

Ambient Assisted Living and Personal Health Records – Requirements and Challenges

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Abstract

We face enormous medical and health services demands due to the Covid-19 pandemic. This fact implies that the healthcare sector does not manage to cope with the considerable pressure from patients who experienced Covid-19, from which some fail to survive. The hospitals and medical practitioners everywhere were faced with significant stresses, and they were unable to cope with these problems. The patients were scared and unsatisfied with medical help, and the healthcare staff was exhausted everywhere. One of the solutions was implementing the concept of e-health with the usage of e-PHR of the patient and using some components of ambient assisted living (AAL), telemedicine, and telehealth. Many sensors for measuring vital signs of life are available on the market. Some applications can collect these data from IoT devices (sensors), wearables, or other devices that can help monitor the patient’s healthcare condition in a pandemic situation. In this way, healthcare professionals can access patients’ vital conditions and take actions such as e-prescription and e-referral. In the paper, we highlighted some aspects of possible healthcare improvement for the patients using AAL devices who can assist in improving access to medical and healthcare professionals, especially for the patients with chronic diseases, some disabilities, the elderly and children. This concept is based on the e-PHR concept, which understands that the patient owns their data and can access their e-Personal Health Record.

Keywords

Ambient Assisted Living, e-PHR, telemedicine, telehealth, e-health

1. Introduction

With the advent of the Covid-19 pandemic, the world became aware of the need for e-health and services related to telehealth and telemedicine. The workload of the health sector due to a pandemic has led to an increased demand for more health and

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medical services worldwide. Particularly affected were those citizens who have chronic diseases and some disabilities and need frequent health or medical care. It was clear that the world's moves toward e-health services are accompanied by an intelligent environment that needs to be intensively developed to overcome the gap between the required services and those delivered. Suppose we add to this that more and more citizens are reaching old age, and thus their abilities are decreasing, and they need more attention and help from health and social staff. In that case, it inevitably concludes that health and social workers are becoming more burdened. They should use new technologies that can help improve the quality of everyday life of this elderly population and relieve these employees by applying technology.

It should be noted here that the number of citizens with some disability is constantly growing, and thus the need to provide services for them is growing. Due to these facts and the ageing of the world population, new policies, systems and technologies are needed to support healthy ageing and people with disabilities [19, 20, 6]. These policies may include the use of new technologies to track activities of the older people to reduce their need for daily physical assistance and thus extend their autonomous lives. Adherence to healthy habits, medical control and proper nutrition, monitoring sleep or monitoring their vital parameters of life can be helpful and, in this way, should solve the problems with the growing need for health and social services. The second possibility is to monitor the health status of citizens who are not very old and do not suffer from specific pathologies. It can be a strategic approach to detect possible changes in their vital life parameters and if react and be understood as a warning for some neurodegenerative diseases at a very early stage [29].

Let us consider that the lack of physical activity can be connected with ageing and low social activity, depression and function of cognitive decrease [7]. We can state that Ambient Assisted Living (AAL) technologies have to be used to intervene and support the elderly in different stages of ageing. AAL also can provide disabled people with a high level of independent living. AAL aims to introduce innovative methods, technologies and devices that should help people from focus groups to connect, monitor their health, get some help and live independently and without much help from others [13, 31]. AAL aims to develop products and services that will help address problems differently, find solutions to the challenges of ageing, and help caregivers achieve their tasks.

The AAL concept can include technologies with smart devices, wearables, and part of the devices according to the concept of Smart cities that help this category of citizens. These IoT sensors can be wearables / or static, IoMT class devices, various auxiliary sensors and applications for monitoring metabolic processes, movement, nutrition etc. Of course, all this data has to be collected, and for this reason, many researchers worked on creating reference models for AAL. As a result, numerous reference models and architectures have been developed [30].

