, as well as the research tools that will be used. Finally, the data analysis steps will be described.

Research scope: The scope of this research is to demonstrate how the usage of MAMEM creates shifts on the target variables, namely the ability of participants to manage and author multimedia content, as well as their experienced social inclusion evidenced by shifts in the respective indicators. More specifically, the research methodology described below will be called in to evaluate MAMEM impact on the three axes of relevant indicators: a) participation and social capital, b) empowerment and well-being, and c) education and employment.

Research process prerogatives: The research that will be carried out needs to take into consideration the following elements:

1. The use of MAMEM as a factor influencing social inclusion needs to be validated through pre and post MAMEM usage data.
2. The research tools need to be "disability friendly", that is, the research tools need to be easy to use. They should not exhaust individuals with physical impairments who sometimes experience energy limitations. The interview process needs to last for as long as it may be convenient and acceptable in relation to the disability that the sample subjects are experiencing.
3. Data will need to be collected both from the sample of people with disabilities, as well as from their caregivers. Monitored data of computer usage will be compared to self-reported data of computer usage of both care givers and sample subjects. In addition, monitored data of computer usage will be compared to the social inclusion data collected before, as well as after the usage of MAMEM.
4. The MAMEM platform will be used by each participant for one week or a maximum of two weeks. We esteem that this is rather short a time to note deep changes in social integration patterns and outcomes. So, the research tools need to make provisions for the evaluation of **changes in practices** that could potentially lead to heightened social integration in the future. The research tools will not focus on evaluating specific social inclusion outcomes, according to the defined indicators, but will focus on evaluating **trends** in computer use and in attitudes, towards these outcomes.
5. The MAMEM platform will have to be used **for the same number of days** by all participants, to ensure full comparability of results within the sample.

The research process: The research process will involve a pre MAMEM usage interview and a post MAMEM usage interview. A specially briefed and trained research assistant will carry out both interviews at the home of the participant. Each interview will be carried out confidentially and in privacy. The participant will be reassured of the confidentiality of the personal information they provide, and of the anonymity with which all of their data will be treated in the data analysis. The caregiver interviews will be carried out, likewise, in privacy, and the same reassurance of confidentiality and anonymity will be provided. The research will unfold over three distinct stages,

preceded by a research preparation stage.

Research preparation: At this stage two pilot interviews will be carried out with the participants, to ensure that the questionnaire wording is well understood. This is standard research practice for questionnaire wording optimisation, and will be carried out by the MDA team. The finalized questionnaires will be forwarded to SHEBA and AUTH.

Stage 1: Research induction

During the research induction the participant subjects and caregivers will be provided with:

a) A thorough explanation of the purpose of the research.
b) The research assistant will go through the informed consent form, clause by clause, with the participants, ensuring that they understand the anonymity and confidentiality clauses included in the consent form.
c) Participants will be provided with an explanation and a demonstration of "audio diaries" and of the process of audio recording their feedback on their computer.
d) Participants will be provided with an introduction to the data monitoring software.
e) The data monitoring software will be installed in their conventional digital devices, and it will collect data of computer usage for the number of days that the MAMEM platform will be used by the participants. Computer usage data will be collected for the pre agreed number of days before MAMEM usage and for the same number of days during MAMEM usage.

Stage 2: Pre MAMEM social inclusion interview

a) An informed consent form will be signed by each participant and their care giver. The consent form will include an honesty clause and a full explanation of the data monitoring software to be used pre and post MAMEM training.
b) Instructions will be given regarding a priming "honesty task" which will then be administered to the participant.
c) Each participant will go through the social inclusion questionnaire. The participants will respond to the open questions at the end of the structured questionnaire, and their responses will be audio recorded and transcribed by the research assistant. Each interview will be deemed to be complete once there is a fully completed questionnaire, with fully transcribed open questions. At the end of Stage 2 the research assistant and the research participants agree on a convenient date for the Stage 3 post MAMEM usage interview and the research assistant confirms that there will be prompt reminder notification regarding that interview date. The data of Stage 2 will reflect patterns of social integration that are possible with conventional digital devices (computers, tablets and smartphones). These data will provide the benchmark for evaluating the impact of MAMEM on the participants' social integration.

Stage 3: Post MAMEM use social inclusion interview

During Stage 3, the research assistant will take each participant through the post usage social inclusion questionnaire, and the open questions at the end will be again audio-recorded and transcribed.

