Coding practice in national and regional kidney biopsy registries

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Abstract

Background: Kidney biopsy registries all over the world benefit research, teaching and health policy. Comparison, aggregation and exchange of data is however greatly dependent on how registration and coding of kidney biopsy diagnoses are performed. This paper gives an overview over kidney biopsy registries, explores how these registries code kidney disease and identifies needs for improvement of coding practice.

Methods: A literature search was undertaken to identify biopsy registries for medical kidney diseases. These data were supplemented with information from personal contacts and from registry websites. A questionnaire was sent to all identified registries, investigating age of registries, scope, method of coding, possible mapping to international terminologies as well as self-reported problems and suggestions for improvement.

Results: Sixteen regional or national kidney biopsy registries were identified, of which 11 were older than 10 years. Most registries were located either in Europe (10/16) or in Asia (4/16). Registries most often use a proprietary coding system (12/16). Only a few of these coding systems were mapped to SNOMED CT (1), older SNOMED versions (2) or ERA-EDTA PRD (3). Lack of maintenance and updates of the coding system was the most commonly reported problem.

Conclusions: There were large gaps in the global coverage of kidney biopsy registries. Limited use of international coding systems among existing registries hampers interoperability and exchange of data. The study underlines that the use of a common and uniform coding system is necessary to fully realize the potential of kidney biopsy registries.

Keywords: Kidney biopsy registry, Systematic review, Coding, Renal pathology, Nephropathology

Background

The percutaneous kidney biopsy is the gold standard to diagnose renal disease, especially glomerulonephritis [1]. Microscopic examination of kidney tissue gives information about diagnosis and pathogenesis and provides insight in activity and chronicity [2, 4], thereby influencing therapeutic decision-making and determining prognosis. Almost all renal diseases are orphan diseases. The small number of cases is an obstacle to gather experience for nephrologists and pathologists, facing the overlap and variety of clinical presentations, the complexity of histologic patterns and the many additional clinical data and laboratory values that are needed to interpret kidney biopsies adequately. The rarity of renal diseases also hinders the collection of a sufficient number of
cases for research [3]. This is why nephrology and renal pathology often are practiced in larger hospitals or hospital networks with regional or national collaborations. Even if networks and collaborations greatly facilitate teaching, research and policy-making, there is still need for large patient and biopsy series in order to better understand kidney disease and optimize treatment and care. As a result, kidney biopsy registries have been established.

Registries compile knowledge, foster collaboration and provide research data. Medical registries systematically collect a defined set of data from patients with specific health characteristics in a central database for a specific purpose [5]. Several clinical kidney registries exist, of which the United States Renal Data System and the ERA-EDTA Registry are probably the best known [6, 7]. However, these registries focus on chronic kidney disease and renal replacement therapy and mainly collect clinical diagnoses and clinical data. The scope of these registries is not kidney biopsy diagnosis or pathology data. In comparison to these well-known big clinical registries, little is known about the number, the size and the geographic distribution of specific kidney biopsy registries.

If little data exist about kidney biopsy registries, the coding practice of these registries is even less known. A coding system eliminates the variability inherent to spoken or written language and thus can be used to store, aggregate and exchange data. In the context of kidney biopsy registries, important information from a pathology report will be stored as codes. Primarily this applies to the pathology diagnosis, but also morphologic findings or reaction patterns might be coded. If the joint usage of a coding system is crucial for aggregation and exchange of data on rare diseases, it seems strange that so little is known about coding systems used by kidney biopsy registries.

In view of these issues, our study aims to (1) give an overview over kidney biopsy registries, (2) explore how these registries code renal disease and (3) identify needs for improvement of coding practice.

Methods

Literature search

A PubMed search was undertaken in order to find kidney biopsy registries, with specifications 'kidney OR renal AND registry AND biopsy'. The search was last updated on 29th March 2019.

A first selection round screened the papers on the basis of their title. Articles were excluded based on the following criteria: review articles, articles about transplantation registries, renal registries based exclusively on clinical data, oncological registries and single center registries. We also excluded local or national pathology databases recording pathology diagnoses in general, however not specifically dedicated to medical kidney disease. These databases usually lack other characteristics of kidney biopsy registries such as yearly reports, publications or a dedicated webpage to renal disease. The Danish National Pathology Data Bank (Patobank) was kept as the only such database, as the former Danish Renal Biopsy Registry was incorporated into this database and kidney biopsy data continued to be published [8]. Inactive registries or temporary registries were excluded as well. Articles from or about registries that at least spanned a defined geographical region (regional or national kidney biopsy registries) were withheld. In this first selection round, we found 2 renal registries that did not record any pathology data and 3 major research consortia that will not be further discussed here because they met the exclusion criteria.

