

A Review of Information Technologies Used in Health Care on the Example of Treatment of Haemophilia Patients

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Abstract

Objective: Discussion information technologies and tools that can be used in health care in Poland in the field of haemophilia treatment.

Methods: The research was conducted through participant observations and analysis of existing technologies.

Results: The existing development of IT systems may contribute to helping in the treatment of haemophilia and facilitating functioning with the disease in question by creating dedicated IT systems, implementing already available technologies and using new solutions. In this regard, augmented reality (AR) and the Metaverse can be used to create IT systems to support patients and medical staff in agent administration training.

Implications and recommendations: The publication overviews current solutions and aims to indicate the direction of using new technological solutions. In practical terms, the work defines the directions that can be used in augmented reality and the Metaverse.

Originality/value: The value of the work is the analysis of the medical issue from the point of view of management and quality sciences. In addition, it has been expanded to include an analysis of technological solutions.

Keywords: haemophilia, information systems, Augmented Reality, Metaverse, medical care

1. Introduction

The use of information technologies in health care is now a common phenomenon, and their use to support the treatment of the population covers an increasingly wide range of cases. Tools designed for this purpose often resemble those known for commercial use, barely differing from them – only adapted to this strictly defined purpose. They therefore utilise similar technologies. The development of information solutions offers an increasingly broad range of possibilities for their implementation in health and medicine.

The challenges faced by public health care systems require, both for the benefit of people and maintaining the ability to finance it, prudent and, at the same time, efficient implementation of information technologies wherever it can be used, reducing costs and improving the comfort of patients' medical care.

Haemophilia is a rare disorder. In the case of severe and moderate forms of the disease, patients require constant care from a haematologist and prophylactic, lifelong treatment. It is considered an incurable disease.

Therefore, the authors undertook a study to analyse and discuss the current information technology tools used in healthcare in Poland in the field of haemophilia treatment. The study was developed based on tools used by patients with haemophilia and entities involved in their treatment.

Moreover, the study includes considerations regarding the potential application of new information technologies that have not yet been used in patient care in Poland but may contribute to improving the quality of care for individuals with hemophilia. For this purpose, 2 emerging solutions have been selected: Augmented Reality (AR) and Metaverse.

The research aims to answer the following questions:

RQ1. What ICT solutions are currently used to support the treatment of patients with hemophilia and what tools are planned to be introduced in Poland in the near future?

RQ2. How can emerging technologies, such as AR and the Metaverse, support the treatment of patients with hemophilia?

The article begins with an introduction outlining the purpose and research questions. This is followed by a presentation of the theoretical background, research methodology, results, discussion, and conclusion.

2. Theoretical Background

Polish healthcare is organized into two sectors: public, which plays a dominant role, and private, which has gradually increased its share of health services, particularly in recent years. Access to public healthcare is guaranteed at the constitutional level, and key healthcare solutions are implemented within this framework, available free of charge as part of health insurance. Most medical organizations operate based on this system or via contracts with the National Health Fund, the central institution for healthcare. The functioning of the healthcare system is secured by public funds, primarily financed through mandatory health insurance contributions. However, Poles are increasingly using private health insurance, with this market expected to grow by an average of 7% annually over the next five years (PMR, n.d.).

A survey conducted in June 2023 by the Public Opinion Research Centre (CBOS) titled 'Use of Health Benefits and Insurance' (Felisiak, 2023) revealed that 24% of respondents used only public healthcare services in the six months before the survey, while 11% relied solely on private services. The largest group, 51% of respondents, accessed medical services covered by public and private insurance.

Notably, there has been a decline in those using only public medical services and an increase in simultaneous use of both systems. The importance of healthcare is underscored by the fact that only 14% of respondents did not use these services at all in that same timeframe.

The private health sector mainly provides basic services, such as access to general practitioners, specialists, diagnostic laboratories, and dentists. High-cost services, such as drug or therapeutic programmes – especially in oncological treatment – are strictly the domain of the public system. This is also true for patients with haemophilia, whose treatment is managed under a dedicated, ministerial public programme.