The data to be analysed will include:

1) The pre MAMEM and post MAMEM monitored computer usage data, expressed in numeric forms: i.e. number of likes, posts, chats, emails, skype interactions, fora visits etc.
2) The pre MAMEM interview filled in questionnaires, with transcribed open questions.
3) The post MAMEM interview filled in questionnaires, with transcribed open questions.
4) The audio diary transcriptions per participant.

6.2 The research sample

The research sample will involve a control group of people with SCI, PD, NMD disabilities, who are matched for age, gender and education with the experimental group. The control group will comprise users of conventional digital devices. The experimental group will proceed to the use of MAMEM and to pre and post social inclusion evaluations. Each site (SHEBA, AUTH and MDA) will be in charge of recruiting the participants. The sample specifications and inclusion/exclusion criteria will be those delineated in D6.3 (D6.3, MAMEM Consortium, 2016).

6.3 Research tools

6.3.1 The honesty clause in the informed consent form

The informed consent form will be read to both the participant and their care giver. Both will be asked at the end if it is very clear that all information they provide will be confidential and will be treated anonymously in the analysis, and that they agree to participate in the study contributing their personal, genuine opinions. Once they agree, they will be asked to sign the informed consent form.

6.3.2 The honesty priming vocabulary task

The honesty priming vocabulary task has the purpose of introducing the mandate of honesty to participants in a nonintrusive, implicit way, by virtue of bringing forward in their mind the consideration of concepts like truthfulness, genuineness, honesty. The objective is to minimize social desirability bias. The interviewer will state: “here are a few practice questions, to familiarize you with the spirit of this research”. Consider the word “plain”. Now, which of the following three words is most similar to it? The 4 words which will be used for honesty priming, through choosing a synonym out of three, will be: Honest, Genuine, Secure, Plain. The honesty priming vocabulary task is included in Section 3 of the questionnaire, in Appendix A.

6.3.3 The audio diary guidelines for participants

It is important that the audio diary guidelines are non-directive and open ended. The interviewer will state to the participant the following:

Your personal view and opinion of how MAMEM works for you is very important and can only partly be captured in a questionnaire. You will need to record your opinion, in your own words, on your media player after you have used MAMEM for 2 days, for 4 days, and at the end of the trial period. There is no right or wrong way to do this, just whatever comes to your mind as interesting to note and record. Please try to record your opinion right after you have finished a session at the computer using MAMEM. Each recorded opinion may last from 5 to 10 minutes or more. The questions you may want to ponder every time you express your opinion are the following:

- How is MAMEM making an impact in how you use your computer?

- How does it influence the way that you interact with people online?
- How does it influence the way you seek information, resources, or contacts and networks?
- What would be different if you were to be using MAMEM continuously?
- There is no right or wrong answer in explaining if and how MAMEM makes (or could make) a difference in your daily life.

6.3.4 The social inclusion questionnaire

The questionnaire will incorporate open and closed questions that measure all relevant social inclusion indicators. Closed questions will allow the person with the disability and their caregiver to provide quantifiable information, which will allow statistical, correlation analysis. Open questions will provide freedom of expression to the interviewees, and will also provide a foundation for deeper understanding and analysis of the quantitative data.

The questionnaire sections:

- **Section 1:** includes demographics and clinical information
- **Section 2:** includes the "honesty priming" questions. These are multiple choice questions and invite the respondents to select synonyms for specific words like "genuine", "honest", "secure", and "plain". The objective here is to draw the attention of the respondent to the concept of honesty in a nonintrusive, implicit way. Research has proven this to be a tool that elevates response sincerity.
- **Section 3:** Includes computer usage habits. This part will include two of the questions used in D6.1, which will serve as a benchmark.
    - **How much is your social life affected by your disability?**
    - **Please indicate your main uses of your computer system and the three most important ones**
- **Section 4:** Includes the "honesty priming" questions and then the core social inclusion scales
    - **Part A:** involves a question that lists digital activities and tracks the extent to which the participant feels that they contribute to their feeling included in society. This information will allow us to compare activities rated highly in social inclusion against the data on digital activities accrued by the monitoring tools, during usage of MAMEM.
    - **Part B:** is based on the Warwick – Edinburgh Well Being Scale and addresses the Well Being and Empowerment measurement axis. It evaluates the sense of confidence, optimism and contribution that is experienced by the MAMEM user. It is esteemed that these aspects become stronger when the individual feels part of the society, of a community or network. In that sense this part would best reflect changes in social inclusion following more extensive use of MAMEM over time.
    - **Part C:** measures online interactions, and addresses the Participation and Social Capital measurement axis. It measures the extent to which the user feels that he/she has been able to meet people online, make new connections, and interact with them. It also

measures the extent to which the user feels satisfied with reading and producing content.