The context of usage of AAL – indoor/outdoor environment can be restrictive for the technologies used. In addition, this usage influences whether they are invasive or not, in which citizens' category they are applied, and whether they are people with chronic diseases, disabled persons or healthy persons. On the AAL usage influence, did we have to get just warnings, do some vital signs parameters have to be monitored, or do some correlations between data have to be detected as time sequences and functionalities are implemented? Many choices can be made for sensors and techniques with used methodologies in the different environments and the different users.

The scope of AAL systems is comprehensive and demands the inclusion of high numbers of stakeholders, making them even more complex. However, although several reference models (RMs) and reference architectures (RAs) have been proposed, we found that the standardization legislation and technological maturity in this field are still unsatisfactory in linking AAL systems with PHR (personal health records) of the patient. PHR is the core part of monitoring patients' health conditions allowing them to receive health, social and medical services using e-health, telemedicine and telehealth, i.e. gaining consultant help from a distance if they need it.

For this reason, the paper is structured as follows. In the first section after the Introduction, the overview of related works highlights the AAL models and architecture that proposed solutions for the domain, focusing on those who connect AAL concepts with patients' PHR and e-health services. The third section highlights the prerequisites for using AAL services with PHR and e-health services. This part highlights the ability of AAL systems that are very useful for the patients with special needs, especially for the elderly, that have to be provided with safe ageing and higher quality of life and health services through e-health. The needs and data challenges for the proposed reference model suitable for this AAL-PHR connection are considered in the fourth section. The data flow has to be defined according to previously described rules and selected RM for AAL-PHR. The fifth section provides a discussion and research results in order to highlight the proposed model. In this part, increasing the citizens' digital health literacy to use the e-health services and create their PHR are considered. Different alert algorithms that have to be activated in the case of need (if some vital signs of life are out of normal parameters) are discussed in the paper. Concluding remarks draw some research conclusions and give some future action recommendations.

2. Related works

The substantial increase in the average age of the world population and the growth of the number of elderly citizens inevitably increases the number of citizens with reduced abilities for normal living, i.e., some disability or incapacity.

According to statistics, 8.5% of the population is over 65 years old [19, 20]. Therefore, it increases the need for caregivers, at home or out of home, centers for rehabilitation and support centers that burdens the health sector to provide a decent life for older citizens and a better quality of life with active and productive ageing at affordable costs. For this reason, AAL is considered a socio-technical system that provides welfare-oriented services primarily through network artefacts embedded in AAL spaces [9].

The scenarios that AAL have to be offered are complex. A vital source of this complexity is the built-in heterogeneity of the end-user population when arranging their homes and beyond, the physical limitations of users, etc. [11]. The design of these systems requires compliance with several characteristics and norms. It needs to be personalized, adaptable to some capabilities, and responsive to dynamic device changes. It should also be able to adapt to environmental constraints. The AAL platform should have the ability to anticipate user preferences. Perception sensors and actuators should be acceptable to the system [22], and non-invasive and invisible devices are recommended [28]. The system must be able to sense, reason and act in its environment with the ability to communicate and interact [9, 11].

Due to the importance of the concept, many efforts have been made to create a reference model (RM) and reference architecture (RA) of the AAL domain to provide a framework for the development of this type of system. Efforts have led to the creation of multiple architectural models and architectures that have been evaluated according to numerous criteria [9]. However, it is still concluded that researchers cannot agree on the most appropriate RA due to a lack of standardization, which is a crucial success factor for any infrastructure and data flow management due to the heterogeneity of sources and their complex nature.

However, the most appropriate architecture for integrating the AAL domain with the PHR is the Feelgood [10] project's architecture. It incorporates the RM of PHR clinical IS, monitoring services, PHR services, measuring devices, portable storage media, trusted software services, and Authorization, Authentication and Accounting (AAA) services. The part represents the AAL domain for measurement devices and portable media to collect and record data into their media and then in PHR servers if FHIR (FH7) standards provide appropriate ontological support.