In the 21st century, significant progress in healthcare can be seen, especially in medicine, just as in the previous century. This development has made it possible to treat diseases once deemed lethal or impossible to fight. Advances in pharmacology, where new drugs are introduced yearly to combat various cancers, enhance patients' chances of extending their lives and improving their quality of life.

3D printing in healthcare is increasingly common, providing measurable benefits and opportunities. As a rapid prototyping technique, 3D printing offers advantages over traditional tissue engineering methods regarding model shape, maintenance, flexibility, and reproducibility (Sarecka-Hujar B. et al., 2016). Innovations in implants and prosthetics, utilising modern materials like bone substitutes and bioabsorbable components, have also led to more advanced solutions. Additionally, innovations such as medical robots, nanorobots, and new technology dressings highlight ongoing progress in this field.

An inseparable factor for the discussed progress, especially in the context of increasing the efficiency of healthcare, is the development of the digitalisation of society, which is followed by the simultaneous coupling of information technologies with this field. The development of e-medicine, understood as any application of information technologies in healthcare (Wurm et al., 2008) provides a wide range of new possibilities in the treatment of patients.

3. Methodology

The research was carried out by using participant observations (Apanowicz, 2002, p. 81) as a result of performing professional activities in a healthcare facility based on an employment contract. This made it possible to learn about the processes related to treatment and the documentation of IT solutions. The detailed research methodology is presented in Figure 1.

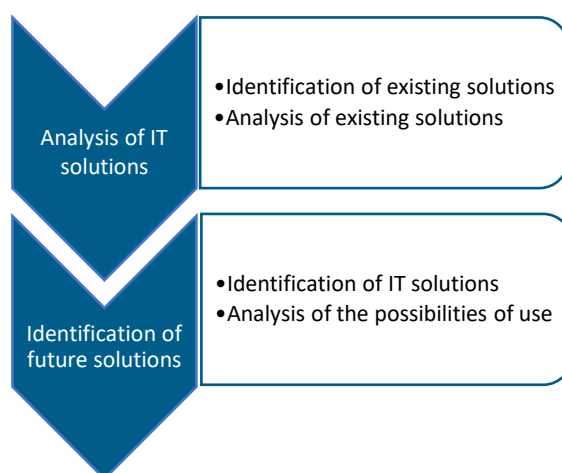


Fig. 1. Research methodology

Source: own elaboration.

The results of each stage are presented in the section describing the results.

4. Findings

In the information society, IT technologies play a crucial role for citizens, private sector organizations, and state institutions. The state has a responsibility to protect freedoms and ensure the rights of individuals, as outlined in the Polish Constitution, particularly Article 68, which guarantees the right to health protection and equal access to public healthcare services regardless of financial status. This obligation is reinforced by international law, such as Article 35 of the Charter of Fundamental Rights of the European Union (Romaniuk & Brukało, 2015). State institutions utilise information and communication technologies, collectively known as e-health, to fulfil this obligation, with Internet of Things (IoT) solutions also gaining prominence (Płaciszewski, 2022).

E-health solutions are dedicated at the national level to all patients, also to patients with bleeding diatheses, including haemophilia, and use such tools as:

- e-prescriptions,
- e-referrals,
- e-sick leaves,
- e-queue,
- Electronic Medical Records (EMR),
- Online Patient Account (IKP),
- mobile applications and IT systems (medical informatics),
- teleconsultations.

The concept of IoT has its source in the title of a presentation prepared in 1999 by Ashton (2009) and is currently defined from the point of view of technical standardization, among others by the International Telecommunication Union (2012) as a global infrastructure for the information society, enabling access to advanced services through interconnections (physical and virtual) of things based on existing and interoperable information and communication technologies (ICTs). The ITU explains that by leveraging the ability to identify, collect, process, and communicate, the Internet of Things fully uses 'things' to offer services for all kinds of applications while ensuring that security and privacy requirements are met (International Telecommunication Union, 2012).

The Internet of Things has a significant potential to be implemented in many aspects of life. Rot and Blaike (2017) point to branches of the economy such as transport (to means of transport) and trade and services (in hotels, banks, or restaurants. In addition, the possibility of using IoT to manage urban infrastructure (as part of the smart city concept (Rot, 2017) as well as human *per se* – to monitor and improve health and well-being – has been noted.

