

Digitalization and Virtual Organization in Health Care Services: The Case of European Reference Networks

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ARTICLE INFO	ABSTRACT
<p>Article Type: Research Article</p> <p>Keywords: Digitalization in Health, E-Health and Telemedicine, European Reference Networks, Rare Diseases.</p> <p>Corresponding Author(s)</p> <p>¹. Muhammed Yusuf AYDAMAK ². Şebnem YÜCEL</p> <p>E-mail:</p> <p>¹. muhammedaydamak@gmail.com ². sebnemaslan@selcuk.edu.tr</p> <p>Article Application Date: 19.06.2025</p> <p>Article Acceptance Date: 27.08.2025</p>	<p><i>In the study, it is aimed to examine and reveal the organizational structure and functioning of the European Reference Networks selected as a case study and the networks that make up it. The research is a qualitative case study. European Reference Networks is the case examined in the study and the context is digitalization in health care. In the research, interviews were made with the network coordinators using a semi-structured interview form and the data were subjected to thematic analysis. Research participants evaluated the European Reference Networks in five main themes and seventeen sub-themes. Participants think that the established system is a pioneer for digitalization in health. Although all of them accept the virtual organizational structure of the system, there are differences of opinion on whether to define it as a health organization or not. However, since they are the first and only example, they consider that they experience the disadvantage of innovation. As a result, European Reference Networks is a new and important point for digitalization in health services. It is a visionary example for health management and health system organizations.</i></p>

1. INTRODUCTION

Digitalization is redefining existing business and service areas. It leads to new organizational structures and management approaches (Alavi and Leidner, 2001). One of these areas affected by digitalization is health care (Kay et al., 2006). However, the time and space independence feature of digitalization enables virtualization and network-based organizational structures (Bloomberg, 2018; Mohammad, 2009). Such a development transforms the traditional doctor-patient relationship. In some cases, physical service delivery can replace virtual service delivery (Higgins et al., 2011). Therefore, network-based organization and virtual presentation of health services reveals the virtual organizational structure in health care (Aas, 2013).

European Reference Networks (ERNs), which established in the European Union (EU) in 2017, has become an example of a new understanding in this field. ERNs are “*multinational virtual network system*” that virtually connects healthcare organizations, healthcare professionals and patients through telemedicine tools (Gulhan, 2020). ERNs are accepted as the most important cooperative cooperation of the EU (Morciano, 2015). Moreover, it is considered that ERNs will enable “high quality and cost-effective” health care and will create a paramount “added value” for the EU in this respect (Plate and Tiburgs, 2014). In line with these points, it is considered that the innovator design and active operation of ERNs as a multinational health system in a completely virtual organizational structure constitutes an substantial specimen in digitalization of health services. In this respect, it is important to examine the structuring and activities of ERNs.

ERNs brought together more than 300 health organizations in 26 EU countries and in 24 different specialties. In this respect, ERNs is a huge international organization system serving rare and complex disease patients (European Commission, 2017a). ERNs uses three main information and communications technology (ICT) systems: “Clinical Patient Management System (CPMS)”, “Collaborative Platform” and “ERNs Web Site” open to the public (European Commission, 2017b). However, the most important tool is CPMS (Gulhan, 2020). CPMS has been developed to provide remote collaboration by sharing clinical data in diagnosis and treatment and to share scientific knowledge (European Commission, 2019). In this respect, CPMS is the main processing and communication mechanism in healthcare delivery of ERNs (Amin et al., 2022).

However, in addition to service delivery, ERNs operate in various fields, from training health professionals to cooperation with patient organizations and developing health policies (Bernts et al., 2019). In this context, when looking at the functioning of ERNs, a patient within the scope of ERNs first receives health care from the national health care provider, but if its physician needs consultation, it can get consultation by establishing a virtual association with the relevant ERNs Network or health professionals in other networks by using CPMS (Talarico et al., 2021; Jara et al., 2020).

2. METHODS

In this section, the methodology of the research is explained under each heading.

2.1. Importance and Purpose of the Research

In the research, it is aimed to examine the organizational structure and activities of ERNs and to evaluate the digitalization process in health within the framework of digitalization in health services. At the same time, the fact that ERNs is a multinational organization as well as being a virtual organization is considered to increase the importance of study.

2.2. Type of the Research

In the research, case study method which is one of the qualitative research designs was used. Case research studies a current phenomenon, situation or event within the framework of its own reality and allows the event to be examined in the context of why and how questions by using multiple data sources (Yin, 2012). The main point in the case study is to describe and analyse the case that is studied within the framework of the phenomenon. The case constitutes the context in the case study at this point (Meyer, 2001; Heale and Creswell, 2013). Case studies have 4 different designs: holistic single case, holistic multiple case, nested single case and nested multiple case. However, in the case studies on organizations, nested patterns are generally appropriate if the purpose of the research and the research questions are about organizational integrity (Yin, 2012).