- **Part D:** addresses the Education and Employment axis by measuring the extent to which the user feels that MAMEM generates more opportunities for exploring employment options, developing business ideas, finding customers online, learning new skills, belonging to professional resource groups, finding health resources and support groups.
- **Part E:** measures bonding and bridging social capital. The users are asked to evaluate to what extent they are establishing connections of trust and support on line, whether they feel part of a larger community.
- **Part F:** includes a list of open reflective questions. The user has the opportunity to express in his/her own words whether and how MAMEM has improved their connection with others, their communication, their sense of being integrated socially, and of belonging to a greater community that can provide connections, support, learning and employment opportunities.

The questionnaires for the participants and their caregivers are included in Appendix A and B.

6.3.5 Data analysis

Given the small size of the control group and experimental group of people with disabilities, the use of both quantitative data analysis and qualitative content analysis will be instrumental in providing a clear understanding for the impact of MAMEM on social inclusion. The qualitative content analysis will supplement the quantitative, statistical analysis and will provide a framework for the understanding and interpretation of data.

1st wave (benchmark, pre MAMEM)

Hypotheses for data analysis:

1. A non-statistically significant difference of social integration scores/indexes between the control group of healthy people and experimental group of people with disabilities.
2. A non statistically significant difference of social integration scores/indexes between the experimental group of people with disabilities and their caregivers.
3. A statistically significant difference in the monitored data scores of those with higher social inclusion scores in the pre MAMEM interview

Statistical analysis tools:

1. Non parametric tests for independent samples, i.e. Mann-Whitney U test, Kruskal-Wallis ANOVA to test mean differences, Fisher's exact test for categorical data (for hypotheses 1). The Mann – Whitney U test is a non parametric test of the null hypothesis that two samples come from the same population against an alternative hypothesis, especially that a particular population tends to have larger values than the other (Mann, Whitney, 1947). The Kruskal Wallis ANOVA is a non parametric method for testing whether samples originate from the same distribution. It is used for comparing two or more independent samples of equal or different sample sizes (Kruskal, Wallis, 1952). Fisher's exact test is a statistical significance test used in the analysis of contingency tables. It is especially employed when sample sizes are small (Fisher, 1922).

2. Non parametric tests for paired samples, i.e. Wilcoxon signed-rank test to evaluate mean differences, exact McNemar's test for categorical data (for hypothesis 2). Wilcoxon signed rank test is a non-parametric statistical hypothesis test used when comparing two related samples, matched samples, or repeated measurements on a single sample to assess whether their population mean ranks differ (Wilcoxon, 1945). McNemar's test is a test used on paired nominal data. It is applied to 2 × 2 contingency tables with a dichotomous trait, with matched pairs of subjects, to determine whether the row and column marginal frequencies are equal (that is, whether there is "marginal homogeneity" (McNemar, 1947).
3. Spearman's rank correlation between monitoring software data and social integration scores/indexes (for hypothesis 3). This is a nonparametric measure of statistical dependence between two variables. It assesses how well the relationship between two variables can be described using a monotonic function (Spearman, 1904).

2nd wave (follow-up, post MAMEM)

Hypotheses for data analysis:

1. A statistically significant difference (higher scores in the post MAMEM interview data) of social integration indices between the experimental groups of MAMEM users and the control group of healthy users.
2. A statistically significant difference (higher in the post MAMEM interview data) in social integration indices within experimental groups of caregivers.
3. A non-statistically significant difference of social integration scores/indexes between the control group of people with disability and the control group caregivers and patients.
4. A non-statistically significant difference in the social integration indices between the experimental group of people with disabilities and the group of their caregivers. Likewise, a non-statistically significant difference is expected between the people with disability in the control group and their caregivers.
5. A statistically significant difference in the accrued monitored data between users and non-users of MAMEM
6. Higher social integration scores are positively correlated with higher scores in monitored data.

