Mobile Apps for People with Dementia: Are They Compliant with the General Data Protection Regulation (GDPR)?

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Abstract: Mobile apps have the potential to improve the overall patients and caregivers’ quality of life and, particularly, of those with dementia. The ability to stimulate cognitive functions, keep the brain active and helping people to be as independent as possible in their daily lives are considered highly valued characteristics. But despite those advantages, there is a lack of security standards and guidelines focused on mobile apps and the general sense is that those provide low or no privacy/security and commonly do not comply with current regulations.

We analysed eighteen apps with the ability to stimulate cognitive functions for people with dementia to verify if they were GDPR compliant. Results show that most analysed apps (78%) do not provide any information regarding how personal data are processed, and if they do, this is not clear. Also, users’ consent to allow that processing is rarely sought (11%). In conclusion, GDPR mandated requirements are still not implemented in most of the analysed mental health apps to ensure privacy and security in the interactions between users and mobile apps. This work intends to bring awareness to this issue to both researchers and developers, especially in the area of healthcare and mental health.

1 INTRODUCTION

Mobile devices have an important place in our daily life as they have been transforming our personal lives and work environments. More specifically, the variety of applications available today, have completely transformed our interaction with mobile devices and the information we search and exchange. Mobile apps offer a variety of solutions in many different fields including healthcare, where its impact has been very significant. In this domain there is a noticeable development of health related apps offering intelligent tools and services to support healthcare interventions according to the users’ condition (Papageorgiou et al, 2018). Patient care and monitoring, diagnosis, medical education and communication are being carried out with smartphones (Yasini and Marchand, 2015). Google’s Play Store (Android system) and Apple’s App Store (iOS system) have available mobile health applications (mHealth apps) for patients all over the world related to medication control and update, appointments management, blood pressure monitor, diabetes control, fitness, nutrition, mental health, and many others. Apps have also been proving to have the potential to improve the overall quality of life in patients with dementia (Yamagata et al, 2013).

Although the variety of apps for both patients with dementia and their caregivers is wide, are those prepared to ensure security and privacy of users’ data? And are those applications in compliance with the several legal requirements of the new European General Data Protection Regulation (European Union, 2016; GDPR, 2017)?

Due to the advanced processing capabilities of smartphones, many apps in addition to collect users’ health data to help them better comprehend their health status and to promote their overall wellbeing, they also store and process other sensitive information such as user’s health related data, location, lists of contacts and personal photographs (Papageorgiou et al, 2018; Rosenfeld et al, 2017). Also, many of them have not been tested properly in terms of efficacy and safety (Armontrout et al, 2018).

This situation can compromise users’ protection, privacy and security due to a lack of data protection safeguards and control (EDPS, 2016). All this is even more worrying when apps are for people with dementia, whose cognitive impairment can put them at an increased risk of privacy breaches and harm (Rosenfeld et al, 2017).

Therefore, and in order to verify the state of privacy and security in the interactions between users and mobile apps and the protection of individuals’...
personal data, in this paper we searched for apps available in online play stores, with the ability to stimulate cognitive functions for people with dementia. The main goal was to analyse if the selected apps follow the several legal requirements for GDPR data protection compliance.

This paper is organized as follows: section 2 presents the state of the art and section 3 describes the methods used to analyse the apps for people with dementia and if they are in compliance with the GDPR. Section 4 presents the results of our analysis, section 5 discusses the obtained results while section 6 concludes the paper.

2 STATE OF THE ART

Technological advances bring numerous benefits for our society on a daily basis. Smartphones and apps are becoming more accessible to everyone and are increasingly used anytime and anywhere in today's world. It is estimated that 78% of the Portuguese population use smartphones and 72% of users accessed the internet “on the move” (Instituto Nacional de Estatística, 2016). Mobile apps have been incorporated into the personal and social routines of the global population. The diversity of apps available today for the general public is enormous, and in recent years, the development of apps for mental illness has expanded significantly (Armontrout et al., 2018). These apps aim to improve mental health and well-being, helping mental illness recovery and encouraging beneficial habits that improve emotional health (Bakker et al., 2016).

