

## DIALYSIS/TRANSPLANTATION ΑΙΜΟΚΑΘΑΡΣΗ/ΜΕΤΑΜΟΣΧΕΥΣΗ

### Electronic health services in end-stage renal disease. From Galen to the 20th century

Chronic kidney disease (CKD) is a serious public health issue. According to international data, one out of ten individuals suffers from a degree of chronic kidney injury. Unfortunately, there is no official data in Greece, and this is particularly worrying. It is therefore of paramount importance to move from the traditional way of archiving to the use of electronic health records and online applications. The use of electronic health records (EHRs) for document storage and retrieval is increasing in both developed and developing countries, leading to widespread use of EHRs by nephrologists. Moreover, in the last years, electronic and mobile health (telehealth), defined as the comprehensive use of new technologies in the health sector is rapidly evolving and gives promise to the field of nephrology in order to achieve optimal CKD management. Our hospital's Nephrology Department, in collaboration with the Information Technologies Institute of Centre for Research and Technology, with the support of the Hellenic Society of Nephrology, developed the first national online application of patients dialysed via a tunnelled central venous catheter. In December 2018, the application was notified to all dialysis units in order to register their data and to collect all necessary information for management of the disease. Moreover, the Nephrology Department is the first hospital unit in Greece to design and develop an electronic care system to improve chronic kidney disease patients' healthcare management both at inpatient and outpatient level, called e-NeΦros. These applications promote an electronic collaborative environment allowing direct information exchange among physicians, interconnection with patients and ultimately more efficient management of the healthcare system's resources. In conclusion, in CKD, focus should be placed on electronic healthcare actions and information systems with personalised healthcare services and patients should be actively involved in the management of their disease through the electronic healthcare network.

#### 1. INTRODUCTION

The concept of data recording and the use of statistical reasoning make its appearance already from ancient years. Emperor Yao had taken a census of the population in China in the year 2238 BC. Governments of ancient Babylonia, Egypt, Greece and Rome all gathered detailed records of population and resources. However, early signs of a rudimentary statistical analysis of medical observations emerge during the first century AD in Galen's writings. Among his other major contributions to medicine, Galen laid down many of the principles of scientific investigation and he is considered now as the pioneer of capturing the basic principles of biostatistics.<sup>1</sup>

Centuries later, the word statistics originated in the eighteenth century Germany and described the science of the state, a descriptive and non-quantitative framework of reference and terminology offered by university professors to princes of the numerous German states. In 1960's, along with computing evolution and worldwide information exchange, it became easy to systematically collect and statistically process large quantities of data about specific groups of patients managed in clinical practice, and so the concept of evidence based medicine was born and the first patient registries appeared.<sup>1</sup>

The term registry is defined both as the act of recording or registering and as the record or entry itself. Therefore, "registries" can refer to both programs that collect and

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store data and also the records that are created. The term patient registry is focused on health information as opposed to other record sets.<sup>2</sup> E.M. Brooke, in a 1974 publication of the World Health Organization described them as *“a file of documents containing uniform information about individual persons, collected in a systematic and comprehensive way, in order to serve a predetermined purpose”*.<sup>3</sup>

The development of patients' registries the last few decades helped describe the natural history, epidemiology, and burden of a disease; they can capture variations in treatment and outcomes to help evaluate safety, quality and value of patient care. Ultimately, their data may help researchers develop hypotheses about disease mechanisms or treatment approaches and inform healthcare policy and potentially improve quality.<sup>4</sup>

Especially in nephrology, the existence of many registries for End Stage Renal Disease (ESRD) patients has helped in the thorough study of the disease's epidemiology and clinical outcomes in a way that sets an example for other scientific disease registries. European Renal Association – European Dialysis and Transplant Association (ERA – EDTA) Registry was founded in the year 1964 and for many years it was the sole source of information of epidemiology, therapeutic management, complications and outcomes of the disease. Similar registries from the US and other parts of the world appeared later on.

However, in the early 1990's, the great increase in the number of patients and the difficulties of data collection that emerged, became an obstacle for the proper function of the ERA – EDTA Registry and many countries developed their own national or regional registries. So, in 2000, the ERA – EDTA Registry was reorganized, transferred from London to Amsterdam, and data collection started from the already existing registries of the European countries and were presented at the annual Congress in Vienna in 2001.