Therefore, the case study method is suitable for the purpose of the research. The European Reference Networks are a case in point. Considering the creation of ERNs by bringing together 24 different subnets, the “nested single case design”

was preferred among the case study designs in the study. In line with the chosen pattern, ERNs are the only nested states while 24 subnets are nested analysis units. In other words, ERNs are the case examined. In terms of ERNs being the first and only virtual organization established in health services, it was analysed and described as a sample case. In this respect, the study is a descriptive case study. The phenomenon of the study is digitalization.

2.3. Research Questions

The research questions of the study are as follows:

1. What are the expert opinions on the organizational place and importance of ERNs in the digitalization process in health?
2. What is the information in the direction of expert opinion about the collective cooperation and practice of ERNs between health institutions?
3. With general information about the three basic ICT tools that ERNs use, how do experts evaluate these applications in terms of digitalization?
4. What are the evaluations of the experts about the health services carried out together with the virtual consultation processes within the networks?
5. What is the information about the future place of ERNs with digitalization?

2.4. Research Participants and Data Gathering

In the research, a semi-structured interview form was used to collect the data. There are five open-ended questions about digitalization in health and ERNs in the interview form. In addition, descriptive information was obtained by first asking the participant to introduce himself in the interview form. The population of the research is the coordinators of the 24 subnets that make up the ERNs, in line with the purpose and scope of the research. Purposive sampling method, one of the non-probability-based sampling types, is used to determine the sample (Creswell, 2013). Within the scope of the study, 7 participants were interviewed.

Table 1. Descriptive Information About the Participants in the Research

Participant	Medical Speciality and Degree	Country	Interview Date	Interview Type	Interview Time
P.1.	Pediatry / Professor Doctor	Netherlands	25.2.2022	Online Meeting	50 minute
P.2.	Oncology / Professor Doctor	France	27.4.2022	Online Meeting	23 minute
P.3.	Urology / Professor Doctor	Netherlands	27.5.2022	Written Answer	-
P.4.	Medical Genetics and Oncology / Doctor	Italy	1.7.2022	Online Meeting	25 minute
P.5.	Nephrology and Pediatry / Professor Doctor	Germany	14.7.2022	Online Meeting	38 minute
P.6.	Pediatry / Professor Doctor	Italy	17.8.2022	Online Meeting	39 minute
P.7.	Cardiology / Professor Doctor	Netherlands	8.9.2022	Online Meeting	34 minute

Data were collected between February 16, 2022-October 31, 2022. Except for one participant who responded to the interview form in writing, all data were obtained through an online meeting. One meeting was held with each participant. In addition, the real identities of the participants were hidden by paying utmost importance to participant privacy during the research and anonymous identities were given to the participants by coding as P.1. (Participant 1), P.2. (Participant 2), P.3. (Participant 3) etc.

2.5. Data Analysis of the Research

Interview data were analysed by thematic analysis method. The data obtained in this direction was first written down, read in its entirety, gathered under the relevant question groups, and coded. The main themes and sub-themes were created by checking the coding and grouping similar codes.

2.6. Validity and Reliability of the Research

The interviewees are both therapeutic and academic experts for their disease group. In other words, the research participants have the qualifications of being expert health professionals, professional health managers and digital health applications executives. These qualifications of research participants increase the validity and reliability of the study. Expertise support was also received from an academician working in the field of health management at a university in Türkiye, who is professor and the head of health informatics and technologies division. It is assumed that the expert opinion will contribute to the validity and reliability of the data.

2.7. Limitations of the Research

ERNs have a wide range of stakeholders in different perspectives. In the study, ERNs were discussed and analysed only its organizational structure. In addition, since the stakeholders are from different circles, there are professionals with quite different titles in ERNs. However, only network coordinators were accepted as participants and interviews were conducted with them during the data collection process. In line with the opinions of the coordinators, it was tried to obtain information about the whole of ERNs. Therefore, different, or deeper information can be obtained with the participation of different stakeholders. Since information about the entire organization was investigated in the research, no restrictions were applied to the participants regarding whether they were included in the research or not. It was tried to be interviewed with each participant who accepted to participate in the research on a voluntary basis.

3. RESULTS

While expressing the research findings, the opinions of the participants were included in italics when necessary. The views of the participants on ERNs are discussed in 5 main themes and 12 sub-themes. These themes are shown in the Table 2.

Table 2. Study's main themes and sub-themes

No	Main Themes	Sub-themes
1	Digitalization in Health and ERNs	ERNs Virtual Healthcare Organization
2	Collective Collaboration of ERNs	Type of Collective Collaboration
		Collective Collaboration Impact Factors
3	ERNs Digital Health Systems	Clinical Patient Management System
		Interoperability
		Information Management Security
4	ERNs Digital Healthcare Delivery	Healthcare Delivery
		Quality
		Factors Affecting Healthcare Delivery
5	Future of ERNs	Financing
		Development of ERNs
		Sustainability

3.1. Digitalization in Health and ERNs Main Theme

Participants expressed a common view that ERNs work in a completely digitally organized structure and virtual way in the network structure. However, there is disagreement as to whether ERNs should be defined as a "health care organization". According to some participants, ERNs are virtual health services organization that provides health services directly, while according to others, it is the virtual organization that brings health institutions together.