In a second selection round, remaining articles where screened using the same criteria on the basis of abstract and full text. We did not need to apply language restriction: all titles and abstracts were available in English. The search was complemented by information from personal contacts.

The same search was also run on the Cochrane library.

Questionnaire

An online questionnaire consisting of nine questions was developed for identifying characteristics of kidney biopsy registries and for evaluating how kidney biopsy registries code (see Supplementary material appendix 1). The questionnaire contained both multiple choice questions and open questions. Questions 1 to 7 yielded easy-to-present results, whereas questions 8 and 9 needed more qualitative interpretation. In order to better understand coding systems and lists, we gave registries an example of a diagnosis/conclusion from a pathology report (mesangiproliferative glomerulonephritis, IgA nephropathy, M1 E0 S1 T0 C1, see Supplementary material appendix 1), with the question to code this according to their current practice. In addition, in an open question format we encouraged respondents to provide us with suggestions for the future.

All kidney biopsy registries were contacted by AD or SL via an email to a contact person either found on the registry website, in published articles or by personal contacts. The contact persons were given information about the study project, and were kindly asked to answer the online questionnaire via a link provided in the email. When no reply was received, after 2 weeks a reminder email was sent. Answers to the questionnaire were analyzed by AD and SL. When present, discrepancies were discussed and resolved. As a second approach, we investigated the papers published by the registries and
websites -where available- to obtain information on the registries and to understand their coding systems.

Methods were carried out in accordance with relevant guidelines and regulations. Because this study did not involve experimental protocols nor the collection, use or transmission of individually identifiable data, institutional ethics committee review or approval was not required. Similarly, patient informed consent was not applicable to this study since the collection of data via the questionnaire did not involve patient data but collection of registry data.

Results

Literature search

The literature search retrieved 1501 articles (Fig. 1). The first selection round resulted in 141 articles, the second one in 93 articles. From these we identified 14 kidney biopsy registries (13 are kidney biopsy registries proper and 1 is a national pathology database; we will for simplicity use the umbrella term ‘registries’ for all). Through personal contacts, additional 2 registries could be identified, bringing the total number of kidney biopsy registries to start with to 16. A second search on the Cochrane library retrieved 193 articles, but screening based on title did not withhold a single article.

In Table 1, we give an overview of available websites, annual reports and 1-2 relevant research papers from the identified registries, typically one paper describing the set-up of the registry and one more recent paper.

Most of the registries were located in Europe (n = 10; Fig. 2). There was 1 registry in North America (Canada), 1 in South America (Uruguay) and 4 in Asia (Japan, Malaysia, The Philippines, Taiwan).

Questionnaire

Fifteen of 16 registries filled out the online questionnaire, thus the response rate was 94%. Three of these 15 responding registries proved to be regional renal biopsy registries, while 12/15 were organized in a national fashion. Data for the one registry that did not respond were analyzed based on published literature [33].

What type of information do registries collect?

All registries collect the pathology diagnosis, as this was an inclusion criterion for this study. Fourteen of 16 collect the clinical diagnosis for the same biopsy episode. Fifteen of 16 registries record clinical data related to the kidney biopsy diagnosis (such as blood pressure) and 11/16 pathology data related to the kidney biopsy diagnosis.

![Fig. 1 Graphical representation of the search strategy to identify medical literature about kidney biopsy registries](image-url)
Eight of 16 registries collect clinical data related to the transplant diagnosis (such as post-transplant serum creatinine levels) and 3/16 registries collect pathology data related to transplant biopsies (such as degree of interstitial fibrosis) (Table 2).

