Health Policy and Technology (2018) 7, 73–80

Available online at www.sciencedirect.com

ScienceDirect

journal homepage: www.elsevier.com/locate/hlpt

Enabling informed policymaking for chronic kidney disease with a registry: Initiatory steps in Iran and the path forward

Zahra Niazkhani[a,b,1], Mojgan Cheshmekaboodi[a,c,1], Habibollah Pirnejad[a,d,e,*], Khadijeh Makhdoomi[b,f], Ahmad Ali Nikibakhsh[b,g], Saeed Abkhiz[f,2], Azam Mivefroshan[f,2], Laleh Jafari[f,2], Javad Zeynali[f,2], Hashem Mahmoodzadeh[g,2], Ali Taghizadeh Afshari[b,h,2], Roland Bal[e]

[a]*Department of Health Information Technology, Urmia University of Medical Sciences, Urmia, Iran*
[b]*Nephrology and Kidney Transplant Research Center, Urmia University of Medical Sciences, Urmia, Iran*
[c]*Student Research Committee, Urmia University of Medical Sciences, Urmia, Iran*
[d]*Patient Safety Research Center, Urmia University of Medical Sciences, Urmia, Iran*
[e]*Erasmus School of Health Policy & Management (ESHPM), Erasmus University Rotterdam, Rotterdam, The Netherlands*
[f]*Department of Adult Nephrology, Urmia University of Medical Sciences, Urmia, Iran*
[g]*Department of Pediatric Nephrology, Urmia University of Medical Sciences, Urmia, Iran*
[h]*Department of Urology, Urmia University of Medical Sciences, Urmia, Iran*

Available online 31 January 2018

KEYWORDS
Chronic kidney disease;
Renal Insufficiency, Chronic;
Registries;
Minimum data set;
Mixed method;
Iran

Abstract
Objectives: Chronic kidney disease (CKD) registries have been used for more than half a century. Iran lacks a comprehensive registry to capture data of all CKD patients for an informed care planning and policy making. We aimed to identify the objectives and possible challenges for developing a CKD registry and also to define its minimum data set (MDS) in our healthcare context.
Methods: This was a mixed-method study conducted in Iran from fall 2016 till summer 2017. The qualitative part included document analysis and 26 semi-structured interviews with 17 clinicians and managers involved in CKD care. This data was analyzed using the "grounded theory". Then, a modified Delphi survey was conducted. Percentages and mode values were used for analysis.

*Corresponding author at: Urmia University of Medical Sciences, Orjans Alley, Resalat Blvd, Urmia 571478334, Iran. Fax: +984432240658.
[1]Both authors contributed as first authors.
[2]Equal contributions.

https://doi.org/10.1016/j.hlpt.2018.01.004

Results: Our participants' leading interest in a CKD registry was centered on providing a coordinated, good-quality care for all CKD stages with particular emphasis to capture events and monitor trends for patients in earlier stages. They highlighted the required financial, technical and human resources as main challenges for a smooth registry implementation. Furthermore, a clinically oriented MDS comprising of 168 elements (with a majority having more than 90% agreement with mode 2) was extracted. It mainly collects demographics, medical history, encounter sessions, diagnostic examinations, medications, vaccinations and mortality data.

Conclusions: We reported the initiatory steps taken to establish a CKD registry in an Iranian healthcare context. We focused on the information needs and priorities of our main stakeholders and based our intended registry on addressing those needs. We hope this approach will facilitate its endorsement and advance the efforts for a sustainable, good-quality CKD care.

Introduction

Chronic kidney disease (CKD) is one of the leading global health problems due to its increasing prevalence and associated complications [1]. According to a recent systematic review and meta-analysis, the prevalence of CKD has been estimated between 11% and 13% worldwide [2]. This review highlighted that information on earlier CKD stages is still limited despite a higher prevalence. This is of particular concern in developing countries [3]. In Iran, different studies have provided varying estimates of the disease in adults ranging from 12.6% to 23.7% [4-6]. In a study of Iranian children, a higher prevalence of CKD was found compared to western countries [7]. Adding to this existing CKD burden is *a growing trend* in coming years, which has been predicted in a population based modeling study [8]. Still, many aspects of CKD care are poorly understood due to limitations in existing data. For example, it is not completely clear how care is accessible for different groups with regards to gender, ethnicity and socioeconomic status or how progressive the disease is across different regions of the country. To be able to keep up with the growing CKD trend, accurate and up to date patient data is required in all stages for informed policy making and management planning, as acknowledged by scholars in the field [9].