3.1.1. ERNs Virtual Healthcare Organization Sub-theme

Participants express the virtual organizational structure of ERNs within the categories of "network structure", "management function" and "disadvantaged group". Firstly, participants agree that ERNs are a completely virtual organization based on network structure. However, they have different views on whether ERNs are healthcare organizations or not. P.1. and P.5. stated that the ERNs is a wholly digital virtual healthcare organization. P.2. and P.3. define it as a virtual health services organisation in a partial sense. However, P.7. recognises ERNs as virtual organizations, but states that it is unclear to define it as health organisations. In terms of being a coordinator in a managerial position, P.3. and P.4. express an opinion on the management of ERNs. Accordingly, the most fundamental factor is good and effective teamwork and cooperation. P.3. stated the necessary managerial features for virtual network systems administrators such as ERNs as "cooperation skills". P.6. offers a broader perspective. P.6. stated that ERNs have a gigantic structure. Therefore, having good managerial skills and teamwork are essential to manage such a large system, but beyond that it is more important to have visionary qualities. Because the manager can't do anything alone and the most important decision of the manager is to choose good teammates. P.7. stated that health care has the potential to be more accessible to the society through the establishment of ERNs in a virtual structure. P.6. explains the scope of ERNs from a digitalization perspective: "*ERNs are network. ... the activity of the ERNs is actually to spread the knowledge of all the technology to create the research project to understand how to better generate the data. The ERNs is a facilitator, is a catalyst of the activity of the different providers.*"

3.2. Collective Collaboration of ERNs Main Theme

Participants evaluate the collective cooperation created by ERNs in terms of health professionals and patients in general, specific to their networks, and they describe it as their greatest achievement. However, they also point out that there are serious challenges to this great achievement, especially the distribution of memberships.

3.2.1. Type of Collective Collaboration Sub-theme

This sub-theme is evaluated in two categories as "cooperation with patients and patient organizations" and "mutual cooperation between health professionals". Participants state that interaction with patients and patient organizations is a necessity for the ERNs and this is still being carried out very strongly with a participatory approach. Limited or difficult access to services is a key factor in this requirement, as ERNs focus on rare and complex diseases and the incidence of such patients is very low. Participants emphasize the inclusive role of patient organizations. This quality is a fundamental factor for ERNs. However, they also emphasize that there are various difficulties in this process.

According to the participants, the cooperation between health professionals is quite good on the basis of mutual satisfaction. The main factor at this level is that health professionals have adopted this cooperation with intrinsic motivation. However, the level of cooperation has gone through a process parallel to the development of ERNs, since ERNs are a newly established organization. P.1. stated that health professionals were satisfied with this situation. P.2. views this type of co-operation from the perspective of success and development. Accordingly, providing cooperation is a success and it has enabled health professionals to be aware of each other. P.5. also sees this situation from the perspective of success and shares the same views with P.2. According to P.6., health professionals develop a common working understanding in terms of their fields of expertise by collaborating. This collaboration also leads to the expansion of the inclusion role of ERNs, resulting in more health professionals/health institutions being invited to participate actively.

3.2.2. Collective Collaboration Impact Factors Sub-theme

Participants evaluate this sub-theme with perspective of these categories: "trust", "time", "financing", "managerial quality and behaviour", "integration with other health systems", "geographical distribution", "organizational learning" and "working principle".

P.1. expresses that it is the obligation to fulfilment of the financials need for the sustainability of cooperation between health professionals. P.4. expressed the same opinion. On the other hand, P.3. said that health professionals have difficulty in allocating time for collaborations. P.3. drew attention to the trust factor and expressed the following opinion: "*... it takes time to build such a system and the trust needed by experts working together in new virtual surroundings*".

P.7. stated that the factor affecting the collective cooperation is the quality and behaviour of the manager. Accordingly,

managers should have good relations with their colleagues by being politically neutral. Moreover, they should not put themselves forward. P.5. states that ERNs cannot fully integrate with other health systems and this situation is a factor affecting collective cooperation. In another view, P.1. stated that the organizational learning cycle is an important factor for collective cooperation. The feedback mechanism on the results obtained regarding the work and services carried out with collective cooperation in ERNs should be effective and functional in terms of organisational learning. As another factor influencing collaboration, participants stated that they have developed a common shared understanding among stakeholders in ERNs, which has a positive reflection on collective collaboration.