The possibility of using IoT to improve human well-being, also in the context of health, has led to the popularization of the Internet of Medical Things (IoMT) in the literature. This was primarily thanks to the technology industry and research institutions, which began to work intensively on solutions in remote patient monitoring, telemedicine and smart medical devices¹.

IT solutions currently available in Poland, dedicated to supporting the treatment processes of haemophilia patients, do not use the latest solutions available on the market, limiting themselves to implementing technologies that have been in common use for many years. However, this does not change the fact that their existence simplifies the care of the sick and their daily life. These solutions supporting the treatment of haemophilia patients include the 'Rescue Factor' and the Electronic Patient Logbook. Below, these solutions are presented for the preparation of the e-haemophilia solution. The last part presented the results of considerations focusing on the possibility of using AR and Metaverse technologies to support the treatment of haemophilia patients.

¹ Companies such as IBM, GE Healthcare, Philips, and technology startups have been launching innovative IoMT products and services in recent years, which has contributed to the popularization of the term.

4.1. Currently Functioning

1. IT system 'Factor to the rescue'

For patients with haemophilia, especially severe and moderate types, who take coagulation factor constantly, as a preventive measure, or on demand – in the event of bleeding, it is essential to issue a doctor's order for a coagulation factor, and in some situations also desmopressin. However, the IT system used by the doctor for this purpose is not integrated with the Online Patient Account (IKP) system but is a completely separate tool for the operation of which the National Health Fund is responsible. An online system of orders for coagulation factor concentrates and desmopressin for haemophilia patients, as part of the National Programme, is available in the form of a website, being called, after the National Programme for the Treatment of Haemophilia Patients, 'Factor to the Rescue'. Its functioning, as in the case of other Central Medical Systems of the National Health Fund, is the responsibility of Asseco Poland. The system of the 'Factor to the Rescue' website operates based on Electronic Health Records (EHR), and the database it supports primarily contains information (apart from distinguishing patients, such as name, surname and PESEL) relating to the bleeding diathesis of a specific patient – this data is entered into the system based on the basic document issued by the doctor of the Treatment Centre under the National Programme confirming the presence of the disease in the patient – the Treatment Chart, which is handed over, after being issued, to the National Blood Center and Regional Blood Donation and Hemotherapy Centers. Figure 2 shows the main page of the system.



Fig. 2. Home screen of 'Factor to the rescue'

Source: (Narodowy Fundusz Zdrowia, n.d.).

2. Digital Logbook for Haemophiliacs

It is important to closely supervise patients who take their medications. This helps ensure they take their medications correctly and for the recommended duration.

First, it helps patients stay healthy. When patients are monitored while taking their medications, they are more likely to take them regularly. This can help patients stay healthy for many years and reduce the chance of getting certain diseases, like arthritis. The doctor is informed in advance about the approaching depletion of the patient's stock, which in turn allows him to issue a new order for the next series of the factor in time. It should be emphasized that patients treated prophylactically receive a supply of the agent based on an order issued by a doctor, which in many cases is sufficient for several months. The total dose of the agent can range from 60,000 to 180,000 units of the concentrate, equivalent to dozens of boxes containing several vials, each with 500 to 1,200 units of the agent.

Patients may have difficulty tracking how much refrigerant they have used and how much is left if they do not have an updated logbook.

Savings in healthcare expenditures are another benefit. Most of the money spent on the National Programme each year goes to buying and providing medicines to patients.

To avoid unnecessary costs, it is important to ensure that patients use the refrigerant correctly and do not lose it.

The worrying thing is that around 2024 and 2025, many haemophilia patients taking coagulation factors will not be able to use a technology-based tool to track their factor administrations. Currently, this solution is only available to patients covered by home deliveries of the refrigerant, which was introduced under the National Programme on April 1, 2020 (Ministerstwo Zdrowia, 2019).