Disease registries have a great potential to provide reliable observational data for a specific group of patients [10]. Their implementations have been associated mostly with a positive impact on healthcare processes and outcomes [11]. Furthermore, such registries can potentially become an efficient policymaking tool [12]. The oldest renal registry was founded in Europe in 1964 [13]. In a recent systematic review, 144 renal registries were identified worldwide with varying aims, structures, and CKD patients targeted [14]. Noteworthy is that a majority of these registries were based in developed countries and focused on end stage renal diseases (ESRD). Unfortunately, the number of renal registries in developing countries was not prominent in this review. In Iran, the transplant office in the Iranian Ministry of Health and Medical Education has taken the initiative to establish a transplant registry, which includes kidney transplantations. A comprehensive renal registry that also includes the early stages of CKD, however, has not so far been in place at neither national nor local levels. Therefore, to address this deficiency, a renal registry development project was started in the West Azerbaijan province in 2016. This article describes the initiatory yet crucial steps taken to establish such a registry at our healthcare context. As a fundamental step in designing any disease registry [10], we first and foremost aimed to define the objectives of founding a renal registry in our context, to identify opportunities, threats and challenges along the way, as well as to extract its essential minimum data set (MDS).

Methods

This was a mixed method study conducted in two phases: 1) a qualitative study using interviews and document analysis, and 2) a quantitative study using a modified Delphi survey. The details of these two, including the process to extract MDS for a CKD registry, are described below. The study started late fall 2016 and lasted till late summer 2017. Before the start of the study, it was approved by the research ethics committee of UUMS. Formal written consent was not sought from the participants because acceptance of our invitation for an interview and also submission of completed questionnaires by the survey participants were taken as implied consent. Even so, before any data collection, we informed our participants about the confidentially of any information provided by them.

Phase 1: qualitative study

In this part of the study, we used interviews and document analysis. We interviewed 17 key experts with the knowledge of merits and pitfalls of CKD care in our context. As individuals with different types of knowledge, expertise and skills are involved in CKD care, we invited representatives of all key stakeholders i.e., physicians, nurses and data managers to participate in our study (please see the result section). Our interview participants were identified through a purposive sampling after interviewing their first group. During interviews, we focused on the questions to define the objectives of such a registry in our healthcare context, and to identify opportunities and possible threats and challenges along the way. We were interested to analyze how these issues might affect establishing a given CKD registry. More than one interview was held with some of our participants but in different occasions. Interviews

Table 1 Details of interviews with study participants.

Professions and roles	Number of interviews held
Adult nephrologists	7
Pediatrics nephrologists	5
Kidney transplant surgeons	2
Adult and pediatrics nephrology and transplant nurses	8
Managerial key informants in the vice chancellor of clinical affairs	2
Managerial key informants in the society of kidney patient support charity	2

were in-depth, semi-structured, one-on-one and face-to-face. Interviews lasted 30–45 min each. After ensuring the confidentiality of information provided, 12 interviews were voice recorded and transcribed verbatim and analyzed before conducting a new one. During the other interviews, interview notes were concurrently taken and their contents were approved by the participants. This helped to organize the questions for the consequent interviews and to check the validity of our preliminary interpretations with the participants. The interviews were continued until data saturation was achieved.

We analyzed our qualitative data using a "grounded theory" approach [15]. In this method, data was coded around the areas of our research interests and aims until the main themes emerged. The overall data analysis for the present study was conducted by the first and the corresponding authors independently and the resulting themes were discussed in multiple meetings till consensus was reached.

Phase 2: quantitative study using a modified Delphi survey

We reviewed the literature and also the official websites of leading CKD registries already identified in [14], in both international and national levels of developed and developing countries, and extracted their common data elements whenever they were publicly available (for example please see [13,16–24]). To cover all CKD stages, we were interested in all renal registries encompassing either earlier, later or entire CKD stages. To the list of extracted common data elements, we added the data items of interest for our main stakeholders or future users (i.e., nephrologists, nurses and care managers) especially those data items mentioned as essential for data management tasks. By incorporating these two sources, we developed the first version of a questionnaire. The questionnaire consisted of data items organized in 10 categories in English. In front of each item, it was documented which country's renal registry included that item. Participants were asked to rate the necessity of inclusion of an item in the MDS using a three-point likert scales i.e., "very important = 2", "important = 1" and "not important = 0".

In order to select MDS, we used a modified Delphi survey defined as "Delphi rounds plus a physical meeting" [25]. This method has already been used successfully to develop a MDS for clinical fields [26,27]. In round 1, we distributed the questionnaire to 14 physicians, nurses and managers in nephrology care. Following review of the first round's responses, it was decided that two slightly different questionnaires would be distributed in the second round to target pediatrics and adult patient registrations individually. This was mainly because of the sake of greater clarity and some slightly differing information needs of our clinicians for pediatrics and adult patient populations. Round 2 of the Delphi was conducted through sending an email survey to key informants working in other medical universities and inviting them to rate the data elements. A sampling was not used for this purpose and the inclusion in this invitation was merely based on our familiarity with participants.