The most prominent factor among the impact factors is the geographical distribution in terms of membership-centre distribution. Participants evaluate this factor from the perspective of the concept of inequality and consider it among the most important problems faced by ERNs. According to P.1., the current situation in the geographical distribution of ERNs is a political problem in which a number of quite different factors are effective, including funding, time, national health systems/policies and EU intervention/regulation. At this point, P.2. indicates an imbalance in the current geographic distribution. This imbalance is a problem for ERNs. P.2. draws attention to the position of the national authorities and expresses the view that they should approve more centres. According to P.3., there is no problem in this regard. P.3. draws attention to the work of national authorities and centres that their activity is decisive. In other words, instead of distribution, the activity of the stakeholders in the system is decisive. Another participant P.4., this is a political problem. P.4. emphasized the difference between Western and Eastern Europe. System differences between Western and Eastern European countries are effective in the formation of the problem. P.4. considers it difficult to find specialist centres in Eastern Europe. P.5. states that the current state of the geographical distribution is a problem. Political factors are effective in the emergence of this problem. The policies being implemented in terms of the political systems of the countries are effective. However, according to P.5., the main factor is the absence of standardized criteria in the process of evaluating the membership of health centres: *"We also try to compensate for that by nominating affiliated partner centres in countries where ERNs is not represented. But this is only a partial solution to the problem. Indeed, it should be that the Member States should agree on standardized criteria for ERNs memberships so that they would have similar numbers of payoff centres according to the population size in the different countries."* (P.5.). P.6. states that it is difficult to assess inequality by only looking at the number of centres, but it still needs to be tackled: *"... the number of centres is a relatively indicator of inequality. But regarding the access to diagnosis, to therapy, to management, because still in Europe we have countries where we do not have a diagnosis for the rare diseases, we do not have a newborn screening, we do not have therapies that available in Europe, so this is the inequality we have to fight."* (P.6.). P.7. says that the current situation in geographical distribution is of political origin as a result of the difference between the existing systems of the countries. However, it is not yet of a nature to be considered a problem. Similar to P.1, P.7. also drew attention to the interventionist/regulatory behaviour of the EU. P.7. stated that as coordinators, they were limited in certain subjects. They could not make evaluations and inferences at certain points.

3.3. ERNs Digital Health Systems Main Theme

Participants express their views on ERNs digital health systems within the framework of CPMS. They state that the current version of CPMS, it is not user-friendly. They expect this to change with the new version. This change progresses in parallel with the development of ERNs. Finally, the participants evaluate the current situation regarding the interoperability and security of the system.

3.3.1. Clinical Patient Management System Sub-theme

Participants define the CPMS as three different categories: "system sustainability", "system availability" and "consultation". According to P.7., the sustainability of the use of CPMS in ERNs is a controversial issue. The most fundamental factor is the issue of reimbursement in ERNs. ERNs are very poorly reimbursed. Also, P.7. and P.1. state that CPMS can only be used in the context of consultation at the moment, and this is still its main function. In this respect, the level of use of CPMS has been limited to its basic function. According to P.1. and P.7., this level of use is also not systematic and is individual use only on a case-by-case basis. However, they wanted to expand the scope of CPMS in the development process and use it for different purposes such as research studies. Participants evaluated the use of CPMS in relation to data management in general.

According to the participants, CPMS is an important tool developed. However, since ERNs are a new organization, CPMS also has the disadvantage of innovation. Therefore, the participants stated that they had difficulties in the use of CPMS.

The main difficulty is that data entry into the system takes too long. Another important factor is related to the different multidisciplinary nature of ERNs. In performing the consultation in CPMS, different types or structures of data are needed for each case, depending on the area of expertise. In this respect, satisfaction with CPMS increases for the expertise network that needs the least. They also stated that in terms of data management. CPMS provides relative ease of use, especially in data storage and sharing. Another important source of problems in this regard is access to the system. Some participants state that access to the system is very difficult and there are health professionals who do not have access.

3.3.2. Interoperability Sub-theme

Participants state that CPMS is currently a stand-alone system. In this respect there is no interoperability for CPMS. P.2. stated that CPMS is an independent tool on top of national systems. P.5. states that CPMS is independent, and this is addressed at the point of data entry. According to P.5., since CPMS is not connected with national systems, patient data has to be uploaded separately by doctors. P.6. expressed the hope that this situation will be overcome in the future and CPMS will be made interoperable with national systems.

3.3.3. Information Management Security Sub-theme

Participants evaluated information security management in ERNs in the categories of "cybersecurity" and "security legislation/policy". Participants expressed their opinions mainly within the framework of General Data Protection Regulation (GDPR). In this respect, the virtual system of ERNs has to be fully compliant with GDPR legislation. Participants state that there is a level of protection in terms of cyber security, but there will always be a risk phenomenon for cyber security breaches. Participants emphasize that virtual systems are designed and put into service by the EU. Since the system design is done by the EU, they think that the EU will take the necessary measures regarding information security. For example, P.7. stated that the EU's entry procedure to CPMS is regulated as security priority. Accordingly, login to the system is a two-stage procedure as a password and a verification code, and for this, approval by the EU is required. In this context, the participants generally stated that information security management in ERNs is at a good level. However, only P.5. express a hesitation for: *"We have of course the usual precautions for cyber security in our common databases. Some ERNs only have federated systems where they can share data or analyse data in the different centres. So there is the data do not leave the unit. And so the cybersecurity is the same as the cybersecurity of the hospital system that is the federated registries for instance, and regarding the CPMS system, this is still on us well protected server of the EU, but it's not too much cyber secure. I think there are it's not into end encrypted data transmission and so on."* (P.5.).