The obligation to provide the tool in question has been assigned to entities awarded a public contract for domestic clotting factor supplies. The entity selected for the supply of clotting factors VIII and XI was Takeda Pharma (Zakład Zamówień Publicznych przy Ministrze Zdrowia, 2021). The digital logbook for patients with haemophilia (Digital logbook) provided by this entity is known as Zero Bleeds. The app is relatively accessible and intuitive. Patients can also use the logbook offline. The basic functions of the application (in particular the bleeding and infusion log) are available on the main screen or using a drop-down menu from the side, on the left – as shown in Figure 3.

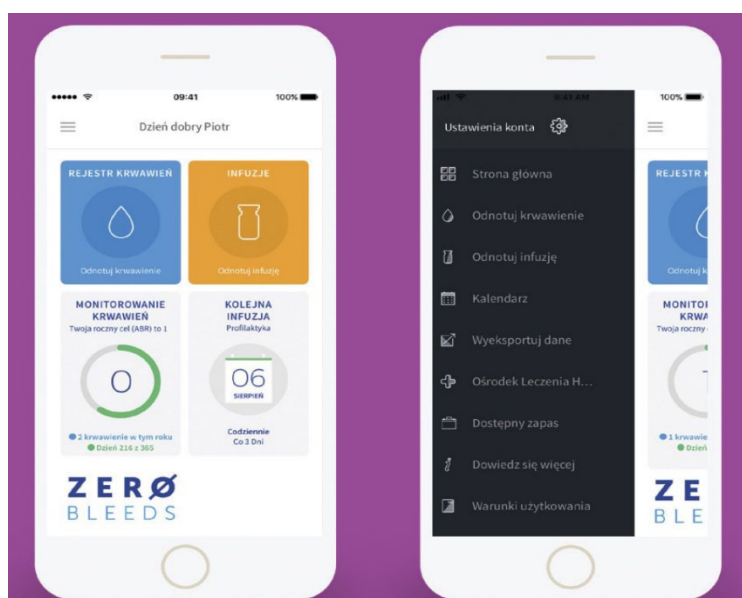


Fig. 3. Digital logbook Zero Bleeds – homescreen and sidepanel of application

Source: (Zerobleeds, 2021).

After clicking on the 'infusions' tile, to the patient can complete information related to the infusion of clotting factor I. It is important to enter the reason for the infusion – the patient can choose one of five options:

- prevention,
- treatment of bleeding,
- operation,
- dental care,
- other.

In the diary, the patient can provide information about the occurrence of bleeding, its location on the body, date and time, and also include a photo.

Events recorded in the logbook are forwarded to the treatment centre (if the patient uses the online application) – so that the patient’s doctor can see them. In addition, this data can be found collectively in the application, in the calendar module (see Figure 4).

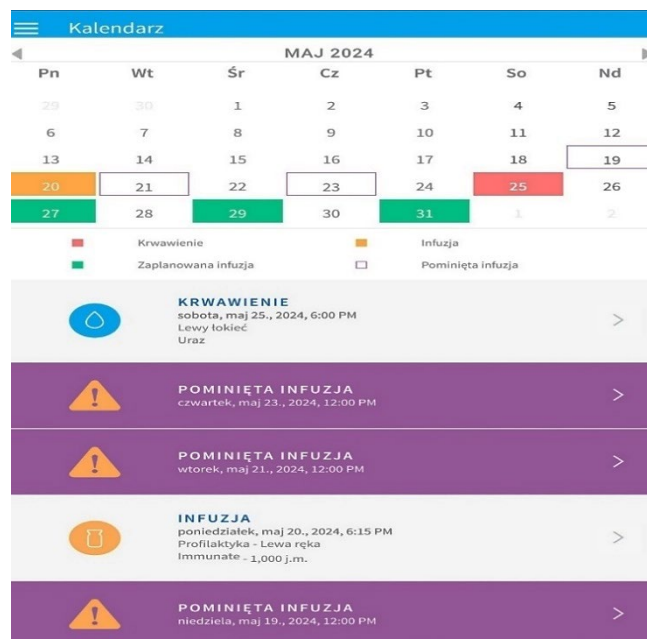


Fig. 4. Digital logbook Zero Bleeds – calendar

Source: (Zerobleeds, 2021).