Statistical analysis tools for the second wave:

1. Non parametric tests for paired samples, i.e. Wilcoxon signed-rank test to test mean differences, exact McNemar's test for categorical data.
2. Non parametric tests for independent samples, i.e. Mann-Whitney U test, Kruskal-Wallis ANOVA to test mean differences, Fisher's exact test for categorical data.
3. Spearman's rank correlation between monitoring software data and social integration scores/indexes. (for hypothesis 6)

Content analysis

The answers to the open questions as well as the diary entries will be transcribed. Content analysis will be used to detect key themes and issues. The emerging themes will establish a framework that will help us go deeper in understanding quantitative responses.

7 Conclusions

This report has presented a social model of disability as the foundation and groundwork for the analysis of social inclusion related to persons with disability. It has shown that in order to study social inclusion we need to establish a definition of disability that no more relies on the issue of physical impairment, but on the extent to which the social environment excludes individuals with physical impairments from complete and full participation. MAMEM purports to transcend physical impairment limitations and provide its users with the full potential for social participation and integration.

In order to measure the impact of MAMEM on social integration, and following the review of up to date research as well as the findings of WP6, an integrated system of social inclusion indicators was developed. This system of indicators involves three main axes: a) the participation and social capital axis, b) the well-being and empowerment axis, and c) the education and employment axis.

A methodology was then designed to evaluate social inclusion, on the basis of these indicators. In the context of this methodology, computer usage data will be monitored before and after the use of MAMEM, and will provide a framework of how computer usage changed as a result of MAMEM. The hypothesis is that MAMEM facilitates a broader use of digital devices and a wider participation and interaction with people, networks and resources. Moreover, the participants and their caregivers will respond to a questionnaire that measures social inclusion according to the aforementioned indicators, and this questionnaire will be administered before and after the usage of MAMEM. In addition, the participants will keep audio diaries of their MAMEM experience of computer usage, activities and impact.

The analysis will track shifts and changes in monitored data before and after MAMEM usage, as well as track for any changes in the social inclusion indicators reflected in the pre and post interview questionnaire.

The anticipated constraint of the study will be the short duration of a few days that the study participants will use the MAMEM platform. However, it is expected that even this short time of usage will indicate MAMEM's potential in breaking down barriers of social isolation and exclusion for people with disabilities.

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9 APPENDIX A

QUESTIONNAIRE PART 1

A. Demographic information

Subject code: _____

(*Instructions to interviewer: create the code like this: NMD -#- XX.*

 # - according to participation order, XX – according to the first letters of the subject's first and last name. Make sure you match the subject's code to his/hers real name in a separate coding form. Subject's real name will be kept in the coded list together with the informed consent by the PI of each site according to privacy regulations)

Date:	Age:	Gender:
_____	_____	Male \ female
Single \ married \	Number of children:	Ages of children:
Divorced \ widower	_____	_____
Educational years:	Occupation:	If employed:
_____	_____	Full time \ partial
Hours employed per week		

B. Clinical information

1. Diagnosis (*which kind of NMD your diagnosis is related to*): _____
(Instructions to interviewer: if needed, consult with MD/medical records)

1. Years since first diagnosis: _____
2. Have you had any spinal surgery because of your disease? Yes / No
3. Are you in a wheelchair? Yes / No
4. Are you bedridden? Yes / No

_____

5. In which of the following parts of the body do you present partial or complete immobility?

	Tongue	Jaw	Neck	Shoulders	Arms	Elbows	Wrists	Hands	Fingers
Complete									
Incomplete									

QUESTIONNAIRE PART 2

Here are some easy vocabulary practice questions to introduce you to the spirit of this research.

a. Of the following three words which one is the closest synonym to the word “plain”:
[_] neutral [_] simple [_] basic

b. Of the following three words which one is the closest synonym to the word “secure”
[_] safe [_] comfortable [_] protected

c. Of the following three words which one is the closest synonym to the word “honest”
[_] open [_] sincere [_] truthful

d. Of the following three words which one is the closest to the word “genuine”
[_] real [_] straightforward [_] true

QUESTIONNAIRE PART 3

a. Computer use habits

1. How is your social life affected by your disability?
   - ☐ My social life is normal.
   - ☐ There is no significant effect on my social life apart from limiting energetic aspects, such as dancing.
   - ☐ My social life is restricted and I do not go out as often.
   - ☐ My social life is restricted to my home.
   - ☐ I have no social life and feel lonely.