Innovative solutions for people with some kind of mental health issues are particularly valuable. However, the progression of the mHealth market comes with a growing concern for the security and privacy of smartphones and their installed apps (Papageorgiou et al., 2018). Many apps do not follow design principles and privacy guidelines and many times there is a lack of clinical evidence as to their potential benefits (Bakker et al., 2016). Thus, despite of the massive development on a digital level, society began facing questions related with regulation which, in addition to allow innovation, should provide quality and help to ensure security and privacy of users and their personal data.

In order to respond to the lack of security standards or guidelines to follow, as well as, the low or non-existent protection of users personal data, the European Commission adopted, in 2016, a new stricter legislation for protecting and controlling the processing of individuals' personal data of European member states, the General Data Protection Regulation (GDPR) (European Union, 2016).

2.1 General Data Protection Regulation (GDPR)

On May 25 2018, the new European Union (EU) General Data Protection Regulation (GDPR) has come into force to regulate the principles and rules applicable to the processing of personal data (European Union, 2016; GDPR, 2017). GDPR is designed to protect user’s personal data processing, and to ensure that the user is in control of their personal data, rather than companies or businesses.

This new regulation replaces the Data Protection Directive 95/46/EC and it will also help to change the way systems are designed and developed (Krempel and Beyerer, 2018).

The GDPR is applicable to all businesses and organisations that process and hold personal data of a European citizen (e.g. hospitals, public authorities, public organisations, etc.) establishing a uniform framework for data protection legislation across the European Union. This means that now the entire EU is governed by a single regulation instead of each country having their own data protection laws (European Commission, 2018).

GDPR is having a major impact, and as it happens in society in general, also mobile app companies and app owners should implement several procedures to comply with it in order to ensure privacy and security in the interactions between users and mobile apps. Nowadays, there is a lack of security standards or guidelines to follow and the majority of existing mobile apps provide low or no security protection (Mirkovic et al, 2011).

Although GDPR regulation has been decided since 2016, the authors could not find in the research literature works that can provide clear methods to translate the key changes that need to occur between previous and current GDPR legislation regarding users’ interactions with mobile apps. Designing and providing clear privacy notices on smaller screens is not easy. Also capturing and managing user’s consent as required by GDPR is technically challenging. And although GDPR does not contain any exact step-by-step guidelines, it gives a list of the general rules that should be kept in mind when designing and developing software. Some of the GDPR key changes are described by GDPR (GDPR, 2017), the Official Journal of the European Union (European Union, 2016) and by the Portuguese National Commission for Data Protection (CNPD, 2017) (more details in section 3).
2.2 The Use of Mobile Apps by People with Dementia

The world is experiencing demographical changes due to a significant ageing increasing. One effect related with the ageing population is a growing number of people with dementia (Alzheimer's Disease International, 2015).

Dementia includes a group of symptoms associated with memory loss; difficulties with problem solving, language, thinking and concentration; decline of social skills; periods of mental confusion and changes in normal emotional reactions severe enough to reduce a person's ability to perform everyday activities (Alzheimer’s Association, 2018; UKS Mobility, 2016).

Some problems experienced by people with dementia are related with short-term memory, keeping track of a personal object, paying bills, planning and preparing meals, remembering appointments, traveling out of the neighbourhood and even losing the interest in activities that they used to enjoy (Alzheimer’s Association, 2018). Alzheimer's disease (AD) is the most common form of dementia, accounting for about 50% to 70% of all cases (Alzheimer Portugal, 2018). This disease causes a global, progressive and irreversible deterioration of various cognitive functions (memory, attention, concentration, language, thinking, among others). This deterioration results in changes in behaviour, personality and functional capacity of the person, making their daily activities difficult to perform (Astell et al, 2008).

A person living with dementia will require more and more care as their condition progresses. However, during the early or mildest stage of dementia there are a number of things that can be done to help the person maintaining their independence for as long as possible and to keep the brain active (UKS Mobility, 2016). As a result, technology to assist people with dementia (and more specifically with Alzheimer) is highly needed. According with Christina Yamagata et al. (Yamagata et al, 2013), technology can improve the quality of life for individuals suffering from cognitively debilitating diseases.

Nowadays the majority of people own a smartphone and in recent years several mobile apps have been arising with the aim of helping people with dementia to keep them active and to be as independent as possible in their daily lives. Mobile devices and proper apps may allow patients and caregivers to individualize the care to their own needs, empowering this entire patient’s population.

Even more, apps that provide the use of the brain, memory, and solving problem games, help stimulate the brain, the cognitive ability and reduce symptoms of older adults and patients suffering from AD (Yamagata et al, 2013).