Data analysis

In both rounds, percentages and mode values were used for outcome measures as indicators of agreement on the three-point scales. Decision to include an item was based on achieving consensus when greater than 60% of respondents rated that item as "very important = 2" or "important = 1" indicating a clear majority. If greater than 60% of participants scored an item as "very important" with mode 2, that item was considered mandatory in our intended CKD registry. The remaining selected items, which commonly had mode 1, were considered voluntary. Comments provided by the respondents in the questionnaires were also analyzed thematically. Quantitative statistical analyses of the rating of data items were undertaken with the SPSS software version 16. Meetings were held with senior adult and pediatric nephrologists to discuss the results of analysis and to make decisions on the final data categories and items.

Results

Qualitative results

In total, 26 interviews were conducted with 17 key experts who were 5 adult and 2 pediatrics nephrologists, 2 kidney transplant surgeons, 4 nephrology nurses in the nephrology and kidney transplant wards, 4 experts from Urmia University of Medical Sciences' vice chancellor of clinical affairs and the charity organization for supporting patients with kidney disease. Table 1 provides details of these interviews.

Objectives and expected benefits of a CKD registry

The interviews revealed that all our interviewees commonly believed that developing and establishing a CKD registry would be a pivotal step to provide a qualitative, coordinated CKD care. We identified the following perceived goals that can be achieved by establishing a viable CKD registry. In the views of our participants, especially physicians, the most notable goal with a CKD registry would be collecting accurate data and information of CKD patients in different stages, particularly those in earlier stages before they develop into ESRD. The following quote spells the point out:

> *"…In my opinion, the most important issue is that we first need to know the exact number of our CKD patients in the province and then think about designing and implementing interventions …. [after knowing the number] we need to think what we can do to stop [or slow down] the progress of their disease into ERSD with interventions such as medications, patient education or life style changes …." (A senior nephrologist, 27th of November 2016).*

Having accurate data would provide physicians with the opportunity to track and monitor the progress of CKD patients more closely and actively in the early stages. They told us the tales of multiple patients who had been in earlier CKD stages but due to different reasons nephrologists had lost track of patients' renal function trajectory and then these patients came back for follow-up visits in their final CKD stages. Our nephrologists expected that recalling such lost to follow up patients to receive evidence-based CKD care would be a much easier task by registering and actively chasing them. This way, clinicians might be able to prevent or at least to delay the rapid progression to ESRD saving hundreds of kidneys. In order to have a thorough overview on the CKD patients in our region, it was proposed that all patients would be targeted for registration regardless of their stages except when they do not give consent for registry or receive kidney transplantation.

Our interviewees stated that having reliable data in such registry will have multiple benefits. It will facilitate organizing and also managing a more coordinated CKD care by informing the main stakeholders such as nephrologists, nephrology nurses, internal medicine specialists and family physicians, governmental and non-governmental organizations as well as policy makers. It can also aid clinicians to control CKD complications such as cardiovascular diseases, anemia and metabolic bone disorders before they become urgent or irreversible. Next, conducting research on epidemiology or the clinical aspects of CKD care in our setting will be promoted. On that account, the main CKD causes and also contributing factors on its progression trajectory can be better known. Last but not least, such information would inform policy makers' decisions regarding health system planning and capacity building for CKD care as one of our interviewees remarked on this issue:

> *"…the financial data we receive are accurate because we have their official documents; but about the other [patients' non-financial, clinical] data, they are often incomplete because we do not have the necessary infrastructure for reliable data collection, although some are collected on line… Because our planning is based on the data which is sent to us, therefore the [clinical] recorded data is very important for us." (A registry manager, 20th of December, 2016).*

Challenges and opportunities

Our results also showed that although a CKD registry was considered instrumental in achieving the above mentioned goals and benefits, our participants were deeply concerned about a number of challenges that may undermine the efforts for the registry establishment or threaten its success and maintenance. The most frequently mentioned challenge in our study was the shortages of financial and human resources to cover up required workload. As emerged, it seemed a prerequisite to recruit designated individuals with information technology knowledge to collect necessary data from various sources and then populate the registry with those data. If data entry tasks are to be assigned to clinicians, then their motivations for cooperation should properly be addressed. For example, it was suggested that financial or other ways of compensations for this increased workload could be considered such as decreased shift work. It should also be noted that in addition to the nephrologists and nurses in academic hospitals and clinics, other clinicians such as internal medicine specialists or even family physicians are currently involved in providing CKD care in the community. In order to have their contribution in a given CKD registry, attractive secondary benefits either financial or non-financial might be compelling.