2. Please indicate your main uses of your computer system and the three most important ones:
   (*Instructions to interviewer: can choose more than one; mark an x next to the important three uses*)

☐ Social participation (Facebook, forums, etc.)	
☐ Productive activities (writing, editing, etc.)	
☐ Study (on-line courses, articles, etc.)	
☐ Games	
☐ Recreation (movies, music, crossword puzzles, blogs, etc.)	
☐ Communication (email, Skype, etc.)	
☐ Activities of daily living (purchases, payments, bank, etc.)	
☐ Information (Wikipedia, governmental sites, news, maps, etc.)	
☐ Other: _____ _____	

QUESTIONNAIRE PART 4
Social inclusion measures

Q1. I will read you some digital activities and I would like you to tell me how much does each of them contribute to your feeling included in society and able to make the most of resources available for your benefit. Please rate these activities from 5 (contributes very much) to 1 (does not contribute)

	Contributes very much	Contributes somewhat	Mixed feelings	Contributes little	Does not contribute
Active use of digital technologies overall					
Active participation in social media like Facebook, Twitter, Instagram					
Active participation in business, education sites like Linked In, Quora, Academia edu, etc.					
Attending online courses					
Engaging in online job hunting					
Participating in groups, for a, relevant to your interests and needs (health or otherwise)					
Playing online games with others					
Watching /reading content (videos, movies, books, articles)					
Using specialized software and apps relevant to your hobbies (e.g. photoshop, Picasa, etc.)					
Using digital technologies to earn income					
Hiring help online and finding support on issues that concern					

you					

Q2. I will read you some statements that reflect feelings about life, and I would like you to rate how true they are for you on a scale of 5 to 1, where 5 means the statement is totally true of you and 1 means that they statement is not at all true of you:

	Very true of me	Somew hat true of me	Mixed feelings	Rather not true of me	Not at all true of me
Over the past week, I have been feeling useful.					
Over the past week I have been feeling confident.					
Over the past week I have been feeling optimistic about the future					

Q3. I will read to you some statements now, which have to do with online interactions, and I would like you rate how true they are of you on a scale of 5 to 1, where 5 means the statement is totally true of you and 1 means that they statement is not at all true of you:

	Very true for me	Some what true	Mixed feelings	Rather not true of me	Not at all true of me
Over the last week I have been able to meet new people on line					
Over the last week I have particularly enjoyed not just reading but also writing content					
Over the last week I have been able to find people online that I am attracted to					
Over the last week I have been able to find friends online that I might meet face to face					

Q4. Pre MAMEM: How do you rate opportunities you have had access to, up to now?
Q4. Post MAMEM: Now that you have used MAMEM for some time, rate how much it facilitates opportunities you have access to?
Please rate the statements from 5 to 1, where 5 means you feel you have had access to a lot of opportunities and 1 means there have been no opportunities.

	Lots of opportunities	Some opportunities	Not enough but not a few opportunities	Rather few opportunities	No opportunities really
Exploring employment and income options					
Developing business ideas					
Finding customers					
Learning and developing new skills					
Meeting like minded individuals					
Belonging to professional resource groups					
Finding health information and resources					
Asking for support/help from experts and/or mentors					

Q5. Pre MAMEM: I will read you some statements now regarding your connection with people online and I would like you to rate how true these statements are for you on a scale of 5 to 1, where 5 means the statement is totally true of you and 1 means not at all true of you

Q5. Post MAMEM: I will read you some statements now regarding your connection with people online over the past week that you have been using MAMEM, and I would like you to rate how true these statements are for you on a scale of 5 to 1, where 5 means the statement is totally true of you and 1 means not at all true for you

	Very true of me	Somewhat true of me	Mixed feelings	Rather not true of me	Not at all true of me

There is one or more people online that I can turn to for advice on important things that concern me					
When I feel lonely there are people online I can talk to					
There are people I interact with online would give me support or help if I needed it					
Interacting with people on line makes me feel like a part of a larger community					
I come in contact with interesting people all the time					
Interacting with people online makes me want to try new things					

Q6. To what extent do you feel that the use of MAMEM has helped improve your online communication and interactions with people? (Ask this question only following the use of MAMEM, at the second stage interview)
5: It has helped very much 4: It has helped somewhat 3: Not sure 2: It has rather not helped 1: It has not helped at all

Q7. Pre MAMEM: Please describe some ways in which your digital/online activities improve your overall life, or if this is not the case, why is that?