3.4. ERNs Digital Healthcare Delivery Main Theme

Participants evaluate the ERNs digital healthcare delivery in 3 sub-themes as non-clinical activities, quality, factors affecting service delivery and healthcare delivery.

3.4.1. Healthcare Delivery Sub-theme

Healthcare delivery sub-theme was evaluated with the categories of "service delivery base and scope", "digitalized service" and "cross-border healthcare". Participants emphasized that the health service offered in ERNs is a digital service, as a natural consequence of the fully digital structure of ERNs. The digitalized health service offered at ERNs with the concepts of mobility (patient and information mobility) and digitalization. They also mention several principles regarding service delivery and scope. They also express opinions not only in terms of service delivery but also in terms of organizational structure. According to P.1., the health service provided in ERNs consists only of information sharing, that is, a consultation process in which health professionals mutually share their expertise regarding patient cases. P.1.'s opinion about the philosophy of ERNs is as follows: *"We say that the patient should not travel, but knowledge must travel."* (P.1.). As a parallel to this view, P.6. stated: *"ERNs has been created in order not to have the patient traveling but actually medicine traveling to patients."* (P.6.). On the other hand, P.3. emphasizes information mobility: *"... to provide evidence for guidance of clinical care and equal access and quality of care by the principles of Share, Care and Cure (if possible)."* (P.3.). Participants evaluate the cross-border health service in ERNs from 2 different perspectives as patient and information mobility. In terms of patient mobility, the opportunity for patients to travel physically and receive health services from other international service providers within the ERNs is very limited. This limitation is caused by difficulties such as insufficient reimbursement. In this regard, according to the participants, cross-border health service in ERNs is in the form of information mobility based on information sharing through CPMS.

3.4.2. Quality Sub-theme

Participants expressed the relationship with quality in a broad perspective, including service delivery and organizational activities of ERNs. They also stated that quality is under the influence of various factors, primarily financing. According to the participants, the ERNs quality system is under development in parallel with the progress of ERNs. P.1. stated that although the quality system is well designed, it has negative aspects in terms of increasing the workload with the lack of financing. The quality system is highly bureaucratic, and this is the main disadvantage for the workload. For this reason, there is a need for more time and budget to improve the quality system. P.4. stated that in addition to bureaucracy, there is also a lack of qualified personnel. P.5. has considered the issue of quality both for ERNs as a whole and specifically for the network of which he is the coordinator. P.5. stated that the quality system established centrally by ERNs is still at a very basic level. However, improvement efforts continue. P.5. also stated that they apply a special quality management for the internal functioning of their ERNs network and it is quite efficient. Approaching the subject within the framework of quality assessment, P.7. stated that the quality assessment is made by both the national authorities and the EU. However, the central evaluation by the EU produces a more efficient output. This difference lies in the central evaluation. Accordingly, although the structure and effectiveness of the national assessments differ for each country, the EU evaluates the same efficiency for the whole system every year within the same standards. Among the participants P.6. approaches the subject from a different angle. Emphasizing the organizational learning process, P.6.'s view is as follows "*I think that during the first five year we have understood what we are and I think that in the next 5 year we will have a better check in to evaluate the quality management. ... But we are learning and I think that in the next five years we will have the right indicators to check the quality.*"

3.4.3. Factors Affecting Healthcare Delivery Sub-theme

According to the participants, the factors affecting the ERNs digital health service delivery consist of the categories of "financing", "time" and "lack of qualified health personnel". Accordingly, the most fundamental factor is financing. The main challenge faced by ERNs in the financing factor is reimbursement. In addition, participants state that ERNs will produce more cost-effective services. Reimbursement and cost-effective service evaluation are associated with digital service delivery. Accordingly, the fact that health professionals are in different countries in virtual consultation poses a serious problem in terms of national procedures in service reimbursement. However, the same situation is a cost-effective service for patients. Patients access cross-border service at virtually minimal cost, which would normally be very costly. P.5. stated that the first five-year period of ERNs is never repaid, while there is currently a limited repayment opportunity of €200 per case in EU financing. P.6. stated that there is no possibility of repayment and that the EU only provides financing for CPMS consultations and said that all other activities of health professionals at ERNs are on a voluntary basis. According to P.1., there are two important impact factors. The first is the lack of specialist health personnel. By referring to the point of specialist health professionals in P.2., the lack of qualified health personnel in medical documentation is expressed along with the lack of physicians and nurses. It is challenge to find healthcare professional specialized in rare diseases because there are many different types of rare diseases. The second important factor is the workload faced by experts in the field and the associated time: "*They are very busy and we cannot yet pay them. So, then they say my manager does not allow me because I have to work in the hospital. I cannot just sit on the computer with you. These kind of things.*" (P.1).