However, this RA of Feelgood is not the most suitable according to the evaluation [9], which shows that from all the analyzed, the RAFAALS RA for AAL systems [11], based on Service-oriented architecture (SOA) has the most suitable parameters [11]. The only architectural design that deals with the data flow, collection, processing and integration is RAFAALS. It is also easy to be understood. It supports interoperability and can easily integrate new elements in it. The architecture is independent of any material or software features. In addition, any of the existing components are replaceable.

Researchers are aware of the need for personalization in AAL systems, as personalized environments may differ significantly from individual to general population [8]. Therefore, some researchers propose collaborative filtering models that enable highly personalized AAL data-driven models for the network-training unit. Such models can benefit indoor and outdoor activities related to AAL [12], especially if previous data on their behavior are available to personalize and prevent unusual situations.

Many systems and methods have been developed for AAL systems to monitor continuously biological, behavioral, or environmental data, implement interventions, and assess their vital signs. By developing systems that collect data from heterogeneous sensors and additional data from citizens, new information can be obtained regarding physiological, psychological, emotional and ecological conditions. [12] Behaviors analysis can be done by detecting anomalies while comparing actual behavior with what is expected, and social activities and group interactions can be monitored, whether it is in the home environment or retirement neighborhoods, nursing homes, rehabilitation centers, or indoor or outdoor settings. These are often activities such as nutritional guidance, physical exercise promotion, cognitive practice, social activity, and positive care planning.

The technologies used to develop AAL systems range from simple IoT and IoMT devices to more sophisticated sensor networks of environmental sensors, smart devices, camcorders, robots, and more. These diverse technologies use data complex in size, heterogeneity, and sampling frequency and are often big data. Data management inevitably has to involve complex communication protocols with high-security controls because the sensitive personal data must be secured and legal requirements must be met [2]. In addition, the energy consumption, the possibility of detecting defects as well as interoperability between devices and equipment vendors should be taken into account. Many more technical issues should be considered when designing such a complex ALL-PHR structure [3, 9, 10, 11, 12].

Although they are widespread, the diversity of technologies requires meeting specific requirements, such as being non-invasive, readily accepted by citizens, and not influencing users' daily activities. In addition to the wide range of devices, four main categories of technologies can be distinguished. The first category consists of wearables that require user acceptance. The second one is less invasive, smart objects or furniture, the next category is related to environmental sensors, and the fourth one covers social assistance robots [12]. Wearables are useful because they carry information, inside and outside. They detect movement, behavior, vital signs of life, and possible falls (devices for monitoring vital signs of life for various parameters, gyroscopes, etc.). The intention is to incorporate them into mobile phones and smartwatches to free people from wearing more special wearables. They provide valuable data for medical staff if they are

connected and send data into their PHR [12]. It should be noted that many efforts have been made to create a variety of precise techniques for personalized tracking of many SMART devices using intelligent methods and technological frameworks to achieve effective monitoring of data. For example, that can be used to obtain tools for alarming staff and caregivers who care for the people who wear these devices [18].

Every day's SMART devices are objects that use IoT / IoMT and sensors as well as processors to identify them and communicate with them, i.e. to be smart and remotely controlled, providing residents of the home/institution with a wide range of possibilities: detecting anomalies, preventing injuries, increasing safety, or assessing health problems. For example, the first signs of cognitive impairment can be easily seen in behavioral variations during meal preparation or stove handling. Smart devices in the home and their use are limited only by the imagination of designers and users' requirements and have the potential to monitor the daily behavior of users at home and their habits and detect inappropriate behavior. They can be smart boxes from which medicines, carpets, refrigerators, doors, pillows, and many other devices are taken to provide data using different methods and algorithms for the users' daily activities. If these data are available to health and medical staff, they can quickly conclude the patient's health status [14, 15].

Environmental monitoring sensors are non-invasive devices that can overly warn of air pollution, temperature or other parameters and are helpful in the AAL environment. These include devices for analyzing radio frequency devices and microwave sensors, intelligent optical systems and more that can help detect behavior and aid in movement, sleep etc. Not all data from these sensors are needed in the patients' PHR. As a consequence, some data can be entered into auxiliary databases. They will then be extracted with the help of intelligent data, if necessary [21].