In the year 1986, in Greece, the Greek Transplantation Coordination and Control Service was founded in order to register epidemiological data and keep the records of Renal Replacement Therapy and Transplant patients. Ten years later, a cooperation of the Greek Transplantation Coordination and Control Service with Hellenic Society of Nephrology resulted in the development of the Hellenic Renal Registry, a national registry which, from 2000, is part or the new ERA – EDTA Registry.<sup>5</sup>

In the era of patient-centred care, high quality registries with complete clinical, humanistic and economic information on patients are essential to help monitor and improve patient outcomes and provide valuable information that

can impact healthcare procedures, policy, and ultimately population health. However, although many of the existing renal registries that have been established around the world contain useful data of ESRD patients, less than half provide information accessible to the general public, and few have suitable patient-level data availability and access needed to generate evidence to support improved patient care. There is also a lack of uniformity of type and quality of data collected, laboratory information, medication or therapeutic modality details, and most importantly, they lack of longitudinal data or data for non-dialysis dependent CKD patients. The concept of Electronic Health Records and Electronic Personal Health Records (EHR and EPHR) comes to fill that gap.<sup>4,6</sup>

## 2. ELECTRONIC HEALTH RECORDS AND ELECTRONIC PERSONAL HEALTH RECORDS

As defined earlier, a registry is an organized system that uses observational study methods to collect uniform data (clinical and other) to evaluate specified outcomes for a population defined by a particular disease, condition, or exposure, and that serves one or more pre-determined scientific, clinical, or policy purposes. While both registries and EHRs use clinical information at the patient level, registries are population focused, purpose driven, and designed to derive information on health outcomes defined before the data are collected and analyzed. On the other hand, EHRs are focused on individuals and are designed to collect, share, and use that information for the benefit of that individual. While in practice there may be some overlap in functionality between EHRs and registries, their roles are distinct, and both are very important to the health care system.<sup>2</sup>

EHRs were first developed in the 1960s as clinical information systems for document storage and retrieval. In the last two decades and with the advancement of technology, they have evolved into a much more sophisticated tool. They include data relating to an individual patients' health such as visit history, test results, medications or treatment plans, and allow electronic communication between individual providers. These data can be used by any health unit the patient visits and centrally by the health service provider. Additionally, the ability of EHRs to store and retrieve data longitudinally can be used for meaningful clinical research.<sup>7</sup>

Use of EHRs for CKD patients could help to improve identification and quality of care delivered to patients. With the use of EHRs for referrals, Veterans Health Affairs (VHA), one of the largest healthcare systems in the United States in early 2000, managed to improve the rates of patients

starting dialysis with a fully functioning arteriovenous fistula rather than a central venous catheter. The pilot project initiated by Kaiser Permanente of Hawaii, a non-profit organisation that used their EHRs documentation and risk stratification, succeeded in having more patients start dialysis as outpatients rather than in an inpatient setting.<sup>7</sup> Finally, the Cleveland Clinic Health System hospitals managed to collect data using their EHRs from 57,276 patients who visited the outpatient clinic from 2005 to 2010, that met the criteria of CKD and formed a CKD registry with the ambition to provide opportunity for outcomes research studies along with improving the care delivered to these patients (CKD screening, surveillance and or management).<sup>6</sup>

One step further, EPHRs are electronic applications that offer individuals more than just access to their health information. They also allow increased patient involvement in their own medical decision-making and promote patient-centred care. Patients with CKD may benefit from electronic PHRs due to their regular follow-up appointments, frequent tests and need for education on disease and life-style topics.<sup>8</sup> A large cohort of 11,352 CKD patients in the United Kingdom showed that up to 75% of patients kept using the EPHR for 1.5 year after their initial sign-up<sup>9</sup> and a small survey from Canada found that the majority of respondents felt that patients should have access to their personal health data while almost three quarters would use an EPHR if it was available.<sup>10</sup>

### 3. TELEHEALTH

Telehealth is defined by the US Department of Health and Human Services as the use of electronic communication and telecommunications technology to support long-distance clinical healthcare, patient and professional health-related education, and public health administration.<sup>11,12</sup> E-health in general is a broad umbrella term that brings together a number of different modalities, such as mobile health, telehealth, connected health, gaming in healthcare, ubiquitous healthcare ect. and aims to optimise the delivery of healthcare with enhanced health outcomes at individual and population level and also improve provider and patient experience of care at reduced cost.<sup>11,13</sup>