3.5. Future of ERNs Main Theme

Participants draw a future prediction for ERNs, evaluate them in a very broad perspective, where there are many impact factors.

3.5.1. Financing Sub-theme

According to the participants, financing is among the biggest challenges that ERNs will face in the future. Even, according to some participants, it is the most fundamental and biggest challenge. While financing is a main source of motivation for ERNs members in terms of repayment, it is the most basic need for all kinds of activities such as education in the context of budget. Therefore, the participants evaluated the financing issue in terms of "repayment system" and "budget requirement". According to P.1., the international nature of ERNs is a procedural issue at the point of reimbursement. It means that there is no clear functioning in the reimbursement system. The absence of a centralized reimbursement

system creates uncertainty, and the diversity of national systems makes repayment impossible. In addition, according to the statements of all participants, some initiatives have started to be carried out in ERNs to establish a reimbursement system. At this point P.4. draws attention to the scope of the reimbursement system. P.4. stated that it is a priority to include CPMS sessions in the scope of reimbursement. However, according to P.4., it is debatable what other actions would be covered by reimbursement. Another participant P.7. stated that the future of ERNs will depend on whether there is a reimbursement system. At this point, opinion of the P.6. who made an evaluation in terms of the budget is as follows: "... we need the money; we need the support by the governments, and we need the technology. But these are not obstacles. I mean, these are signs of progress and ... the only difficulties sustainability is indeed to find a way that we have the right granted to do everything we can." (P.6.).

3.5.2. Development of ERNs Sub-theme

Participants evaluate the development of ERNs around 3 categories, which consist of "membership of ERNs", "qualified expert personnel" and "interaction and cooperation". Participants evaluated ERNs membership in the context of BREXIT and non-EU countries in terms of the expansion and inclusion of ERNs. Owing to BREXIT, ERNs suffered a serious loss, especially in specialist healthcare professionals. In addition, different methods are applied to ensure the protection and execution of cooperation despite this situation. The participants stated that they approached the participation of non-EU countries positively in principle to the extent of their expertise. However, participants think that political factors are an obstacle to this situation in terms of membership status. The subject on which the participants agree on both BREXIT and non-EU countries is "financing". Accordingly, it is a prerequisite for health professionals and health institutions that will participate in or will operate within the scope of ERNs to participate in the sharing of finance.

"It all depends on whether there is expertise in these countries and if there is an expert in Türkiye, ... I'm fine. ... But the problem is that, and that is also the reason that the EU wants the UK out is that they are not paying anymore for the system. So the ERNs system as a whole has a budget for something like, what is it, €25 million a year and that is paid by the European countries that are a member of the EU and even non-European country would join, then I think it's fair to ask them a share of their budget. And that is then what has to be arranged." (P.7.).

Participants state that the need for qualified specialist personnel will increase in parallel with the expansion of ERNs. The priority areas of need are the employees who are not directly related to the provision of health services. According to P.6., the scope of ERNs is becoming more and more complex. P.6. defines this complexity as "non-obvious clinical environment". ERNs may have a very close interaction with this field, which consists of professionals such as engineers, mathematicians, or physicists. According to the participants, interaction and cooperation will have an important place in the development process of ERNs. ERNs are a precursor to other similar initiatives, enabling healthcare professionals to interact and collaborate. However, participant also state that ERNs will be in a position where other relevant stakeholders (researchers, institutions, etc.) in the field in question will want to establish contact in terms of expanding coverage. According to P.3., the support of the EU is very important in this widening scope. P.4. offers a broader perspective. The ERNs as a pilot project for a wider and more comprehensive organisation of healthcare services across the EU.

3.5.3. Sustainability Sub-theme

Participants state that ERNs have a weakness for innovation in terms of being a new organization, and they also experience a disadvantage in bureaucracy. These disadvantages pose a challenge to the sustainability of the ERNs organization. The participants also stated that the existing structure of ERNs should be preserved and that the existing structure is a very suitable system. In this respect, the sustainability of the existing structure can be ensured by making certain improvements. P.1. and P.4. refer to the maintenance of the virtual organizational structure while maintaining the network system of ERNs. P.1. argues that there should be interaction between national regional centres and international centres of expertise. P.4. said that ERNs as an umbrella organization is important for the functioning of different national systems as a whole. P.1. also stated that ERNs are in a complex situation as they are a newly established organization and operate in a very wide field of action. According to P.7., who draws attention to bureaucracy, ERNs are faced with bureaucracy difficulties at a level that can disrupt the current operation as of the current situation. The current state of the bureaucracy in ERNs with the metaphor of "beast".