3 METHODS

Google’s Play Store and Apple’s App Store offer a wide range of apps in various categories. As for instance, the number of available apps in the Google Play Store was recently placed at 2.6 million apps in December 2018, being the majority of them free to download (Statista, 2018).

Over recent years, numerous mental health apps have been developed and made available to smartphone users. Particularly, for people with dementia, there are several types of apps with different approaches (daily aid, memory training, relaxation, games, caregiver management and information apps) and various apps contain games and activities that can help stimulate the exercise of the brain (UKS Mobility, 2016).

We decided to look for useful apps with the ability to stimulate cognitive functions such as memory, attention, concentration, language and thinking. Our choice is related to the fact that the use of this type of apps could help to slow down the progression of Alzheimer’s and dementia, on their first stages.

Due to Android's popularity, we decided to test Android apps from Google’s Play Store, but because of its huge dimension, it was difficult to do a full review of all apps, so there was the need to take into account the selection criteria. We have selected: (i) free mobile apps with the ability to stimulate cognitive functions for people with dementia, (ii) in English and Portuguese languages, (iii) that matched the search terms “Alzheimer and memory”, “Alzheimer and cognitive games” “Dementia and memory”, “Dementia and concentration”, “Preventing dementia”, and (iv) with high rating by their users (four and five stars). We also included in our analysis four more apps (marked with an “a”) suggested by UKS Mobility (UKS Mobility, 2016) as being useful and beneficial apps for dementia patients and that could make life a little bit easier for all involved.

At Google’s Play Store, after choosing the application section, we introduced our search terms, and then at the price menu we chose only the free apps, available for downloading at Google’s Play Store without any cost.

The reasons that led us to choose the apps in two languages are related to the fact that Portuguese is the...
authors’ native language and we were very interested in having a perception about what type of applications are available in our country for this specific public and if the GDPR requirements implemented in them would vary; and in English, because it is considered a universal language, both in research and technology domains, and also because of the high volume and diversity of apps in English available in the app’s market.

Therefore, we started with the apps’ selection according to the criteria, followed by its installation, and test of its various functionalities relating to GDPR challenges.

Although initially, we had 33 apps selected, our analysis includes only 18 apps. We decided to exclude the apps: (i) exclusive for iOS system (due to the unavailability of the equipment at that moment), (ii) that did not work properly or could not be fully used once installed (i.e., the app blocks in some parts or the images do not show up for some reason), and also (iii) those who were not directly related to our study context (e.g., daily aid apps such as calendar events and medication reminder, or apps to be used by caregivers).

The selected apps were all designed to challenge and improve cognitive skills (such as memory, attention, processing, precision, and comprehension) and they can be divided into small groups. Therefore, four apps (22%), Brain Booster Game, Elevate Brain Training, Lumosity Brain Training and Memory Billionaire Lite offer different activities and games to enhance brain function and increase confidence which is particularly important for a person with dementia. One app (6%) Alzminder Lite, in addition to cognitive games, it also offers other functions such as voice reminders, music player, talking photo album and an emergency button. Six of them (33%) are just composed by memory games: Alzheimer, Brain Score: Connect Dots, Brain Training (PT), Cake Memory: Match Card Cute Games, Memory Game Brain for Dementia and Memory Game to Improve Intelligence. In terms of visual, musical and written tips for conversations and memory support we have one app (6%), the app Memory Box. In its turn, Rimentia - Brain Training (one app (6%)) is a simple colour puzzle that aims to improve the cognitive abilities of the mind and improve memory through colours. Three of our apps (17%) consist in a simple set of games designed to help slowing down the progression of Alzheimer’s and dementia: Alzheimer’s Speed of Processing Game - ASPEN, Brain Mayo and MMSE. Another one (6%), The Dot Game, is a very simple game designed for people with cognitive and/or physical challenges. More than just a memory game, BrainyApp 2.0 (one app (6%)) helps users to track and monitor their brain health over time. In addition to cognitive activities, it also offers many daily workout tips for users to become physically active, eating better and interacting with other people in social activities.

Next, the authors indicate whether the tested applications comply with the following GDPR challenges (EDPS, 2016; European Union, 2016; GDPR, 2017): a) Installation; b) Privacy policy; c) Terms and conditions; d) Request for consent; e) Special categories of data (explicit consent); f) Portability of personal data, and g) The right to be forgotten.