Moreover, in order to lessen data entry workload and make it a pleasing experience, it was advised that the data items and the efforts required for their entry should be kept as minimal as possible, particularly in early implementation stages. Next challenge highlighted by our participants was a fragile infrastructure to deploy the information and communication technology across the province for sharing data through a registry. In their views, a comprehensive single source of patient data is greatly lacking in the current healthcare system. Therefore, the data must be compiled from multiple sources and then should be validated by qualified individuals to be credible for clinical decisions and policy making purposes.

Alongside the above mentioned challenges, the following opportunities were also identified in the way of establishing a CKD registry for our setting: 1) ownership of the project by clinician leaders i.e., medical informaticians, nephrologists and transplant surgeons, 2) the focus and emphasis on collecting clinically relevant, rather than financial and administrative, data items aiming to promote a sustainable, qualitative CKD care, and 3) project alignment with the university's top research priorities and recent initiatives such as a large CKD screening project newly funded by the National Institute for Medical Research Development (NIMAD) of Iran.

Quantitative results

In total, 18 local and national experts in nephrology care participated in the Delphi survey. In the first round, from 14 invited participants, all completed the questionnaire (100% response rate). Eleven did so in the second round from which 4 were new participants all invited from other academic centers across the country (i.e., Tehran, Shiraz and Kermanshah universities of medical sciences). The majority of the survey participants were physicians (60%) and men (53%). All were experienced and key experts in their professions or managerial roles.

Data elements

The final validated data elements in our study were composed of 168 elements in 11 categories. These categories were consisted of demographics (16 elements), history of patient's CKD (11 elements), patient's other clinical histories (16 elements), patient family history (4 elements), current visits (17 elements), dialysis (34 elements), laboratory tests (46 elements), medications (17 elements), vaccinations (2 elements), ultrasonography results (3 elements) and mortality data (2 elements). Table 2 provides details of these data elements, their percentages and modes.

Discussion

In this study, we aimed to characterize the main objectives of founding a CKD registry in our healthcare context. Our participants' leading interest in establishing a registry was centered on providing a qualitative and coordinated care for their CKD patients, particularly those in earlier stages. They assumed that collecting and collating reliable information of CKD patients would enable conducting research and planning tailored prevention and management strategies in order to appropriately target in need patients. Using the Delphi survey, we defined a MDS to develop such a registry. The resulting MDS was more clinically oriented mainly because our participants put the quality of care at the center stage.

Despite the higher incidence and prevalence in earlier CKD stages, the majority of renal registries capture data of ESRD patients undergoing renal replacement therapy (RRT) [14]. The United States Renal Data System (USRDS) for ESRD patients has been operational since 1989 [28]. Till rather recently, however, this country lacked a comprehensive surveillance program to capture and track all aspects of CKD especially for those not yet receiving renal replacement therapy. Therefore, a CKD surveillance system was established to encompass all CKD stages aiming towards primary prevention, earlier detection and implementation of optimal disease management strategies in 2010 [29]. So far, very few registries have aimed to collect data on earlier CKD stages. In

Table 2 Minimum CKD data set identified in our study for designing a CKD registry.