Social assistance robots are a technology that is rarely used due to the still high cost. However, it can be used to humanize some activities in hospitals, rehabilitation centers. Wherever there is a need for frequent repetitive and quick reactions, such as carrying food, lifting or grabbing objects, delivering, and releasing medical staff. It is also important to personalize the human-robot interaction by providing the robot with human-like social skills, such as natural language processing, user emotion assessment, etc. [12, 16].

All data collected from AAL systems have to be analyzed for AAL situations. Some use data from heterogeneous sensors and advanced analysis techniques such as Artificial Intelligence (AI), Support Vector Machines (SVMs), and machine learning, which should lead to anomaly detection and intervention. The cost of AAL systems largely depends on this. They generate vast amounts of data to personalize systems and refine their reactions. Only some information obtained from data using intelligent algorithms needs to be stored in the user's PHR. Those

required for healthcare personnel include falls, loss of consciousness, balance, physical inactivity, sensory measured vital signs of life, and similar data requiring medical intervention [12, 17].

However, it must be acknowledged that AAL systems play an essential role in achieving greater well-being for the elderly and disabled by significantly improving their quality of life and providing distance services, improving autonomy, emergency treatment and comfort services [18]. Significant advances in miniaturization, wireless technology, processing and computing power have driven innovations in the healthcare sector, leading to the development of all these related medical devices capable of detecting, recording, generating, analyzing and transmitting data and creating information about warnings and conditions. Together with the data itself, these devices create a useful infrastructure of software applications, medical devices, and mobile applications connected to various medical devices [23]. These health services can provide real-time life-saving monitoring in medical emergencies, such as asthma attacks, heart attacks, diabetes, falls, and similar emergencies. With these systems, if connected to the PHR available to the physician of their choice, the patient can also receive assistance from remote locations by activating alerts and prompt intervention by emergency medical teams. This can drastically improve patient care [1, 21, 23] and even provide e-referrals and e-prescriptions to patients [25].

3. Prerequisites for connection of PHR and AAL data

The model that integrates AAL data with the PHR of the patient assumes that the data collected by the AAL systems are following the health standards FH7 and all data collected should be following the ontology used as a basis for creating standard PHR [1, 21]. Furthermore, due to the sheer volume of data obtained from the many different types of AAL systems, estimated to be over 50 billion devices [18], it is necessary to typify the devices and their measurements. Furthermore, it is important to investigate how that information affects the health of users and how to proceed, whether to alert caregivers, relatives or loved ones.

It is especially necessary to analyze data for measuring vital signs of life that should alert medical personnel and caregivers to take swift action to save their lives or provide emergency care. Because these data collected from AAL systems are big data, it is often necessary to analyze them first using the big data analysis tools and machine learning methods that are most suitable for this purpose. These data can help detect the condition and the need to alarm the caregiver. These data have to be recorded as additional data that can be accessed via PHR by selected doctors or caregivers – medical staff [5].

We believe that it is necessary to create additional data that would lead to data detected as information from AAL systems. These additional PHR extended

functionalities that will collect data on user health-related situations detected by AAL systems are important to healthcare professionals and patient care and should be subject to detailed analysis. For example, suppose we consider the wide range of AAL devices that collect data and alert users to the situation. In that case, it can not be ignored that the flood of health professionals' data from such AAL generated data can lead to confusion, inability to analyze in time and information flooding. Therefore, it is necessary to define priorities for those data that mean life-threatening and alarming situations. Such requirements certainly require an interdisciplinary approach to solving the problem of involving medics and defining these priorities. Furthermore, to avoid information flooding in the PHR of the patient, it is necessary to determine the data that will be stored in the external tables that can be accessed through the PHR of the user.