**Table 1** Overview of websites, key publications (2 are shown) and data reports of national and/or regional kidney biopsy registries included in this study

| Identified registries or data repositories | Website                                                                 | Publications (see references) | Data Reports |
|------------------------------------------|------------------------------------------------------------------------|-------------------------------|--------------|
| British Columbia Glomerulonephritis Network | [http://www.bcrenalagency.ca/health-professionals/professional-resources/promis](http://www.bcrenalagency.ca/health-professionals/professional-resources/promis) | [9, 10]                       | –            |
| Czech Registry of Renal Biopsies         | [http://www.nefrol.cz/en/experts/renal-biopsy-registry](http://www.nefrol.cz/en/experts/renal-biopsy-registry) | [11]                          | –            |
| Flemish Collaborative Glomerulonephritis Group Registry | [http://www.nbvn.be/blog/organisatie/fcggin-english](http://www.nbvn.be/blog/organisatie/fcggin-english) | [12]                          | [https://www.renalconference2018.com/images/Presentaties/Zaterdag/Wim_Laurens-Amie%20Dendooven%20FCGG_Flemisch_Collaborative_Glomerulonephritis_Group_Current_Status_of_the_Registry_and_Future_Perspectives.pdf](https://www.renalconference2018.com/images/Presentaties/Zaterdag/Wim_Laurens-Amie%20Dendooven%20FCGG_Flemisch_Collaborative_Glomerulonephritis_Group_Current_Status_of_the_Registry_and_Future_Perspectives.pdf) |
| Italian Registry of Renal Biopsies       | [http://www.irrb.net/](http://www.irrb.net/)                          | [13, 14]                      | –            |
| Japanese Renal Biopsy Registry (J-RBR)  | –                                                                      | [15, 16]                      | Japan Renal Biopsy Registry and Japan Kidney Disease Registry: Committee Report for 2009 and 2010. Sugiyama H et al. Clin Exp Nephrol. 2013;17:155–73. |
| Limburg Renal Registry                  | –                                                                      | [17, 18]                      | –            |
| Malaysian Registry of Renal Biopsy      | [https://www.macr.org.my/emrmb/zAu_login.jsp](https://www.macr.org.my/emrmb/zAu_login.jsp) | –                             | [https://www.msn.org.my/nrr/mrrb_report.jsp](https://www.msn.org.my/nrr/mrrb_report.jsp) |
| National Pathology Database Denmark (PATOBANK) | [http://www.patobank.dk/index.php?id=1&lang=da](http://www.patobank.dk/index.php?id=1&lang=da) | [19, 20]                      | [https://www.patobank.dk/](https://www.patobank.dk/) |
| Norwegian Renal Registry                | [http://www.nephro.no/nrr.html](http://www.nephro.no/nrr.html)        | [21, 22]                      | [https://www.nephro.no/nmr/AARRAPPORT_NNR_2018_ToC.pdf](https://www.nephro.no/nmr/AARRAPPORT_NNR_2018_ToC.pdf) |
| Philippine Renal Disease Registry       | [http://www.nkti.gov.ph/index.php/services/specialty-centers/renal-disease-control-program-redcop](http://www.nkti.gov.ph/index.php/services/specialty-centers/renal-disease-control-program-redcop) | –                             | On request via National Kidney and Transplantation Initiative, Philippines |
| Polish Registry of Kidney Biopsies       | –                                                                      | [23, 24]                      | –            |
| Scottish Renal Biopsy Registry          | [http://www.srr.scot.nhs.uk/Biopsy-Registry/Main.html](http://www.srr.scot.nhs.uk/Biopsy-Registry/Main.html) | [25, 26]                      | [https://www.srr.scot.nhs.uk/Biopsy-Registry/Main.html](https://www.srr.scot.nhs.uk/Biopsy-Registry/Main.html) |
| Spanish Renal Registry                  | [https://www.senefro.org/modules.php?name=home&lang=ES](https://www.senefro.org/modules.php?name=home&lang=ES) | [27, 28]                      | [https://www.senefro.org/contents/webstructure/REGN2019_2_.pdf](https://www.senefro.org/contents/webstructure/REGN2019_2_.pdf) |
| Swedish Renal Registry                  | [https://www.medscinet.net/snr/rapporterdocs/Svenskt%20Njurregister%202019rapport%202019.pdf](https://www.medscinet.net/snr/rapporterdocs/Svenskt%20Njurregister%202019rapport%202019.pdf) | [29, 30]                      | –            |
| Uruguayan Registry of Glomerular Diseases | –                                                                      | [31, 32]                      | [https://www.nefrologia.hc.edu.uy/index.php/prevencion-glomerulopatias](https://www.nefrologia.hc.edu.uy/index.php/prevencion-glomerulopatias) |
| National Renal Biopsy Registry, Taiwan  | [https://www.tsn.org.tw/enVersion/about.aspx](https://www.tsn.org.tw/enVersion/about.aspx) | [33]                          | –            |

(such as number of glomeruli). Eight of 16 registries collect clinical data related to the transplant diagnosis (such as post-transplant serum creatinine levels) and 3/16 registries collect pathology data related to transplant biopsies (such as degree of interstitial fibrosis) (Table 2).