In this way, the data provided by patients covered by home deliveries allow treatment centres to assess first of all, whether a given patient is following the prophylaxis recommended by the doctor (Zero Bleeds informs the doctor and the centre, among other things, about the last time the patient was logged in to the application) – as well as how meticulously it is carried out – the doctor gains access to information about the infusions of the agent omitted and planned as part of prophylaxis. The tool also makes it easier for the doctor to decide whether the currently recommended dose of the factor is appropriate or whether the patient requires follow-up tests – the indicated action is possible thanks to information on recorded intramuscular and intra-articular bleeding – the goal is to avoid bleeding. In the event of their excessive appearance, it is necessary to take appropriate action.

4.2. Future Plans – E-Haemophilia, i.e. an Electronic System for Handling Haemophilia Patients

The National Programme for the Treatment of Haemophilia Patients for 2024-2028 includes plans for a comprehensive ICT tool aimed at supporting haemophilia treatment (Ministerstwo Zdrowia, 2023). Although the programme does not explicitly mention this tool, it is implied by the footnote regarding the inclusion patients in home deliveries, suggesting it may be the ‘e-haemophilia’ system. This designation is listed on the eHealth IT Systems website, indicating its intended use to improve patients’ IKP accounts.

The task of launching the system is carried out under the specific objective entitled ‘Strengthening supervision over the use of medicinal products in the above-mentioned group of patients, and increasing the knowledge of medical personnel involved in providing specialist care to this group of patients’. It has been divided into the following stages.

- The first refers to the completion of the construction of a teleinformatics system for the service of the haemophilia patient, including records of patients with haemophilia and related haemorrhagic diatheses, and its launch, maintenance and development.
- The second refers to the expansion of the system with functionalities:
 - administration of clotting factor concentrates and desmopressin during hospitalization,
 - selected imaging studies,
 - results of genetic tests,
 - other results of specialized tests – specific to the diagnosis of haemophilia and related haemorrhagic diatheses.
- The third refers to the expansion of analytical mechanisms, using the data available in the system. This activity is to include the implementation of:
 - inference and alerting mechanisms for medical personnel based on data patterns, and
 - analytical mechanisms supporting, among other things, the determination of the full cost of patient care.

On the government website of e-Health IT systems it is indicated that the haemophilia system should provide the following services (Systemy Informatyczne e-Zdrowia, n.d.):

- electronic logbook of a patient with haemophilia or haemorrhagic diathesis,
- electronic demand for blood products, recombinant clotting factors, desmopressin and emicizumab,
- electronic registry of patients with haemophilia and haemorrhagic diatheses,
- coordination of care for patients with haemophilia and haemorrhagic diatheses,
- billing of services,
- implementing supplies from closed pharmacies, tendered suppliers and the RCKiK.

According to the plans of the state unit of the e-Health Center (CEZ), the haemophilia solution will become an additional utility – a panel available to patients from the level of the IKP Account. CEZ, through its platform (pacjent.gov.pl), operates the Online Patient Account (and the mojIKP application).

So far, over 18 million 418 thousand patients have set up an IKP (as of 21.05.2024 (Narodowy Fundusz Zdrowia, n.d.)). The tool allows for using specific medical services digitally while organizing and sharing medical information about the patient's health. Reaching for IKP in 2025, it is possible, among others:

- to use tools such as e-prescriptions and e-referrals, e-sick leaves and medical certificates issued in connection with illness or maternity,
- to view the history of treatment, including the control of medical events, issuing sick leaves,
- to check treatment plans in terms of appointments and individual medical care plans (IPOM) arranged through the e-Registration system,
- to obtain access to a list of all prescription drugs purchased since 2019, as well as a drug database containing information on commercial and international names of drugs sold in Poland and their manufacturers,
- to download EDM, including:
 - descriptions of diagnostic tests,
 - laboratory test results with a description,
 - hospital discharges.

The plans presented above, included in the National Program for the Treatment of Haemophilia Patients, give hope that by 2028, i.e. by the end of the current edition (2024-2028), the processes of care for haemophilia patients will be supported by making the e-Haemophilia tool available.

4.3. Additional Solutions

After analysing the challenges faced by individuals with hemophilia in their daily lives, as observed through collaboration with this group of patients, the authors conclude that solutions that should be implemented in the relatively near future include AR and/or the Metaverse.