In order to verify if the GDPR challenges are taken into account within the analysed apps, for each of the above challenge we checked the:

- **Installation** - before the app is installed it needs to communicate to the users the type of access that the mobile app will have in the user mobile phone;

And if it included required GDPR items and/or functionalities, such as the:

- **Privacy Policy** - the app should inform users (in a plain and understandable language) the purposes of data collection, what personal data is being collected from users, why, and how it is kept private. A layered notice can be used, where the initial notice to the user contains the essential information and further information is progressively available through subsequent links;

- **Terms and Conditions** - instead of using a long and never-ending “Terms and conditions”, companies have to make it clear and transparent and describe in a simple way the rules, requirements, restrictions and limitations that users must accept in order to use the service;

- **Request for Consent** - users have the right to freely express their consent. This can be done by clicking on a button or checking a box. Companies cannot rely on “presumed consent” which takes consent implicitly just because someone is using the app;

- **Revoking Consent** - functionalities to revoke users’ consent for each category of personal data processed should be provided as users
have the right to change their wishes and revoke their decisions at any time;

- **Special Data Categories** (explicit consent) - considered as more sensitive data (biometric data, race, ethnic origin, politics, religion, genetics, health, sex life and sexual orientation), it can only be processed if the user has given explicit consent. Information can be provided through icons and images to show when certain categories of personal data are processed;

- **Portability of Personal Data** - the user has the right to request their personal information and transfer it to another data controller;

**The Right to be Forgotten** - users should have the opportunity to track their profile, edit information and delete it entirely if they wish. Mobile apps must provide functionalities to edit and request deletion of users’ personal data.

<table>
<thead>
<tr>
<th>App Name</th>
<th>Installation</th>
<th>Privacy policy</th>
<th>Terms and conditions</th>
<th>Request for consent</th>
<th>Revoke consent</th>
<th>Special categories of data</th>
<th>Portability of personal data</th>
<th>The right to be forgotten</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alzheimer</td>
<td>Photos/ multimedia/files</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>n/a</td>
<td>n/a</td>
<td>n/a</td>
<td>n/a</td>
</tr>
<tr>
<td>Atminder Lite</td>
<td>Identity, contacts, location, SMS, mobile phone, photos/multimedia/files, camera, microphone</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>n/a</td>
<td>n/a</td>
<td>✓</td>
</tr>
<tr>
<td>Alzheimer’s Speed of Processing Game - ASPEFEN</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>n/a</td>
<td>n/a</td>
<td>n/a</td>
<td>n/a</td>
<td>n/a</td>
</tr>
<tr>
<td>Brain Booster Game</td>
<td>Photos/ multimedia/files</td>
<td>x</td>
<td>x</td>
<td>n/a</td>
<td>n/a</td>
<td>n/a</td>
<td>n/a</td>
<td>n/a</td>
</tr>
<tr>
<td>Brain Mayo</td>
<td>App purchases, SMS, photos/multimedia/files, Wi-Fi connection information, device ID and call information</td>
<td>It states that “Privacy policy” is provided by Google but it is not available in the app. The user must allow to continue</td>
<td>Same as in “Privacy policy”</td>
<td>x</td>
<td>x</td>
<td>n/a</td>
<td>n/a</td>
<td>Connection is done through a Gmail account and it is not possible to delete it</td>
</tr>
<tr>
<td>Brain Score: Connect Dots</td>
<td>App purchases, Wi-Fi connection information</td>
<td>It states that “Privacy policy” is provided by Google but it is not available in the app. The user must allow to continue</td>
<td>Same as in “Privacy policy”</td>
<td>x</td>
<td>x</td>
<td>n/a</td>
<td>n/a</td>
<td>Connection is done through a Gmail account and it is not possible to delete it</td>
</tr>
</tbody>
</table>

✓ app complies  ✗ app does not comply  n/a not applicable
Table 1: Analysis of applications for Alzheimer and dementia and their compliance with GDPR (cont.).