Category			Data Items (% with mode)
Demographic information (16)			• 100% with mode 2: First and last names, date of birth, national identification number, gender, height and weight (for BMI), blood group, socioeconomic status, place of residence (city and province), contact number (fixed and mobile), type of insurance • 90.9% with mode 2: level of education • 81.4% with mode 2: provider name (hospital or care center)
History of patient's CKD (11)			• 100% with mode 2: The main cause of CKD and the history of other kidney related symptoms or diseases; pathologic report of kidney biopsy; history of nephrotoxic drug use; age and serum creatinine level when first diagnosis made; date of first visit by a nephrologist; the Renal Replacement Therapy (RRT) method used for the first time; date of the first RRT; history of renal TX • 90.9% with mode 2: CKD stage when first diagnosis made
Patient's other clinical histories (16)			• 100% with mode 2: Diabetes mellitus (including diabetic nephropathy), cardiovascular diseases (including history of angioplasty and vascular graft), history of hyperlipidemia, hematological disorders, thyroid disorders, bone disorders, cancer, congenital diseases, metabolic diseases, pre-dialysis immunosuppression use (more than 3 months per 12 months), • 100% with mode 1: chronic lung diseases • 90.9% with mode 2: psychiatric disorders, infectious diseases (including hepatitis, CMV and HIV), smoking and alcohol use • 90.9% with mode 1: drug allergies
Patient family history (4)			• 100% with mode 2: History of any kidney disease in the first degree family member (including hematuria), diabetes, hypertension, cardiovascular diseases
Current visits (17)			• 100% with mode 2: visit date, systolic and diastolic blood pressure values, heart rate, Ultra filtration (in 24 h), height and weight (for BMI), edema status, features of uremia (e.g., cardiovascular complications, acid-base or electrolyte complications, central or peripheral nervous system manifestations, etc.), hyperlipidemia status, hematological disorders, current RRT method; age and serum creatinine level whenever a change in the patient's CKD stage is occurred (including at ESRD) • 100% with mode 1: heart rate and thyroid disorders • 90.9% with mode 2: current CKD stage
Dialysis (34)	Hemodialysis (7)		• 100% with mode 2: vascular access, frequency of dialysis per week, type of dialysis solution, urea reduction ratio % • 90.9% with mode 2: blood flow rate • 81.8% with mode 2: type of dialysis filter and KT/V
	Peritoneal dialysis (27)	Peritoneal catheterization (8)	• 100% with mode 2: type of catheter, catheterization method, duration of catheterization, omentectomy report, catheter functioning status inside the operating room, any complications occurred during and after catheterization • 100% with mode 1: exit site quadrants
		Dialysis session (12)	• 100% with mode 2: Type of dialysis solution, volume of the solution, symptoms at the onset of dialysis, duration of dialysis session, the frequency of dialysis per week, the cause of any dialysis failure, the patient's RRT or state whenever peritoneal dialysis is stopped (such as full recovery, HD, TX, etc.,) • 66.7% with mode 2: the compounds used in the dialysis fluid, time to leave the solution in the peritoneum, the number of cycles per day, serum potassium pre-dialysis, serum potassium post-dialysis
		Peritonitis cases (7)	• 100% with mode 2: Peritoneal fluid analysis, treatment of peritonitis (i.e., antibiotics used, duration of treatment, change of an antibiotic), final result of peritonitis treatment • 66.7% with mode 2: peritoneal fluid culture and antibiogram test
Laboratory tests (46)			• 100% with mode 2: Complete blood count (WBC with diff, RBC, Hg, Platelet), Creatinine, Creatinine clearance, Bicarbonate, Potassium, Sodium, Urea, Calcium, Phosphate, FBS, Hg A1c (for diabetic patients), CRP, Iron, TIBC, Ferritin, Liver function tests (i.e., ALP, ALT, AST, Albumin, Bilirubin), iPTH, Thyroid function tests (i.e., TSH, T4, T3), Hepatitis B, Urine full report (including RBC, WBC, protein, glucose, ketone and bacteria), Urine volume (in 24 h), Urine protein test (in 24 h urine), CMV test, Venereal disease research laboratory (VDRL) test • Between 62.5% and 90.9% with mode 2: Urea clearance, ESR, Lipid profile (i.e., Triglycerides, HDL, LDL, total Cholesterol), Hepatitis C, Toxoplasmosis test

Table 2 (*continued*)

Category	Data Items (% with mode)
Medications (17)	• 100% with mode 2: Antihypertensive agents, Anti- hyperlipidemic agents, Anti-diabetic agents (including Insulin), Erythropoietin agents, Iron supplements, Folic acid, Vitamin D3, Calcium, Phosphate binders, Sodium bicarbonate, Growth hormone (for pediatrics), Antihistamines, Opioid analgesics, and details of a medication (name, unit, frequency, dosage, route) • 87.5 with mode 2: Allopurinol, Laxatives, • 90% (45% with mode 2 and 45% with mode 1): Anticoagulants,
Vaccination (2)	• 100% with mode 2: Vaccination type and date (including Hepatitis vaccine, Pneumococcal vaccine, Influenza vaccine, Meningitis and Tetanus vaccines (only for pediatrics))
Ultrasonography results (3)	• 100% with mode 2: Abdominal (including urinary tract), Neck • 90% (45% with mode 2 and 45% with mode 1): Pelvic
Death data (2)	• 100% with mode 2: Date of death, the main cause of death

Abbreviations: Chronic Kidney Disease (CKD), End Stage Renal Disease (ESRD), Body Mass Index (BMI), Renal Replacement Therapy (RRT), Kidney transplantation (TX), Hemodialysis (HD), Cytomegalovirus (CMV), Human Immunodeficiency Virus (HIV), White Blood Cells (WBC), Red Blood Cells (RBC), Hemoglobin (Hg), Fasting Blood Sugar (FBS), Erythrocyte Sedimentation Rate (ESR), C-Reactive Protein (CRP), Total Iron Binding Capacity (TIBC), High Density Lipoprotein (HDL), Low Density Lipoprotein (LDL), Alkaline Phosphatase (ALP), Alanine Aminotransferase (ALT), Aspartate Aminotransferase (AST), Intact Parathyroid Hormone (iPTH), Venereal disease research laboratory (VDRL), KT/V: a number used to quantify dialysis treatment adequacy)

Australia, to address the data gap on earlier CKD stages, a surveillance program including a registry was established to include all public health renal practices across the province of Queensland [30]. To collect data of all CKD patients, the Indian Society of Nephrology embarked on developing a CKD registry as a nationwide data warehouse [23]. The Serbian pediatric CKD registry also included CKD stages 2-5 [24]. Similarly, in our study, registry aims were set to embrace all CKD stages of both adults and children patients with particular emphasis to capture events and monitor trends for patients in earlier stages enabling better care planning and policy makings for future.