4. Data in PHR and AAL – needs and challenges

The data available to the patient and stored in the patient's PHR are created according to the FHIR standard ontology, which involves using patient data from the patient-centric system. This cloud-based system [1, 3, 21] contains the patient's personal health data collected in various ways, by direct input into PHR, through labs measurements, images from multiple medical devices, data entered by the physician, scanned by the patient, data from doctor visits and diagnoses according to the IC10 classification. The possibility of using other data is not limited and depends on the patient's needs. Even the information of public interest as exposure data can be used by the patients and their selected physicians to assess their health risk from ambient living conditions (Figure 1: High-level robotic system model).

An important issue for this paper is the part with the AAL Data Repository. AAL data can be very extensive and collected in different formats. If it were possible to obtain information on life-threatening situations for the patient, it would mean that they would be received in the form of warnings, and alerts related to the patient's PHR from intelligent agents who would assess the situation according to previously defined algorithms for generating alerts, depending on some devices [17, 18]. Many examples use SVM algorithms and other machine learning methods to detect behavior using different types of sensors and sensor networks [24].

For the independent living of the elderly and maintaining a quality of life, one of the key components of AAL applications is human activity recognition (HAR) [18]. This can be done with one of the big data analysis tools. Emerging studies have shown that high levels of accuracy in behavioral classifiers and the detection of behavioral abnormalities can be achieved. Accelerometer and gyroscope sensors were used on smartphones to collect data on the activities of the elderly and caregivers and then make personalized models for each patient individually

[24]. These activities include motion detection, food tracking, social networking, navigation and localization. There also possible to have comprehensive monitoring of the elderly related to having a 3-tier architecture with perception, network and application layers. Diagnostic information also can be included with sensors for measuring cardiac parameters such as pressure, temperature, heart rate, and ECG monitor associated with a mobile application. Mobile apps can record data on a mobile device and then send them to the patient's PHR. The selected doctor by the patient has access to PHR, and if that data is outside the normal range, an alert is sent to the doctor or caregiver. After receiving this alert, they can respond immediately or in time and take appropriate action to save their life and improve their life parameters [24].

These are just a few examples of AAL usage that can be associated with PHR and patient status warnings. The use of AAL technologies for warning and improving the health care of patients in need is limited only by the imagination of the designers of AAL-PHR systems. Some of these technologies are already widely used in some hospitals, and the possibility of data connectivity and service integration is increasing every day [24, 18, 21].

5. Results and discussion

The model from Figure 1: High-level robotic system model [1, 3, 21] preparation is planned to be implemented in 4 steps (Figure 1: High-level robotic system model): First step is the definition of the sensor infrastructure. The second step is planning the database structure – the repository where it is planned to store the data collected by the sensors. The third step is the analysis of the necessary AAL actions that are important to alert them to and the fourth step is the evaluation of the patient behavior, which is the subject of interest and with whose PHR we want to relate the data from the AAL structure [1, 18]. According to AAL systems detections, the alert of the responsible staff or the selected doctor is triggered by an intelligent agent, software that is triggered by the appearance of indicators for the state in the PHR structure. Details for preparation steps for creating the model presented in Figure 1: High-level robotic system model are shown in Figure 1: High-level robotic system model.

The first step defines the needs of AAL sensors for a specific patient. In this step, the needed sensors for this patient are defined, depending on his chronic disease or motor impairments or some other problems. In this step, the functionalities that have to be covered and the needed sensors for measuring vital signs of life have to be defined. Examples of this type of AAL system can be seen in [24], where conditions are determined using infrared sensors to detect the patient's condition and movement. This step is essential to set up the necessary infrastructure and define the data collection in the next phase. The usual structure of re-

positories for data collection for some parts related to PHR data is determined by the FHIR standard ontologies available for use for medical and health purposes.

Collecting data in some big data formats for many of the sensory data is an important part of being used to identify the behaviour of a specific PHR owner using artificial intelligence, machine learning, and other AI methods used to detect normal and abnormal behaviour of the patient or his vital parameters of life. In the third step, it is necessary to define the conditions that will be subject to warning of the selected doctor or caregivers and which should be defined as changing states of indicators in PHR to activate the ALERT and to warn the person responsible for providing care or the selected physician who has access to the patient’s PHR [24, 7].