**How much experience do registries have?**
There is a wide variability in the age of these registries. However, most registries exist for a long time and thus have a strong experience base: 11/16 exist for more than 10 years and 6/16 are even more than 20 years old. Two registries have recently been established (< 5 years).

**How do registries code kidney biopsy diagnoses?**
When it comes to coding practice, a common line is that either nephrologist (7/16) or pathologist (3/16) or both (5/16) code. Two registries have additional coding assistance, in one by an administrator/study nurse, in another by an informatician or coding expert and an epidemiologist. (Table 2).

Looking at coding systems, most registries use a proprietary coding list to register diagnoses, either
exclusively (9/16) or in combination with another coding system (3/16). One registry uses SNOMED (both an older SNOMED version and SNOMED CT). Two registries use the ERA-EDTA PRD [34]. Two more registries use a combination of a proprietary coding list and the ERA-EDTA PRD system. One registry uses a proprietary list, ICD-10, SNOMED (older version) and SNOMED CT.

In general, registries are relatively satisfied with the (often proprietary) system they use, with 9 of 14 reporting a 4 for user satisfaction on a scale of 0 to 5, where 0 means ‘totally unsatisfied’ and 5 means ‘very satisfied’.

Next, registries were asked to code a typical diagnosis of IgA nephropathy M1 E0 S1 T0 C1. The responses illustrate the diversity of systems in use (Table 3). Often (combinations of) letters and ciphers serve as codes for predefined diagnostic terms, as in the ERA-EDTA PRD codes used by 5/15 registries and in some proprietary coding list (e.g. British Columbia, Poland and Flanders). In fact, the largest number of registries using the same code value is 5, which are the registries using the ERA-EDTA PRD codes. Of course, code values from registries with proprietary coding systems are different. However, one could assume that code terms for the concept ‘IgA nephropathy’ are at least the same. This is not the case; even if all registries code for the diagnosis ‘IgA nephropathy’, only 5/14 registries use proprietary coding systems use the exact identical code term ‘IgA nephropathy’. Examples for variations and specifications used are ‘IgA nephritis’, ‘IgA nephropathy, primary’ and ‘IgA nephropathy with crescents’.

The responses also illustrate various coding policies. Looking at the proprietary coding systems, in some instances only the diagnosis itself is coded (e.g. Malaysia and Spain), in other instances also morphology data are rendered in a code (e.g. Czech Republic, Japan, Limburg, Philippines and Poland). The same holds true for the established coding systems: in ERA-EDTA PRD the diagnosis as such is coded (‘IgA nephropathy’), whereas in the (older versions of) SNOMED, histologic patterns (‘Diffuse mesangial proliferation’ or ‘Tubular atrophy’) are coded as well.

Self-reported problems and suggestions for improvement

In an open question format, we asked the contact persons from the registries about the advantages and disadvantages of their system. Eleven of 15 registries answered this question with a comment on problems of their registry or with a suggestion for improvement.

The lack of maintenance and updates of the coding system was the most common comment, mentioned in some form by respondents from 6 registries. Two registries mentioned a problem with interoperability with international systems. Other issues were mentioned once: ambiguity related to lack of coding rules, insufficient coding possibilities (not all diagnoses included, no morphology diagnoses, too many irrelevant codes), difficulties retrieving data from the system, problems to code more than one diagnosis per biopsy, necessity of a system for transplant biopsies and finally the need to record histopathological patterns and findings.

Suggestions for improvement included the need for a simple system (mentioned twice), the need for a consistent system (mentioned once) and finally the need to code prospectively (mentioned once): this means coding when making the diagnosis and not when data are recorded in the registry (i.e. retrospectively).