It has been noted that the priorities of stakeholders are key for a renal registry to succeed [10,31]. Outlining objectives with main stakeholders' full engagement is extremely important to fulfill their information needs, soundly. Following this approach, we defined a MDS that most commonly focused on capturing items that are of paramount importance from quality of care perspectives. Unavoidably, there are likely different perspectives among researchers and clinicians in other settings. For example, in some renal registries, it is necessary to capture financial data (see for instance [20,32]). In our qualitative study, the participants expressed their unwillingness for such data items to populate this registry. Because we put our clinicians' needs at the center stage, it is possible that our primary MDS used to initiate the registry is not comprehensive enough to address all the questions of researchers with broad research interests. Yet, such registries provide the basic information necessary to identify and recruit a representative research samples, as the experience of UK renal registry also shows [33].

To gain success, MDS in patient registries should be flexible enough to incorporate new data elements based on evolving needs of clinicians and researchers [31]. For example, since conception of Korean renal registry in 1985, it has been evolving to include more and more clinically relevant data items, such as dialysis adequacy and lab data [34]. This was the case in USRDS as well, in which other objectives such as conducting economic and biomedical research were added later on in 1994 [35]. We may also need to go through data revisions to capture additional information or to clean away superfluous data items after primary implementation phase. Fortunately, the in-house development of this registry makes its tailoring according to evolving needs more feasible. Moreover, in several renal registries, MDS of kidney transplantations were incorporated within ESRD registries [18-21]. Nevertheless, we did not consider any MDS for kidney transplant in our study. This was mainly because of an already existing registry for transplantations in Iran. Therefore, we decided to avoid redundant or duplicate workload for our clinicians. It would be more productive if such registries with complementary aims could be linked to share data in future.

Information technology including registry systems has multiple benefits especially for chronic diseases [36,37]. Chronic care such as care delivered to CKD patients is highly collaborative. New models of care are needed for improved CKD care [38]. A renal registry can play an important role in the implementations of chronic care models for CKD [39]. Moreover, renal registries can facilitate establishing national CKD surveillance systems, as shown by successful initiatives in developed countries [29,30,40]. In a study of clinicians' attitudes towards a CKD registry in the United States, they believed that it has the potential to support their practice by identifying patients fallen out of care, recognizing CKD progression, tracking quality metrics and abnormal lab values, and providing evidence based decision supports [41]. Our participants had similar attitudes towards the potential benefits of a CKD registry. Yet, they highlighted the workload of data collection and the required financial, technical and human recourses as potent inhibitors of a successful implementation if not considered and secured beforehand. These issues have played an important role in failure of a number of renal registries in developing countries [17]. We too should carefully consider the identified challenges and

threads when we embark on full implementation and maintenance of such a registry in our healthcare context. It should be noted that, in the light of successful experiences of implementing national registries such as cancer and trauma in Iran, the prospect to secure the required resources from the Iranian ministry of Health is promising for CKD registry implementation.

Limitations

While we believe that our study is the first practical initiative to establish a CKD registry in our health care context, we recognize there were limitations. First, this research was conducted at provincial health care level. Therefore, further studies are needed for findings to be generalizable to the whole country. Although we believe the list of MDS identified in our study is inclusive and relevant from the quality of care perspectives, this data set may need to be vetted by a larger group of clinicians to be applicable nationwide. Further, we used the Delphi survey to reach a consensus on the data items. This method has been shown to be a useful method to define the objectives of such systems, their associated measures and data items [29]. However, one of its limitations is that minority opinions are marginalized. Finally, it is possible that important items were overlooked or not considered in our study. After initial implementation, we remain open to necessary modifications by collecting and collating suggestions for future possible MDS revisions.

Conclusion

We reported the initiatory steps taken to establish a CKD registry in an Iranian healthcare context. We focused on the information needs and priorities of our main stakeholders in order to define the objectives of establishing a CKD registry in Iran and its MDS. Our results showed that the quality of care perspectives influenced both the registry objectives and its MDS. Although, the required workload for clinicians was identified as the main challenge in this study, collecting minimally needed data longitudinally may benefit clinicians by addressing their main information needs about their patients. We hope this approach will facilitate its endorsement. It is noteworthy that, following the current study, we developed a renal registry system that, by the time of this report, was in pilot phase at an academic renal center affiliated to Urmia University of Medical Sciences. We hope that the insights gained in this study will advance the efforts of our clinicians, researchers and policy makers for a good-quality CKD care.