<table>
<thead>
<tr>
<th>Brain Training (PT) (a)</th>
<th>App purchases</th>
<th>Very extensive and confusing</th>
<th>Very extensive and confusing</th>
<th>User can control options such as the automatic login, allow other users to find user’s profile, allow other people to see user’s activity</th>
<th>×</th>
<th>n/a</th>
<th>n/a</th>
<th>×</th>
</tr>
</thead>
<tbody>
<tr>
<td>BrainyApp 2.0 (a)</td>
<td>Location, photos/ multimedia, tiles, microphone, device ID and call information</td>
<td>Very extensive and confusing</td>
<td>Very extensive and confusing</td>
<td>The user can control features such as notifications, location, connection to Facebook</td>
<td>√</td>
<td>In order to proceed the user has to share some health information such as heart health, physical activity, mental challenges, and type of diet. But this is not an explicit consent</td>
<td>The user has the option to share the obtained results</td>
<td>It is possible to delete profile but according with their privacy policy they will retain all the information</td>
</tr>
<tr>
<td>Cake Memory: Match Card Cute Games</td>
<td>×</td>
<td>×</td>
<td>×</td>
<td>n/a</td>
<td>n/a</td>
<td>n/a</td>
<td>n/a</td>
<td></td>
</tr>
<tr>
<td>Elevate - Brain Training (a)</td>
<td>App purchases</td>
<td>Very extensive and confusing</td>
<td>Very extensive and confusing</td>
<td>×</td>
<td>×</td>
<td>n/a</td>
<td>n/a</td>
<td>×</td>
</tr>
<tr>
<td>Lumosity Brain Training (a)</td>
<td>App purchases, location</td>
<td>Very extensive and confusing</td>
<td>Very extensive and confusing</td>
<td>×</td>
<td>×</td>
<td>n/a</td>
<td>n/a</td>
<td>×</td>
</tr>
<tr>
<td>Memory Billionaire Lite</td>
<td>×</td>
<td>×</td>
<td>×</td>
<td>n/a</td>
<td>n/a</td>
<td>n/a</td>
<td>n/a</td>
<td>n/a</td>
</tr>
<tr>
<td>Memory Box</td>
<td>×</td>
<td>×</td>
<td>×</td>
<td>n/a</td>
<td>n/a</td>
<td>n/a</td>
<td>n/a</td>
<td></td>
</tr>
<tr>
<td>Memory Game Brain for Dementia</td>
<td>×</td>
<td>×</td>
<td>×</td>
<td>n/a</td>
<td>n/a</td>
<td>n/a</td>
<td>n/a</td>
<td></td>
</tr>
<tr>
<td>Memory Game to Improve Intelligence</td>
<td>×</td>
<td>×</td>
<td>×</td>
<td>n/a</td>
<td>n/a</td>
<td>n/a</td>
<td>n/a</td>
<td></td>
</tr>
<tr>
<td>MMSE</td>
<td>Wi-Fi connection information</td>
<td>×</td>
<td>×</td>
<td>n/a</td>
<td>n/a</td>
<td>n/a</td>
<td>n/a</td>
<td></td>
</tr>
<tr>
<td>Rimentia - Brain Training (PT)</td>
<td>App purchases</td>
<td>×</td>
<td>×</td>
<td>n/a</td>
<td>n/a</td>
<td>n/a</td>
<td>n/a</td>
<td></td>
</tr>
<tr>
<td>The Dot Game</td>
<td>×</td>
<td>×</td>
<td>×</td>
<td>n/a</td>
<td>n/a</td>
<td>n/a</td>
<td>n/a</td>
<td></td>
</tr>
</tbody>
</table>

✓ app complies × app does not comply n/a not applicable
4 RESULTS

The authors carried out an analysis to evaluate whether the selected apps presented in Table 1 comply with GDPR guidelines (those that can be applied to mobile apps). The results are shown in Table 1 and organized as follows: the first column has a list with the apps’ name and in the remaining columns we reflect on the compliance of each app with the several points mentioned above.

Our analysis contains in some parts a small description which can help to better comprehend that specific functionality; symbols such as “✓” when the app complies with a certain point; “×” when the app does not comply with it, and “n/a” in cases when that point is not applicable to the app (e.g., in some cases the user does not need to register or insert personal data, thus, the “right to be forgotten” would not be applicable).

We also present Table 2, which shows a summary of the results collected in Table 1.