Telehealth applications for patient education and self-management include web-based applications, short message service (SMS) text messaging, mobile health applications, video conferencing, interactive voice response with simple-to-use telephone technology ect.<sup>11</sup>

The internet is ubiquitous in society and many digital educational materials in CKD are now available in various

forms. The National Kidney Disease Education Program is the most well established example. This website contains several links to educational topics, with content directed at an elementary school level reading capability targeted for the patient ([www.nkdep.nih.gov](http://www.nkdep.nih.gov)). Moreover, it goes beyond the provision of static educational content, with the development of social support systems for those affected by kidney disease. For example, as of January 2020, the National Kidney Foundation (NKF) has over 247,000 “likes” on Facebook ([www.facebook.com/nationalkidneyfoundation](http://www.facebook.com/nationalkidneyfoundation)) and 31,200 followers on Twitter ([twitter.com/nkf](http://twitter.com/nkf)).

One of the most important technological trends nowadays is “mobile computing”, a term including various forms of hardware such as smart phones and tablet computers that allow the user to download mobile health applications via the Internet and support self-management practices. Many of these programs allow patients to view their home-recorded data i.e. blood pressure, weight, eating habits and potentially communicate and submit them to their healthcare provider.<sup>11</sup>

Several reports show improved outcomes in patients with chronic disease with the use of this information and communications technology tools for monitoring, training and self-management compared with or as an addition to usual care; however, there are few such applications in CKD.<sup>14</sup> Personal involvement of CKD patients in their healthcare is of great importance in slowing the progression of the disease as much as in reducing adverse safety outcomes and achieving other goals such as medication adherence, lifestyle modification and nutritional adaptation.<sup>8</sup>

### 4. CUFF TUNNELLED CATHETERS DATABASE INITIATIVE

Although cuff tunnelled catheters (CTC) are considered inferior to arteriovenous fistulas and grafts in all nephrology guidelines, there is a growing prevalence in many developed countries such as Italy, Belgium and Canada, as shown by the DOPPS study.<sup>15</sup> According to 2016 data, in Greece, approximately 3,000 patients (24.7%) underwent haemodialysis via a tunnelled central venous catheter. However, there are no official data regarding other important issues such as who placed the catheter or why the catheter is the first choice, or information about the catheter tip location, its lifetime, its complications, or the morbidity and mortality rates of these patients. This results in a lack of public health strategy regarding this sensitive group of patients.

A collaborative initiative started in June 2018 between our hospital’s Nephrology Department and the Informa-

tion Technologies Institute of the Centre for Research and Technology-Hellas with the support of Hellenic Society of Nephrology. It constitutes the first integrated online application for the recording, study and management of patients undergoing dialysis with a permanent central venous catheter. In December 2018, the application was notified to all public and private dialysis units in Greece in order for them to register their data and to collect all necessary information for the management of the disease.

The application consists of a general questionnaire per dialysis unit and a special questionnaire for registering information for each patient, in compliance with the General Data Protection Regulation (GDPR). The general part includes information for all the patients of a unit such as the number of patients with cuff tunnelled catheters, the type of catheter used and catheter placement parameters such as who placed it, the type of complications arising and their management. The special part consists of questions for each patient such as demographics, type of vascular access fistula or catheter, the reasons of choice of this type of access, possible complications regarding the use of the catheter, such as early or late catheter dysfunction or thrombosis and infections, its lifespan and the reason for abandonment. Each unit can have access to these answers, receive analytical reports annually and exchange information with all other dialysis units.

The purpose of this initiative is the creation of a database of all dialysis units in Greece that offers the opportunity of recording, retrieving and exchanging all the necessary information on patients dialysed with cuff tunnelled catheters in order to achieve better clinical management of this sensitive group of chronic patients.

## 5. THE E-NEΦROS PILOT PROJECT

“G. Papanikolaou” University General Hospital is gradually implementing electronic and mobile health (e/m health) practices. The Nephrology Department is the first hospital unit in Greece to design and develop special digital services to improve chronic kidney disease patients’ healthcare management. Since February 2016, it co-operates closely with Greek scientists and Greek technology providers from the Centre for Research and Technology Hellas (CERTH). The department has recently developed an electronic care (e-Care) system called “e-NeFros”. The e-NeFros platform is an integrated system that includes many e-health tools and automated procedures that will affect CKD management in approximately 30–40% of cases in the beginning, with the prospect of full coverage of patients hospitalised or monitored remotely by the Nephrology Department and aims to gradually digitalise and automate all the department’s practices.