Discussion

In this paper, we give an overview over national and regional kidney biopsy registries and combine a literature search with an online questionnaire to research registries’ current way of kidney biopsy coding. Additionally, we report suggestions for improvement of coding practice.
### Table 2: Overview over kidney biopsy registries. Data are based on an online questionnaire except for one registry.

| Registry | Data collection | Diagnosis registered | Tx included | Coverage (years) | Coding system | Who codes | Self-reported satisfaction (0–5) |
|----------|-----------------|----------------------|-------------|-----------------|---------------|-----------|----------------------------------|
| 1 British Columbia Glomerulonephritis Registry | C, P | C, P | No | Regional | 5–10 | x | Nephrologist 4 |
| 2 Czech Registry of Renal Biopsies | C | C, P | No | National | > 20 | x | Nephrologist 4 |
| 3 Flemish Collaborative Glomerulonephritis Registry | C, P | C, P | No | Regional | < 5 | x | Nephrologist Pathologist 4 |
| 4 Italian Registry of Renal Biopsies | C, P | C, P | Yes | National | > 20 | x | Nephrologist Pathologist 3 |
| 5 Japanese Renal Biopsy Registry | C | C, P | Yes | National | 11–20 | x | No data 3 |
| 6 Limburg Renal Registry (Netherlands) | C, P | C, P | Yes | Regional | > 20 | x | Pathologist 3 |
| 7 Malaysian Registry of Renal Biopsies | C, P | C, P | Yes | National | 11–20 | x | Pathologist 3 |
| 8 National Pathology Databank Denmark (PATOBANK) | No data | P | Yes | National | 11–20 | x | Pathologist 2 |
| 9 Norwegian Renal Registry | C, P | C, P | No | National | > 20 | x | Pathologist 3 |
| 10 Philippine Registry of Glomerular Disease | C, P | C, P | Yes | National | 11–20 | x | Nephrologist Pathologist 4 |
| 11 Polish Registry of Renal Biopsies | C | P | No | National | 5–10 | x | Pathologist No data |
| 12 Scottish Renal Biopsy Registry | C, P | C, P | Yes | National | 11–20 | x | Nephrologist 3 |
| 13 Spanish Registry of Glomerulonephritis | C, P | C, P | No | National | > 20 | x | Nephrologist 4 |
| 14 Swedish Renal Registry | C, P | C, P | No | National | < 5 | x | Nephrologist 4 |
| 15 Uruguayan Registry of Glomerular diseases | C, P | C, P | No | National | > 20 | x | Nephrologist Pathologist 4 |
| 16 National Renal Biopsy Registry Taiwan | C | C, P | Yes | National | 5–10 | x | Nephrologist No data |

C clinical data, P pathology data. aOnly clinical data, no pathological data related to Tx; bProprietary codes based on ERA-EDTA PRD; cSNOMED (older version), but mapped to SNOMED CT; dDid not participate in the online questionnaire; data based on published paper [33]
First of all, we note that most kidney biopsy registries are situated in European countries and some in Asian countries (Fig. 2). There is one more registry in North America (Canada) and one in South America (Uruguay). In contrast to the high number of registries in Europe, there are large geographical areas without a single kidney biopsy registry. This is comprehensible in areas like sub-Saharan Africa, where resources for the collection and processing of kidney biopsies might be limited [35]. On the other hand, it is surprising that highly populated countries and/or countries with a high standard of healthcare systems such as the USA, China or India do not have established kidney biopsy registries covering a defined region on the national or regional level [36, 37].

Table 3 Coding practice in kidney biopsy registries in this study

| Registry                                      | Coding system      | Code(s)          | Code text                                           |
|-----------------------------------------------|--------------------|------------------|-----------------------------------------------------|
| British Columbia Glomerulonephritis Network  | Proprietary        | G23.1 V3         | IgA nephropathy-primary Hypertensive/benign/ischemic nephrosclerosis |
| Czech Registry of Renal Biopsies             | Proprietary        | 1730             | IgA nephropathy with crescents                       |
| Flemish Collaborative Glomerulonephritis     | Proprietary (FCGG-NBVN) ERA-EDTA PRD | 3a 1128          | IgA nephropathy, primary IgA nephropathy-histologically proven |
| Group Registry                               |                    |                  |                                                     |
| Italian Registry of Renal Biopses            | ERA-EDTA PRD       | 1128             | IgA nephropathy-histologically proven               |
| Japanese Renal Biopsy Registry (J-RBR)       | Proprietary        |                  | Mesangiproliferative glomerulonephritis IgA nephropathy Interstitial fibrosis Arteriosclerosis |
| Limburg Renal Registry                       | Proprietary        |                  | IgA nephropathy                                    |
| Malaysian Registry of Renal Biopsy           | Proprietary        |                  | IgA nephropathy                                    |
| National Pathology Database Denmark          | SNOMED (older version) | T71000 M46862 S67300 M53300 M58000 | Kidney Diffuse mesangial proliferation IgA nephritis Glomerulosclerosis Tubular atrophy |
| Norwegian Renal Registry                     | ERA-EDTA PRD NNR 2013 NNR 2011 | 1128 300 3 | IgA nephropathy-histologically proven IgA nephropathy |
| Philippine Renal Disease Registry            | Proprietary        |                  | Mesangiproliferative glomerulonephritis IgA nephropathy |
| Polish Registry of Kidney Biopsies           | Proprietary        | 124              | Class IV (diffuse proliferative) lesions according to Haas classification in IgA Nephropathy |
| Scottish Renal Biopsy Registry               | ERA-EDTA PRD       | 1128             | IgA nephropathy-histologically proven               |
| Spanish Renal Registry                       | Proprietary        |                  | IgA nephropathy                                    |
| Swedish Renal Registry                       | ERA-EDTA PRD SNOMED (older version) | 1128 M46862 D45870 M5440 M52200 | IgA nephropathy-histologically proven |
| Uruguayan Registry of Glomerular Diseases    | Proprietary        | 1151             | IgA nephropathy                                    |