Acknowledgements

The authors gratefully acknowledge the time and effort of all participants in our study. This study was resulted from a Master of Science thesis in the Medical Informatics domain at Urmia University of Medical Sciences (grant number 1395-01-52-2560). We also thank the support provided by the Clinical Research Development Unit of Imam Hospital in Urmia, Iran.

Author contribution

ZN, HP and MCH designed the study. MCH collected data. MCH and ZN analyzed data. All authors contributed in the analysis and interpretation of data. ZN drafted the article and revised it according to the other authors' comments. All authors approved the final version.

Funding

This study was supported by a student grant at Urmia University of Medical Sciences (grant number 1395-01-52-2560).

Competing interests

None declared.

Ethical approval

This study was approved by the research ethics committee of Urmia University of Medical Sciences (ethic code number: IR.UMSU.REC.1395.356).

References

[1] Couser WG, Remuzzi G, Mendis S, Tonelli M. The contribution of chronic kidney disease to the global burden of major noncommunicable diseases. Kidney Int 2011;80(12):1258–70.

[2] Hill NR, Fatoba ST, Oke JL, Hirst JA, O'Callaghan CA, Lasserson DS, et al. Global prevalence of chronic kidney disease - a systematic review and meta-analysis. PLoS One 2016;11(7):e0158765. [PubMed PMID: 27383068].

[3] Nugent RA, Fathima SF, Feigl AB, Chyung D. The burden of chronic kidney disease on developing nations: a 21st century challenge in global health. Nephron Clin Pract 2011;118(3):c269–c277.

[4] Najafi I, Shakeri R, Islami F, Malekzadeh F, Salahi R, Yapan-Gharavi M, et al. Prevalence of chronic kidney disease and its associated risk factors: the first report from Iran using both microalbuminuria and urine sediment. Arch Iran Med 2012;15(2):70–5.

[5] Safarinejad MR. The epidemiology of adult chronic kidney disease in a population-based study in Iran: prevalence and associated risk factors. J Nephrol 2009;22(1):99–108.

[6] Sepanlou SG, Barahimi H, Najafi I, Kamangar F, Poustchi H, Shakeri R, et al. Prevalence and determinants of chronic kidney disease in northeast of Iran: results of the Golestan cohort study. PLoS One 2017;12(5):e0176540.

[7] Gheissari A, Kelishadi R, Roomizadeh P, Abedini A, Haghjooy-Javanmard S, Abtahi SH, et al. Chronic kidney disease stages 3-5 in Iranian children: need for a school-based screening strategy: the CASPIAN-III study. Int J Prev Med 2013;4(1):95–101.

[8] Tabrizi R, Zolala F, Nasirian M, Baneshi MR, Etminan A, Sekhavati E, et al. Estimation of the prevalence of chronic kidney disease: the results of a model based estimation in Kerman, Iran. Med J Islam Repub Iran 2016;30:338.

[9] Nafar M, Mousavi SM, Mahdavi-Mazdeh M, Pour-Reza-Gholi F, Firoozan A, Einollahi B, et al. Burden of chronic kidney disease in Iran: a screening program is of essential need. Iran J kidney Dis 2008;2(4):183–92.

[10] Gliklich R, Dreyer N, Leavy M. Registries for evaluating patient outcomes: a user's guide. In: Rockville MD, editor. Agency for Healthcare Research and Quality. 3rd. ed.. .

[11] Hoque DME, Kumari V, Hoque M, Ruseckaite R, Romero L, Evans SM. Impact of clinical registries on quality of patient