Therefore, when the user starts with the app installation s/he must be informed which type of access that the mobile app will have in the user mobile phone in order to be installed. In 18 apps, 7 (39%) of them do not inform about the data they need, and 8 (44%) apps need to access personal data such as location, contacts and photos. The most required access is to “Photos/multimedia/files”, which allows access to almost every file stored in mobile devices. When the access is related to “Wi-Fi connections”, it can reveal information about all Wi-Fi connected devices, the user’s location, etc. Users allow or are obliged to allow access to personal data in order to be able to install mobile app to their mobile devices. The lack of transparency and appropriate justifications during the installation, rise several issues in relation to personal data protection and privacy.

When “Privacy policy” is applicable, we verified that in 14 (78%) apps the “Privacy policy” is not present/visible and the user has to consent in order to continue (even though s/he cannot have access to that information), or the user is confronted with a very extensive text full of difficult terms to understand (this happened in 4 (22%) apps) (Figure 1). In 14 (78%) apps, the “Terms and conditions” are inexistent and in 4 (22%) apps (as it happens with the privacy policies) the information presented to users is not concise, clear or simple to understand.

Table 2: Summary of the results presented in Table 1.

<table>
<thead>
<tr>
<th>Apps that comply</th>
<th>Installation</th>
<th>Privacy policy</th>
<th>Terms and conditions</th>
<th>Request for consent</th>
<th>Revocation consent</th>
<th>Special categories of data</th>
<th>Portability of personal data</th>
<th>The right to be forgotten</th>
</tr>
</thead>
<tbody>
<tr>
<td>11 (61%)</td>
<td>0 (0%)</td>
<td>0 (0%)</td>
<td>2 (11%)</td>
<td>1 (6%)</td>
<td>0 (0%)</td>
<td>1 (6%)</td>
<td>2 (11%)</td>
<td></td>
</tr>
<tr>
<td>Apps that don’t comply</td>
<td>7 (39%)</td>
<td>14 (78%) Not present / visible</td>
<td>14 (78%) Not present / visible</td>
<td>5 (28%)</td>
<td>6 (33%)</td>
<td>The user has</td>
<td>0 (0%)</td>
<td>3 (17%)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>4 (22%) Very extensive and continuing</td>
<td>4 (22%) Very extensive and continuing</td>
<td></td>
<td></td>
<td>to share some health information but without an explicit consent</td>
<td>2 (11%)</td>
<td>1 (6%)</td>
</tr>
<tr>
<td>Not applicable</td>
<td>0 (0%)</td>
<td>0 (0%)</td>
<td>0 (0%)</td>
<td>11 (61%)</td>
<td>11 (61%)</td>
<td>17 (94%)</td>
<td>17 (94%)</td>
<td>10 (55%)</td>
</tr>
</tbody>
</table>
user’s profile, allow other people to see user’s activity, but there are no options to change consent. In the app “BrainyApp 2.0” it is possible to control features such as notifications, location, connection to Facebook and the user can change his/her options at any time (Figure 2).

Figure 2: Example of the features control such as location.

The “Special categories of data” is just applicable in the app “BrainyApp 2.0” and after installation the user has to answer some health questions such as heart health, physical activity, mental challenges and type of diet. Taking into account the GDPR, health information is sensitive and the user must give explicit consent. But in this app the user has to answer the questions in order to continue. Thus, this cannot be considered as an explicit consent. This app also allows to share with others on the Community page the progress obtained.

The last column of Table 1 is “The right to be forgotten” and this feature makes sense when the user has to make a registration (e.g., with an email account) or when s/he needs to provide some personal or sensitive data. Thus, 2 (11%) apps have the option to delete the user’s profile; 3 (17%) don’t allow the user to delete his/her profile; 2 (11%) apps do not have that option although the user needs to register through a Gmail account, and 1 (6%) app enables to delete the profile but, according with their privacy policy, they will still retain all information that were collected until then (Figure 3).

Figure 3: The app will retain the information collected prior to user’s request for deletion.

5 DISCUSSION

With the lack of adequate legislation, technologies have expanded without any kind of control. Even with the introduction of the new GDPR five months ago, mHealth apps, which may include sensitive personal data, are still not following the required basic key privacy changes, at least for the area of dementia.