AR – Augmented Reality. AR is poised to become a technology used directly by patients in their daily lives. AR connects the real world with the digital world, superimposing digital elements on the environment, which humans perceive (Arena et al., 2022). The real-time interactivity of AR experiences, facilitated by cameras, motion sensors, GPS, and displays, is a crucial aspect that enhances their efficacy and applicability across various domains (Cyrek, 2025). Integrating AR into medical practice is a significant development in this field. The technology has been implemented in various surgical procedures (Ho-Gun & Jaesung, 2016), and has applications in psychotherapy (Exorigo Upos, 2022), demonstrating its potential in diverse fields.

Moreover, augmented reality turned out to be beneficial in developing training and educational applications, which underscores its multifaceted utility. In the treatment of patients suffering from haemophilia, it could initially be used to create a tool that would facilitate training for patients and medical staff in the intravenous administration of coagulation factors. However, self-administration of this injection poses a significant challenge. The ‘exotic’ nature of this procedure often leads to reluctance or refusal by medical staff, particularly outside specialized treatment centres, to administer the injection to patients with haemophilia. This reluctance can cause problems in cases where patients are away from home, and an injury occurs, that requires urgent administration of the factor.

Many patients encounter difficulties in self-injection due to concerns, such as puncturing the skin or damaging the veins. Some patients may also hesitate due to concerns about their ability to administer the injections correctly. Patients who do not require daily administration of the factor as a preventive measure but rather in response to bleeding encounter an additional challenge. This is due to the stress associated with unexpected events, injury, stroke, and lack of practice. For this group of patients, developing an AR tool to provide step-by-step guidance through combining ampoules with the agent, applying them into a syringe, and subsequently administering them intravenously would be advantageous. This tool would help patients maintain their sense of autonomy and security, which is crucial for their mental well-being.

Metaverse. Technology, defined by Ondrejka (2004) as an online environment and a real place where users can interact and meet others, do business and have fun, using the real world as a metaphor, is translated in the literature on the subject in many, albeit relatively similar, ways. The Metaverse could be used, among other things, in telemedicine – enabling remote consultations between patients and doctors without the need to move from the local environment the patients reside. This would contribute to improving the accessibility of health care for people living at a considerable distance from treatment centres, as well as the elderly or disabled. This is of fundamental importance because treatment under the National Programme limits the locations of haemophilia treatment centres only to provincial capitals². The technology in question could be used in rehabilitation and occupational therapy of patients as the number of appropriate specialists – physiotherapists who would have the competences to cooperate with patients with haemophilia, is critically low in Poland. Using the Metaverse would allow patients with haemophilia, as in the case of neurological patients after a stroke (www10), to conduct independent exercises or work remotely with a specialist without the need to move – in both cases in virtual reality (Politechnika Warszawska, 2023).

Ontologies. An ontology can be considered as a tool for storing knowledge, as well as a tool for finding and creating knowledge. As Gruber (1993, p. 199) points out, an “ontology is an explicit specification of a conceptualisation”. In the paper of Husáková and Bureš (2020, p. 9) it can be found that the clinical

² The exception here is the children’s treatment centre in Zabrze.

pedigree information system called OntoFam uses the formal Family Heat History Ontology (FHHO). The purpose of this ontology is to model the knowledge of patients with haemophilia type I. Shah et al. refer to the use of a gene ontology to try to determine how the disease is passed on to the next generation. Laffan (2016) writes: “we used a cluster analysis based on the Human Phenotype Ontology, combined with next-generation sequencing techniques, to more easily identify patients with similar phenotypes that are thought to arise from the same genetic defects. Preliminary results confirm this approach in clusters and have also identified a number of new genes that are important for normal and pathological platelet physiology”.

5. Discussion and Conclusions

In the mid-2020s, health care is the foundation without which no country or economy can function properly. The ageing society and the constant decline in the birth rate in Western European countries, especially in Poland, means that the number of health services provided within the healthcare system will only grow, generating costs that will create significant pressure on the state budget. Information technologies are widely implemented in health care, also in the Polish public system – without some of them, such as database technology, on which all medical documentation systems (EHR) are based, health care systems would not function.