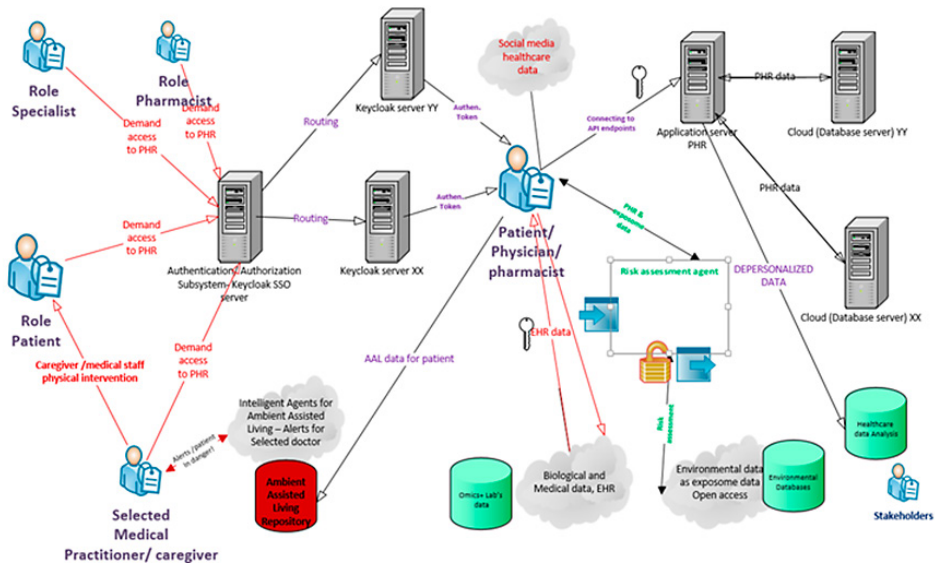


Figure 1: Proposed PHR-AAL connected model with alerts for caregivers and selected medical practitioners with intelligent agents from the AAL system

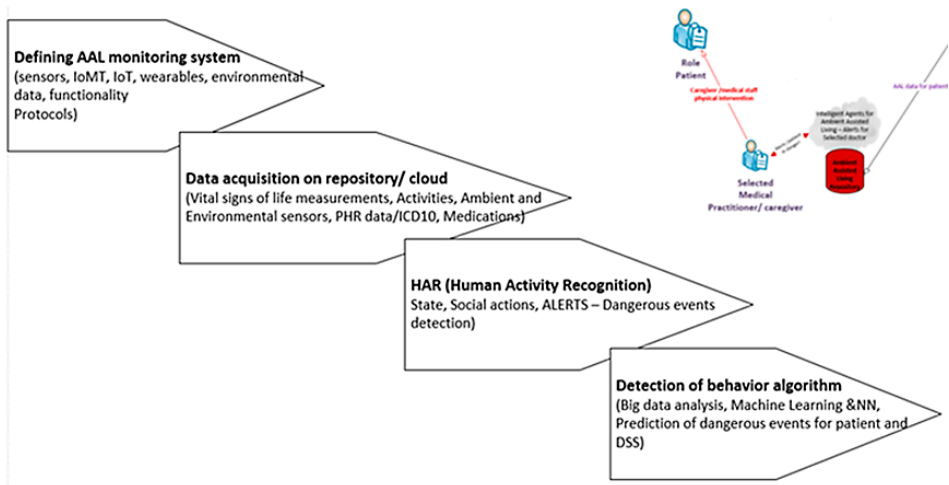


Figure 2: Four Steps in PHR-AAL model preparation

The fourth step concerns the personalization of each patient’s behaviour and the development of a specifically tailored model for each patient. To adjust the parameters of a particular patient and his behavioural parameters to normal and ability to detect anomalies, a big data analysis is needed from the data collected by the machine learning methods and other AI methods that should lead to the specific set of settings of its parameters that should alert for disturbance of its normal state. This means that the mechanism AAL -data analysis – alert – sending data about the condition – time of intervention is activated immediately or a prediction for future deterioration of the condition and the period in which that deterioration will occur. The intelligent agent triggers and alerts the people in charge – caregivers or chosen doctors who immediately intervene for the patient and decide on future activities based on the analysis of the results obtained from the specific AAL systems. This AAL system can or cannot be part of the PHR, but is accompanied and available for analysis by selected physicians and caregivers.