Q7. Post MAMEM: Please describe if and how MAMEM use has impacted your online activities. And if it has indeed impacted your life…. How so? If not…. Why not?

Q8. Pre MAMEM: Please describe to me some ways in which digital/online activities make you feel included in society, or if this is not the case, why is that?
Q8. Post MAMEM: Please describe to me some ways, if any, in which the use of MAMEM has facilitated your digital/online activities making you feel included in society. And if this is not the case, why is that?

Q8.1. Pre MAMEM: Interviewer, ask those interviewees who affirm that digital/online activities improve their life and/or social inclusion:

Which specific activity has most enhanced your life and sense of being included in society? And how so?

Q8.1 Post MAMEM: Interviewer, ask those interviewees who affirm that MAMEM has facilitated digital/online activities: Which specific activity has most enhanced your life and sense of being included in society? And how so?

Q9. Pre MAMEM: What is your biggest issue in using the computer/tablet to connect and participate in the digital world, that you wish MAMEM would address?

Q9. Post MAMEM: If you were to be using MAMEM on an continues basis, can you describe in your own words what you think might be the impact on your life, your connecting with people and your goals? And in the case you do not anticipate any impact, why is that?

10 APPENDIX B

QUESTIONNAIRE FOR CARE TAKERS

QUESTIONNAIRE PARTS ONE AND TWO ARE EXACTLY THE SAME FOR CARE TAKERS AS FOR THE PERSONS WITH DISABILITIES

QUESTIONNAIRE PART 3
Social inclusion measures

Q1. I will read you some digital activities and I would like you to tell me how much does each of them contribute to the person you care for feeling included in society and able to make the most of resources available for their benefit. Please rate these activities from 5 (contributes very much) to 1 (does not contribute)

	Contributes very much	Contributes somewhat	Mixed feelings	Contributes little	Does not contribute
Active use of digital technologies overall					
Active participation in social media like Facebook, Twitter, Instagram					
Active participation in business, education sites like Linked In, Quora, Academia edu, etc.					
Attending online courses					
Engaging in online job hunting					
Participating in groups, for a, relevant to your interests and needs (health or otherwise)					
Playing online games with others					
Watching /reading content (videos, movies, books, articles)					
Using specialized software and apps relevant to their hobbies (e.g. photoshop, Picasa, etc.)					
Using digital technologies to					

earn income					
Hiring help online and finding support on issues that concern them					

Q2. I will read you some statements that reflect feelings about life, and I would like you to rate how true they are for the person you care for, on a scale of 5 to 1, where 5 means the statement is totally true of them and 1 means that they statement is not at all true of them:

	Very true	Somew hat true	Not sure DK	Rather not true	Not at all true
Over the past week, they have been feeling useful.					
Over the past week they have been feeling confident.					
Over the past week they have been feeling optimistic about the future					

Q3. I will read to you some statements now, which have to do with online interactions, and I would like you rate how true they are the person you care for on a scale of 5 to 1, where 5 means the statement is totally true of them and 1 means that the statement is not at all true of them:

	Very true	Some what true	Not sure DK	Rather not true	Not at all true
Over the last week they have been able to meet new people on line					
Over the last week they have particularly enjoyed not just reading but also writing content					
Over the last week they have been able to find people online that they may be attracted to					

Over the last week they have been able to find friends online that they might meet face to face					

Q4. Pre MAMEM: How do you rate opportunities the person you care for may have had access to, up to now?
Q4. Post MAMEM: Now that they have used MAMEM for some time, rate how much it facilitates (or may facilitate) opportunities they have access to?

Please rate the statements from 5 to 1, where 5 means you feel you have had access to a lot of opportunities and 1 means there have been no opportunities.