Thus far, in the care of patients with hemophilia in Poland, dedicated solutions have been successfully implemented that, while reducing costs, also improve processes such as issuing prescriptions for clotting factor (Factor to the Rescue) – available to all patients – and monitoring factor administration and consumption (digital logbook), though in this case, only for selected patients. The culmination of these efforts in implementing IT solutions for this patient group will be the launch of the e-Factor system which will integrate all previously introduced solutions into a single tool, making them accessible to all patients. Additionally, it has the potential to enhance patient condition analysis through functionalities for e.g. storing patients’ test results.

The analysis of patients’ needs and behaviours suggests that further development of IT solutions that will contribute to improving their quality of life while generating additional savings for the healthcare system should focus on the implementation of tools using augmented and virtual reality.

Table 1 summarises the above considerations.

Table 1. Summary answers to research questions

Research question	Answer
RQ1. What ICT solutions are currently used to support the treatment of patients with hemophilia and what tools are planned to be introduced in Poland in the near future?	Tools based on database technology remain in use, using – to a varying extent – EHR allowing for efficient issuing of prescriptions for coagulation factor and registration and monitoring of factor administration by patients. As part of the current National Programme, it is planned to implement the e-Hemophilia tool, absorbing the functionalities of previously used tools, allowing all patients and doctors, from the level of a single application, to manage the basic treatment of a disease entity.
RQ2. How can emerging technologies, such as AR and the Metaverse, support the treatment of patients with hemophilia?	AR and Metaverse can be used to create tools for training hemophilia patients and medical staff in intravenous administration of clotting factors, as well as remote visits to a hematologist and physiotherapist. These technologies can solve problems related to the administration of a factor by a hemophilia patient, especially in emergencies when medical assistance is needed outside the place of residence. At the same time, it will facilitate the access to medical care for people excluded from transport. Ontologies can be used to store and share knowledge regarding the hemophilia disease and also to use other ontologies to create the whole picture.

Source: own elaboration.

Augmented reality could, therefore, be used in the first place to create a tool that would allow for training patients with haemophilia and medical staff in the intravenous administration of coagulation factors. Currently, the issue of the ability to inject to administer it is problematic – due to the ‘exotic’ nature of this type of procedure, medical staff outside haemophilia treatment centres often refuse or are very reluctant to administer the agent to a haemophilia patient. This is particularly problematic when the patient is away from home (e.g. on holiday) and a random event, such as an injury, occurs, causing a sudden need to administer the factor.

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Przegląd technologii informacyjnych wykorzystywanych w ochronie zdrowia na przykładzie chorych na hemofilię

Streszczenie

Cel: Omówienie technologii informatycznych i narzędzi, które są lub mogą być wykorzystywane w ochronie zdrowia w Polsce w zakresie leczenia hemofilii.

Metodyka: Badania zostały przeprowadzone za mocą obserwacji uczestniczących oraz analizy istniejących technologii.

Wyniki: Istniejący rozwój systemów informatycznych może przyczynić się do pomocy w leczeniu hemofilii, poprzez tworzenie dedykowanych systemów informatycznych oraz wykorzystywaniu nowych rozwiązań. W tym zakresie można wykorzystać rozszerzoną rzeczywistość (AR) i Metaverse do tworzenia systemów informatycznych dla wspomagania pacjentów i kadry medycznej w zakresie szkoleń podawania czynnika.

Implikacje i rekomendacje: Publikacja stanowi przegląd obecnych rozwiązań i wskazania kierunków wykorzystania nowych rozwiązań technologicznych. W aspekcie praktycznym praca stanowi określenie kierunków możliwych do wykorzystania rozszerzonej rzeczywistości i Metaverse.

Oryginalność/wartość: Wartością pracy jest analiza zagadnienia medycznego z punktu widzenia nauk o zarządzaniu i jakości. Dodatkowo poszerzona została ona o analizę rozwiązań technologicznych.

Słowa kluczowe: hemofilia, systemy informatyczne, rozszerzona rzeczywistość, Metaverse, opieka medyczna