The proposed model has a patient-centric architecture and strong AAA security Keycloak server control. This strong Authentication control provides cross border healthcare usage, routing patients to a suitable database server that acquires patients’ data in the country of living. The patient can grant permission for their PHR to the selected medical staff, enabling e-health services over distance. The patient can use e-prescription and e-referral services [25] and services for assessing the risk from public environmental services for pollutants [26]. The patient and their doctor can also use labs and biomedical data from the patient’s EHR, provided by state Hospital Information systems (scanned documents saved into cloud-based patient’s PHR). Besides this, they can have a part of data con-

nected with sensors that measure their vital signs of life and data from AAL system that can trigger alerts and demand the caregivers/doctors' intervention. It is done because of the patient's dangerous condition in which the patient is in the moment. For the patients with some chronic diseases, alerts should provide life-saving and rapid caregivers/ doctors intervention. This model has to provide safe living conditions for the elderly, disabled citizens, and patients with chronic illnesses.

This approach requires a complex AAL structure, support servers, application and data service. Still, some of them can be done in a fog-computing environment on the local network [28]. Such an analysis is related to the cost of such systems and the benefits that can be obtained by people who need monitoring and improved quality of life for independent living under supervision. In the long term, the investment pays off because it frees up many caregivers and physicians who can serve a much larger number of patients remotely in their homes. In this way, they will yet have control over their vital signs of life, thus including AAL systems in the control process and their connection to PHR available to those caring for the patient.

6. Conclusion

The psychosocial factors of human-technology interaction, communication, and their usage have to be considered when developing AAL systems and connecting them with the PHR of the users. Together with data usage and processing of AAL data, these factors are worthy of further investigation by the scientific community. The aim is to develop complex, intelligent systems for independent living support, improvement of healthcare services, tele monitoring and consultation, social participation and well-being.

In this paper, some attempts to propose a PHR-AAL model that will connect AAL data with alerts that are important for the health status of PHR owners are made according to the previously made analysis of PM and RA. This type of communication should be done at the necessary level of alertness for a condition that should be predefined and deviate from the patient's normal behavior – whether it is movement or some vital signs of life with wearables or IoMT / IoT sensors measurement. The trend of deviations from normal behavior should be detected in advance, and algorithms have to be trained using machine learning or other intelligent methods. Alarms should be predefined, and the alert's location should be determined to provide an immediate response to Caregivers / Selected doctors and allow an immediate response if needed. The need for this connection is increasing due to the workload of the medical staff due to the pandemic and the growing number of chronically ill, elderly and disabled citizens. They all need regular monitoring to ensure independent living with the help of AAL systems

that provide multiple forms of monitoring of their health, condition and need for health and social care.

The model involves creating a patient-centric health record in a system in which the patient owns the data and is the one who shares their health record with the selected doctor that they decide to give grant permission and will need to take care of their health. This model can be connected to health institutions that assist patients with special needs and reap the benefits of the symbiosis of e-health, PHR, telemedicine, AAL and remote assistance using IoMT, Mobile applications and SMART devices related to the cloud with established security measures and protection following the law on the protection of personal information [2, 5]. The use of data from public data services does not require any higher security mechanisms. It can be used to assess the risk of environmental conditions as exposome data, at the place of residence [4, 26]. This concept may include the use of known ontologies that may contribute to the integration of environmental data of different nature as exposures [27] and the use of genetic information about users associated with different diseases and the quantification of the impact on each. Of course, such research requires multidisciplinary teams of medical researchers, specialists, geneticists, immunologists, and data scientists who can connect data and ontologies, define links, and detect human behavior for each specific PHR.

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