It is not reassuring that all the analysed apps do not comply with two of GDPR key challenges related to the availability of a clear and objective privacy policy as well as terms and conditions for the use of an app. Even before GDPR, users were expecting to have some information available to help them understand how and what type of processing their data was going to have. But this analysis shows that a vast majority of the analysed apps do not have an available privacy policy or terms and conditions (78%) at all, suggesting little or no user control of their personal data once entered into the app. This is particularly problematic for people with dementia, who would be exposed to high risk of loss of privacy if their data were shared without consent. In its turn, those apps that have a privacy policy (22%), the information provided is too general, long and vague, and with a lack of clarity. This is especially concerning for apps targeting people with dementia, whose users may lack the cognitive capacity to interpret the often long and illegible terms and conditions full of legal, confusing and ambiguous terminology. This ends up raising the issue of whether people with cognitive problems may have the capacity to make informed choices about providing their data. At the same time, it can place them at an increasing risk of privacy breaches.
According with the GDPR the essential information should be clear and made available to the user, followed by options for the user to specify what personal data can or cannot be processed, preferably with icons or pictures. Clearly, this situation is not happening at the moment. These are basic privacy mandatory requirements that should be made available for every type of app, much so for people with dementia, who need more care and clarity when exposed to this technology.

Another critical issue is that one third of the analyzed apps do not inform the user about what type of data and features the app will be accessing when running while more than a third request some type of personal data to be installed to fully function. This disparity of procedures is not helpful and, many times, there is no need to request personal data unless the apps have more complete features such as health advisors, health journals or functionalities that allow data to be shared, for instance, with health professionals. However, apps to train brain activity and cognition, even if they follow users’ progress, they commonly do not need to require personal data, nor even data from special categories such as health related data (as shown in Table 1, for almost all apps this GDPR key requirement is not applicable). Still, if they do, they need to make users well aware of what data are being processed, how and what security measures are in place and consent must be provided at all times before that processing starts. Contrary to this, most analyzed apps do not provide the opportunity to give consent to the various parameters. Further, in the cases where this is possible (11%), there is no liberty for the users to change their mind and revoke that previously given consent.

As to the right to be forgotten, even when the user creates an account and introduces personal data, a small number of cases allow users to delete their profile entirely, again, not in conformance with GDPR.

Limitations. During this research the authors could not find information and studies about the impact of the new GDPR on the development of mHealth apps and more specifically in cases of apps for people with dementia, to be able to compare with.

Our sample is very small because, as a first study in this area, we decided to focus on a restrict group of apps that specified in their description that they were designed to improve the cognitive function of people with Alzheimer's disease and dementia. Due to time constraints only one researcher did the selection and revision process. However, used methods can be reused/improved by other researchers and re-applied for a larger sample. Also, we have just experimented and tested apps for Android, making exclusive applications for iOS system excluded in our study.

6 CONCLUSION

Despite all the advantages that apps seem to offer to keep the brain active and help people with AD and dementia to better cope with their disease, there are several security and privacy concerns that are still not addressed. This is particular important for this group of people as they can potentially be more vulnerable and less aware to online dangers and privacy breaches as they may lack the cognitive capacity to interpret and fully realize the problems.

Through this study we found that most available analyzed apps do not provide any information about how they process and treat personal data or, if they do, it is not done in a very clear manner. Furthermore, most of the key requirements mandated by GDPR are still not implemented in the available apps and so these do not comply with regulation to ensure privacy and security in the interactions between users and mobile apps, for European citizens.

This work intends to bring awareness to this issue to both researchers and developers, especially in the area of healthcare and mental health. Further, it aims to give some recommendations for future research, e.g., (1) structured guidelines or principles should be made available online for all mobile app developers during the app creation process, to ensure transparency and to be as much as possible GDPR compliant, (2) the generalized use of simple, clear, transparent and understandable Privacy Policy, always available through a button in the menu configurations or even in another visible part of the app, (3) mandatory use of explicit consent, thus when a user is making a registration on a mobile app, s/he should be asked to opt-in to have their data collected or receive communications (emails or notifications) and this could be done through a consent screen on the app launch. This screen should also show information about what user’s data will be collected and how they are going to be processed, (4) available functionality where users can ask for their data to be removed or can request their data to be deleted and have an opt-out of communications/notifications, (5) strong encryption algorithms of personal data by default, (6) every mobile app must include contact information of the business or app developer, so that users can contact them and have a quicker and clearer support, and, most importantly, (7) the existence of app regulations made by credible entities related to
the app content specially those created for sensitive and vulnerable groups of people.

Future work includes the integration of iOS apps in the study as well as re-applying the same methods to a larger sample, within the same domain.

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