care and clinical outcomes: a systematic review. PLoS One 2017;12(9):e0183667.
[12] Ornerheim M. Policymaking through healthcare registries in Sweden. Health Promot Int 2016. http://dx.doi.org/10.1093/heapro/daw064.
[13] Jager KJ, Wanner C. Fifty years of ERA-EDTA Registry-a registry in transition. Kidney Int Suppl 2015;5(1):12–4.
[14] Liu FX, Rutherford P, Smoyer-Tomic K, Prichard S, Laplante S. A global overview of renal registries: a systematic review. BMC Nephrol 2015;16:31.
[15] Corbin J, Strauss A. Basics of Qualitative Research. Techniques and Procedures for Developing Grounded Theory. 3rd ed.Sage Publications; 2008.
[16] Shah B, Kirpalani A, Sunder S, Gupta A, Khanna U, Chafekar D, et al. A prospective, multi-centre, observational study to examine kidney disease progression in adults with chronic kidney disease - CKDOD - Study design and preliminary results. BMC Nephrol 2015;16:215.
[17] Davids MR, Eastwood JB, Selwood NH, Arogundade FA, Ashuntantang G, Benghanem Gharbi M, et al. A renal registry for Africa: first steps. Clin kidney J 2016;9(1):162–7.
[18] The South African Renal Registry. [cited 23 November]. Available from: ⟨http://www.sa-renalsociety.org/Registry.asp⟩; 2016.
[19] The Australia and New Zealand Dialysis and Transplant Registry (ANZDATA). [cited 10th of December]. Available from: ⟨http://www.anzdata.org.au/v1/index.html⟩; 2016.
[20] United States Renal Data System. [cited 4th of December]. Available from: ⟨https://www.usrds.org/⟩; 2016.
[21] Renal Registry UK. [cited 28 November]. Available from: ⟨https://www.renalreg.org/⟩; 2016.
[22] Samuel SM, Tonelli MA, Foster BJ, Nettel-Aguirre A, Na Y, Williams R, et al. Overview of the Canadian pediatric end-stage renal disease database. BMC Nephrol 2010;11:21.
[23] Rajapurkar MM, John GT, Kirpalani AL, Abraham G, Agarwal SK, Almeida AF, et al. What do we know about chronic kidney disease in India: first report of the Indian CKD registry. BMC Nephrol 2012;13:10.
[24] Peco-Antic A, Bogdanovic R, Mulic B, SPNWG. Serbian pediatric chronic kidney disease registry - SPEKID. BANTAO J 2007;5(2):32–6.
[25] Boulkedid R, Abdoul H, Loustau M, Sibony O, Alberti C. Using and reporting the Delphi method for selecting healthcare quality indicators: a systematic review. PLoS One 2011;6(6):e20476.
[26] McCann LJ, Kirkham JJ, Wedderburn LR, Pilkington C, Huber AM, Ravelli A, et al. Development of an internationally agreed minimal dataset for juvenile dermatomyositis (JDM) for clinical and research use. Trials 2015;16:268.
[27] Lerner EB, Drendel AL, Falcone Jr. RA, Weitze KC, Badawy MK, Cooper A, et al. A consensus-based criterion standard definition for pediatric patients who needed the highest-level trauma team activation. J Trauma Acute Care Surg 2015;78(3):634–8.
[28] Collins AJ, Foley RN, Gilbertson DT, Chen SC. United States Renal Data System public health surveillance of chronic kidney disease and end-stage renal disease. Kidney Int Suppl 2015;5(1):2–7.
[29] Saran R, Hedgeman E, Plantinga L, Burrows NR, Gillespie BW, Young EW, et al. Establishing a national chronic kidney disease surveillance system for the United States. Clin J Am Soc Nephrol 2010;5(1):152–61.
[30] Venuthurupalli SK, Hoy WE, Healy HG, Salisbury A, Fassett RG, group CQ. CKD.QLD: chronic kidney disease surveillance and research in Queensland, Australia. Nephrol Dial Transplant 2012;27(Suppl 3). [iii139-45].
[31] Davids MR, Caskey FJ, Young T, Balbir Singh GK. Strengthening renal registries and ESRD research in Africa. Semin Nephrol 2017;37(3):211–23.
[32] CKD Registry of India. [cited 15th of December]. Available from: ⟨https://www.ckdri.org/main.aspx⟩; 2016.
[33] Caskey F, Cullen R. UK renal registry 18th annual report: introduction. Nephron 2016;132(Suppl 1):1–8.
[34] Jin DC. Dialysis registries in the world: Korean Dialysis Registry. Kidney Int Suppl 2015;5(1):8–11.
[35] USRDS1994 Annual Data Report. 1994 [cited 14th of September]. Available from: ⟨https://www.usrds.org/atlas94.aspx⟩; 2017.
[36] Green CJ, Fortin P, Maclure M, Macgregor A, Robinson S. Information system support as a critical success factor for chronic disease management: necessary but not sufficient. Int J Med Inform 2006;75(12):818–28.
[37] Nelson EC, Dixon-Woods M, Batalden PB, Homa K, Van Citters AD, Morgan TS, et al. Patient focused registries can improve health, care, and science. Br Med J 2016;354:i3319.
[38] Johns TS, Yee J, Smith-Jules T, Campbell RC, Bauer C. Interdisciplinary care clinics in chronic kidney disease. BMC Nephrol 2015;16:161.
[39] Zuccaro L. Improving chronic kidney disease management using Wagner's model for chronic care. Univ Ott J Med 2015;5(1):1–4.
[40] Bello AK, Ronksley PE, Tangri N, Singer A, Grill A, Nitsch D, et al. A national surveillance project on chronic kidney disease management in Canadian primary care: a study protocol. BMJ Open 2017;7(8):e016267.
[41] McBride D, Dohan D, Handley MA, Powe NR, Tuot DS. Developing a CKD registry in primary care: provider attitudes and input. Am J kidney Dis 2014;63(4):577–83.