We asked contact persons to code the following situation: Biopsy: 15 glomeruli, 1 cellular crescent, 2 lesions of segmental glomerulosclerosis, 4 lesions of global glomerulosclerosis. Tubular atrophy in around 20% of the cortical area. Moderate arteriosclerosis and arteriolosclerosis. IH: dominant IgA positivity. Diagnosis: mesangiproliferative glomerulonephritis; IgA nephropathy; Oxford classification: M1 E0 S1 T0 C1

Data are depicted literally as mentioned by the registry contact persons.

A substitute might be large-scale single center registries, which often serve as tertiary referral centers. Prominent examples are the Toronto Glomerulonephritis Registry, the Renal Biopsy Laboratory (Department of Laboratory Medicine and Pathology) at Mayo Clinic or the Division of Nephropathology at the University of North Carolina at Chapel Hill [38–40]. A second alternative might be large research consortia (for example the NEPTUNE in the USA, just to mention one) that might fill in this gap [41]. However, research consortia are often more focused on thematic research than epidemiologic research. Finally, another possible substitute are end-stage renal disease registries [42]. For example, the US Renal Data System (USRDS) registers diagnoses of patients with

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end-stage renal disease using ICD-9 and ICD-10 codes [6]. However, since end-stage renal disease registries do not incorporate pathology diagnoses, the registry data do not necessarily reflect the kidney biopsy diagnoses, and certainly not important morphological patterns or other key changes. Another drawback is that only patients with ESRD are covered. Since many renal diseases do not lead to end-stage renal failure, data about these diseases are thus lost. For a review on renal registries proper, we refer to the paper of Liu et al. [42].

As an alternative to registries, epidemiologic data related to kidney biopsies might be collected retrospectively [36]. There are plenty of such publications. However, these publications usually present epidemiologic data on a single-center, regional or national basis at a certain time point or over a restricted time period. There is no prospective data collection or continuous monitoring of biopsy data as it would be provided by a registry. Therefore, even if these retrospective analyses add valuable knowledge, they are not really an alternative for proper kidney biopsy registries which can follow epidemiological developments over a long period of time using a consistent dataset [43].

Not only registry number in a defined geographical area is variable, there is also a variety in set-up of the registries, which sometimes include transplant biopsies, but more often do not. In many registries, nephrologists and pathologists collaborate and it varies from registry to registry if the nephrologist codes or the pathologist codes or both.

It is noteworthy how old many registries are. These old registries allow for studies about the long-term course of kidney disease and underline the usefulness of kidney biopsy registries [44, 45]. The age of the registries is also reflected by the coding systems and mappings used. This is exemplified by the use of or mapping to older and no longer updated SNOMED versions in Denmark, Sweden or the Netherlands. In fact, lack of maintenance and updates of coding systems was the most common problem reported by the registries.

Registries where the nephrologists play a central role, especially in Europe, often map to ERA-EDTA PRD. This is understandable, as ERA-EDTA PRD is the uniform coding system for dialysis registries in Europe [34] and thus, is a known tool for registering renal disease. However, using ERA-EDTA PRD for biopsies can be challenging, as many morphology-based diagnoses are lacking in ERA-EDRA PRD (this was also one of the comments brought forward by the registries).