	Lots of opportunities	Some opportunities	Not enough but not a few opportunities	Rather few opportunities	No opportunities really
Exploring employment and income options					
Developing business ideas					
Finding customers					
Learning and developing new skills					
Meeting like minded individuals					
Belonging to professional resource groups					
Finding health information and resources					
Asking for support/help from experts and/or mentors					

Q5. Pre MAMEM: I will read you some statements now regarding the connection with people online and I would like you to rate how true these statements are of the person you care for on a scale of 5 to 1, where 5 means the statement is totally true of them and 1 means not at all true of them
Q5. Post MAMEM: I will read you some statements now regarding their connection with people online over the past week that they have been using MAMEM, and I would like you to rate how true these statements are of them on a scale of 5 to 1, where 5 means the statement is totally true of them and 1 means not at all true of them

	Very true	Somew hat true	Not sure DK	Rather not true	Not at all true
There is one or more people online that they can turn to for advice on important things that concern me					
When they feel lonely there are people online they can talk to					
There are people they interact with online would give them support or help if they needed it					
Interacting with people on line makes them feel like a part of a larger community					
They come in contact with interesting people all the time					
Interacting with people online makes them want to try new things					

Q6. To what extent do you feel that the use of MAMEM has helped improve their online communication and interactions with people? (Ask this question only following the use of MAMEM, at the second stage interview)
5: It has helped very much 4: It has helped somewhat 3: Not sure 2: It has rather not helped 1: It has not helped at all

Q7. Pre MAMEM: Please describe some ways in which their digital/online activities improve their overall life, or if this is not the case, why is that?
Q7. Post MAMEM: Please describe if and how MAMEM use has impacted their online activities.

And if it has indeed impacted their life…. How so? If not…. Why not?

Q8. Pre MAMEM: Please describe to me some ways in which digital/online activities make them feel included in society, or if this is not the case, why is that?
Q8. Post MAMEM: Please describe to me some ways, if any, in which the use of MAMEM has facilitated their digital/online activities making them feel included in society. And if this is not the case, why is that?

Q8.1. Pre MAMEM: Interviewer, ask those interviewees who affirm that digital/online activities improve their life and/or social inclusion:
Which specific activity has most enhanced their life and sense of being included in society? And how so?
Q8.1 Post MAMEM: Interviewer, ask those interviewees who affirm that MAMEM has facilitated digital/online activities: Which specific digital activity has most enhanced their life and sense of being included in society? And how so?

Q9. Pre MAMEM: What is their biggest issue with computer usage that they hope that MAMEM would address?
Q9. Post MAMEM: if they were to be using MAMEM on an on going basis, can you describe in your own words what you think might be the impact on the life of the person you care for, their connecting with people and their goals? And in the case you do not anticipate any impact, why is that?

11 APPENDIX C – INFORMED CONSENT FORM

I the undersigned:

1. General Background and importance of research. In order to develop better solutions for people with spinal cord injury (SCI/NMD/PD) towards wider usage of computers and participation in social networks and resources, the efficiency of the MAMEM platform in respond to this need must be evaluated. For this reason, people with disabilities and their caregivers are asked to participate in this research, which involves two interview sessions, before and after use of the MAMEM platform.
2. I agree to participate in the research for the development and optimization of the MAMEM technology, which aims at encouraging the social integration and empowerment of people with disabilities, via facilitating their use of digital devices.
3. I agree to use the MAMEM platform for the designated period of ….. days.
   In this period I agree to make use of MAMEM in the usual routines that I use my PC/Tablet device.
4. The principal investigator in charge of this project is _____ of Organisation _____
5. I understand that I am free to choose not to participate in the MAMEM research, and that I am free to discontinue participation at any time In the experiment, all without compromising the right to receive the standard treatment.

6. I confirm that am free to choose not to participate in the MAMEM research, and that I am free to discontinue participation at any time In the experiment, all without compromising the right to receive the standard treatment. Indeed in the case of questionnaire completion - I may not answer all the questions in the questionnaire or some of them.
7. All those involved in the study guarantee to keep my personal identity secret and my name will not be published in any advertising, including scientific publications.

8. All the information and data that I will provide will be treated anonymously and confidentially at all times.

9. I understand that there are no right or wrong answers in this research, and that my opinions, expressed truthfully and honestly, will be of immense value to the development of MAMEM.

10. The study will involve two interviews, of three quarters of an hour duration each, one before the use of MAMEM and one after the use of MAMEM. It will also involve audio recorded reports.

11. The expected benefits to the participant or to others, as a result of the study is the validation of the usefulness of MAMEM in promoting social integration of people with disabilities.
12. Hereby I declare that the above agreement was given voluntarily, that I understood all of the above. In addition, I received a copy of this informed consent form, subject and date, duly signed.