One of the most fundamental building blocks for the future in the sustainability of ERNs is the linking between ERNs and national health systems. Participants highlight mutual cooperation between ERNs and national health systems.

Accordingly, ERNs may be in a complementary position for national health systems that have difficulties in providing services for their citizens in the field of rare diseases. As a matter of fact, according to P.2., ERNs are a complementary structure for these national health systems. Emphasizing data sharing between ERNs and national health systems, according to P.4., integrating ERNs into national systems is one of the biggest changes to be made in the future. P.6. stated that there should be a complete integration between ERNs and national health systems. It is also thought that this could set an example for other international initiatives in the field. P.4. compared to the other participants, it refers to a very different point. P.4. makes an evaluation by distinguishing between managers and administrators. According to P.4., which states that the system, structure and functioning of ERNs were created and made available by the EU, network coordinators are essentially administrators, not managers. However, the operation of this order is successful.

4. DISCUSSION

In the research, it is aimed to examine the organizational structure and activities of ERNs and to evaluate the digitalization process in health within the framework of digitalization in health services. At the same time, the fact that ERNs is a multinational organization as well as being a virtual organization is considered to increase the importance of study.

The organization of ERNs is a completely digitized system, but the main subject is the "data" axis. This is clearly stated in the statements of the participants. In this respect, ERNs are formed on the basis of data and data-driven information generation system, based on a fully digitized workflow. It can be stated that this situation is compatible with virtual organization theory. The main point in the virtual organization theory is that the network members have a high level of knowledge.

It is thought that the reason for the difference in participant views on whether ERNs should be defined as a virtual health organization is due to the field of activity of ERNs. According to the participants, who defined ERNs as virtual health services organization in the partial sense, health service delivery is a very limited point of the activities carried out by ERNs. In this sense, the aim of ERNs is to bring together expertise based on data and knowledge in the focus of rare diseases. Thus, it is to operate in a very broad perspective, from health information production to health policy planning, by bringing together expertise. However, P.1. and P.3., it is not a correct understanding to define ERNs as purely health services organization for the provision of health services, which will be quite limited compared to this broad perspective. In addition, they agree with the other participants that ERNs are in the organizational structure that operates completely digitally/virtually in health services. The primary function of the virtual organizational structure is collaboration, and in ERNs it is a virtual system.

Cooperation in the ERNs system exists on two different bases. These two basics are "health professionals' mutual cooperation" and "cooperation with patients and patient organizations". Cooperation with patients and patient organizations is crucial for ERNs. Because, according to the participants, "patients" are at the centre of the ERNs system. In fact, according to P.2., this is a necessity. Rare disease patients, who are the focus of ERNs, are in a disadvantaged position in society. In this respect, it is important to meet the needs of a disadvantaged group in the society, especially health services.

Geographical distribution is a factor that deeply affects the level of cooperation provided by ERNs. At the same time, this factor also affects the main purpose of existence of ERNs. The main purpose of ERNs is to ensure the elimination of geographical differences by providing cooperation through cooperation. However, as of the current situation, it is seen that the inequality in geographical distribution has not been eliminated yet. This situation is also reflected in the statements of the participants. Along with the geographical distribution, financing also appears as an important impact factor. In this regard, persistent inequality in geographical distribution and insufficient funding are major challenges for ERNs in the future.

The operation of ERNs is built in the perspective of interoperability. Participants express interoperability as a dimension of ERNs by considering it in two different ways. In terms of CPMS, there is no interoperability between different digital systems. CPMS is a stand-alone, exclusive system. However, the participants state that they want this situation to change, and they expect the interoperability situation to be implemented. The participants state that they have adopted the decentralization approach in the organizational structuring of ERNs. However, if the necessary situational conditions arise, the central management approach may also be appropriate. According to the participants, an important point of ERNs in terms of organizational approach is that it is a central organization that combines centres of expertise.

5. CONCLUSION AND RECOMMENDATIONS

Digitalization inevitably paves the way for new changes in the social order. It affects healthcare and has led to widespread use of digital tools. However, this workflow-related situation turns into a new dimension with ERNs. ERNs bring an innovative understanding to the structuring of health care systems. ERNs is a completely virtual organized system in the field of health services. This innovative feature makes ERNs a natural example. In this study, the organization of ERNs is described by in-depth analysis and presented with various findings.