Most registries use proprietary coding systems. In this study, we did not investigate specifically why people prefer proprietary coding systems. It is very likely, though, that the use of proprietary coding systems is related to the fact that many international terminologies are not designed for pathology purposes. International coding systems covering pathology needs such as SNOMED and SNOMED CT are highly complex. Practical application of these systems might be hampered due to heterogeneity or lack of renal disease classifications in the past. Another reason could be the way registries are established and managed. This is often done by enthusiastic committed medical professionals [19]. Informaticians and coding experts are probably rarely involved. At least, our survey shows in terms of coding, that only one registry had coding assistance by an informatician or coding expert and an epidemiologist.

Sometimes these proprietary systems are mapped to international terminologies, though often they are not. Clearly, data collection in regional or national registries in itself is a tool to standardize coding of diagnoses from different centers. However, when no mapping is available, the downsides of proprietary coding systems are obvious: since clinical concepts have many synonyms, the terms chosen by registries for a specific concept will be variable. Of course, code values will differ from system to system. Therefore, there is no means to easily exchange data with other registries, countries or even consortia.

Our coding task for registries “kidney biopsy with IgA nephropathy” highlights these difficulties. As IgA nephropathy is one of the most common nephropathies worldwide [46], the entity is relatively straightforward to code and this coding task is a daily routine in all registries. However, comparison or aggregation based on key information - the diagnosis IgA nephropathy - is not possible without profound manual interaction because terms used are different and a unique code is missing. If already a common entity like IgA nephropathy requires manual interaction to aggregate data, it is easy to anticipate how difficult it would be to compare and aggregate data from rare kidney diseases, morphological patterns or key histological findings. These observations clearly underline the necessity for a common coding system.

In addition, the coding task reveals a second challenge. Some registries only code the main diagnosis “IgA nephropathy” while others code additional morphological findings. For example, a minority of registries codes the morphological reaction pattern. Moreover, if registries code for morphological patterns, then they do it in different ways. The example illustrates that an investigation of data from several registries concerning morphological reaction patterns in a particular disease would not yield reliable data. Consequently, to ensure the best use of registry data, it would be advisable to establish coding rules in addition to a common coding system.

As renal pathologists use morphological patterns as a basis of diagnostic categorization, apart from clinical correlations, it is not difficult to conceive that systems
originally designed for mortality statistics (such as ICD) or for registering end-stage renal disease (such as ERA-EDTA PRD) are imperfect for registering biopsy diagnoses. Thus, this research emphasizes the need for a consensus coding system that can be used by pathologists and that maps to other, more general and interchangeable, health terminology systems.

The present study has several limitations. First, the study is constrained to regional or national kidney biopsy registries. We excluded the investigation of research consortia or time-limited research registries, single center registries and pathology databases. Second, kidney biopsy registries that do not actively publish or maintain a website may have remained undetected. However, it is unlikely that such registries would have adopted any well-established renal pathology coding system.

In conclusion, our study shows large gaps in kidney biopsy registry coverage around the globe. Among existing kidney biopsy registries, there is limited use of international coding systems, hampering comparison of findings and aggregations of data. One reason might be the perceived lack of a coding system suitable for kidney biopsies. Another main reason is the long lifespan of many kidney biopsy registries, which makes continuous updating of coding systems in relation to knowledge increase challenging. There is a need for an international coding system that meets the needs of kidney biopsy registries in order to utilize the potential of these registries.

Supplementary Information
The online version contains supplementary material available at https://doi.org/10.1186/s12882-021-02365-3.

Additional file 1 Appendix 1. Online questionnaire sent to kidney biopsy registries.

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Authors’ contributions
AD and SL set up the study, gathered data from the literature search and questionnaire and performed the analysis. NM, MN, LG, AR, CC, JLG, CC, MAH, MS, RY, MG, RV, TD and SB provided data about coding in registries. Together, RC, LG, HH and KA form the Steering Group of the KBC project and advised on the conduct of the study. TQN contributed in data analysis. MH and HP advised on interpretation of coding systems. All authors read and approved the final manuscript.

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Availability of data and materials
Most data are represented in the paper; complete data from the current study are however available from the corresponding author on reasonable request.

Declarations
Ethics approval
Because this study did not involve the collection, use or transmission of individually identifiable patient data, institutional ethics committee review or approval was not required.

Consent for publication
Patient informed consent was not applicable to this study since the collection of data via the questionnaire did not involve patient data.

Competing interests
None of the coauthors declares a competing interest related to this article.

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