## 6. CONCLUSIONS

As the new electronic era has already entered the health sector and evolves in nephrology too, the use of EHRs for obtaining high-quality data for research projects and improving patient care shows promising results and is expected to rise in the future. Moreover, electronic and mobile health practices and information systems, varying from digital tools and modules for administrative and organisational purposes of a unit, to the most personalised health applications offer a more complete interactive healthcare management and benefit the doctors, the patients and the national healthcare system.

## ΠΕΡΙΛΗΨΗ

### Ηλεκτρονικές υπηρεσίες υγείας σε νεφρολογικές παθήσεις τελικού σταδίου. Από τον Γαληνό στον 20ό αιώνα. Η ελληνική εμπειρία

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Η Χρόνια Νεφρική Νόσος (ΧΝΝ) θεωρείται σοβαρό πρόβλημα δημόσιας υγείας. Σύμφωνα με διεθνή δεδομένα, ένας στους δέκα ενήλικες πάσχει από κάποιο βαθμό χρόνιας νεφρικής βλάβης. Στην Ελλάδα δεν υπάρχουν επίσημα στοιχεία. Είναι, λοιπόν, αναγκαίο το πέρασμα από τον παραδοσιακό τρόπο αρχειοθέτησης στις διαδικτυακές εφαρμογές υγείας. Τα τελευταία χρόνια, με τη ραγδαία εξέλιξη της τεχνολογίας της Πληροφορικής και των Επικοινωνιών, η χρή-

ση των ηλεκτρονικών ιατρικών φακέλων ασθενών για την καταγραφή και την ανάκτηση πληροφοριών αλλά και η αξιοποίηση μίας νέας μορφής υγείας, της κινητής υγείας (mobile health-telehealth), αυξάνεται τόσο στις ανεπτυγμένες, όσο και τις αναπτυσσόμενες χώρες και δίνει πολλές ελπίδες και στον τομέα της νεφρολογίας για καλύτερη διαχείριση της ΧΝΝ. Το Νεφρολογικό Τμήμα του νοσοκομείου μας μαζί με το Ινστιτούτο Πληροφορικής και Επικοινωνιών του Εθνικού Κέντρου Έρευνας και Τεχνολογικής Ανάπτυξης (ΕΚΕΤΑ) και την Ελληνική Νεφρολογική Εταιρεία ανέπτυξε την πρώτη πανελλήνια διαδικτυακή εφαρμογή ασθενών υπό αιμοκάθαρση μέσω κεντρικού φλεβικού καθετήρα με υποδόριο τούνελ που το Δεκέμβριο του 2018 κοινοποιήθηκε σε όλες τις μονάδες αιμοκάθαρσης. Κάνοντας ένα βήμα παραπάνω, το Νεφρολογικό Τμήμα είναι το πρώτο τμήμα στην Ελλάδα που, με τη βοήθεια επιστημόνων του ΕΚΕΤΑ, ανέπτυξε και σχεδιάζει να χρησιμοποιήσει την ηλεκτρονική πλατφόρμα e-NeFros, με σκοπό τη βελτίωση της παροχής υπηρεσιών υγείας τόσο σε νοσηλευόμενους όσο και σε εξωτερικούς νεφροπαθείς ασθενείς. Οι εφαρμογές αυτές παρέχουν ένα ηλεκτρονικό συνεργατικό περιβάλλον με ανταλλαγή πληροφοριών μεταξύ ιατρών, δυνατότητα διασύνδεσης με τους ασθενείς και, τελικά, αποτελεσματικότερη διαχείριση των πόρων του συστήματος υγείας. Συμπερασματικά, στη ΧΝΝ πρέπει να δοθεί έμφαση σε δράσεις ηλεκτρονικής υγείας με ταυτόχρονη εξατομίκευση και ο ασθενής θα πρέπει να συμμετέχει ενεργά στη διαχείριση του νοσήματός του.

**Λέξεις ευρητηρίου:** Ηλεκτρονικές υπηρεσίες υγείας, Στατιστική Υγείας, Κεντρικός φλεβικός καθετήρας cff, Χρόνια νεφρική νόσος

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