It is concluded that ERNs are built as a completely digital-based system and digitized the service delivery, especially considering its international nature. This process continues to evolve, although it is faced with a variety of different and rather large disadvantages as of the current situation. In this respect, ERNs will set a very innovative organizational structure example for health services in line with digitalization in health. Based on the developments in the literature, it can be assumed that there may be a health care system in the future where our health can be monitored at any time, through physically shrunken hospitals, virtual visits and control examinations for healthcare professionals and patients, or smart health devices equipped with internet of things (IoT). Therefore, it can be predicted that in the future, health services will provide digital health services to the society by ensuring interoperability of e-health and telemedicine applications and IoT smart devices. However, it is very difficult to express that health services will be provided completely digitally. In cases where health workers need to physically examine, there will be a situation to provide health services in a physical way. As a result, it is evaluated in the study that the sample of ERNs is associated with this assumption about the provision of health services in the future. In line with these points, it can be assumed that the organization of health services in virtual health service delivery will be similar to the ERNs system. Therefore, in e-health and telemedicine applications and IoT, in the provision of health service between doctor and patient; It can be assumed that the sharing of resources, data transmission, training and organizational activities can be done similarly to the system of ERNs virtual organization.

6. REFERENCES

Aas, I. H. M. (2013). The health sector towards the information age: the telemedicine virtual organization. *Us-China Education Review B*; 3(8): 646-50.

Alavi, M. & Leidner, D. E. (2001). Review: knowledge management and knowledge management systems: conceptual foundations and research issues. *MIS Quarterly*; 25(1): 107-36.

Amin, A. S., Biller, R., Charron, P. & Wilde, A. A. M. (2022). European Reference Network for rare, low prevalence, or complex diseases of the heart (ERN GUARD-Heart): 5 year anniversary. *Eur Heart J.*; 43(23), 2173-76.

Bernts, L. H. P., Jones, D. E. J., Kaate, M. M., Lohse, A. W., Schramm, C., Sturm, E. & Drenth J. P. H. (2019). Position statement on access to care in rare liver diseases: advancements of the European Reference Network (ERN) RARE-LIVER. *Orphanet J Rare Dis*; 14, 169.

Bloomberg, J. (2018). Digitization, digitalization, and digital transformation: confuse them at your peril. Accessed: <https://www.forbes.com/sites/jasonbloomberg/2018/04/29/digitization-digitalization-and-digital-transformation-confuse-them-at-your-peril/?sh=4dd3779d2f2c> Accessed Date: 23 Jun 2023.

Creswell, J. W. (2013). *Qualitative inquiry and research design: choosing among five approaches* (4th ed). SAGE Publications.

European Commission (2017a). *European Reference Networks working for patients with rare, low-prevalence and complex diseases: share.care.cure*. Luxembourg: European Union.

European Commission (2017b). *3rd Conference on European Reference Networks - conference report*. Vilnius: European Commission.

European Commission (2019). *Commission Implementing Decision (EU) 2019/1269 of 26 July 2019 Amending Implementing Decision 2014/287/EU Setting Out Criteria for Establishing and Evaluating European Reference Networks and Their Members and For Facilitating The Exchange of Information and Expertise On Establishing and Evaluating Such Networks (Text With EEA Relevance)*. <https://eur-lex.europa.eu/legal-content/EN/TXT/PDF/?uri=CELEX:32019D1269>

Gulhan, I. (2020). A unique e-health and telemedicine implementation: European Reference Networks for rare diseases. *J Public Health (Berl.)*; 28: 223-25.

Heale R & Twycross A. (2018). What is a case study? *Evid Based Nurs*; 21(1): 7-8.

Higgins, O., Sixsmith, J., Barry, M. M., Domegan, C. A. (2011). *Literature review on health information-seeking behaviour on the web: a health consumer and health professional perspective*. Stockholm: European Centre for Disease Prevention and Control.

Jara P., Baker A., Baumann U., Borobia A. M., Branchereu S., Candusso M., et al. (2020). Cross-cutting view of current challenges in paediatric solid organ and haematopoietic stem cell transplantation in europe: the European reference network TransplantChild. *Orphanet J Rare Dis*; 15: 16.

Kay, M., van Andel, M. O. G., Klint, K & Tristram, C. (2006). *Building foundations for eHealth: progress of member states: report of the Global Observatory for eHealth*. Switzerland: World Health Organization.

Meyer, C. B. (2001). A case in case study methodology. *Field Methods*; 13(4): 329-52.

Mohammad, K. (2009). E-Leadership: the emerging new leadership for the virtual organization. *Journal of Managerial Sciences*; 3(1): 1-21.

Morciano, C., Laricchiuta, P., Taruscio, D. & Schünemann, H. (2015). European reference networks and guideline development and use: challenges and opportunities. *Public Health Genomics*; 18(5): 318-20.

Plate, A. & Tiburgs, W. (2014). *First conference on European reference networks: report*. Brussels: European Commission DG SANTE.

Talarico R, Aguilera S, Alexander T, Amoura Z, Antunes AM, Arnaud L, et al. (2021). The impact of COVID-19 on rare and complex connective tissue diseases: the experience of ERN ReCONNECT. *Nat Rev Rheumatol*; 17(3): 177-84.

Yin, R. K. (2012). *Applications of case study research (3rd Ed.)*. SAGE Publications.